

**FROM THE INCINERATOR TO THE BANK: A FEMINIST QUALITATIVE  
STUDY OF PRIVATE CORD BLOOD BANKING IN CANADA**

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**Abstract**

This is a feminist, qualitative study of private umbilical cord blood banking in Canada. Drawing on in-depth, semi-structured interviews with 12 women who banked cord blood, 6 key informants from 4 different private cord blood banks, and 3 healthcare professionals, I consider what private cord blood banking can tell us about contemporary biopolitics, the production of biovalue in corporeal materials, the promise of “biological insurance,” and the social actor of neoliberalism.

My research makes several key contributions to sociological literature on stem cell science, health and contemporary biopolitics. First, I make a feminist, empirical contribution to social science scholarship on private cord blood banking specifically. Second, I expand on the biovalue literature by demonstrating the social production of biovalue in a specific cord blood unit. I show that the production of biovalue in cord blood units is a social process that involves tensions and negotiations between women, private banks and clinicians across different expert discourses and profane knowledges.

Third, I critically examine the metaphor of private cord blood banking as “biological insurance.” Private cord blood banks emphasize the future, speculative promises of regenerative stem cell therapies and market their services as a form of insurance. Contrary to this position, I show how in some cases cord blood fails to provide the protection it promises. Fourth, this study challenges contemporary literature on the active subject in health. I argue that women’s experiences of cord blood banking show that the conventional interpretation of the active subject as a rational, calculating subject that engages in contemporary health strategies in a hopeful manner requires revision. I show that women act as precautionary actors who bank in a context of uncertainty and fear.

By providing an in-depth, empirical examination of women’s experiences of private cord blood banking, I offer a feminist, critical account of a contemporary biopolitical strategy in the Global North: health optimization through private tissue storage. I challenge biopolitics scholarship that presents an over-generalized,

acritical account of contemporary biopolitics and argue for greater analytic and empirical attention to the everyday experiences of people who engage in health optimizing practices.

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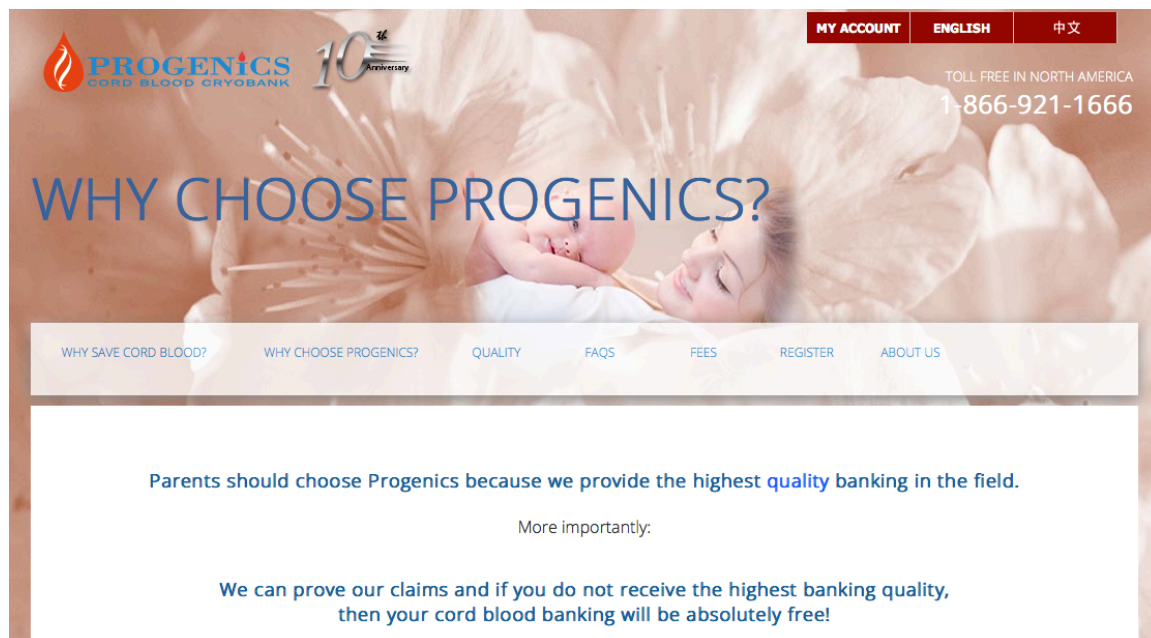
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## Chapter 1: Introduction



(<http://www.progenicscryobank.com/en/whychoose/>)

*CReATe offers you the opportunity to collect and save your baby's cord blood stem cells for potential medical uses to treat life-threatening diseases. If you do not choose to bank your baby's cord blood, it will be discarded after birth. Cord blood-derived stem cells have been successfully used on thousands of patients to treat numerous conditions and diseases and there is exciting new research on many additional conditions that it could be used for in the near future.*

(<http://www.createcordbank.com/cord-blood-program-2/>)

### Introduction

The first time I looked at the website for a private cord blood bank, I was fascinated by the collection of images and messages. I saw pictures of happy couples and healthy children alongside pictures of a bloody umbilicus and a collection bag full of blood. Next to these images were catchy phrases that promised prospective parents security for their children against future disease if they banked cord blood.

On the website was a list of the diseases that cord blood could currently treat and, even more impressive, there was a much longer list of diseases that cord blood could potentially treat. I wondered if women were actually paying to bank cord blood. Were pregnant women buying into the promises of future health and participation in regenerative medicine<sup>1</sup> that private banks offered? How were women learning about cord blood banking? I certainly had not heard about it until I stumbled across it in my own academic research. I was interested in private cord blood banking as an empirical site that articulates the promises of stem cell science and regenerative medicine with people's everyday lives. I wanted to know more about women's experiences with cord blood banking and how they oriented to its promises of future health.

When I started this project, much of my knowledge of stem cell science was based on human embryonic stem cell (hESC) research and popular writing . Journalists and social scientists alike focused on the controversies and debates over, and governance of, the procurement and use of hESCs in scientific research. Despite all the promises and hype surrounding hESCs and their regenerative potential, I knew that the chasm between stem cell laboratory science and actual clinical treatment by stem cells is great. Understandably, social scientists studying hESC science focused primarily on the ethical and political controversies and debates, the work of scientists in laboratories, or discourses of hope and hype by industry and biotech company leaders (e.g. Rajan 2006; Thompson 2013). As a sociologist interested in health and contemporary biosciences, I wanted to examine the interface between stem cell science and lay people, primarily in relation to their health decisions. Private cord blood banking provided me with an empirical site that ostensibly offers women and couples an opportunity to ensure future health by banking their cord blood. Women and couples can pay to keep the cord blood post-

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<sup>1</sup> Regenerative medicine is the field of medicine that aims to provide therapeutic treatment and cures based on the generative capacity of biological tissues, such as stem cells (Perpich 2004).

birth to be used as a clinical treatment in the future. Banking umbilical cord blood is to bank on the promises of stem cell science.

Umbilical cord blood is the blood that circulates in the umbilical cord and placenta and mediates the transport of nutrients and waste between the mother and unborn during pregnancy. Women can pay a private cord blood bank to store the cord blood that is collected from the umbilical cord and placenta after they give birth. If a woman banks cord blood in a private bank, the cord blood is saved for her and her family to be used as therapeutic treatment in the future, if needed. The scientific literature (discussed below) confirms that cord blood is clinically valuable because of the relatively high amount of blood stem cells in the blood. Blood stem cells, also known as hematopoietic stem cells, can regenerate the blood and immune system; thus, cord blood has been used clinically to treat a number of blood and immune system diseases such as, anemia and leukemia. Given this relatively new clinical use for cord blood, clinicians and commentators refer to the recent transformation of cord blood from “waste” to “clinical gold” (Waldby & Mitchell 2006). What was considered by most to be part of the “detritus of birth” and discarded as biological waste in the incinerator is now considered by many to be clinically valuable biological material that should be banked. Private cord blood banks encourage women and couples to save their cord blood from incineration and bank it for future use.

This study is a feminist, qualitative examination of private umbilical cord blood banking in Canada. Specifically, I examine women’s practices and experiences of banking cord blood and consider what this can tell us about private cord blood banking and contemporary biopolitics. This project is informed by Foucauldian literature on contemporary biopolitics, sociological work on health and biovalue, and feminist scholarship on new reproductive technologies. The data for my research was generated through in-depth, semi-structured interviews with 12 women who banked cord blood, 6 key informants from 4 different Canadian private cord blood banks (in Ontario and British Columbia), and 3 healthcare professionals

with experience in cord blood collection. Each chapter is organized around an analytic theme drawn from these in-depth interviews. I have supplemented my analysis of women's experiences with analysis of qualitative interviews from key informants at private cord blood banks and healthcare practitioners who have had experience with cord blood collection. These supplemental interviews provide context and additional details regarding private cord blood banking.

In this Chapter, I present the key contributions and arguments of this study. Next, I provide an overview of private cord blood banking in Canada (the context of this research) and a review of cord blood science in order to situate this sociological project contextually and historically. In this review, I focus on the main debates or points of discussion regarding cord blood banking in Canada. Much of this work is limited to an ELSI (ethical, legal and social implications) framework. I review the social science literatures that frame this dissertation in Chapter 2. In the present chapter, following a description of the Canadian context, I provide a brief history of the scientific and clinical work leading to the use of cord blood as a transplant therapy. I also outline the current therapeutic uses and future promissory uses of cord blood. These two sections provide a summary of the scientific and clinical literatures regarding the current clinical uses and limits of cord blood. These literatures are significant for sociological research since they are the expert discourses that provide the necessary pre-condition for private cord blood banking. I conclude with an outline of each chapter in this dissertation.

### **Key Contributions and Arguments**

My research makes several key contributions and arguments. First, I make a feminist, empirical contribution to social science scholarship on private cord blood banking and the use of female reproductive tissue. Female reproductive tissue, such as ova, is a necessary biological "substrate" or "research tool" in many areas of contemporary bioscience and regenerative medicine. To date, there has been no in-depth qualitative study of women's experiences of private cord blood banking in

Canada. Feminist scholars have astutely critiqued the erasure of women in both social science and clinical scholarship that examines the use of female reproductive tissues, such as ova and cord blood (e.g. Dickenson 2007). I address this erasure by foregrounding the experiences of women who have banked cord blood privately. I argue that women work to bank cord blood and that their gendered labour is critical to successful cord blood collection.

Second, I expand on the biovalue literature by examining the production of biovalue in cord blood as a social process, not primarily a technical or economic one. Much of the social science literature on biovalue defines it as surplus value and many scholars have applied this concept as inherent to certain biological tissues that have regenerative capacities, such as stem cells (Waldby 2000; 2002). Others have critiqued this definition of biovalue for its under-theorization and have challenged scholars who fetishize biovalue (e.g. Birch & Tyfield 2012; Helmreich 2008). I argue that biovalue is not an inherent quality of biological tissues and that the production of biovalue is not only the work of technicians and knowledge experts, but also of women who bank. Through my empirical work, I show that the production of biovalue in specific cord blood units is a social process that involves tensions and negotiations between women, private banks and clinicians across different forms of knowledge (e.g. clinical, scientific-numerical, and lay). Cord blood's value is not a surplus value, but is in its potential use value as a therapeutic treatment.

Third, I critically examine the metaphor of private cord blood banking as "biological insurance." Private cord blood banks emphasize the future, speculative promises of regenerative stem cell therapies and market their services to prospective parents as "biological insurance" for their children and families. Contrary to this position, I show how private cord blood banking does not provide the protection that the metaphor of insurance promises. Women described feeling compelled to buy "biological insurance" through moralizing language of being a "good mother" and to avoid feelings of profound guilt. This moralizing language, I suggest, indicates an expansion of maternal responsibility to include the

accumulation of biological materials for the purposes of ensuring health in the future. Lastly, I argue that the need for “biological insurance” is produced through encouraging women to engage in a fearful imaginary in which their child will become sick in the future. Hope in cord blood, according to women, is inseparable from fear and anxiety. They are two sides of the same coin.

Fourth, this study challenges contemporary literature on the active subject in health or the neoliberal medical subject and builds on critical literature that examines the social actor of neoliberalism. I argue that women’s experiences of cord blood banking show that the conventional interpretation of the active subject as a rational, calculating, sovereign subject that engages in contemporary health strategies in a hopeful, detached manner requires revision. This dominant characterization of the active subject is produced in discourse, is highly uniform in the literature, and its continual reproduction by social scientists effectively elides and erases the social complexities and challenges of people who engage in contemporary biopolitical strategies. I show that women who bank cord blood are not hopeful investors in biotechnological futures. Instead, they act as precautionary actors who bank in a context of uncertainty and fear. They must exercise precaution because the possibility of harm – that is, the loss of their child to a disease that could be treated with cord blood – is so great that they are compelled to act. I argue that women who bank are less calculating, optimistic investors and more fearful, anxious gamblers hedging their bets. Finally, I contribute to the social science literature that critiques rational decision-making in health by showing that women who bank do not conform to the linear model of decision-making in biomedical discourse.

### **Canadian Context**

The first Canadian cord blood banks opened in 1996. Since then, the private cord blood bank industry has grown significantly. Currently, there are 8 private cord blood banks in Ontario, Alberta, and British Columbia. In 2011, the largest private cord blood bank company, Inception Biosciences, bought the largest bank in

British Columbia, Lifebank, to form a new company, Inception Lifebank. In addition to the private banks, there are 4 public banks in Canada: 2 public banks are part of larger private banks, 1 public bank is a provincial bank in Quebec and is administered through Hema-Quebec, and lastly, the National Public Cord Blood Bank (NPCBB) is a national, publicly funded bank administered through the Canadian Blood Services.<sup>2</sup> The opening of the first of four collection sites for the NPCBB in September 2013 is a significant milestone for cord blood banking in Canada. The NPCBB is the first national, publicly funded cord blood bank and offers a viable option for Canadian women and couples to donate cord blood.<sup>3</sup>

The growth of private cord blood banking in Canada has occurred with little public debate. In part, this may be due to the lack of ethical concern regarding the use of blood stem cells vis-à-vis human embryonic stem cells. The governance of human embryonic stem cell production and use has received a great deal of public attention and debate in North America and many other countries because of the moral and ethical concerns regarding embryos and their potential for personhood (Thompson 2013). Blood stem cells, on the other hand, do not have the potential to develop into a person and thus many people consider their use to be ethically non-problematic. Although there has been some debate over the relative merits of public versus private cord blood banking among clinicians and bioethicists, the public has largely remained outside and unaware of these debates. In one of the first articles published on private cord blood banking in the *Canadian Medical Association Journal*, Hass (1999) described clinicians' concerns about private banking because of the low likelihood that it would be used in the future. The Society of Obstetricians and Gynaecologists Canada (SOGC), in 2000 and again in 2005, recommended

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<sup>2</sup> See Appendix A for a list of cord blood banks in Canada.

<sup>3</sup> The NPCBB opened its first collection site in Ottawa in September 2013 and will open sites in Brampton, Calgary, and Vancouver in 2014. They recently announced that BC Women's Hospital in Vancouver, BC, will be the collection hospital. Internationally, Canada is late in opening a national, public cord blood bank; it is the last of the G8 countries to establish one (<http://campaignforcanadians.ca>, downloaded Apr. 10, 2014). While private cord blood banks dominate in Canada, this is not the case in other countries. The issue of private versus public banks has been widely debated internationally.



against private cord blood banking because of the low likelihood of use.

However, the SOGC was in favour of public cord blood banking.<sup>4</sup>

In 2004, Saginur, Karaboyan & Knoppers published a key paper examining the ethical and legal issues of cord blood banking in Canada. The authors pointed to concerns regarding the ambiguity of the legal status of cord blood and the lack of regulation of private cord blood banking. Saginur et al. (2004) argued that until the legal status of cord blood as property is clarified, the ownership rights of cord blood remain ambiguous. Although body parts cannot be legally owned as property in Canada, Saginur et al. (2004) point out that private cord blood banks use the language of cord blood as property in their contracts with clients. Ten years later, in 2014, this ambiguity regarding the legal status of cord blood remains. The authors also cautioned against private cord blood banking. Reviewing the literature regarding private banking, they argued for increased oversight and regulation given the ethical concerns of exaggerated marketing claims and a lack of demonstrated clinical efficacy. The authors also expressed concern regarding the imposition of a private banking system in a publicly funded health care system in Canada and possible issues of disparity of health services. In short, they recommended increased research and regulation regarding cord blood banking in Canada.

Since this 2004 paper, Knoppers and colleagues have shifted emphasis from a critical assessment and identification of concerns related to private cord blood banking to a discussion of the need for a national public cord blood bank in Canada (Plant & Knoppers 2005; Sheremeta 2006a; Sheremeta 2006b; Sheremeta, Plant & Knoppers 2005). Rather than following up on concerns regarding private banking, the authors argue for private-public partnerships as an effective means to pay for the high cost of cord blood banking and cord blood transplant. Their arguments are similar to those often made by proponents of privatization of health care services in Canada. Plant & Knoppers (2005) argue that given the high cost of public cord blood

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<sup>4</sup> Since November 18, 2013, the SOGC has been reviewing the 2005 clinical practice guidelines regarding cord blood banking to provide updated guidelines.

banking and the already heavy demands on public health care dollars, public-private partnerships in cord blood banking may be an effective alternative. They further suggest that a private banking system will free up more donated cord blood units in the public system and that private cord blood banks will ensure greater advancements in research given their vested interest in moving research forward. Currently, there is a favourable environment for the further development of private and public cord blood banking in Canada. The key legal and ethical concerns outlined in Saginur et al.'s (2004) paper, such as the legal status of cord blood, marketing practices of private banks and regulations to ensure women and couples receive accurate information, have not been addressed. Much of the literature on the ethical, legal and social issues concerning cord blood banking is limited in scope because its questions and analyses are framed primarily around abstract ethical and legal principles.<sup>5</sup>

### **A Short History of Blood Stem Cells**

In this section and the following one, I provide a brief discussion of the scientific and clinical literatures of blood stem cells and cord blood banking in order to provide relevant contextual information to situate this sociological study. This scientific knowledge is important because it is the authoritative discourse towards which clinical knowledge of cord blood orients and provides the pre-condition for the emergence and growth of private cord blood banks. The transformation of cord blood into a biological material that has potential clinical value and, thus, is worth saving was made possible because of scientific knowledge that posited the regenerative capacities of blood stem cells. Private banks represent the scientific and clinical discourses on blood stem cells and uses of cord blood as more certain and imminent than do scientists involved in the research. The science and clinical uses of cord blood stem cells are complex and critics of private banking are concerned that much of this complexity is glossed over by private banks. Below, I

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<sup>5</sup> See Appendix B for a review of the international ELSI literature.

provide a review of the scientific discourse that explains current knowledge of what blood stem cells are, how they were first “discovered,” and what they can be used for clinically. In particular, I aim to highlight the limitations of cord blood use according to scientific and clinical discourses. Two important points to keep in mind regarding the limitations of current cord blood use include: one, the finite number of cord blood stem cells available in each collection limit cord blood’s clinical use; and two, many of the conditions marketed as potentially treatable by private banks (e.g. Type 1 diabetes, cerebral palsy and Alzheimer’s Disease) are still very much in the experimental stages.

In the 1970s, researchers began examining the use of fetal liver cells<sup>6</sup> for their hematopoietic properties (that is, their ability to produce all types of blood and immune system cells: red blood cells, white blood cells, and platelets) and found they were capable of hematopoiesis (that is, the production of blood and immune system cells) and were less immunologically sensitive than adult cells (Gluckman & Rocha 2005). Clinical trials using fetal liver cells to treat patients with severe immunodeficiency were conducted, but these studies were short lived because of the low success rate and the difficulties in obtaining fetal liver cells (Gluckman & Rocha 2005). After the Chernobyl disaster in 1986, research on the use of blood stem cells and identifying sources of these cells gained renewed interest because of the clinical need to treat people who were living with the effects of irradiation (Gluckman & Rocha 2005). The first successful allogeneic transplant<sup>7</sup> using blood stem cells from cord blood to treat Fanconi’s anemia was in 1988 and involved three groups of researchers and clinicians in two countries. Arleen D. Auerbach (clinical geneticist) and colleagues, had developed a prenatal genetic test for Fanconi’s anemia, Hal E. Broxmeyer (microbiologist and immunologist) and colleagues, had

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<sup>6</sup> Hematopoietic cells circulate throughout the fetus and are localized in the liver and bone marrow. After birth, hematopoietic cells are found almost exclusively in bone marrow (Gluckman & Rocha 2005).

<sup>7</sup> Allogeneic transplant refers to the transplantation of tissues or cells from one person to another. Autologous transplant refers to the transplantation of tissues or cells from one person back into the same person.

identified blood stem cells in cord blood, and Eliane Gluckman (hematologist) had clinical expertise in transplant treatments for patients with Fanconi's anemia (Gluckman & Rocha 2005). In this first experimental transplant of cord blood, Gluckman et al. (1989) transplanted the cord blood of a sibling into a young boy diagnosed with Fanconi's anemia (i.e. an allogeneic transplant from a related donor). The unborn sibling had been genetically tested *in utero* for HLA match<sup>8</sup> and a negative diagnosis for anemia. The experiment was a success and the young boy who was treated is currently healthy and shows no signs of Graft versus Host Disease (GvHD) (see footnote 5 for explanation of GvHD) (Gluckman & Roche 2006).

Since this successful transplant in 1988, many clinicians and commentators describe cord blood as having been transformed from "medical waste" to "clinical gold" because of its relatively high concentration of hematopoietic, or blood, stem cells and hematopoietic progenitor cells (Broxmeyer 2005). Prior to this, cord blood was considered clinical waste, or the detritus of birth, and discarded as biological waste after birth. As pluripotent stem cells, blood stem cells are clinically useful because of their ability to regenerate or self-renew and differentiate into the cells that make up the blood and immune system: red blood cells (carry oxygen), white blood cells (fight infection), and platelets (essential for blood clotting). When used in transplant therapies, a physician injects the blood stem cells into the patient where the cells travel to the bone marrow, engraft, and differentiate to restore the cells in the blood and immune system (Broxmeyer 2005).

The history of blood stem cell use in clinical therapies predates the recent hype and attention given to stem cell treatments and before the birth of the new field of regenerative medicine. Blood stem cells derived from bone marrow have

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<sup>8</sup> HLA refers to Human Leukocyte Antigen, protein markers on cells that are unique to each person and identifies "like" from "non-like" cells. Every person receives half of her/his HLA markers from one genetic parent and the other half from the other genetic parent. An HLA match is necessary to ensure that the blood stem cells do not identify the host cells as "non-like" cells or "foreign" and launch an immune response against them. When this happens, this condition is called Graft versus Host Disease (GvHD) and is one of the key clinical concerns associated with blood stem cell transplants.

been used to treat diseases, such as leukemia, since the 1950s (Morena & Gatti 2010). However, proponents of cord blood stem cells point out several clinical advantages of cord blood, or naïve, blood stem cells over bone marrow, or adult, blood stem cells. Cord blood stem cells are more immunologically naïve,<sup>9</sup> easier to collect, and are more readily available at the time of need (i.e. they are stored and wait for a match to be identified) than blood stem cells in bone marrow (McKenna & Brunstein 2011). Because of its immunological naivety, cord blood stem cells are less likely to cause GvHD and thus are particularly advantageous in allogenic transplants. A major limitation to cord blood stem cells, however, is the limited or finite amount of stem cells present in any cord blood collection. As Gluckman (2009) and colleagues point out, a minimum amount of blood stem cells must be transplanted to be clinically efficacious. According to Gluckman (2009) there is agreement among researchers and clinicians that one of the main criteria for a successful blood stem cell transplant is a sufficient amount of blood stem cells. Researchers and clinicians agree “that the minimum number of nucleated cells (NC)/kg should be  $3 \times 10^7$ /kg or  $CD34^+ 2 \times 10^5$ /kg” (195).<sup>10</sup> Researchers have been successful in addressing this limitation by taking advantage of cord blood stem cells’ immunologic naivety and pooling cord blood units for one transplant. Currently, the amount of cord blood collected in one unit is sufficient to treat people approximately 110 pounds or less (Bordet et al. 2010).

Blood stem cells in cord blood also have very different social and cultural meaning than blood stem cells derived from bone marrow. First, cord blood stem cells attracted the public’s attention following the social and cultural hype and excitement around genetics and the promises of embryonic stem cell research and

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<sup>9</sup> Clinicians and scientists refer to cord blood stem cells as being “immunologically naïve” by which they mean transplanted cord blood stem cells are less immunologically primed and are less likely to trigger an immunological response to their host cells than are bone marrow (i.e. “adult”) blood stem cells.

<sup>10</sup> I discuss these numerical measures and the use of numerical knowledge in producing biovalue in cord blood in further detail in Chapter 4. I show in Chapter 4 that there may be wide variance in the amount of cord blood collected and that even units below the minimum recommended volume established by the private bank may be banked.

regenerative medicine. Thus, many people associate cord blood stem cells with speculative stem cell futures. Private cord blood banks also emphasize future speculative possibilities of blood stem cells in their marketing. Second, a bone marrow transplant requires that the donor undergo a surgical procedure and thus there is a person identified with the blood stem cells. Cord blood stem cells, on the other hand, are de-personalized both temporally (i.e. the cord blood stem cells may have been collected at a much earlier time than when it is used) and through anonymization procedures (i.e. if the cord blood is donated to the public bank it will be anonymized).

Cord blood banking is also closely associated with practices in clinical care in labour and birth (Hutton & Hassan 2007). Specifically, cord blood is collected during the third stage of labour which is the stage between the birth of the baby and delivery of the placenta (Tan et al. 2008). Women are at greatest risk for postpartum hemorrhaging at this stage and as such, many clinical organizations including the Society of Obstetricians and Gynaecologists Canada (SOGC), recommend “active management” during the third stage of labour (Tan et al. 2008; SOGC 2009). Active management involves the administration of drugs (e.g. oxytocin to stimulate contraction of the uterus), clamping the umbilical cord, and assisting with the delivery of the placenta (SOGC 2009). The timing of clamping the umbilical cord has a direct impact on the amount of cord blood collected. The sooner the umbilical cord is clamped the greater the likelihood that a sufficient volume of cord blood will be collected. Conversely, the later the cord is clamped the less likely a sufficient volume of cord blood will be collected. Advocates of delayed cord clamping argue that the newborn benefits from receiving nutrient rich blood following birth. Currently there is clinical debate over when, early or delayed,<sup>11</sup> the

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<sup>11</sup> Before the 1950s, in medical practice in the USA, “early clamping” was defined as clamping one minute after birth and “late clamping” was defined as clamping up to 5 minutes after birth (American College of Obstetricians and Gynecologists (ACOG) 2012). Following a series of studies that showed that healthy newborns achieved about 90% blood volume after their first few breaths, the time before clamping was shortened (ACOG 2012). Currently, there are debates over clamping time and definitions, but for full term births “early clamping” is generally thought to be clamping up to 30

cord should be clamped. Proponents of delayed clamping point to a number of clinical benefits including increased placental blood flow to the newborn which is rich in oxygen, iron, immunoglobulins, and stem cells that may be important for tissue regeneration (Hutton & Hassan 2007; Hutton et al. 2013). These benefits are most critical for babies born preterm (ACOG 2012; Garofalo & Abenhaim 2012). Others point to several clinical risks of delayed clamping including increased risk for newborn jaundice, difficulties with resuscitation of the newborn if this is needed, and increased risk for postpartum hemorrhaging (ACOG 2012). Because of the potential increased risk for postpartum hemorrhaging, the SOGC (2009) recommends delayed clamping for preterm babies, but not delaying clamping for term babies. Other clinicians, such as Garofalo & Abenhaim (2012) and Hutton & Hassan (2007), recommend delayed clamping for both preterm and term babies arguing that there is no evidence of increased incidence of postpartum hemorrhaging in cases of delayed cord clamping.

The debate over the timing of clamping has two important effects for cord blood banking. First, delayed cord clamping decreases the likelihood of collecting a sufficient amount of cord blood stem cells. The more placental and cord blood that flows into the newborn, the less cord blood there is for collection. Second, the benefits to the child of delayed cord clamping presents a current use for cord blood – that is, to optimize the health of the newborn through its infusion immediately post birth – and thus challenges the “waste” argument in favour of banking cord blood. According to the “waste” argument, cord blood should be banked because if it is not, its potential health benefits will be wasted, or lost, because it will be thrown out as biological waste. The resolution of the debate over the timing of cord clamping will have significant implications for both public and private cord blood banking. Knowing the clinical benefits of cord blood infusion into the newborn introduces a third option regarding cord blood for women and couples. Prospective parents must

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seconds after birth and “delayed clamping” longer than 30 seconds after birth (Garofalo & Abenhaim 2012).

now weigh the benefits of cord blood for present use in the newborn against future potential use as treatment in the future (Brown 2013).

### **Current Therapeutic and Future Speculative Uses of Cord Blood**

Since the first cord blood stem cell transplant in 1988, approximately 20,000 cord blood stem cells transplants (mostly allogeneic) have been conducted internationally (Broxmeyer 2013). According to the World Bone Marrow Association (a leading international organization on blood stem cells), as of 2013 there are approximately 600,000 cord blood units available in 158 public cord blood banks internationally (Baudioux 2013). Statistics for private cord blood banks are not available since most private banks are not required to disclose this information. Currently, cord blood stem cells are used to treat leukemias, lymphomas, blood cell proliferation disorders (such as anemias, sickle cell disease, thalassemia, some inherited immune system diseases (such as erythropoietic porphyra), and some inherited metabolic disorders (such as Lesch-Nyhan syndrome) (Gluckman & Roche 2006; Rosell & Virt 2004). These conditions are treated with an allogeneic cord blood transplant, either by a related (i.e. family member, usually a sibling) or unrelated (i.e. non-family member) donor. Autologous cord blood transplants have been used for people who have had a solid tumor cancer that did not originate in the blood or immune system (e.g. retinoblastoma) whose cancer was treated with radiation. In these cases, the cord blood stem cells were transfused to reconstitute their immune system that had been decimated by the radiation. Thus, autologous transplants are used primarily in current treatment regimes to address the effects of cancer treatments and not to treat the disease itself.

Although private banks emphasize autologous use of cord blood (i.e. they emphasize banking a child's cord blood for that child's future use), the vast majority of cord blood uses are allogeneic. While cord blood transplants were initially used to treat more children than adults, statistics collected by Eurocord, an international registry, shows that as of 2006, more adults have been treated with cord blood



transplants than children. This coincides with an increase in the use of two, or doubled, unrelated cord blood units in one transplant. Gluckman (2009) writes that this procedure, which pools two cord blood units that are closely matched to treat one person, effectively addresses the limitation of cord blood transplants due to the relatively small amount of cord blood collected in a single unit. The efficacy of doubled, unrelated cord blood units is achieved in large part because of the immunologically naïve nature of cord blood stem cells. Although scientists have been studying *ex vivo* expansion techniques to increase the number of blood stem cells in cord blood, they have yet to be successful (Ballen et al. 2013). Thus, allogeneic cord blood transplants are considered to be an effective treatment option for adults and children who have the diseases listed above (Broxmeyer 2013; Gluckman 2009). Based on these current therapeutic uses, many clinical organizations, such as the SOGC and ACOG, recommend donating cord blood to a public bank for allogeneic use.

Private banks emphasize the promissory uses of cord blood. Many of these experimental and clinical trials take advantage of the non-hematopoietic stem cells and factors in cord blood to treat a number of conditions including Type 1 diabetes and neurological disorders such as cerebral palsy (Harris 2005; McKenna & Brunstein 2011; Sun et al. 2010). Sun et al. (2010) have shown that following cord blood transplantation in a young child with a neurological disorder, cord blood cells have engrafted and differentiated in the brain leading to the production of new neural tissue. A key site of regenerative medicine is in the area of neurological repair to treat conditions such as Parkinson's Disease, brain injuries, and spinal cord injuries. Cord blood applications in regenerative medicine have used both autologous and allogeneic transplants and have shown some promising results; however, limiting factors continue to be the relatively low number of stem cells in cord blood and HLA-matching (Korbling et al. 2005). These future uses also hold the promise of treating conditions that are more prevalent than the current treatable conditions. In addition to neurological conditions and Juvenile diabetes, researchers

are examining the use of cord blood in cardiac disease and Alzheimer's Disease. The potential to treat and renew function in chronic and common conditions is a key promise of regenerative medicine. Currently, although promising, these uses are still in various stages of experimental and clinical trials and thus, lead researchers in cord blood research, such as Gluckman et al. (2011), caution against private, autologous banking. Whether or not these experimental uses will enter clinical practice remains highly speculative.

### **Chapter Outline**

In Chapter 2, I discuss the literatures and theoretical framework of this study and the methodological approach. This Chapter provides a discussion of the scholarship that determines the analytic stance of my work and situates its main contributions. My project is framed by Foucauldian biopolitics literature, social science literature on bioeconomies, and feminist scholarship on reproduction and reproductive politics. According to Foucault, "By [*biopower*] I mean a number of phenomena that seem to me to be quite significant, namely, the set of mechanisms through which the basic biological features of the human species became the object of a political strategy, of a general strategy of power, or, in other words, how, starting from the eighteenth century, modern western societies took on board the fundamental biological fact that human beings are a species. This is roughly what I have called biopower." (Foucault 2007: 16). Foucauldian and Foucauldian-inspired scholars characterize contemporary biopolitics as having been transformed by advancements in molecular science and medicine. I review some of the key characteristics in this conceptualization of contemporary biopolitics and follow this with several important critiques of this literature. Specifically, I draw on scholars from a range of social science disciplines who argue that the dominant view of contemporary biopolitics, as put forward by Rose, Rabinow and colleagues, is limited in its social critique of biopolitical strategies and over-generalizes Western, middle-class biopolitics to a global arena. In this Chapter, I also provide an

evaluative review of the social science literature on bioeconomies, biovalue, and biocapital. Scholars suggest that a feature of contemporary biopolitics of neoliberalism is the increasing role of market economies in matters of science and health. Private cord blood banking is a for-profit industry made possible by scientific and clinical discourses that constitute cord blood as a potentially valuable biological material. Although cord blood does not enter market circulation, private banks generate profit by selling women and couples a service based on the production of cord blood as valuable. Chapter 2 concludes with a discussion of feminist literatures on reproduction and reproductive politics that frame my research. Many of the issues outlined by feminist scholars regarding the dual streams of women's bodies for reproduction and regenerative medicine are relevant to the practice of private cord blood banking. The second half of this Chapter provides a discussion of the methodological approach and research methods used in this study. This study is a qualitative study that is influenced by critical ethnography and feminist methodologies. I outline my research methods, access to the field, sample, and analytic methods.

Chapters 3 to 6 are analytic chapters with each chapter focusing on a specific analytic theme emerging from the data. In Chapters 3 and 4, I provide a detailed description and analysis of the process of private cord blood banking to examine the work women do to bank cord blood and the production of biovalue. Chapter 3 examines women's work in banking cord blood beginning from when they learn about cord blood banking to packing and transporting the collected cord blood to the private bank's laboratory for processing. I argue that women's labour is critical to private cord blood banking. In Chapter 4, I examine the production of biovalue in cord blood and show that producing biovalue is a complex social and technical process that involves tensions and negotiations across multiple knowledges. The cord blood unit received by the bank must be processed and cryopreserved. I demonstrate that cord blood's biovalue is its potential use value and that this value is unstable. It is not an inherent biological quality, but is produced through

negotiations and tensions between the for-profit aim of the private bank and the meanings and values of cord blood for women. I show how cord blood's biovalue can also be "lost" if it is determined to be clinically useless when it is needed.

In spite of the uncertainty of cord blood's potential biovalue, private banks market their services as "biological insurance", a subject I turn to in Chapter 5. Private banks promise future health security through biological accumulation or hoarding. I show how women described banking cord blood because of fear and guilt and I describe one woman's experiences with the failure of cord blood to ensure her child's health. I argue that "biological insurance" is sold by a marketing strategy that is aimed at women's fear and hope for their child. I suggest this strategy operates through women's anxieties about their child and changing ideas and expectations about controlling future health through biological means.

In Chapter 6, I draw on women's experiences of private cord blood banking to challenge the Foucauldian abstract neoliberal medical subject in health. Most social scientists writing on the active neoliberal medical subject begin their analyses assuming that women and couples act responsibly and prudently by making a rational investment in future health when they pay to bank cord blood. However, women's accounts of banking cord blood differed from this conventional understanding of the neoliberal medical subject. I show that women do not act as rational decision-makers, but draw on emotional reasoning to bank. While they act in an effort to be responsible mothers, they orient to private banking as precautionary actors. Women presented complex narratives of having to make decisions in a context of uncertainty and acting with precaution because the possibility of harm – that is, the loss of their child to a disease that could be treated with cord blood – was so great that they were compelled to act.

In the concluding Chapter, I outline the key arguments of this study, propose a series of elements for a sociological critique of private cord blood banking, and consider some implications of my work in this dissertation for health policy. I end with some reflections on contemporary biopolitics.

## **Chapter 2: Theory and Methods**

### **Theoretical Orientation and Literatures**

This study is informed by Foucauldian and post-Foucauldian work on contemporary biopolitics. In addition, I draw on theoretical and empirical literatures that examine the interface of contemporary biosciences and biotechnologies, health, and feminist approaches. This scholarship covers a range of disciplines which include sociology, anthropology, and science and technology studies (STS). The field of biopolitics scholarship is broad; thus, I focus the following theoretical overview on Foucauldian and post-Foucauldian biopolitics scholarship that examines contemporary or molecular biosciences and medicine. I do so since much of the existing social science literature on private cord blood banking and stem cell related science draws on, or makes reference to, Foucauldian and post-Foucauldian work. I begin with a discussion of contemporary biopolitics and how it has largely been conceptualized in Western social science; I then turn to key debates and critiques of this dominant conceptualization. Next, I discuss the theoretical terrain that brings together biopolitics and economics by examining the literature on bioeconomies, biocapital and biovalue. I provide a discussion of how these concepts are situated within a biopolitics framework and examine some of the key debates in this literature. Lastly, I review some significant works by feminists who examine reproductive technologies and regenerative bioscience and medicine. I draw on this feminist literature for two key reasons: first, the site of reproduction and reproductive technologies is an important biopolitical site and coincides with the site of cord blood collection; second, this project is a feminist one. Following an evaluative review of some of the key points and debates in these three areas, I provide a discussion of the epistemological framing of this study, and end with a detailed review of the project's research methodology.

## Biopolitics

Biopolitics, or the “politics of life,” is a concept and analytic framework widely used by social science scholars working at the intersections of health, the social, and political. Writers use the concept loosely and often. Social scientists using biopolitics as a conceptual and analytic framework can be divided into two broad streams: those who apply it to a Marxist-inspired theoretical approach and those who draw on a Foucauldian understanding of biopolitics. Scholars in the first stream use the concept of biopolitics broadly to refer to the range of political debates, ethical challenges, and public engagement emergent with the contemporary biosciences and medicine. In this sense, biopolitics is understood as the politics *of* the biological and conceptualized through a Marxist understanding of power and conflict in which different groups struggle against one another for control. An example of this approach is Klawiter’s (2008) study of the biopolitics of breast cancer in which she examines the emergence and growth of the feminist political movement around breast cancer and women’s health in North America. I do not take this approach to biopolitics since private cord blood banking is not a site of political activism or political movements, nor is there much public debate over it. I situate my work within the second stream, a Foucauldian conceptualization of biopolitics. Foucault’s concept of biopolitics differs significantly from the Marxist approach by theorizing it as an historical shift that occurred in eighteenth century Europe as political power came to incorporate a new function: implanting life and intensifying health. Biopolitics, according to Foucault, has as its ultimate aim “optimizing the human species at the level of life and health” (Weir & Mykhalovskiy 2010: 22). Biopolitical projects act on collectivities, populations, and the bodies of persons (Weir & Mykhalovskiy 2010: 22).

Foucault writes, “By [*biopower*] I mean a number of phenomena that seem to me to be quite significant, namely, the set of mechanisms through which the basic biological features of the human species became the object of a political strategy, of a general strategy of power, or, in other words, how, starting from the eighteenth

century, modern western societies took on board the fundamental biological fact that human beings are a species. This is roughly what I have called biopower.” (Foucault 2007: 16). According to Foucault, biopower and biopolitics, emerged in 18<sup>th</sup> century Western Europe, with the establishment of the biological sciences and the inclusion of humans as a species among other species in the life sciences. With this fundamental ontological and epistemological shift in human beings as one of many biological species, the optimization of individuals and populations through measures of health and life became a central political function. Foucault writes that in the 18<sup>th</sup> century, the historical threshold of modern medicine, there were two concurrent processes underway: one, the development of a *medical market* with a growth in medical experts aimed at providing clinical medicine for individuals and families; and two, the development of a *politics of health* in which disease became known as a political and economic problem to be managed through public policy (Foucault 2000: 90-91). The imperative of health of the human species became a key personal, political and economic concern and strategies aimed at optimizing health acted concurrently on the population (e.g. public hygiene and health programs) and individual bodies (e.g. clinical care of individuals).

In his book, *The History of Sexuality Vol. 1*, Foucault (1978) defined biopolitics and anatomo-politics as the two poles of biopower that emerged in a particular historical moment and geographical place. According to Foucault, biopolitics referred to strategies aimed at optimizing the health of the population while anatomo-politics were disciplinary techniques aimed at the health of individual bodies. Biopower and biopolitics emerged with the shift from sovereign rule to a liberal political regime. The sovereign ruled according to the right to “*take life or let live*” (Foucault, 1978: 136) while the latter governs through a strategy to “*foster life or disallow it to the point of death*” (Foucault, 1978: 138). According to Foucault, biopolitics reflects a modern rationale of governance in which the health of the population and individuals has become the central object of political calculation. The health of the population has come to be known by, measured, and governed

according to the metrics of vitality and health such as population statistics of morbidity and infant mortality. Individuals are governed by disciplinary and pastoral powers and incited to take up health practices to manage her/his own health. According to a Foucauldian framework, biopolitics is historically specific and associated with a particular political regime and prevailing expert knowledges; thus, biopolitical operations or strategies will change under different historic and material conditions, and changes in political forms and strategies. Concepts such as “health,” “life,” and “illness” are not self-evident categories determined solely by an objective, realist science, but are produced in and through power/knowledge relations. How these concepts or objects are produced, known, defined, measured, and governed are shaped by particular forms of expert knowledge and discourse, and ways of knowing that dominate at a specific time and place.

### **Contemporary Biopolitics**

Theorizing contemporary biopolitics requires accounting for changes in political governance, from liberal and social welfare political regimes to advanced liberal or neoliberal political regimes, and accounting for the emergence of molecular bioscience and biomedicine. In governmentality literature, neoliberalism follows the social welfare state and is characterized by a retraction of the state and state surveillance technologies (i.e. social welfare projects such as community health programs) and an increase in the role of the market and individual responsibility (Rose 1999). Alongside this shift in political regime was a shift in the political subject from the “welfare subject” who views her/himself in relation to a larger social group and has a shared responsibility with others in a social group, to the “active subject” who views her/himself as an individual responsible for her/himself only (Rose 1999). The individual active subject is the object of health governance technologies in advanced liberalism. With the rise of molecular bioscience and medicine, scholars argue that how the active subject is governed (i.e. the modes and techniques of governance) and how the subject comes to know her/himself and



understand her/his own body and health has shifted from molar to molecular forms of knowledge, identity, and personhood (e.g. Novas & Rose 2000; Rabinow 1996; Rose 2007; Franklin 2001).

Molecular bioscience, or the science of sub-microscopic biological entities, emerged in the 1930s and has shaped contemporary biotechnologies and medicine. Genomic, post-genomic and stem cell science have their roots in the early work of molecular scientists working on DNA, RNA, and viruses (Yoxen 1981). The application of molecular science to clinical practice has led to the development of new fields in medicine, namely personalized medicine and regenerative medicine. Personalized medicine refers to individualized therapies based on one's genetic make-up. The exemplary application of personalized medicine is in the field of pharmacogenomics in which knowing one's genetic pre-disposition to detoxifying particular medications, in theory, can be used to "tailor" drug treatment to the individual (Hedgecoe 2004). Regenerative medicine is based on the "power" of stem cells and their ability to regenerate and differentiate into other forms of cells (Perpich 2004). The promise of regenerative medicine is the manipulation of the stem cells' ability to provide biological treatment, such as regenerating a new liver, for a patient who has liver disease.

Foucauldian-inspired, or post-Foucauldian, work in contemporary biopolitics has been largely shaped and led by the work of Rose, Rabinow and colleagues. Much post-Foucauldian scholarship that examines new biotechnologies and health begin from Rose and colleagues' characterization of contemporary biopolitics. The result is that much of this literature reproduces the view of Rose and colleagues with little critical examination. Given the importance of their work, I provide a brief discussion of some of the main claims or arguments made by these scholars that have had a strong hand in shaping this body of scholarship. This review is not an exhaustive review of their work, but rather a review of some of the key distinctions or shifts that they argue characterize contemporary or molecular biopolitics.

First, the rise of molecular bioscience has led to an epochal shift from the molar to the molecular leading to a flattened ontology and new targets of governance technologies (Novas & Rose 2000; Rabinow & Rose 2006; Rose 2007). Scholars argue that there has been a fundamental shift in paradigm or “way of thinking” in bioscience and medicine from the molar, or organism and population, level to the molecular, or genomic, level. Diseases are now known and categorized according to genetic mutations, or SNPs (single nucleotide polymorphisms), and the goal is to tailor treatment to one’s genetic make-up (i.e. personalized medicine). This shift in scale also means greater individualization and responsibility for one’s own health and a “flattening” of the body in health from a body of depth (i.e. an understanding that disease is located in the deep interior tissues of the body) to one of digital flatness (i.e. an understanding that the locus of disease can be found in a genetic sequence that is digitized).

Second, genomic and post-genomic science has led to new forms of subjects and personhood. Scholars argue that there is a new form of identity, the “genetic individual” or “somatic personhood” (Novas & Rose 2000), and new forms of social organization, biosociality, based on this new biological or genetic identity (Rabinow 1996). Genetic individuals are governed through risk techniques that operate at sites of predictive genetic testing. For example, Polzer (2006) shows how women who undergo predictive genetic testing for breast and ovarian cancers are incited to manage their genetic risk. Unlike single gene disorders, such as Huntington’s Disease, most diseases or conditions (including breast and ovarian cancers) have a highly complex relationship between genotype and expression of the disease or disorder. In other words, in most cases, the O-GOD (one-gene-one-disease) model does not apply. Increasingly, diseases are understood to be associated with a genetic predisposition to the disease, leading to the application of genetic tests that aim to identify whether or not people have genetic mutations that are associated with increased likelihood or susceptibility to the disease. These tests produce people with a range of “genetic susceptibilities” to developing a disease. The

categorical distinction of genetically “at risk” and “not at risk” have shifted to a scale where everyone potentially can fall along a scale of susceptibility (Rose 2001). This is not unlike the shift in older forms of medicine from the categorical distinction between “normal” and “pathological” to a scale in social medicine where everyone is “pre-symptomatically ill” (Armstrong 1995). In many cases, people are advised that they can manage genetic susceptibility through a range of lifestyle and health practices, such as following a particular diet and/or specific exercise regimens.

Third, contemporary biopolitics is characterized by the dominant operations of a pastoral or a positive form of power that acts, not through discipline or repression, but by inciting action through expert discourses and guidance. The neoliberal medical subject in contemporary biopolitics is one who knows oneself and is known primarily through one’s genetics or biology, seeks out information about one’s health and acts to optimize health. Scholars argue that what distinguishes the contemporary molecular period from the previous molar period is that biology is no longer thought to be outside the realm of human intervention. Thus, while active subjects in the past have been incited to maintain health through preventative strategies, such as quitting smoking, now subjects are incited to act to optimize or enhance health at the level of one’s own biology through body transformation (Rose 2007).

Fourth, in the 21<sup>st</sup> century, biopolitics has been replaced by “ethopolitics.” Rose (2007) writes: “If ‘discipline’ individualizes and normalizes, and ‘biopolitics’ collectivizes and socializes, ‘ethopolitics’ concerns itself with the self-techniques by which human beings should judge and act upon themselves to make themselves better than they are” (27). Foucault defined ethics as “reflexive government of the self by the self,” in contrast to morals which stand as external codes used to govern others (Valverde 2004: 77). Ethics, for Foucault, are practices or techniques of the self based on established codes that orient an individual in relation to the universal (Foucault 1997). For example, monks or followers of a particular religious code who follow a particular set of practices are engaged in ethics. By introducing the concept

of ethopolitics, Rose aims to emphasize the pre-eminence of a form of power that functions by governing individuals through their own self-reflexive governance of their corporeal, or biological, selves. For Rose, ethopolitics emphasizes greater individual responsibility rather than collective responsibility and governance of conduct through reflexive self-governance rather than external forms of coercive, disciplinary power. The individual is increasingly responsible for managing and optimizing her/his health and improving one's self through private means offered by the market rather than through social, collective strategies of the state. Rose (2007) writes that his aim in examining contemporary biopolitics is to move "beyond sociocritique" (39-40). In writing this, he explains that he takes a different view from social scientists who are "highly critical or deeply suspicious" of contemporary developments in biomedicine. While he acknowledges that there is space for criticism, he is more concerned with examining what he considers to be broader epochal shifts in contemporary biopolitics.

Scholars working in various disciplines including, sociology, anthropology, STS, and geography, have responded to this dominant view of contemporary biopolitics and offer alternative lines of inquiry and critique. To begin, scholars argue that the shifts and changes outlined may be accurate for some biopolitical strategies in the Global North, but to extend this singular characterization of contemporary biopolitics to all sites is an inaccurate over-generalization (e.g. Braun 2007; Raman & Tutton 2010; Weir 2006). For example, Raman & Tutton (2010) argue that the reduction of biopower to biopolitics and biopolitics to ethopolitics effectively reduces health governance to individual self-governance "from below" and state power to a pastoral power. While recognizing that changes have occurred with the rise of molecular bioscience and medicine, they challenge the claim that we have experienced an epochal shift to the molecular level. As Raman & Tutton (2010) point out, much genomic information only has meaning when interpreted vis-à-vis genome wide association surveys (GWAS) or large genetic databases produced through the collection of a population's genomic information. Thus, biopolitical

strategies aimed at the population level remain crucial in the age of molecular bioscience. Santoro (2011) also challenges scholars' claims of "novelty" and epochal shifts attributed to contemporary biosciences arguing that, for example, cord blood and placenta have a long history of use in contributing to the physical health and future social well-being of the newborn. From 17<sup>th</sup> century records of drops of blood from the navel cord being given to the weak looking newborn child of King James II in England to more contemporary practices in which the afterbirth symbolically represents the newborn child (i.e. is considered to be the child's double), Santoro (2011) argues that cord blood and placenta have long been liminal tissues that mediate both maternal and fetal bodies and social and political bodies. He refers to this as the "liminal biopolitics" of cord blood.

Critics of Rose and colleagues also argue that multiple forms of power, including disciplinary and coercive powers, continue to operate on, or target, multiple levels – the molecular, the individual, specific social groups, or the population – and that these forms of power require theoretical and empirical investigation (Braun 2007; Raman & Tutton 2010; Weir & Mykhalovskiy 2010). Braun (2007) offers an alternative to the view of a contemporary biopolitics that assumes coherent, clearly delimited biological subjects who take up practices to optimize health by examining global biosecurity in an age of molecular bioscience. He extends his analysis of biopolitics beyond the affluent West and argues that the rise of molecular bioscience has led to an expansion of global surveillance technologies that act on biological subjects with open boundaries; that is, subjects who can transmit and carry various infections and diseases across borders. Power that operates through global surveillance technologies, is not the pastoral power that Rose and colleagues emphasize, but coercive, disciplinary, and in some cases repressive forms of power that restrict and limit people's movements and actions. Braun (2007) suggests that increased global biosecurity and the exercise of surveillance technologies and powers in the Global South support the conditions of health governance of the privileged individuals in the affluent North (West). Braun

(2007) and others, such as Weir & Mykhalovskiy (2010) and their work on global health vigilance, offer an important corrective to the dominant stream of Western biopolitics described above by extending the analyses of a global biopolitics.

I draw on a critical biopolitics analytic framework to situate my project. In several ways, private cord blood banking is an exemplary case of a contemporary biopolitical strategy in the Global North. It is aimed at individuals to manage their own health through engaging in consumer practices of tissue storage or accumulation. Private cord blood banking is promoted as providing an opportunity for people to participate in future stem cell possibilities and advancements in molecular medicine. The encouragement to bank can be viewed as inciting people to bank cord blood as part of their ethical responsibility to be healthy. Rather than beginning analysis from these claims, I draw on in-depth qualitative interviews with women who have banked cord blood in a private bank to consider how cord blood banking as a biopolitical strategy “plays out” in the everyday lives of people who have participated in it. Moreover, I aim to contribute to a critical biopolitics by attending to women’s experiences and providing a detailed empirical account that is missing from much of the scholarship that examines biopolitics primarily through expert discourses. I show the complex, challenging experiences of women who bank cord blood and argue that they act not as rational calculating investors or entrepreneurs, but as anxious ironic gamblers hedging their bets. I argue that there is a cost to women who are compelled to act and sacrifice on behalf of their children, *for* their children’s health, through moralizing gendered discourses of being a “good mother.” I argue that the emphasis on pastoral power that acts through self-knowledge, individual responsibility and ethical action does not fully capture the experiences of women. Rather, they are compelled to act in response to a moralizing discourse which functions in a disciplinary manner. If women were not to bank and their child should need cord blood in the future, they would have failed as mothers. I suggest that the production of the need to secure future health through banking

cord blood “biological insurance” and the insertion of this need into the population is achieved in part by an expectation of the ability to exercise greater control in a molecular age. Ironically, I show that women must act in greater uncertainty and thus do not exercise rational calculation of risk management, but precaution in uncertainty.

### **Bioeconomies, Biocapital, and Biovalue**

Contemporary biopolitics scholars have also examined the economization and capitalization of genomic, or post-genomic, bodies and the development of bioeconomies. Whether biological bodies are characterized as clearly delimited or open and fluid, scholars recognize that biological materials, information, and processes are coming to be capitalized and valued in novel ways. The contemporary bioeconomy is generally defined in two ways. First, from the work of economists and economic sociologists, the bioeconomy is defined as the collection of economic or capital markets that arise from and depend on the production, circulation, exchange, and/or use of biological materials (OECD 2009) or arise from the immaterial entities of local biological knowledges and trans-local market technologies, such as patents (Birch 2012). A second way of defining bioeconomies is as tissue economies; that is, as a system or network involving the collection, storage, and circulation of biological materials that is not, by definition, aimed at generating an economic profit. The blood banking system is a familiar example of this second form of bioeconomy (Waldby & Mitchell 2006).

Social scientists have theorized the capitalization and valuation of biology through the development of concepts such as *biocapital* and *biovalue*. Writing in the early 1980s, Yoxen (1981) argued that while people have used biological materials for treatments and other purposes (e.g. fermentation) for centuries, what is unique about contemporary molecular bioscience and biotechnologies is the way in which capital – that is, the for-profit industry – is directing the development, use, and/or application of these new biotechnologies. Yoxen referred to the increasing role of

capital in biology as “capitalising life” (112). Since Yoxen’s early formulation of capitalizing life, social scientists have further developed and applied the idea of capitalizing life, or biocapital, to examine developments in contemporary biology and economies. Scholars theorizing biocapital in molecular science come from a range of disciplinary perspectives (e.g. sociology, anthropology, and STS) and draw on Marxist and Foucauldian work in developing and applying this concept. Biocapital is conceptualized broadly ranging from “biology-as-capital” (Franklin & Lock 2003) to a new form of capital produced in new forms of speculative capitalisms (Rajan 2006). Rajan (2006) argues that in the 21<sup>st</sup> century, there are two types of capitalisms that operate: commodity capitalism and market capitalism. He argues that the former is the older system of capitalism based on commodity production while the latter is based on speculation, venture capital, hope and hype and is associated with the biotech industry. The capitalization of biological entities is a central form of capital production in contemporary market capitalism.

In 2000, writing on the Visible Human Project,<sup>12</sup> Waldby introduced the concept of *biovalue* to theorize the changing relationship between bodies, value, and new biotechnologies. Waldby defines biovalue as the surplus value that is produced through harnessing the generative capacities of some, lower order, vital entities (for e.g. fetal and cadaveric tissue) in order to enhance the vitality, or living force, of higher order living entities (2000: 19). According to Waldby, biovalue is “generated wherever the generative and transformative productivity of living entities can be instrumentalized along lines which make them useful for human projects” (Waldby 2000: 33). She defines biovalue within a Foucauldian-inspired biopolitics theoretical framework. Her conceptualization of biovalue allows for considering how the optimization of life and health now promised in contemporary regenerative

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<sup>12</sup> The Visible Human Project is a project of the U.S. National Library of Medicine, funded by the National Institutes of Health; it “is the creation of complete, anatomically detailed, three-dimensional representations of the normal male and female human bodies” (<http://www.nlm.nih.gov/research/visible/>, downloaded Mar. 15, 2013).



medicine depends on constituting some forms of life as marginal, thus enabling their use by and for others.

Many scholars have applied the concepts of biovalue and biocapital in their work on contemporary biosciences. Biovalue has been used to describe the “raw materials,” such as biological and psycho-social information, needed for pharmacogenomics research (Svendsen & Koch 2011), new forms of value attributed to human embryonic stem cells (Rosemann 2011), and the relatively newfound value of cord blood stem cells (Brown & Kraft 2006). In general, scholars have applied the concept of biovalue to account for changing economic and social values of biological materials, processes, and information through technological transformation. With few exceptions, biovalue has received little theorization since Waldby’s initial offering and in many cases, scholars have applied it to refer to an inherent value in biological entities that can be harnessed through new biotechnological and bioscientific manipulation.

Recently, scholars have begun to critique the theorization and application of “bio-“ concepts such as biocapital and biovalue. Most notably, Helmreich (2008) and Birch & Tyfield (2012) critique the work on biocapital and biovalue for a lack of adequate theorization of Marxist concepts. These scholars emphasize the need to begin from a clear Marxist conceptualization of *capital* and *surplus value* in order to better theorize contemporary biological forms. According to Marx’s labour theory of value (1978[1867]: 329-220), money is transformed into capital when human labour produces surplus value in a commodity in circulation. In other words, surplus value is the extra value produced through the work of the labourer. In capitalism, labour is commodified (i.e. labour-power) and workers produce more value than what they are paid through their wages. Capitalism, according to Marx, makes invisible this unequal exchange of wages for labour. Both Helmreich (2008) and Birch & Tyfield (2012) argue that scholars fetishize biocapital and biovalue – that is, erase labour and social relations involved in the production of biocapital and biovalue – by defining or applying both concepts as inherent properties of biological

materials. Birch & Tyfield (2012) extend their critique of the “bio-“ concepts and question whether or not these concepts are even needed; that is, they challenge the claim that the contemporary period is marked by transformations in forms of capitalisms associated with the rise of biotechnologies and molecular science (Rajan 2007) and the claim that biovalue marks a novel form of surplus value that is unique to biological materials (Waldby 2000). They argue that rather than transformations in capitalisms and capital relations, the contemporary bioeconomy is marked by a move away from an emphasis on the production and circulation of commodities to a focus on immaterial entities or forms (Birch 2012; Birch & Tyfield 2012). Birch (2012) suggests that theorizing immaterial forms, such as biological knowledges, and the relationship between local embedded knowledges and trans-local technologies, such as patent laws, is key to understanding the new bioeconomy.

I take the view that biocapital and biovalue are sociologically useful conceptual tools in the study of contemporary biopolitics. As I show in Chapters 3 and 4, women’s participation in private cord blood banking as a strategy to optimize health is inseparable from participating in the production of biovalue and biocapital. Unlike Birch and Tyfield who view these concepts solely as economic concepts and argue that they do not offer anything novel in the field of economics, I suggest that sociologically, biocapital and biovalue act as more than economic concepts. I argue that biocapital and biovalue play an important heuristic role in the study of contemporary bioeconomies and biopolitics and are useful in acting as sensitizing concepts to the social changes associated with the increasing links between capital, molecular biosciences and medicine. Biocapital and biovalue act as important conceptual tools by which to think through and analyze changing ways in which people understand and value life in relation to biological materials, their own and others. I agree with critics who argue that scholars have largely applied these concepts with little theorization and detailed empirical examination regarding the production of biocapital and biovalue. In addition to the concern of fetishization of these concepts, I suggest that beginning analysis from the point of viewing certain

biological entities as biocapital or having inherent biovalue is to begin analysis from within biomedical or bioscientific discourse that establishes these entities as valuable rather than considering how it is that some biological entities come to be capitalized and valued. I suggest that the processes of the capitalization and valuation of biological materials, such as cord blood stem cells, are social as much as they are economic and technical processes and detailed examination of how materials are valued (or not) provide important insight into contemporary bioeconomies, biocapital, and biovalue.

In this project, I conceptualize bioeconomies as both forms of tissue circulation and as market economies that are based on biological materials, knowledge and processes (see Chapter 4). I use biocapital to refer to cord blood as a biological material that enters into a form of capital market through the buying and selling of banking services. I conceptualize biovalue as value that is produced in or attributed to cord blood as a biological object that can be used potentially for ensuring future health. I contribute empirical work that details the production of biovalue and biocapital in cord blood.

### **Feminist Approaches: Reproduction, Reproductive Technologies, and Contemporary Biosciences**

The health and life of individuals and the population are intimately tied to matters of reproduction. In the 21<sup>st</sup> century, biopolitical strategies are deployed at the site of reproduction and the application of reproductive technologies (such as vitro fertilization (IVF) and artificial insemination (AI) to surrogacy and more recently, egg freezing). For example, pregnant women in North America are the targets of a constellation of surveillance and disciplinary technologies aimed at ensuring a healthy child is born (Weir 2006). More recently, amniocentesis, or the application of testing of the unborn child during pregnancy, is used to identify some genetic conditions prior to the child's birth. Feminist scholars, from a range of disciplinary fields, have theorized and critically examined reproductive

technologies.<sup>13</sup> Much of the earlier feminist scholarship in the mid-1980s was critical of the application of reproductive technologies, such as IVF, viewing them as masculine, patriarchal interventions into women's natural biological processes (for e.g. the work of the Feminist International Network of Resistance to Reproductive And Genetic Engineering, or FINRRAGE). Since then, feminist scholars have taken more nuanced views of reproductive technologies examining women's experiences of infertility and their decisions to take up reproductive technologies (e.g. Rapp 1999), recognizing the ways in which these technologies enable some same sex couples to have biologically-related children (Almack 2006; Chabot & Ames 2004), and showing how women are not merely "controlled" by masculine technologies, but also exercise agency and participate in producing themselves as particular objects and subjects through taking up reproductive technologies (e.g. Thompson 2005).

Feminist scholars have critically examined several important areas related to developments in contemporary biosciences. I focus on three related areas: first, the increasing need for female biological materials in assisted human reproductive technologies and regenerative bioscience and medicine; second, questions and concerns regarding the commodification of feminized bodies and biological materials; and third, destabilizing boundaries of personhood through the model of the pregnant body and examination of mother-child inter-relatedness. In contemporary biosciences and medicine, women's biological materials have a dual purpose: reproduction and regeneration (Franklin 2006; Waldby & Cooper 2008). On the one hand, contemporary biosciences have led to the application of techniques at the molecular and sub-cellular level in matters of reproduction. For example, pre-implantation genetic diagnosis applied in IVF procedures have led some feminists, such as Lippman (1991), to caution against concerns of geneticization (see above). Critics of pre-implantation genetic diagnosis also express concerns of creating "designer" babies through active selection of specific genetic traits. For example,

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<sup>13</sup> See Thompson (2005), pp. 55-75 for a historical review of feminist theorizations of reproductive technologies from the mid-1980s to present.

many critical disability scholars argue that selecting against certain traits that are considered to lead to “disability” undervalues the lives of those who are currently living with a disability. They argue that selecting against certain genetic traits emphasizes a biological rather than a social understanding of disability (Kerr & Shakespeare 2002). Some critics have also cautioned against potential speculative applications of gene splicing techniques that would allow for the excision of undesirable genes and insertion of desirable genes prior to embryo implantation (Kerr & Shakespeare 2002). These speculative techniques have not materialized and are far from being applied as common practice. Feminist anthropologists, such as Rapp (1991) and Franklin & Roberts (2006), have shown that women and clinicians who apply pre-implantation genetic diagnosis do so in ways that demonstrate a sensitivity to the moral questions and dilemmas related to the use of this genetic technique.

Feminist and critical scholars have also questioned the application of other forms of molecular interventions at the site of reproduction that can lead to important questions regarding kin relations. Franklin (2007) writes about somatic cell nuclear transfer, or SCNT, which involves removing the nucleus of an oocyte and inserting the nucleus of a somatic cell into the enucleated oocyte and stimulating the oocyte to divide. This process leads to reproductive cloning, as in the famous case of Dolly the sheep. In theory, SCNT can be used for therapeutic cloning to produce cells that are genetically matched with the person who may need biological “repair.” Although reproductive cloning in humans is illegal in all countries, Franklin’s (2007) work on SCNT and Dolly the sheep raise questions of kin relations and the social implications of cloning techniques. Recently, researchers in the United States have made application to the Federal Drug Administration to begin clinical trials on an oocyte modification technique, also known as “three-parent IVF” (Maron 2014). In

this technique a woman who has “defective” mitochondria DNA<sup>14</sup> (mDNA) has the mitochondria removed from her oocyte and replaced by the mitochondria from a woman’s oocyte that has “non-defective” mDNA. This results in an embryo with genetic material from three “parents”: the nuclear genetic material from the woman’s egg and man’s sperm and the mDNA from the woman who provided the “non-defective” mitochondria. The Human Fertilisation and Embryology Authority (HFEA) in the UK published a report on June 3, 2014 stating that it considers these mitochondrial replacement techniques to be “not unsafe”.<sup>15</sup> Commentators suggest that the UK may approve these techniques later in 2014 (Griggs 2013). While this is far from reproductive cloning, feminist and critical scholars caution this level of intervention because it would cross a very important ethical line; that is, it would be a case of germ-line modification. In other words, this would lead to a genetic change, or manipulation, that would be passed down to further generations (Dickenson & Darnovsky 2014). As Franklin (2001) and others have pointed out, contemporary biotechnologies and techniques allow for human interventions into biology at the sub-cellular level allowing for selection and modification at a level previously not possible. Scholars have pointed out that the boundary between “nature” and “culture” is no longer impermeable. Thus, Franklin refers to contemporary biopolitics as the “politics of life itself.”

SCNT and oocyte modification techniques are just two examples of contemporary bioscience techniques that require women’s oocytes as research tools. This leads to the second need and use for women’s tissues in regenerative bioscience and medicine. The dual needs for women’s oocytes – for reproduction in IVF and regenerative science and medicine – creates a larger market for women’s tissues. Feminist scholars have examined the ways in which unused eggs frozen for IVF treatment make their way into laboratories for scientific research and the social,

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<sup>14</sup> Mitochondria are the energy producing organelles in a cell’s cytoplasm. Scientists have identified DNA in mitochondria, called mDNA, and some diseases are associated with particular sequences in mDNA.

<sup>15</sup> <http://www.hfea.gov.uk/8964.html>, downloaded June 7, 2014

discursive, legal, and technical transformations that shift an egg or embryo intended for family and child-producing purposes to a scientific tool used in research (e.g. Ikemoto 2009). The former is endowed with the potential for personhood and women and couples have emotional and social ties with reproductive eggs and embryos whereas the latter are disentangled from kin relations and become embedded in economic, academic, and clinical relations.

Feminists have critiqued the commodification of women's bodies and reproductive tissues associated with the growth of regenerative medicine and reproductive technologies. Scholars have shown how racialized, marginalized, often poor women are targeted for their eggs to be used in regenerative medicine while White, middle-class, college-educated women are recruited for reproductive eggs (Scheper-Hughes 2001). Dickenson (2007; 2008) argues that women's bodies have been commodified for a very long time (for e.g. in prostitution); however, contemporary forms of commodification are increasingly concerning to and reaching the attention of a broader public because of the growing scale (both in terms of geographic circulation and types of biological materials) and the *feminization* of bodies that opens up women's, and men's, bodies for sale. Dickenson (2007) suggests that men's bodies and parts are increasingly entering into global bioeconomies and thus, a concern that was limited in the past (i.e. a concern only for women) is now expanding to include men. Strathern (2005) also suggests that the conceptual designation of some biological entities as "parts" of larger "wholes" enables the commodification, or ownership, of these biological entities. While a "whole" person may not be owned, and here she uses not a legal definition of property ownership, but an anthropological or social definition of ownership as "agency over" something, a "part" of a person may be owned. Scholars have also pointed to questions of legal ownership of body "parts" that exist outside of bodies and may enter forms of circulation (Gold 1996). While the law in Canada, and in many countries, is very clear on the prohibition of owning body parts as forms of property, the growing practice of private tissue banks, including private cord blood

banks, may present some challenges to these laws in the future. As Waldby (2006) suggests, privately banked cord blood stem cells exist as a hybrid form of property that while not legally owned as a form of property by the person who banks it, the person still maintains some legal rights to it. Finally, feminists, such as Dickenson (2007) have also questioned women's rights to ownership of their own biological materials as forms of property. They argue that women have largely been excluded and erased from being active agents in the provision of their biological materials. For example, the language of "harvesting" or "extracting" eggs suggests that women's bodies (and men's bodies in the provision of organs such as kidneys) are passive objects to be mined.

As Thompson (2013) points out, however, the ethics of stem cell related research extends beyond issues of procurement. In her ethnographic study of the "ethical choreography" of stem cell science in the state of California, she argues for the development of "good science" that is a science-with-ethics. For Thompson, a science-with-ethics is one in which ethical considerations are broad and include not only the rules internal to the conduct of science (e.g. do not falsify results), but also attends to the multiple social and political concerns entangled in the development of pluripotent stem cell science. She questions the prohibition of paying women for their eggs, arguing that doing so excludes women from the economic value chain of stem cell science, a value chain in which all other participants (e.g. researchers, biotech companies, etc.) benefit financially. Thompson advocates avoiding the preemptive foreclosure of discussion and debate on complex ethical issues, even those arguments that have been made with the intent of protecting women (e.g. prohibiting payment for women's eggs). The issue of payment is part of the broader ethical question of what form of reciprocity should underscore the procurement and use of biological tissue? Should the same form of reciprocity be applied to the use of eggs for assisted reproductive technologies as for the use of eggs in pluripotent stem cell research? Thompson argues for 'in kind reciprocity' by which she means "models that [seek] to incentivize, empower, recompense, and/or protect donors in



ways that [are] explicitly indexed to the use to which their tissue was being put” (186). Here again, Thompson proposes a model that requires detailed investigation and discussion rather than one that promotes following a set of abstract principles and rules.

Feminist scholars have also examined questions of permeable body boundaries, identity, and personhood arising from the contemporary biosciences, circulation of biological entities, and banking of bodily tissues (e.g. Landecker 2007; Martin 2010). For example, Landecker (2007) shows how the science of culturing cell lines *in vitro* and the production of exogenous hormones in the laboratory disrupted the biomedical boundaries between the “external” environment and “internal” body. Compounds, such as hormones, and biological cell lines could be produced and kept alive outside the body requiring redefinitions of biomedical materials and terms that were defined in part by their production within bodies. Martin (2010) argues that contemporary work on microchimerism – that is, the existence of genetically different, immunologically non-reactive, cells in one body – challenge long-held biomedical discourse that defines an individual as having cells with only one set of genes. Moreover, microchimerism challenges immunological understandings of an individual that defines “self” from “non-self” based on a body’s immune reaction to “foreign” cells. Feminist philosophers and social scientists have also questioned conventional biomedical and legal understandings of individual bodies through examination of the embodied pregnant body and the intercorporeality of maternal and child bodies (e.g. Bigwood 1991; Weiss 1999). Wynn (1997) suggests that even after birth, the mother and child continue to develop and extend as Beings through their shared embodied holding and touching. In questioning how body boundaries are established, undone, and maintained, feminist and critical scholars have argued and shown how scientific and biomedical discourses of bodies are contingent, socially constructed, and may benefit some more than others. Questions of body boundaries and how “parts” are assigned to “wholes” are particularly important in tissue banking. Cord blood banking raises

several important questions related to body boundaries because of its shared, inter-corporeal nature. As Dickenson (2007) writes, establishing the cord blood as the child's based on genetic match is only one way of determining to whom the biological material belongs. Prior to genetic pre-eminence, biological belongingness was determined by whose body "contained" the biological material. In the case of cord blood, it flows in and through a woman's body throughout pregnancy and even at the time of collection the placenta and cord blood continue to be within the woman's body.<sup>16</sup> Women's rights to or agency over the cord blood stem cells on her behalf, are severely limited, if not erased, by the biomedical designation of the cord blood stem cells as the child's.

This study is a feminist project. I share feminist concerns regarding the "sourcing" of women's reproductive tissues and capacities for reproduction and regenerative purposes. I bring women's experiences and accounts to the foreground to address their erasure in much of the commentary and scholarship. In situating private cord blood banking within the broader efforts to extend and intervene in life and health, I consider what cost is exacted from women who bank cord blood. This study also contributes to feminist literature on stem cells and regenerative medicine by providing empirical research on a site in which the promises of stem cell science enter into and are taken up in the everyday lives of women and their families.

### **Epistemological Considerations**

Thus far, I have provided a review of the broader literature and some key points of debate that frame my project. In this section, I discuss some of the ontological and epistemological considerations relevant to this study. While I draw on Foucauldian and post-Foucauldian work to orient my work and my analysis, this

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<sup>16</sup> In the vast majority of cases, cord blood is collected immediately following the birth of the child and before the birth of the placenta. Thus, cord blood is collected while the cord blood and placenta remain in the woman's body, or *in utero*. Some private banks suggest that cord blood can be collected after the placenta has been birthed (i.e. *ex utero*); however, *ex utero* collections may result in low volume cord blood collections.

project is not by epistemological or methodological definition a Foucauldian one. Foucault's method of inquiry, also referred to as a history of the present, is concerned with analysis of rationalizing, expert discourse. Foucault was interested in studying learned and truthful discourses and understanding the effects of rationalizing practices on Western society (Weir & Mykhalovskiy 2010: 19). The objects of inquiry, for Foucault, do not exist externally to discourse, but are produced internally in and through expert discourses. Social scientists concerned with understanding the social domain have pointed to the limitations of a Foucauldian methodological approach. Weir & Mykhalovskiy (2010: 18-19) write:

We argue that the history of the present was formulated by Foucault as analytically distinct from the theorization of institutions, social relations, and social processes... (Weir & Mykhalovskiy 2010: 18)

The gap between the "rational schemas" (Foucault 1980/1994c: 27–28) and their realization in the prison or the hospital is an aporia in Foucault's thought—a seemingly obscure point where his thinking becomes incoherent, threatening to undermine his reasoning. This aporia extends to the relations between discipline and a disciplined society, security and a securitized society. We leave this realization problem to the philosophers. From a social scientific perspective it means that Foucault's work will always remain essentially incomplete because social scientists are interested in the realization of rational schemas in institutions, social relations, and social processes, together with the interaction of truthful and nontruthful knowledge. (Weir & Mykhalovskiy 2010: 19)

Methodologists, Holstein & Gubrium (2013) also point out that while Foucault's method of inquiry is effective in understanding technologies and regimes, his approach is less clear on how to examine the operations of these technologies "on the ground" (261).

Social scientists have bridged this gap in Foucault's approach in different ways. Some scholars who are not historians of the present, but consider their work to be in conversation with Foucauldian projects use ethnographic or other constructionist analytic approaches to provide empirical insight on what is

happening “on the ground.” I consider the work of anthropologist, Margaret Lock, as an example of the use of ethnography and qualitative, interpretive methods to provide detailed understanding of how expert genetic discourses are taken up, or not, by people who are eligible for predictive genetic testing. As I have discussed earlier in this Chapter, detailed ethnographic and qualitative work in contemporary biosciences has been particularly effective in demonstrating the over-generalizations made in contemporary Foucauldian biopolitics literature. Social scientists have shown through detailed empirical work that people can respond to rationalizing discourses and schemas in unexpected and non-determined ways. Although Foucault was uninterested in theorizing the social, it is the object of social science and cannot be reduced to discourse.

Some historians of the present have attempted to bridge the epistemological gap by turning to actor-network theory (ANT) (Weir & Mykhalovskiy 2010). Weir & Mykhalovskiy (2010: 19) discuss how Rose uses the concepts of “modeling” and “translation” borrowed from ANT to analyze how rational discourses are realized in the present. A key limitation of this approach, as Weir & Mykhalovskiy (2010) point out, is that ANT implicitly conceptualizes the various actants that make up a network as co-equal, a flat analysis that does not take into account the vertical relations of law and the political. According to Latour (2005), a doorjamb is analytically the same as a person and both are analytically the same as a law or legal ruling. This kind of analytic or conceptual flatness, while highly useful and appropriate for a laboratory setting, is less effective in empirical sites that extend beyond the laboratory (Weir & Mykhalovskiy 2010).

Social scientists have bridged the gap in Foucault’s work, or addressed its incompleteness, by taking Foucauldian inquiry in a critical realist direction. This approach differs from the work of Weir & Mykhalovskiy (2010) described above in that these post-Foucauldian scholars take inspiration from Foucauldian concepts, but transform them to be epistemologically and ontologically commensurate with a critical realist approach. An example of this transformation can be seen in post-

Foucauldian scholarship that elides the discursive subject with the social actor. The discursive subject, according to Foucault, is produced internally to expert discourses (Foucault 1983). Consistent with Foucault's interest on the operations of expert, truthful discourses, the discursive subject is an abstract form produced in and through discourse. Foucault's subject is not characterized by social memberships including categories of race/ethnicity, gender, and so on. Feminist scholars have pointed out this limitation in Foucauldian work. This subject is known or studied by examining truthful discourses and not by speaking with people about their experiences. On the other hand, the social actor in social science research differs significantly from the Foucauldian discursive subject. As Weir (2008: 2) writes:

Social scientists by and large work with a quite different conception of the human subject: the social actor. Since the beginnings of theorizing social action in the work of Weber a century ago, the social actor has been conceptualized by meaningful practices and intentions. The actor is embodied, with space and time coordinates organized in relation to the actor's body. Actions may be of many types, but in everyday practice (as distinguished from dreams by way of example), the social actor construes the world as a place to act on through conscious practices and plans. For meaningful action to occur, the social actor must be incorporated in human language, which in turn requires the existence of other speakers and actors to whom the social actor orients. The concept of the social actor gives rise to problematics that investigate differing forms of action, how social relations form, how social interaction is organized, how struggles for recognition occur, and how the actor is marked by social memberships from gender to citizenship.

While the concepts of the subject and the social actor differ ontologically and epistemologically, some post-Foucauldian scholars have taken to examining the production of subjects, or "subjectivity," through first-hand accounts of people. This has led to the transformation of the discursive subject to a hybrid form of subject/actor. For example, Waldby (2006) takes this approach in her work on the

entrepreneurial subject in private cord blood banking (see Chapter 6 for detailed discussion).

These are important epistemological considerations in social science scholarship. I do not attempt to resolve the debates and conundrums here, but aim to highlight some of the ways in which scholars have addressed the limitations in Foucauldian work. Foucault's writing on biopolitics, governmentality, and subject production has no doubt been highly influential in shaping scholarship that examines health and contemporary biosciences. Social scientists have responded to the limitations of Foucault's method of inquiry by adapting and transforming his work with varying degrees of success. My study has been influenced by Foucauldian thought, but does not use a Foucauldian method of inquiry. As I explain above, I am interested in examining women's actions, practices, and experiences with private cord blood banking and the *how* of private banking. The social actor rather than the subject of discourse forms the theoretical basis for my analysis here. I bring critical materialist and interpretive methods and analysis together with Foucauldian concepts and aim to place my work in conversation with Foucauldian and post-Foucauldian scholarship. On the question of "experience" and its epistemological standing, I draw on the work of D. E. Smith and her use of everyday experience as a point of analytic inquiry. Experience, as Smith uses it, does not stand for a pre-social expression of a deep, inner "self," but as an account of everyday practices that provide analytic entrance into the "social relations that shape, limit, and organize experience" (Weir & Mykhalovskiy 2010: 23). I turn now to a detailed discussion of my methodological approach and the specific research methods used in this study.

### **Methodological Approach**

This project is an exploratory, qualitative study that draws elements from several qualitative, interpretive approaches. Qualitative research is a broad approach to social science inquiry that is consistent with an interpretive, constructivist ontological view (Lincoln & Guba 2003). In qualitative research, the

researcher aims to situate herself within the social world she examines and applies research methods to understand the experiences and practices of people in their social lives (Denzin & Lincoln 2003; Mason 2002). By describing this project as exploratory research, I emphasize the inductive approach I take in this study. Inductive research begins inquiry and analysis from empirical data and moves to theory development and/or contribution from the data. I am guided by ethnographic research methods, as they are well suited for exploratory, in-depth studies of new empirical sites. Ethnographic research involves multiple methods of data generation (e.g. interviews, field notes, and observation) and allows for further development and clarification of specific research questions as the study progresses (Hammersley & Atkinson 2007). Ethnographic research also aims to make connections between specific local practices and larger, extra-local, social processes (Burawoy 2009; D. E. Smith 1987; 2005). Thus, local practices and experiences in people's everyday lives are examined in relation to larger social processes, discourses, ideologies, and power relations. I position myself alongside proponents of ethnographic research who argue that empirically-grounded, in-depth investigation offers an important political intervention to abstract debates (e.g. Lock 2005; Thompson 2005; Soyini 2005).

As an empirical site, private cord blood banking is a relatively new social and technical process that involves understanding the practices, or *how*, of various social actors (e.g. women who bank, healthcare workers, and technicians working in the laboratory) across various geographic spaces or sites (e.g. hospital or where the cord blood is collected, and the private cord blood bank laboratory). Qualitative and ethnographic methods are well-suited for examining processes and practices. Science and technology studies scholars have applied and extended ethnographic methods to examine increasingly complex scientific and clinical processes that involve multiple actors across different sites. Science and technology studies scholarship has a strong tradition of detailed empirical research in the laboratory opening up the "black box" of scientific processes to social inquiry and analysis (e.g.

Latour 1987; 2005). More recently, scholars such as Rajan (2006) have applied Marcus & Fischer's (1986) multi-sited ethnographic methods to examine the global biotech industry in the USA and India. Extending traditional ethnographies in which the researcher remains immersed in one location with one social group or community, multi-sited ethnographies offer researchers the ability to follow social objects or phenomena across sites. This method of inquiry is increasingly useful as contemporary biosciences and medicine are global phenomena. Other STS scholars have used ethnographic methods to follow and examine practices such as predictive genetic testing for breast cancer across the laboratory and clinic in the USA (Gibbon 2007) and local and global governance of stem cell science in India (Bharadwaj & Glasner 2009). Thus, I draw on these ethnographic studies as examples of the use of ethnographic research methods that follow social processes and material objects across time and space.

### **Research Methods: Semi-structured interviews**

Semi-structured interviews were the key method of data generation for this study. From July 2011 to March 2012, I conducted interviews with 13 women who banked cord blood in a private bank (12 women banked in Canada and 1 woman banked internationally. I did not include the woman who banked internationally in my analysis since my project focused on private cord blood banks in Canada),<sup>17</sup> 6 key informants (1 Executive, 3 Laboratory or Scientific Directors, and 2 Client Services Representatives) who worked in 4 different private cord blood banks, and 3 healthcare professionals (2 nurses and 1 physician). In addition to these interviews, I toured laboratory facilities at two private banks and made field notes of my visits following each visit to provide contextual information. I used notes from my field site visit and interviews as supplemental information.

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<sup>17</sup> I also interviewed 2 women who considered banking, but did not bank. Given the scope and aim of this project, I did not include an analysis of the women who did not bank in this project.



I used Holstein & Gubrium's (1995) work on the *active interview* as my guide to the interviews. Holstein & Gubrium (1995) take that view that interviews are social occasions or events in which both the interviewer and interviewee actively participate in producing data. The interviewer must be sensitive and alert to what the interviewee is saying in order to adapt and adjust to the data or knowledge produced and the direction in which to take the interview. This view stands in direct contrast to positivist or naïve realist approaches that conceptualize the interviewer as collecting data that pre-exists the interview process. While retrospective accounts of events or practices are grounded in specific places and times, how these accounts are shared, what is recalled, and the language used to speak about these practices and experiences will be shaped, in part, by the interactions between the interviewer and interviewee (Mason 2002).

I interviewed three groups of social actors: women who banked cord blood privately, people who worked in private cord blood banks, and healthcare professionals who had participated in cord blood collection. I approached each interview with a general interview guide tailored to each interviewee (i.e. a woman who had banked, or a key informant who worked in a private bank, etc.) and throughout the data generation phase, I re-visited the interview guide and made changes based on new points of insight or interest that emerged from previous interviews. I had different aims or purposes for the interviews with each group. First, interviews with women were a key focus of my study. I wanted to examine the experiences and practices of women who banked privately and to analyze their experiences in relation to a broader biopolitical framework. In these interviews, I asked questions related to how women learned about cord blood banking, what they did to bank cord blood, their experiences of pregnancy and childbirth, and what cord blood banking meant for them and their family. Second, my aim in interviews with key informants in private cord blood banks was to gain a deeper understanding of the process of private cord blood banking from the perspective of those who work in the banks. These interviews provided me with detailed accounts of the social and

technical process of banking cord blood once the bank receives the cord blood unit. I also used these interviews to ask for a tour of the private cord blood bank facility. I tailored these interviews to the particular person I was interviewing. For example, when interviewing an Executive Director I asked questions about the organization and more macro-level operations. However, when I interviewed Laboratory or Technical Directors, I asked specific questions related to the actual processing of the cord blood and how it is done. Finally, I interviewed Client Services Representatives and focused on their direct front-line interactions with women who are interested in banking privately. Third, I interviewed healthcare professionals who had collected cord blood or had been involved in cord blood collection in order to follow the process of banking at the point of collection. I included this third group of actors after I began my project since I did not know when I began that cord blood was collected by health care professionals and not by the private banks.<sup>18</sup> In these interviews, I aimed to understand what they did and also to understand their views of private cord blood banking.<sup>19</sup> All the interviews were conducted in-person (with the exception of one nurse which was conducted over the phone) and were digitally recorded with the participant's agreement. Each interview was 1-2 hours in length, conducted at a location chosen by the participant, and informed consent was reviewed and signed prior to each interview.<sup>20</sup>

### **Sampling Method and Access**

I used convenience and snowball sampling strategies to recruit women, key informants and healthcare professionals in my study. Convenience sampling is a non-representative sampling strategy whereby participants are selected based on their proximity and accessibility to the researcher (Given 2008). Snowball sampling is a sampling technique that involves the researcher asking participants if s/he

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<sup>18</sup> I made an addendum to my initial ethics application to interview healthcare professionals and received approval to the addendum prior to interviewing them.

<sup>19</sup> See Appendices C-G for sample interview guides.

<sup>20</sup> See Appendix H for Informed Consent form.

knows any others who may be interested in participating in the study (Given 2008). Both sampling strategies are appropriate for an exploratory, qualitative study and are particularly useful when the researcher is aiming to sample a population that may be difficult to access or identify. To use a term proposed by Mason (2002), I used an *organic sampling* strategy in which I adjusted and adapted my sampling as my study progressed. This was necessary given the challenges to recruitment. Hammersley & Atkinson (2007) write that a key obstacle in many qualitative projects is gaining access to the population the researcher aims to examine. The three populations I sampled were: women who banked cord blood, private cord blood banks, and healthcare professionals. Before discussing each of these populations in detail, I provide a general overview of my approach to accessing the field of private cord blood banking.

In March 2011, I attended a multi-day educational seminar in Calgary, AB, titled *Understanding Stem Cell Controversies*, hosted by the Stem Cell Network.<sup>21</sup> My goal in attending this seminar was to gain a better understanding of how people working in the field of stem cell science understand social and ethical controversies and to make contacts with people who are working in the field of blood stem cell research and/or blood stem cell banking. I was advised by contacts I made at this conference that I may find it challenging to find private banks that would be willing to speak to me because of the competitive nature of the private cord blood banking industry. They also suggested that recruiting women who had banked might also be difficult; thus, I was made aware of potential obstacles to recruitment.

To recruit women who had banked cord blood privately I used various methods: advertising on online community groups for new moms, advertising at a local community daycare centre, speaking to friend and social networks, and through contacts made through dissertation committee members. The most

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<sup>21</sup> The Stem Cell Network is a non-profit, government funded agency established in 2001 “with a mission to act as a catalyst for enabling the translation of stem cell research into clinical applications, commercial products and public policy.” (<http://www.stemcellnetwork.ca/index.php?page=about-us&hl=eng>, downloaded Apr. 4, 2014).

effective means of recruitment was through the online community groups. I chose two online groups based on the size of the group (i.e. I chose large community groups in order to have access to as large a group as possible) and the focus of the group (i.e. groups geared towards pregnant women or newer mothers with toddlers or young children). I also chose groups close to the Greater Toronto Area for their proximity. I sent an introductory email and a short summary of my research to the online community group organizer and asked if she could send my call for participants out to her group list. Both agreed to do so. Several women I recruited through the online group had their own personal or professional blogs or were part of additional new mother groups and offered to advertise my study through these channels. Many women contacted me via email to express interest in participating in the study; however, they did not respond to my follow-up emails and thus did not participate in this study. Although unconfirmed, I suspect that many women were unable to participate due to time constraints. Many women I interviewed were busy managing caring for their children and working outside the home. In total, I interviewed 13 women who banked cord blood privately and two who considered banking, but did not bank primarily because the cost was prohibitive. All, but one woman lived in the Greater Toronto Area, with one woman living in Vancouver, BC.

When I began this project in the summer of 2011, there were 11 private cord blood banks in Canada. By 2014, one of the largest banks located in Toronto, ON had bought the largest bank in Burnaby, BC and two private banks had closed down; thus, currently, there are 8 private cord blood bank companies in Canada. As with the women participants, I used a convenience sampling strategy with the private cord blood banks. I approached these banks knowing that some or all may be apprehensive about speaking with me because of the competitive nature of the private banking industry. I decided that emphasizing my role as a student who is eager to learn and interested to hear what they had to share would be the most effective way to gain access to the field. When considering which banks to contact, I chose several banks based on their size and history (i.e. I thought older, more

established banks might be more willing to talk to me and would also have more established practices) and their proximity to me. Since most of the private banks are located in the GTA or surrounding areas, I was able to contact several banks to ask if they would be interested in participating in my research. In total, I contacted four banks in the GTA. Many banks offer parent education sessions to women and couples considering banking and I contacted two banks by asking if I could attend their education sessions. Client Services Representatives from both banks agreed to meet with me. When I met with the Client Services Representatives, I explained my research and asked if they could put me in touch with other people in the bank. They both agreed to do so and I was able to interview others who work in different positions in the banks. I contacted two other banks in the GTA by sending emails detailing who I am and asking if they would be interested in participating in my study. One bank declined and a Director from the second bank contacted me to speak with me on the phone first and then agreed to an in-person interview. In addition to the three banks in the GTA, a key informant from one of the banks gave me a contact name and email for a Director at a private bank in the Lower Mainland (British Columbia). In total, I interviewed 6 key informants from 4 different private banks (3 in Ontario and 1 in British Columbia).

In general, most of the key informants were forthcoming in their interviews. They spoke openly about the competition among banks for customers, they were very open to answering my questions and seemed to be interested in my research. I experienced overt skepticism and concern only at one private bank when I began my interview with a Laboratory Director. At the start of the interview, another Executive of the private bank questioned me about my reasons for conducting the research and asked to review my interview guide. He explained that he had met with someone previously for a research interview and that the interviewer had subsequently used the interview material to benefit another private bank. The Executive was clearly concerned that I might also be from a competing bank. I assured him that I was a graduate student at York University and that the Office of

Research Ethics had approved my research project. He asked to view my student card and called York University to confirm that I was indeed a graduate student. The Laboratory Director was present during this exchange between me and the Executive. This set a slightly uncomfortable tone to our interview because I felt that I had to earn her trust in me as a researcher. While I was able to cover all the main question areas, I found that I was not comfortable asking further, in-depth questions in some cases.

After learning that healthcare professionals (nurses, physicians, and midwives) are necessary to collecting the cord blood, I made efforts to interview them. Through the assistance of a nurse who I know through personal networks, I was able to post an advertisement for my study in the labour and birthing unit of a large hospital in the GTA. Unfortunately, this method of recruitment was not successful. I interviewed two nurses who I met through friend networks. Both work in a major hospital in Toronto and both had assisted in births in which women had banked cord blood privately. I interviewed a physician I met, again, through personal channels who has been in practice for several decades and has collected cord blood since the 1990s. I used these interviews to provide information about how the cord blood is collected in clinical settings. Lastly, I attempted to contact a midwifery association in Toronto to interview midwives who had collected cord blood; however, I was unsuccessful in recruiting any participants.

### **Descriptive Summary of Women Who Banked**

Overall, the women who participated in this study shared many social demographic characteristics. I recognize that contacting women through online media and snowball sampling likely resulted in sampling women with more socio-demographic similarities than differences (i.e. women who are comfortable with online technology and have access to technology, women who are from similar social groups, etc.). All the women who banked were in a long-term relationship at the time of banking cord blood and continued to be in the same relationship at the time

of the interview, were White, were in their 20s or 30s, and lived in an urban setting. They all described themselves as being financially “comfortable” and easily able to afford to bank cord blood privately, most had completed post-secondary education, and most also worked in paid employment outside the home. Women who banked all gave birth in a hospital: one was assisted by a midwife, one was planning to have a midwife-assisted birth but had an emergency C-section delivery by a physician, and the others all planned to have a physician-assisted birth. All the women had banked between 2006-2011 with the exception of one woman who had banked in 2003.<sup>22</sup>

### **Data Analysis**

The method of analysis that I used in this project is inductive analysis (Hammersley & Atkinson 2007). Inductive analysis is an appropriate method of analysis for exploratory, interpretive inquiry that is aimed at in-depth understanding of a particular empirical site. Rather than approaching the data with pre-determined concepts, in inductive analysis the researcher begins inquiry from the data to the literature and back again (Hammersley & Atkinson 2007). The process of analysis is an iterative one that involves moving from data to theory/literature and back to data. Analysis begins early in research and is not necessarily a separate, clearly delineated stage of the research process that begins only after all the data has been generated. Preliminary analysis of early interviews can and should inform subsequent interviews as ideas develop and are further shaped with each interview. As Holstein & Gubrium (2013) point out, this approach to analysis has been heavily informed by Glaser & Strauss’ (1967) work on the “grounded theory approach” in which theory is developed from data. Holstein & Gubrium (2013) trace Glaser & Strauss’ work back to Blumer’s symbolic interactionism. According to Blumer (1969) people act according to the meanings and interpretations they attribute to other people and circumstances. Thus,

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<sup>22</sup> See Appendix I for details of the women who participated in this study.

interview data can be analyzed for meanings and interpretations that people bring to their experiences. A limitation of Blumer's symbolic interactionism, however, is its inability to attend to the material conditions of social life. Holstein & Gubrium (2013) conceptualize interpretive practice as the "constellation of procedures, conditions, and resources through which reality is apprehended, understood, organized, and conveyed in everyday life" (254). Examining interpretive practice, according to these authors, turns analytic focus to the *hows* and *whats* of social reality (254).

I began analysis of the data as I transcribed my interviews. At this early stage, I did not begin formal coding of my interviews; however, I began making analytic notes and reflecting on my data and the ideas and themes that framed my research (discussed in the first part of this chapter). I followed this process with each interview I transcribed. As the interviews progressed, I made note of ideas or themes that emerged in the data that I wanted to pursue further in subsequent interviews. For example, in the first couple of interviews I conducted, I noted that women spoke about their concern with collecting a sufficient amount of cord blood so I wanted to provide an opportunity for all women to speak about this or any other concern with the collection process. I also made note of questions that women were not clear on or that did not flow well during the interview so that I could revise them for subsequent interviews. In addition to interview transcripts, I also made descriptive field notes following each interview. The purpose of these field notes was to record the location of the interview, the conditions under which the interview was conducted, any observations I made during the interview that I thought were interesting, and anything unusual or noteworthy that I thought may have been significant to the interview process.

Once I had finished transcribing all of my interviews, I reflected on the analytic notes I had taken and developed a loose coding scheme based on ideas or themes. By "loose" I mean that I used the codes as a way to catalogue and organize broad ideas that I found interesting that I wanted to examine in greater detail. I



organized my data and coded the interviews using *NVivo*. As I coded, I also adjusted the codes to be more specific in some cases or added new codes as I went along. For example, I initially had a code for “family” that I used to categorize all the sections of the interview when women spoke about private cord blood banking in relation to their family. As I continued with coding I adjusted this to “family – form” and “family – opinion” to distinguish between when women spoke about private cord blood banking in relation to the form or make-up of the family and when they spoke about their family’s opinion or reaction to private banking. I used the same coding framework for key informants and healthcare providers since the codes were quite broad. When I needed a new code, for example to organize interview material that dealt with private banking regulations, I added a new code to account for this.<sup>23</sup>

While I was coding the interviews, I continued to go back and forth between the interviews and the literature. By the time I had completed coding all the interviews, I had begun to develop several key themes or ideas that I wanted to focus on further in my analysis. In this next stage, I read through all the sections of interview material that coincided with specific codes and themes. I developed each analytic chapter through this method of analysis. In writing up my analysis, I focused primarily on interviews with women who banked and used the interview data from key informants and healthcare providers to supplement women’s interviews. My analytic purpose for doing so was to provide greater contextual information or a fuller, more in-depth picture.

## **Conclusion**

In this chapter I have provided an overview of the broad bodies of literature and conceptual frameworks that orient this study. My research is informed by a range of social science scholarship that examines contemporary biopolitics, and bioeconomies, and feminist work on reproductive technologies. I draw on qualitative research methods informed by critical ethnography to produce the

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<sup>23</sup> See Appendix J for analytic codes

empirical material analyzed in the following chapters. In the next chapter, I provide a detailed analysis of women's gendered work in banking private cord blood.

### Chapter 3: Women's Work and Private Cord Blood Banking

*"How is cord blood collected?*

*You will be provided with our special collection kit that makes the procedure safe and simple. After your baby is born and the umbilical cord is clamped and cut, your doctor or midwife will collect the cord blood from the umbilical cord in a collection bag. After collection, the cord blood will be couriered to our laboratory for processing. It is a painless process for both mother and child."*

(<http://www.progenicscryobank.com/en/faq/>)

From Progenics' FAQ webpage

#### Introduction

Progenics, a private cord blood bank in Toronto, markets the process of banking cord blood as "safe and simple" and, as they describe above, women are required to do very little. The bank provides the kit, the doctor or midwife collects the cord blood, and the courier transports the cord blood to the bank's laboratory where technicians process and freeze it. Women's active involvement and work in the banking process and in childbirth are effectively erased. According to the private bank, once a woman decides to bank and registers, an established integrated system of experts in the bank and health services will be mobilized to ensure that the cord blood is collected and banked with minimal, if any, work required from her.

In this chapter, I provide a detailed descriptive analysis of private cord blood banking that foregrounds what women do to bank cord blood. In doing so I conceptualize women as active agents who work to bank cord blood rather than as passive participants of cord blood banking. This chapter follows women's work in the private cord blood banking process beginning from women learning about cord blood banking to the collection of cord blood following birth, and transporting the cord blood unit to the private cord blood bank. In providing a detailed description of women's experiences and practices, I show how private cord blood banking is embedded in social and institutional relations, biomedical practices of labour and

delivery, and personal experiences and expectations of childbirth and parenthood. I argue that women's work is crucial to private cord blood banking and by doing so I address the erasure of women in banking. I suggest that private cord blood collection is a type of do-it-yourself health service that requires women to engage in coordinating work with professionals such as nurses, physicians, midwives, and courier services. This lack of formal organization or coordination of practices is due, in part, to the insertion of a consumer, for-profit service into a clinical, hospital practice and the overlapping of clinical and commercial practices that can cause confusion and tension for women and other social actors who are involved in collecting cord blood. Unlike the seamless, stress-free account of banking provided by private banks, I show how some women experience cord blood collection as stressful and an added responsibility during the already challenging experience of childbirth.

In addition to demonstrating how the work of women who pay to bank cord blood involves moving and negotiating between clinical and commercial logics, rules, and personnel, I show how some healthcare professionals (i.e. nurses and midwives) also engage in non-formalized, non-recognized labour in order to ensure a successful cord blood collection. Private cord blood banking is an inchoate, emergent process that depends on this non-recognized labour. I propose that this work is not recognized because it is outside of formal clinical nursing practices as defined and organized by the hospital. Moreover, private bank staff is not actively involved in the cord blood collection and thus, they gloss over the many steps necessary for collection. Thus, nurses and many midwives labour in a space between the two institutional forms, hospitals and private banks, with neither accounting for this additional work. While there is no institutional or formal recognition of this work as healthcare professionals, how nurses and midwives assist with cord blood collection is shaped and ordered by institutional rules, norms and logics. As I mentioned earlier and discuss in greater detail below, nurses in at

least one Greater Toronto Area hospital must work around a prohibition against cord blood collection to assist women who are banking.

I begin this chapter, by providing a brief overview of the feminist literature on labour or work and contemporary bioeconomies. I draw on D. E. Smith's conceptualization of work in this chapter and discuss an application of her concept and method of inquiry in health studies (Mykhalovskiy 2008; Mykhalovskiy & McCoy 2002). Next, I provide a detailed descriptive analysis of the various steps involved in private banking beginning with women learning about private cord blood banking, registering with a bank, receiving the collection kit, collecting the cord blood, providing a maternal blood sample, and packing, labeling and transporting the cord blood unit to the private bank's laboratory. In addition to the interviews of women who banked, I also include analysis of quotes by key informants and a healthcare professional. By doing so, I am able to provide a more thorough analysis of private cord blood banking and demonstrate the disjuncture between how the private banks represent cord blood banking and the actual experiences of women and healthcare professionals who do the work. I conclude this chapter by situating women's work in private cord blood banking within broader feminist, critical discussions regarding women's bodies and reproductive tissues in contemporary bioeconomies.

### **Feminist Literature on Women's Labour and Contemporary Bioeconomies**

From global surrogacy markets and international reproductive tourism to oocyte markets in stem cell research and regenerative medicine, contemporary bioeconomies rely heavily on access to and provision of women's bodies and reproductive tissues. Feminist scholars have shown how gender intersects with race and class leading to the exploitation of some women's labour in international bioeconomies (Scheper-Hughes 2001; 2004) and have argued that the erasure of women's labour in providing reproductive tissues, such as cord blood, removes women from any claims to property rights to their reproductive tissues (Dickenson

2007). Feminists, such as Thompson (2005) and Waldby & Cooper (2008; 2010), argue that labour and modes of production have changed in the 21<sup>st</sup> century. Thompson (2005) contrasts the capitalist mode of production with what she terms a new contemporary “biomedical mode of (re)production” to reflect on some of the key changes in contemporary American biomedicine and bioeconomies (245-276).<sup>24</sup> She argues “that the biomedical mode of reproduction that [she] trace[s] through the human embryo has its own characteristic systems of exchange and value, notions of the life course, epistemic norms, hegemonic political forms, security, and hierarchies and definitions of commodities and personhood.” (2005: 248). According to Thompson, a key distinction between the capitalist mode of production and the biomedical mode of reproduction is that with the latter, reproduction itself is now part of the biomedical economy. In addition, she argues that unlike capitalism which alienates workers from their own labour, in biomedicalism, patients can become alienated from their bodies or body parts.

Waldby & Cooper (2008, 2010) develop the concepts of *clinical labour* and *regenerative labour* to theorize changing modes of (re)production and labour in contemporary bioeconomies. Waldby & Cooper (2008) take as their point of departure for the theorization of clinical labour in contemporary bioeconomies, the work of Marxist feminist scholars, such as Christine Delphy (1984) and Carole Pateman (1988), who re-theorized Marxist thought to account for the reproductive labour of women. According to Waldby & Cooper (2008), Marxist feminists argued against conventional Marxist theory that viewed women’s labour in the home as non-productive or “natural” reproduction that does not produce anything of value. They argued that women’s domestic and reproductive labour, is a “domestic mode of production” that is also a form of productive labour that produces value and is subject to alienation and exploitation as are other forms of productive labour.

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<sup>24</sup> Thompson (2005) does not make any claims of an “epochal” shift to the biomedical mode of (re)production, or biomedicalism. Unlike Rajan (2006), she explicitly states that she does not consider biomedicalism to have replaced capitalism; instead she considers biomedicalism to be one part of the American economy (2005: 247).

Waldby & Cooper (2008) adapt Marxist feminist work to account for current conditions in contemporary bioeconomies in which women's reproductive labour provides the biological materials necessary for neoliberalized forms of commercial reproduction (i.e. oocytes for the growing IVF market) and regenerative science and medicine (i.e. oocytes for stem cell nuclear transfer techniques for therapeutic cloning). They define clinical labour as the labour required by people who provide their biological materials for clinical purposes. For example, women's labour in following particular pharmaceutical regimens in order to hyper-stimulate ovulation of multiple oocytes for oocyte donation is a form of clinical labour, as is the labour of people who participate in clinical trials and are required to follow particular regimens to participate in the trial. Regenerative labour refers to a new mode of post-Fordist labour associated with new regenerative biotechnologies that make use of women's reproductive tissues. They suggest that regenerative labour reflects changing ideas of biological potentiality in which biological materials such as stem cells are understood to have limitless regenerative capacities. Waldby & Cooper (2010) develop the concepts of clinical and regenerative labour, in part, to address the erasure of women's labour in contemporary bioeconomies. Their work is a feminist intervention into the framing of oocytes or female reproductive tissues as "waste" or "surplus" which suggests that these materials are available without anyone labouring to produce them. In sum, feminist scholars have examined women's labour in the new bioeconomies to address the exploitation of women, as an argument for legal property rights or claims for women, and have re-theorized labour in an effort to foreground women and women's bodies in the new bioeconomies. The scholarship that I have reviewed thus far begins its inquiry and theorization of labour from within economic and social theory and draws on concepts interior to these theories. While this scholarship provides very important and insightful analyses, I depart from this approach and draw on D. E. Smith's concept of work to frame my analysis.

In this Chapter, I provide a detailed analysis of women's work in banking cord blood in a private bank. I draw on D. E. Smith's definition of work in which she begins analysis not from a conceptual definition of work or labour, but from the actual everyday practices and experiences of people. This method of inquiry differs from the work of feminists above since it begins analysis from the material experiences of people in analysis with an aim to foreground knowledges that otherwise are not available in expert discourses. Smith defines work as, "what people do that requires some effort, that they mean to do, and that involves some acquired competence" (D. E. Smith 1987: 165). According to Smith (1987), when sociological inquiry begins by applying a conceptual definition of labour, some practices are visible as labour while others are not. For example, if labour is defined as productive, paid labour, a teacher instructing a classroom is conceived of as labour while a mother helping her child with homework in the evening, making her child's lunch, or walking her child to school, is not. That is, the labour that the mother does to produce the social conditions for the child to learn is not conceptualized as labour. In most accounts of the bioeconomy of private cord blood banking, labour is conceptualized as the work of technicians, researchers, or healthcare professionals who have technical skills or expert knowledge (e.g. Birch & Tyfield 2012). Smith (1987) argues that rendering invisible the work of women (e.g. women's work in relation to their children's school) erases them as active agents (165-166). In a similar way, I argue that the erasure of women's work in banking cord blood, as contributing to the production of cord blood as a bankable biological material with value, erases them as active agents in contemporary bioeconomies.

According to Smith's concept of work, practices such as learning about cord blood banking, attending appointments, and making arrangements with others all count as work. This work is textually mediated through discursive texts that act to frame, organize, incite, and/or direct actions in accordance with various forms of knowledges. Scholars in the sociology of health have applied Smith's methodology to examine the experiences of people living with HIV/AIDS (Bresalier et al. 2002;



Mykhalovskiy & McCoy 2002; Mykhalovskiy 2008). They developed the concept of healthwork to conceptualize a range of activities including: finding appropriate physicians, managing and negotiating health care services, taking (or not taking) medication, educating physicians about AIDS, and coping with insults and discrimination (Bresalier et al. 2002; Mykhalovskiy 2008). I take inspiration from their concept of healthwork in my conceptualization of women's work in private cord blood banking. I turn now to women's accounts of private cord blood banking and describe the work they do, their experiences of private cord blood banking, and the institutional arrangements and gaps in banking.

### **Learning About Cord Blood Banking**

Before any woman banked, she had to first hear or learn about private cord blood banking and be alerted to its possibility. Several women recalled hearing about cord blood banking well before they were pregnant, while most came to learn about cord blood banking just prior to or after they became pregnant. For women who knew about cord blood banking prior to pregnancy, they had heard from friends or family members who had banked cord blood or had followed stories about stem cell research in popular media. All the women described learning more specific information about cord blood banking once they were pregnant. Most women learned about cord blood banking through clinical or medical channels including: hospitals, doctors' offices, prenatal classes, and midwives. Learning about cord blood banking was tied to the work they did to follow through with prenatal care, such as attending medical appointments and prenatal classes. Many women recalled seeing marketing materials and pamphlets produced by private cord blood banks in hospital or doctors' waiting rooms. For example, they described waiting for their appointment with their obstetrician or leaving after an ultrasound and noticing pamphlets for cord blood banks in the hallways and waiting areas of these prenatal clinical spaces. One woman, P3, recalled receiving a pamphlet about cord blood banking in the prenatal package that she received from the hospital following a tour

of its birthing facilities and several women described hearing about private cord blood banking from their prenatal instructors.

Most women in this study learned about cord blood banking primarily through online and physical texts produced by the private banks. These texts are marketing materials that private banks produce to sell their services to women and couples and to promote their services to healthcare professionals. In these texts, private banks selectively reference scientific studies that are optimistic about the future applications for cord blood and thus suggest to the reader that cord blood's therapeutic uses are immanent. They draw on clinical discourse that establishes the cord blood as the child's and draws on the metaphors of "waste" and "clinical gold" to establish banking cord blood as a moral good. That is, if a woman banks cord blood she is not being wasteful of her child's valuable biological material, but is being a good moral steward of this important resource. Perhaps most strongly and effectively, private banks draw on lay knowledge and cultural understandings of motherhood and parenting that frame private cord blood banking as a moral responsibility for "good" mothers and parents. These discourses and knowledges frame private cord blood banking as a safe, clinically risk-free, and necessary service for responsible parents who love and care for their child. This particular framing of private banking, however, obscures many important features such as the limitations of cord blood use, alternative ways to know and establish to whom the cord blood belongs, and what kinds of risk are involved with private banking. Women's understanding of private banking is primarily shaped by the multiple discourses and knowledges private banks use in their marketing text.

Several women initiated discussion about private cord blood banking with their physician or midwife to ask them about private banking. Women described their physicians and midwives as advising them to bank if they could afford it, but that if the financial cost was too great and they could not bank women were told they should not worry since the likelihood that their child would need a blood stem cell transplant was so low:

**P4:** She said it's something to consider, to do your research on, um, point of view was, she said, "if you can afford it, do it. If you can't don't beat yourself up over it," basically was her position. You know, she said, "it's like insurance, if you can afford to do it, you know, then do it, absolutely, but if you can't, don't beat yourself up and think, you know, and think you're gonna ruin your kid's life or whatever." That's how she positioned it with us.

These discussions were often very brief and part of women's scheduled clinical appointments with their physician or midwife. Women were required to initiate conversation about cord blood banking with their physician. Apart from advising women of the very low likelihood of cord blood stem cell use, physicians provided very little clinical information about the uses of cord blood stem cells in treatment. Physicians in Canada are under no obligation to discuss cord blood banking as part of routine obstetrical care<sup>25</sup> and in many cases private cord blood banks educate physicians about banking. For the women in this study, their physicians and midwives provided minimal clinical information about private cord blood banking. While the official position of the Society of Obstetricians and Gynaecologists in Canada (2009) is to recommend against private cord blood banking, it seems that in everyday medical practice, the physicians of the women in this study complied with women's decision to bank given the general medical consensus that collecting cord blood poses negligible clinical risk to the newborn. Most women who brought up the topic of banking with their physician or midwife said they had made the decision to bank even before talking with a healthcare professional.

The institutional relations between specific hospitals and private banks are diverse. Some banks, such as Inception Lifebank, have a formal association with specific hospitals, such as Mt. Sinai Hospital in Toronto, while other banks have no formal relationship with any hospital. What this "formal affiliation" or "formal partnership" is, however, is unclear; that is, it is not clear what the obligations are

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<sup>25</sup> In the USA, there is legislation in 17 states that require physicians to inform their pregnant patients about the private and public options of cord blood banking; however, there are no regulations regarding the quality of information provided raising concerns for some clinicians (Sun et al. 2010).

between these two organizations. Of the private banks in Canada, Inception Lifebank, the largest private cord blood bank appears to have the most formalized relationship with hospitals.<sup>26</sup> Many other private banks have informal associations with banks through their Directors or CEOs. For example, Create Cord Blood Bank advertises online that its Director is associated with Sunnybrook Health Sciences Centre and Women's College Hospital. This association seems to be that the physician has practice privileges within the particular hospital. Cells for Life advertises that its laboratory is in Toronto General Hospital and that it has an office in Markham-Stouffville Health Sciences Building. With the exception of Inception, the only formal relationship some private banks, such as Cells for Life, have with a hospital, is a financial one of renter-tenant if the bank or its laboratory is located within the hospital itself. In this case, the bank, as a private business, pays the hospital rent to occupy space in its building.

Private banks make an effort to establish and cultivate relationships with physicians and nurses in hospitals by offering educational classes and talks about private cord blood banking. Some private banks also provide tours of their laboratory facilities to healthcare professionals. I suggest these are “grey” marketing techniques to promote private banking to frontline healthcare professionals who interact with pregnant women and expectant couples in their clinical practices. Through classes, talks, and tours, private banks have an opportunity to present a favourable view of private cord blood banking to physicians which may influence physicians' opinions of banking. If expectant women and couples seek out the advice of their doctor, a physician with a positive view of banking is more likely to encourage banking than one who does not. I suggest that private banks' “grey” marketing techniques, while different in scale, are

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<sup>26</sup> Inception began as the Toronto Cord Blood Programme (TCBP) in 1996 as a service provided by Mt. Sinai Hospital. The TCBP partnered with Inception in 2004 to enable its continued growth and founding physicians and scientists of the TCBP continue to serve on the boards of Inception (<http://www.mountsinai.on.ca/patients/having-a-baby-at-mount-sinai/insception-cord-blood-banking-program>, downloaded May 12, 2014).

not dissimilar from pharmaceutical companies' efforts to market to physicians through the provision of free pharmaceutical samples, free lunches, and other informal perks (Lexchin 1993; Square 2003).

Many private banks also use the space of hospital prenatal units and physician waiting rooms as marketing spaces by placing their pamphlets in these areas. A Client Services Representative of a private bank in Toronto explained to me that many hospitals in the Greater Toronto Area have a policy that they must allow all banks to advertise with pamphlets in their prenatal and obstetrics units. This is particularly important in hospitals that have a private cord blood bank renting space in the hospital. People may incorrectly assume that if a private bank is located in a hospital women can only bank with that particular bank if they give birth in that particular hospital. On one occasion when the Client Services Representative I interviewed was replenishing her pamphlet supply she noticed a Representative from a competing bank throw out all the competitors' pamphlets and leaving only her own company's pamphlets in the display area. These kinds of "cutthroat" marketing tactics speak to the intense competition in the field of private banking. Several private banks also pay physicians and/or midwives who collect the cord blood. Physicians and hospitals do not require payment from private banks;<sup>27</sup> however, some private banks offer this direct financial incentive. An Executive I interviewed explained that there is a wide range of payment practices among private banks. Some private banks pay the specific collecting physician or midwife directly, others pay a fee per collection to the obstetrical unit. At least one bank in the GTA pays midwives, but not physicians for collections.

Private banks benefit from being viewed as having an association with a hospital. Many women spoke about choosing a bank that has a connection with a hospital because of the trust women have with hospitals as reputable clinical facilities. For example, P12 had this to say about her choice of private bank:

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<sup>27</sup> Some hospitals in the GTA will charge women an extra fee to have cord blood collected for a private bank. This fee is required by the hospital and is not associated with the private bank.

**P12:** ...and so I delivered at [name of hospital] and they have a relationship with [name of private cord blood bank] and there's like an office there that you can go to, so I'm assuming that most people probably do that 'cause it's just so easy and convenient and because [name of hospital], then, has that relationship to make sure that it all kind of works smoothly if for whatever reason, like, if you forget your kit at home on delivery day they've got other ones because they have this relationship with them.

When a private bank is located (office, laboratory or both) within a hospital, women assumed that the operations of the bank were co-organized along with the operations of the hospital. I suggest this gives the private bank an appearance of clinical stability and legitimacy. Although P12 assumed that the hospital in which she delivered had a responsibility to make sure that the process “works smoothly” the hospital does not have any obligation or responsibility to do so. For example, while many private banks ask to put their kits in hospital birthing rooms for emergency use, the hospitals are not responsible for ensuring that these kits are available. The elision, or assumption, of the bank as a clinical institution rather than a commercial institution is easily made. For some women, this elision masked the commercial relationship between woman-as-consumer and the bank-as-for-profit-company, and gave it the appearance of a pseudo-clinical relationship between women and the banks.

Social scientists have critiqued the increasing privatization of healthcare services in Canada (Armstrong & Armstrong 1987) and more recently, the emergence of *entrepreneurial hospitals* (French & Miller 2012). With changes to state funding in the 1980s in Canada, hospitals and healthcare services have been more reliant on private money to fund and pay for services. The entrepreneurial hospital, defined as a hospital “that explicitly seeks to constitute patient populations and care infrastructure as distinctive assets (or resources) in pursuit of entrepreneurial aims” (French & Miller 2012: 718), is not about concerns for funding healthcare or hospitals, but about transforming hospitals to a site of

economic growth for Canada. In the case of private cord blood banks, the entrepreneurial aims of the hospital are less clear; however, hospitals generate income by renting space to private banks. Also, private banks prize hospitals because of the access they can provide to potential paying clients. Although hospitals do not directly offer their patients to private banks as their entrepreneurial resource, they make patients available to private banks in an indirect way. This is another way in which hospitals and doctor's offices can be thought to be articulated in contemporary bioeconomies.

Women also learned about cord blood banking when working to prepare for motherhood by attending large commercial events such as the Baby Time Show. Started in 2004, the Baby Time Show is an annual weekend event held in Toronto that brings together retailers and experts to present and talk about all things related to pregnancy, birth, baby and toddler.<sup>28</sup> P6, described seeing cord blood bank booths at the Baby Time Show she attended while pregnant with her child:

**P6:** I don't remember how I first heard about cord blood banking. I think that it was probably something that I had come across in the media or whatever, but never processed it until I had a baby and I went to a Baby Time Show or something and I remember seeing a lot of vendors, um, blood banks have set up booths there and so I first asked about it at the Baby Time Show. But then I got more, I didn't think too too much of it, but then I got more into, like, a discussion about it when, with friends of mine, they were deciding whether or not to bank their cord blood. I think it was the Baby Time Show, that was the first time.

In addition to prenatal work of attending appointments, women also engaged in extensive consumer practices to ensure they had everything they needed for their baby. One woman explained that she had spent many hours researching and shopping for items such as a crib, baby stroller and car seat to ensure she was ready for her baby. At the Baby Time Show, private cord blood banking is one more item to add to the list of items prospective parents must purchase to be well-prepared for

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<sup>28</sup> <http://www.babytimeshows.ca>, downloaded March 15, 2014.

parenthood. I suggest these trade shows can be viewed as an exemplary site in which neoliberal consumerism and parenting come together and women engage in practices of buying the “right” items to be identified as “good mothers.” The presence of private cord blood banks at these trade shows situates private banking among consumer practices that produce women as “good” and “responsible” mothers.

Client Services Representatives from two different private banks also discussed how having a booth at the Baby Time Show is an important part of their marketing strategy. One Representative explained to me that she likes to scope out the competition and tries to ensure that her booth is not too close to any other bank’s booth in the expo:

**CSR2:** We also have a referral program so if you were a client of ours, successfully banked, you went on and referred us to a friend, relatives, whoever, you know, um, for every client you recruit who then banks with us we will offer you a free year storage. So we have one lady who’s got a, 10 clients for us, so I think she gets the medal for that. You know, it’s nice because people say, we always ask our clients, “where did you hear about us? How did you hear about us?” And some of them will say, “through friends,” some of them will say “through the internet.” We have a, a fairly good marketing system so we have ads out in things like church bulletins and parent’s guides and, um, I go to trade shows, I utilize my nursing contacts and I go to healthcare shows so I can access other health care professionals as well. Um, things like the “Baby and Toddler Show” is a *big* [her emphasis] seller for us. We get a lot of clients that way. We work hard for 3 days at it ‘cause we see probably 3,000 people pass our booth. But, you know, you gotta make yourself visible to make something like cord blood banking. And people from all walks of life come, I mean, it doesn’t, I’ve had clients who say, “oh it’s too expensive, it’s too expensive,” I say, “well think of the benefits.” And then they start to reconsider when you start thinking, “OK, well if we could all look into our crystal ball and say our family’s gonna be healthy in 20, 30, 50 years.” I mean there’s nothing to say down the road we’re not gonna be able to use these stem cells for other things like tissue regeneration, that’s a big area they’re working on. Um, heart attack victims may benefit from it. Give them stem cell transplant and it repairs some of that damaged heart muscle. Parkinson’s disease, Alzheimer’s, these are areas they’re working on. We have proven that it’s, that umbilical cord blood is good for 80 different kinds



of diseases, most of them being cancers, you know, leukemias is a big one. Childhood cancer, very big, um, very big success rate.

As the Client Services Representative explains, private cord blood banks use a number of marketing strategies to encourage people to buy their services. Participating in trade expos allow private banks to sell their services to a range of women and couples who might not have been inclined to bank. Perhaps, most importantly, these trade shows enable private banks to market their services face-to-face and sell people on the uncertainty of future health and the promissory claims of speculative future technologies. The dual pronged marketing strategy of many private banks, in the clinic and in the marketplace, shaped how women in this study learned about cord blood banking. Women learned about cord blood banking as they participated in the clinical practices of pregnancy and prenatal care and the commercial practices of preparing for motherhood. Some sought clinical advice from their physician, some spoke to representatives at commercial expos or trade shows aimed at expectant parents, and others looked into private cord blood banking after seeing marketing pamphlets in prenatal classes in clinical wards (e.g. ultrasound) and doctor's offices.

### **Registering With a Bank**

After women had made the decision to bank, the next step was to select and register with a specific bank. Most women spent more time researching which bank to use than researching banking itself and even then, most said they did little research. The choice of which bank to use was a quick one for most women. Many women chose a bank that was located in or close to the hospital in which they delivered, while a couple used the bank that a friend had recommended. As discussed in the previous section, P13 chose her bank because the Director was affiliated with the hospital in which she gave birth. This is how she described her meeting with a Client Services Representative to register:

**P13:** You had to call to, like, set up the appointments or whatever, and we asked a couple questions and, it was weird, I don't remember exactly what happened, but I remember feeling rather dissatisfied. I'm like, "Who are we talking to?" Um, and we just went in and had this brief meeting where I'm sure they told us something or other about the process, not the process, about what it was for, or gave us some sort of spiel. But it was quick. We were in and out in 15 minutes. And then we signed the papers and picked up a kit and brought it and came home

Once they chose a bank, women had several options regarding registering as most private banks offer the options of registering online, by fax/mail, or in person. There is no regulation or standard of practice that requires women and a representative from a private bank meet or talk on the phone about banking prior to registration. Most private banks advertise that they can bank cord blood from a child delivered anywhere in the world as long as the collected cord blood can be received by their laboratory within 48 hours (an AABB requirement). For example, a client representative of a private bank in Toronto told me of one woman who gave birth to her child in Hong Kong and had the cord blood collected and couriered to the bank in Toronto.

Most registration packages ask women for their personal information including their expected due date and medical history and require women to sign an agreement or contract with the bank. Completing the registration process establishes a legal contract between the woman as "Client" and the private cord blood bank. Since the cord blood stem cells are legally the child's based on genetic match, women sign the contract on behalf of their child. The contract establishes a legal relation between the woman (client) and cord blood (Fannin 2013), Canadian law prohibits property rights in the body (i.e. one cannot own, in legal property terms, parts of one's body) and cord blood cannot be bought and sold for profit; however, people have rights of dispensation over their body and body parts (Gold 1996). That is, one has the right to say what can and cannot be done with the cord blood such as what kinds of research the cord blood might be used for. The client maintains rights of dispensation and a type of "ownership" (i.e. the cord blood is

held for their use alone) to their cord blood as long as they pay the required fees. If the client does not or cannot make payments, according to the contract, the cord blood becomes the property of the bank. If the private bank attains rights of “ownership” it may be possible that the cord blood or biological material becomes a form of property that can be bought and sold (i.e. sold for research). As I discussed earlier, in Chapters 1 and 2, there is much ambiguity regarding the property status and rights of ownership of cord blood and other biological materials (Dickenson 2007; Fannin 2013; Saginur et al. 2004). Finally, the contract also removes all legal liability from the banks and health professionals should any problems arise with cord blood collection.

In Canada, cord blood banking is regulated by Health Canada, the body granted statutory authority by the Food and Drugs Act and charged with the responsibility for ensuring the safety of drugs and health products. Cord blood, hematopoietic precursor cells (HPC) and hematopoietic stem cells (HSC) fall under the category of “biologics, radiopharmaceuticals and genetic therapies” and are classified as cells, tissues, and organs for transplantation and not as “blood and blood products”<sup>29</sup> (Geransar 2010). Although HSCs are considered stem cells, they are regulated differently than human embryonic stem cells (hESCs). HPCs are governed under the Food and Drugs Act whereas hESCs are regulated under the Assisted Human Reproduction Act (AHRA). Cord blood HSCs are regulated in the same way as bone marrow HSCs. Cord blood banks are governed by *The Safety of Human Cells, Tissues and Organs for Transplantation Regulations*, or CTO Regulations. The aim of these regulations is to minimize risk to recipients of transplants by ensuring safe practices and handling of the biological materials.<sup>30</sup> Cord blood banks, as source establishments, must be registered with Health Canada and comply with

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<sup>29</sup> Blood and blood products include whole blood, plasma and platelets and are also regulated under “biologics, radiopharmaceuticals and genetic therapies.”

<sup>30</sup> <http://www.hc-sc.gc.ca/dhp-mps/compli-conform/info-prod/cell/index-eng.php>, downloaded April 12, 2014.

CSA standards<sup>31</sup> referenced in the CTO regulations. Thus, the emphasis in Health Canada regulations is to ensure the *safety* of cord blood and its products for *recipients*. The regulations do not regulate the efficacy of cord blood stem cells. In addition to Health Canada regulations and CSA standards, cord blood banks can also voluntarily register with two international bodies that establish practice standards: the AABB and NetCord-FACT. The AABB is an international organization that “advances the practice and standards of transfusion medicine and cellular therapies to optimize patient and donor care and safety”.<sup>32</sup> All the private cord blood banks in Canada are registered with the AABB. The second organization, NetCord-FACT is the Foundation for the Accreditation of Cellular Therapies, and also establishes a set of practice standards for its registered members. At the time of conducting this study, only one private bank, LifeBank in British Columbia, was a NetCord-FACT member. Currently in Canada, there are regulatory gaps and legal uncertainty regarding private cord blood banking. While Health Canada regulations govern source establishments and allogeneic use of cord blood, they remain silent on autologous use of cord blood (Geransar 2010).

A second important process is initiated at the time of registration in order to meet Canadian health regulations for the storage and clinical use of blood products. According to Health Canada regulations, the bank must assess the suitability of the “donor of lymphohematopoietic cells.” Women are required to complete an extensive medical questionnaire regarding their medical and social histories to ensure the safety of the cord blood and blood stem cells. As discussed above, Health Canada is concerned solely with the safety, not efficacy, of the blood stem cells. While Health Canada distinguishes between cord blood and other forms of blood, it views cord blood as clinically equivalent to bone marrow since both provide

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<sup>31</sup> The CSA Standards (2012) that deal with cord blood/HSCs/HPCs are: *Z900.1 Cells, Tissues, and Organs for Transplantation: General Requirements* and *Z900.2.5 Lymphohematopoietic Cells for Transplantation* ([http://www.hc-sc.gc.ca/dhp-mps/brgtherap/reg-init/cell/notice-avis\\_cto\\_gd\\_ld-eng.php](http://www.hc-sc.gc.ca/dhp-mps/brgtherap/reg-init/cell/notice-avis_cto_gd_ld-eng.php), downloaded Apr. 12, 2014).

<sup>32</sup> <https://www.aabb.org/about/who/Pages/mission.aspx>, downloaded Apr. 12, 2014.

lymphohematopoietic cells. In the case of cord blood, even though the blood stem cells are biomedically considered the child's, women do the work of the "donor" since her child is yet unborn and it is her medical and social history that is assessed. She is asked to report on her family's history of certain blood-based diseases, of the baby's father's history of certain blood-based diseases, of any blood products or transfusions she may have received, or of any travels or activities that may have exposed her to any blood-based infections. She is being assessed for whether or not she has any potential for blood-based infections that may exclude her blood from being "safe." Specifically, Health Canada and CSA Standards are screening for HIV, Hepatitis B (surface antigen) or Hepatitis C. According to the private banks, if a woman is positive for any of these 3 infections, she is automatically excluded from banking cord blood. An Executive at a private bank explained to me that if a woman tests positive for a number of other infections when she provides her maternal blood sample post-birth, the results of the test will be reviewed by the Clinical Director of the bank and if allowed to proceed with banking, her cord blood unit will be flagged and labeled as "non-conformance." This label is important should the cord blood stem cells ever be needed for therapeutic use in the future. All cord blood units with a "non-conformance" label must undergo greater clinical scrutiny before they can be considered for therapeutic use.

Women act as the donor in relation to Health Canada regulations that require the completion of this medical questionnaire and at the same time, the contract she signs with the bank constitutes her as a legal "Client" signing on behalf of her child. Cord blood as a shared biological material between women and child presents a complex case that does not conform easily to legal and administrative governance based on abstract individuals. Women do the work of the donor required by Health Canada (i.e. complete the medical assessment, submit their medical and social histories, and provide blood samples); however, they are legally constituted as "guardian" or "trustee" who is acting on behalf of their child and they are not considered to have banked their own biological material. According to an Executive

of a private bank, once the child turns 18, the cord blood “belongs” to the child and the child must sign all future contracts. The Executive was uncertain about what might happen if a case arises in which a child wants to discard the cord blood while the mother/father wants to continue banking. How such conflicts might be resolved remain to be determined since the earliest contracts signed in 1996 are due to expire in 2014.

### **Getting the Kit: A Do-It-Yourself Project**

After registering with a bank, women spoke about getting the collection kit. Women who registered online typically had the kit delivered to their home or workplace while women who registered in-person took the kit home with them after completing the paper work at the bank’s office. They were responsible for bringing the kit with them when they went to the hospital to give birth. The kit is critical to collecting cord blood since it contains all the equipment the doctor or midwife will need to collect the cord blood. Each of the 9 banks in Canada has its own specific kit and as an Executive of a bank explained to me, the banks keep close records of their collection kits.

Although each kit is specific to each bank, a Client Services Representative informed me that all kits have the same basic items. She showed me the items in a kit for her bank which includes: a sterile bag containing anticoagulant to hold the collected blood, a needle to insert into the vein of the umbilical cord and a tube from the needle to the collection bag, a larger plastic bag in which to place the cord blood collection bag, labels for the collection bag and larger outer bag, vials for maternal blood samples post-birth (including a requisition form for a lab and labels on the vials), and a second medical questionnaire for the woman to complete. The label for the collection bag asks women to write down the date and time of birth, the name of the doctor or midwife who collected the cord blood and the woman’s name and birthdate. All of this work is the woman’s responsibility and as I show in the next section detailing the actual collection of cord blood, she must coordinate others to

help with these various tasks that must be done immediately after she gives birth. Doing this work is not as easy as the banks make it out to be, especially when unexpected events arise during the birth.

Women's reaction to the kit varied. Some women, like P1, talked about feeling somewhat anxious or nervous when they received the kit because of the medical or scientific nature of the materials that were in it:

**P1:** Um, a little bit overwhelming. Um, it looked, like I said, that it looked pretty fancy, like this, you know, styrofoam box, but it was wrapped in cardboard, like it looked like a Playstation, like a Wii, like some kind of [laughing], it looked like some fancy, it was like "wow, that's where our thousand bucks are going." Um, and then inside, you know, there were these various, you know, hermetically sealed things and then colour photocopies of, like, pictures of stuff, like what thing, like how to take things out in order. So I felt very like, "OK this is a big responsibility," and there's like needles in there and stuff.

P1 referred to the collection kit as a Wii console and P13 referred to it as similar to having a pizza delivered to her home. Two women recalled receiving the box at work and commented on the plain packaging of the kits. They spoke about the strange-ness of receiving a kit that looked nondescript and ordinary, yet contained all the material required to collect the cord blood. Many women spoke about the unfamiliar and unusual medical and scientific contents of the kit and how this signified an added responsibility for them during childbirth. For example, P1 described it as reminding her of a "big responsibility." Another woman, P4, said she felt nervous when she received it because it was one more thing she had to think about in terms of the birth of her child. She wondered, "Are they gonna remember to do it? Are they gonna get enough?"

The do-it-yourself kit for cord blood banking is similar to other forms of new biotechnologies aimed at capitalizing on people's concern for future health. Childerhose & MacDonald (2013) apply the concept of *domestication* to the widespread use of home pregnancy tests in North America by women beginning in

the latter half of the 20<sup>th</sup> century. They argue that domestication not only refers to the increased work women do to conduct this test themselves, but also to the movement of the application of the test and the production of clinical diagnostic knowledge from the biomedical site of the clinic to the domestic site of the home. I suggest that in a similar way private cord blood banking requires that women and their partners do a significant amount of extra work and opens up the location or sites of this health work to include spaces such as the home and, in some cases, the office. Unlike the use of the home pregnancy test, collecting cord blood for a private bank requires women to enlist the help of health professionals to assist with the actual collection and post-collection work. As I show in the following section, the work of cord blood collection added to women's responsibility and feelings of stress during and immediately following birth.

### **Collecting Cord Blood**

Women's accounts of collecting cord blood were embedded in their experiences of giving birth. Some women spoke about power struggles with doctors regarding medical interventions during birth, unexpected events such as slow dilation and having to decide whether or not to have a C-section, and concerns with increasing levels of medical intervention. In the birthing room, the commercial practices of cord blood collection overlapped with the clinical practices of birthing and this overlap of practices at times led to uncertainty for women and some healthcare providers. In many cases, nurses filled in the knowledge and practice gaps during the collection process.

Women were responsible for telling their doctor or midwife that they were banking privately in order to ensure that the physician or midwife would be prepared to collect cord blood following the birth. Women who had a physician-assisted hospital birth also had to ensure that the nurses and doctor working that



day were told they were collecting cord blood.<sup>33</sup> In addition to informing health care workers about the collection, some women also felt responsible for explaining how to collect the cord blood to their physician. While most nurses and physicians working in large cities with a strong private bank presence would have received some instruction on how to collect cord blood, not all women felt confident that their physician knew how to do this. Many women spoke about feeling anxious about collecting cord blood. P1's sense of anxiety was typical of what women had to say:

**P1:** Yeah, it seemed kind of overwhelming. Um, I had that feeling too, of like, you know, it says things like, "*As soon as the blood has been drawn you have this much time, dah, dah, dah,*" [she says this with a highly urgent tone]. It's like, "oh my god, what if she's born at 3AM?!" [laughing] and like, you know, a little bit of panic around like what if we drop the big bucks and we ship it to them and they're like, "oh you didn't do it right," or "it's too old now," or that kind of thing.

Private cord blood banks require women and couples to collect and have the collection delivered to the bank within a very specific timeline in order to meet standard operating practices. The pressure of having to ensure the timely execution of a technical cord blood collection in the context of birthing uncertainty was a source of stress for women. Women had to organize their partners and healthcare staff to ensure the kit was received by a physician or midwife and ready for cord blood collection.

In addition to concerns about timing of cord blood delivery, women were also concerned about getting "enough" and the quality of the cord blood. The private banks make it clear to women that it is critical that they collect a minimum recommended volume of cord blood in order to have a clinically sufficient amount of

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<sup>33</sup> Most women who had a physician-assisted birth had a different (i.e. attending) doctor than their regular doctor present during the birth.

blood stem cells. For example, P10 had this to say about her concerns with cord blood collection:

**P10:** Yes, I was worried because they said that, um, in a small amount of circumstances you actually don't get enough blood. So I was worried about that. Or I was worried about, and then there was another scenario where you still had to pay apparently, but it might not be worth, like it didn't, I can't, I can't remember what the scenario was, but there is a scenario. One, first scenario is you don't have enough blood, you don't have to pay. Second scenario is you don't have, quality wasn't, kinda like a grey area, I think, there's like a scale I think. So that's what I was concerned about, about being in that scale and not being able to get enough quality and having to make that decision of are we gonna pay for it or not. So I was worried about that...

P10's concerns about collecting a sufficient amount of cord blood are tied to the timing of collection (that is, the timing of cord clamping) and how the cord blood is collected. In appearance, there is nothing noteworthy about the midwife or physician collecting the cord blood after a woman gives birth. S/he receives the baby, clamps and cuts the cord, and inserts the sterile needle into the umbilical vein to drain the remaining cord blood into the bag containing anti-coagulant that is provided in the kit. Nothing about this sequence of steps is technically difficult; nothing about these steps suggests that the midwife or physician is doing anything other than what could be considered her typical clinical birthing practice. This seamless picture is certainly what the banks present in their marketing materials. Although collecting cord blood is not technically complicated according to the nurses and doctor I interviewed, the specific steps involved in collecting it and how much to collect are specific to the bank and are not part of formal physician or midwifery training. All the private banks in Canada provide some information to health care professionals on their website regarding the use of their kit and the collection of cord blood; however, only those banks that are NetCord-FACT accredited are required by this international accreditation body to demonstrate that they have provided training to the health professionals who will be doing the

collection. As explained earlier in this Chapter, NetCord-FACT accreditation is voluntary and not all private banks in Canada have this accreditation. The banks use a number of strategies to educate physicians and midwives in cord blood collection. In addition to providing instructional material online, some banks hold in-person educational sessions for doctors, nurses and midwives to teach them about banking cord blood and how to collect it. The private banks have very specific instructions regarding cord blood collection. According to a Client Services Representative, these instructions have changed over time. In one case in the which the volume of cord blood collected was low, a woman explained that her physician had wanted to “milk” the cord (i.e. manually squeeze the cord blood through the umbilical cord and into the collection bag); however, she did not because the private bank had clear instructions requiring passive collection (i.e. no manual manipulation). Thus, physicians and midwives cannot use their clinical judgement and discretion when it comes to collecting cord blood. As cord blood collectors, they are technicians required to follow a standard operating procedure. Although in appearance physicians and midwives may appear as if they are acting as experts in clinical practice, when they collect cord blood they are, in fact, following the technical requirements of a for-profit commercial process.

Women felt the weight of the responsibility in collecting the cord blood and knew that if anything were to go awry during the collection and transport of the cord blood they would not be able to “re-do” the collection. While women were ultimately responsible for ensuring cord blood collection, the conditions under which it is collected – that is, immediately after childbirth – make it very difficult for women to control what happens. Several women had birthing experiences that they described as traumatic, unexpected, and difficult and under these conditions they had little control over timing and medical interventions with their birth. For example, P4 described being rushed to an operating room for an emergency C-section:

**P4:** Well I was worried. I was really worried, right? Because, you know, you have these visions, I didn't have a vision of some like beautiful birth, I know it's a pretty traumatic event or can be, but you don't have visions of a C-section, you know. The recovery is harder, but, I was worried, right? You want to make sure everything's OK with the baby when things like that happen, somebody was running, they ran me down to the O.R., right? So I kept crashing into things in the hallway, like somebody's on top of me holding my baby up, it's just like, "oh my god, what's going on?" My husband's pulled away 'cause he's gotta get a gown on and all that kinda stuff so.

During her pregnancy with her first child, P4 was diagnosed with preeclampsia, a condition in which a woman has hypertension and high levels of protein in her urine.<sup>34</sup> Because of this diagnosis, her doctor recommended she be induced at 38 weeks. When P4 went into labour, the fetal monitor detected a deceleration in fetal heartbeat with each contraction so she was rushed to the operating room for an emergency C-section. When women experienced difficult births, they had greater concern for cord blood collection. At the crucial moment when the cord blood was being collected, many women felt they had the least amount of control over the process and while a few women did not ask about the cord blood afterward, most felt the need to follow-up on its collection. After an emergency C-section, P12 was uncertain about her cord blood and had to confirm that it had been collected:

**P12:** My husband did *not* [her emphasis] want to see everything. At one point they said, 'Stand up, your baby's gonna be born.' And he stood up and he sat right back down. He's like, 'No.' 'Cause they take, like, all your insides out to get to your uterus so your, like, friggin' organs are like sitting on your stomach. It's really, really gross. Ah, so I guess they did it [i.e. collect cord blood].... I think while I was in recovery... I asked there and said, like, 'Did somebody do what they needed to do?' And they were like, 'Yeah, yeah, yeah.' And then I asked my husband, like, 3 or 4 times if he did what he needed to do and he was like, 'It's done. It's gone there.' Because, you know, you have to do it [i.e. call the courier to pick up the cord blood] within two hours.

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<sup>34</sup> <http://www.mountsinai.on.ca/care/placenta-clinic/complications/placentalinsufficiency/preeclampsia>, downloaded May 2, 2014.

P12's experiences demonstrate the challenges for women of being in the dual positions of a clinical patient and cord blood bank consumer. During her pregnancy, she had imagined having a "natural" birth with minimal medical intervention; however, at week 31 of her pregnancy she was put on bed rest because of early contractions and high blood pressure. Because of these concerns, she was required to monitor weekly her blood pressure and was told to go to the hospital if it was elevated. Eventually, she was induced at week 39 because her blood pressure was continuously spiking and her doctor was concerned that she and/or her unborn child could be in distress. P12 described going to the hospital and feeling like an object as nurses, doctors and residents poked and prodded her. A resident presented an emergency C-section as an option after a series of heightened medical interventions and concerns: she had stopped dilating, her labour was not progressing, her blood pressure was high, and her baby could be in distress. In the end, P12 gave birth to her daughter in a surgical room with 12 different experts (physicians, residents and nurses) in the room with her. Following this difficult birth, P12 was concerned with her cord blood collection and needed to ensure that the healthcare staff and her husband had done everything necessary. She was managing and following up with the various people she had enlisted to help her collect the cord blood.

When women and/or their unborn were considered to be at high clinical risk during pregnancy or birth, the medical apparatus was activated (i.e. specific medical protocols and timelines had to be followed) and physicians asserted their authority. Two women, who had concerns about the medicalization of birth and wanted to avoid using medication, were under a great deal of pressure to concede to physician authority and agree to medical interventions, such as the administration of an epidural and Pitocin. Under conditions in which medical authority is asserted, women felt additionally challenged to ensure that cord blood was collected:

**P3:** Yes. I felt like I needed to. And I think I felt like I really needed to push, um, to, to have it done, um, just because ah, the baby was breech and he was supposed to be very large and I had to have a C-section and then they had to bring in the, um, another guy to actually, another physician to do the surgery, so I had to like say, "OK, now here's the kit, make sure you do this." OK? And like, you know, carried it with me...

Women who challenged their attending physician were chastised and labeled as "difficult." P10 described her experiences of challenging the attending physician who wanted to induce P10's labour and give her an epidural:

**P10:** ... And then it was 7 o'clock at night and I had called my doula, she was, um, she was actually arriving in about 5, 10 minutes, and I was still arguing with the doctor and he kept saying, he was *terrible*, he said, "are you boss or am I the boss?" I started crying. He said, "I," um, and then he had the head nurse come in and give me a scolding saying, "we only have your best interest at heart," etcetera, etcetera. And then I tried to fire him. I said, "I don't feel comfortable with this doctor, I'd like the other doctor," um, and I kinda lied and said, "you know, it's a male," I said, "is there a woman attending on," and I knew there was, but they said that they wouldn't let me have her which I was upset about because this guy was a total asshole. Um, after screaming at me he came in again and said, "how dare you try to fire me." I said, "well I was just trying to switch doctors," and I remember, here I am in labour, like, just give me what I want. Um, so then my doula arrived and she was trying to calm me down because I was crying and I was upset."

In the end, P10 was administered Pitocin to induce labour, but gave birth without an epidural. In the hospital, women were expected to be passive and compliant patients. At the same time, women were also charged with the responsibility of being active consumers to ensure that cord blood was collected. For example, P8 expressed frustration because "everyone kept telling me not to lose sight of the kit" while simultaneously being told she was putting her unborn at risk by refusing to speed up her labour with Pitocin. She questioned what she viewed as a lack of coordination between the hospital and private bank:

**P8:** Um, it was kind of confusing to be honest with you. Yeah, it was a little, it was a little intimidating for a baby-brain mom. My husband just kind of looked at it [i.e. the collection kit] and said, "you deal with it." And um, yeah, it was very medical, like, part of me was just, to be honest with you, why can't the hospital have this available to them? Like, why do I have to carry this around with me? Because, like, the hospital doesn't um, really support you, you bring it, you tell them, you have to remind them to do it, and um, they ah, they didn't really support you. So that part I found a little frustrating. Like, "OK, fine." And having to pay the hospital to collect cord blood, "fine I'll do that, but I don't understand why you guys can't have it on hand." Which, and I can appreciate they don't have it on hand because there's so many different companies out there, but it's just kinda, yeah.

P8 had given birth in a hospital that requires an extra payment of \$250 from women who were having their cord blood collected for a private bank. This is an additional cost that is entirely separate from the private cord blood bank. On appearance these services appear to be coordinated since the physician or midwife delivers the baby as well as collects the cord blood; however, they are separate practices organized by different regulations and logics. The clinical practices of physicians and midwives are organized by a clinical logic that assesses the situation and executes action based on clinical knowledge and the immediate health of the woman and child. In the hospital, the practice of labour and delivery is also organized according to institutional logic and practices based on efficiency and time/resource management (Armstrong & Armstrong 1987). According to clinical logic, the physician or midwife is the expert and the woman is the patient. In contrast, the capital practices of private cord blood banking are not organized by a logic of clinical care, but by technical and standard operating procedure requirements. In private cord blood collection, a woman is the consumer who has enlisted the help of healthcare workers, or technicians, to collect the cord blood according to the private bank's direction. She is actively working to coordinate and oversee the cord blood collection. Ironically, at the critical juncture of cord blood collection, women are immobile and in some cases have just undergone (emergency) surgery and have experienced the physical and mental challenge of giving birth. Still, women must

manage the work of navigating and coordinating between clinical and capital practices. If, for any reason, the cord blood collection is done incorrectly or fails to be done at all, neither the private bank nor the hospital and healthcare staff are liable for this failure. Women and couples shoulder this responsibility on their own and as P8 expresses above, this can be a frustrating and challenging experience.

In most cases, cord blood is collected immediately following the birth of the baby. There are dual priorities of collecting cord blood for the baby's health in the future and allowing the cord blood to pulse for the baby's health in the present. Women spoke about these dueling concerns; one woman recalled someone who decided not to bank because she thought that the cord blood would benefit her baby more if it were allowed to pulse following birth. In some hospitals, such as Sunnybrook, the birthing unit has a policy to allow the umbilical cord to pulse for 45 seconds after the baby is born before the doctor clamps and cuts it. A physician who I interviewed told me that this policy compromises the ability to collect an adequate amount of cord blood for some women and that she would use her discretion in implementing such a policy if a woman is banking privately. Some private banks suggest that it is possible to delay umbilical cord clamping and still collect cord blood for private banking. However, if a low volume of cord blood is collected this may compromise the potential therapeutic use for the blood stem cells. Following cord blood collection, women must provide the private bank with a maternal blood sample.

### **Giving a Maternal Blood Sample**

Women must provide the bank with a post-birth blood sample to be screened for a number of infectious diseases according to Health Canada regulations. In most cases, birthing room nurses took the blood sample soon after the baby was born. However, at least two hospitals in the GTA have a policy that prohibits nurses from collecting post-birth maternal blood samples for the purposes of private banking. Several women had been forewarned by their private bank that nurses may be



unwilling to collect a maternal blood sample. With the exception of 3 women who gave birth in hospitals that prohibit the taking of maternal blood samples, all the women described receiving a great deal of help from nurses. Two nurses I interviewed worked in a hospital that has this prohibitive policy and while neither was certain why this policy was put in place, they offered two suggestions: first, collecting post-birth maternal blood samples increases the workload for nurses; and second, nurses do not want to be held responsible for anything that may go wrong with the cord blood collection. Nurses in these hospitals were also instructed not to help with packing and labeling the cord blood unit for private banking purposes. However, as I show below, in spite of these prohibitions, some nurses continue to help women and couples.

Most private cord blood banks require women to provide a maternal blood sample 5-7 days after giving birth. If a nurse does not collect this blood at the hospital, women must go to a laboratory or to the private bank to have this done. For women who were assisted by a midwife, the midwife was able to collect the post-birth blood sample. However, for one woman, P15, collecting her post-birth blood sample was more difficult than expected. She described the confusion and work involved in collecting this blood sample:

**P15:** Which was interesting because apparently [name of hospital], the nurses won't draw your blood for the, for the cord banking, so [name of private bank] sends the kit without any vials to [name of hospital]. But I had a midwife [i.e. she had a midwife assisted hospital birth] so the midwife would have drawn my blood, um, so the midwife found some vials because it said we need 4 purple vials, she said, "The vials aren't here." So she borrowed them. She took vials from the hospital, 4 purple vials and she drew my blood and then [name of private bank] called me and said, "That wasn't enough blood. We need you to come down now and, and give us a blood sample." And I'm like, "Are you kidding me?! I just had a C-section. I gave you blood. Why didn't you put vials in there?" And she said, "'Cause [name of hospital] won't draw the blood." I said, "But why didn't you ask me? My midwife could have drawn the blood." So that was, um, that was frustrating, that was a very frustrating point.

**I:** So they wanted you to go to their office?

**P15:** To their facility, yeah, on [name of street].

**I:** Oh, and they drew the blood for you?

**P15:** They drew the blood, yeah.

**I:** Do they have a time, like a time line?

**P15:** You have to do it 3 days post-delivery, within 3 days post-delivery. So you're going down when, I wasn't even standing up straight yet. So that was a little, ah, unfortunate.... Yeah, and here you are, we're just in East York so we had someone, my mom stayed with my, like, who do you have to stay with your son? My mom stayed with my son, my husband pulled up on [name of street], I walked up the stairs, I called him, I said, "I'm done," he pulled up on [name of street]. It was *OK*, but if you had to drive from Markham to Toronto, that just would have been awful.

In order for P15 to have her post-birth maternal blood collected, she needed to coordinate the help of her midwife, husband, and mother. She described the physical challenges of going to the private bank three days after a C-section delivery and although she found it challenging to do this, she wondered aloud how other women without this support might do the extra work required when banking. P15 points to an important point regarding private cord blood banking; it requires social as well as financial resources. Making visible women's work also makes visible the social resources many require to assist with private cord blood banking. In addition to the financial resources needed to pay for private banking, P15 relied on social resources of family to help care for her child and drive to the bank since she was still recovering from her C-section surgery.

Another woman, P4, also had to go to a blood collection laboratory to provide a post-birth maternal blood sample after the birth of her second child. P4 had given birth in a hospital in which nurses typically can take the sample after birth, but because of the unexpected risk to her child who was lodged in her birth canal during birth and the ensuing chaos of her delivery the attending nurses were not able to collect her blood:

**P4:** I think it was the next day [after she arrived home from the hospital] actually. 'Cause I remember calling them [the private bank] as soon as I got home, maybe even while I was in the hospital, saying, "look they couldn't take

the blood, ah, while I was, like, the day I delivered the baby physically and while I was in the hospital so, um," they said, "just do it as soon as you can." So I went there the next day.... I was very sore. I was much worse than the C-section actually, after my older delivery [laughing]. It was much worse. I was on a lot more pain meds actually.... Yeah, just the two of us [i.e. she and her newborn], yeah. Just the two of us and, um, I remember somebody telling me, somebody waiting in the waiting room - it's weird things stand out, right? - somebody in the waiting room said, "you shouldn't be out with your baby this young, you shouldn't be in a hospital lab," like, I haven't got a lot of choice [laughs].

Although P4 was in a great deal of pain and did not have childcare for her newborn, she went to the laboratory as soon as possible because she did not want to jeopardize banking the cord blood. Ironically, she is questioned about her parenting when she is doing what is required of her to bank cord blood; a practice that she feels is part of her work as a good parent. The details of P15 and P4's experiences stand in contrast to how a Client Services Representative described how women might drop by a laboratory on the way home from the hospital to provide a blood sample:

**CSR1:** Now, um, what I have suggested to some moms and I don't know whether you, if this would be feasible, um, is on your way home from the hospital, if you can find one that's on your way home, you're dressed and, you know, your husband's with the baby, and maybe you could just swing by and pop in.

The Client Services Representative describes it in such a way that erases the pain and discomfort that women will likely be feeling, and the challenges of coordinating help from others when she advises women to "just swing by and pop in." Collecting a post-birth maternal blood sample may be easy for some women, but as P15 and P4 demonstrate, it is clearly not easy for everyone. In addition, according to a nurse, some women are extremely dehydrated following birth making it very difficult for a nurse to collect a blood sample. In these cases, if a nurse has time she may try to get a blood sample while the woman is in recovery; however if this is not possible, the

woman will have her blood taken at a laboratory. The work of providing a post-birth blood sample requires coordination of nurses or midwives and in some cases partners, friends, and family.

### **Packing, Labeling, and Transporting the Cord Blood Unit**

After women gave birth and the physician or midwife had collected the cord blood, women must ensure that the cord blood unit is correctly labeled and packaged for transport to the private bank's laboratory. At this stage, many women again coordinated the help of nurses, partners, family, and friends. For some women, nurses did the extra work of filling in the gaps when women were unable to manage what was happening with the cord blood. Women spoke about nurses helping their partners to fill in the labels correctly and seal up the cord blood unit in its plastic package to be picked up by a courier. Some women recalled that their nurse filled in the label rather than leaving it to their partner to complete while two women said that their nurse took the collected cord blood to the nursing station to be held there until the courier picked it up. A nurse described what she did when a woman and her partner were banking cord blood:

**N1:** Yeah. So they bring their own, um, box, the big box [i.e. collection kit], um, they'll let me know before so when I'm setting up my delivery tray, I put, just the collection kind of kit that just has the bag and, ah, I open it up and put it on the sterile, ah, table with the rest of the doctor's instruments and things and I just let the doctor know that there's cord blood collection that needs to be done. And they're usually, "Ok, yeah, sure. No problem." Um, so, then it gets done and the doctors just kinda leave it there. The problem I have with cord blood is that they [i.e. private banks] don't educate the parents at all on it. They just give them the box and just, and most of the time the patients haven't even opened it, looked inside, don't know anything about what they're supposed to do with it. They just know that there's a number that they have to call once it's collected for somebody to come pick up. They don't know what they're supposed to do with the tubing, what they're supposed to do, um, with the blood, where it's, what bag it's supposed to go to, what labels are supposed to go on, so they usually look to you [i.e. the nurse] and say, "What am I supposed to do?"

**I:** And the parents are supposed to do all that?

**N1:** Well they are, yeah. And some nurses will say, “Oh I don’t know anything about that. That’s yours.” And just kinda leave it at that, even though they do because we’ve done so many of them. But it becomes a hassle because you’re kinda doing so many other things once the delivery has happened. You’re trying to clean up the mom, you’re checking on the baby, they’re usually really interested in breast feeding right away so you’re trying to get all these other things done, trying to, um, catch up on your charting a little bit if you weren’t able to chart those last fetal heart rates at the end, um, you’re trying to check on her, check her blood pressure, check her fundus, make sure the, er, oxy-, oxytocin is infusing afterwards. Um, so there’s a bunch of different things you’re trying to do and they’re trying to get this cord blood together and you’re kinda saying, “That’s your job.” But the dads are always kinda look-, scratching their head, ‘cause they know it’s an expensive thing for them to purchase and I know that they don’t want to screw it up, um, so I normally help them, but I know a lot of other nurses don’t. They say, “That’s yours. Read the instructions.”

The nurse’s quote paints a compelling picture of the collection and post-collection activities in a hospital birthing room and the work that many nurses do to ensure a successful cord blood collection and transport. She describes the unrecognized, but crucial work of informing the doctor that there is a cord blood collection, of arranging the materials in the kit on the sterile delivery tray for the physician, and of assisting partners with labeling and packing up the cord blood unit. Nurses who assist with the post-collection work do so in addition to their clinical work of managing women’s recovery post-birth and managing the third phase of delivery in which a woman’s uterus must be monitored for hemorrhaging. Clearly, successful cord blood collections by physicians in hospitals depend on the work of nurses, extra work that private banks and hospitals do not recognize or remunerate.

Another important step in cord blood collection is the proper packing and labeling of the cord blood unit for transport to the private bank. The labels require identifying information such as the names of the woman and physician, the date and time of birth and cord blood collection. Nurses often assist partners with these labels since s/he may miss details such as the name of the attending physician and/or the specific time of birth given the excitement and circumstances of the

birthing experience. Packing the cord blood collection involves placing the cord blood in specific biohazard bags and sealing them for transport. Each private bank has its own specific labeling and packing instructions requiring partners and nurses to follow instructions specific to each bank. N1 described one collection for a bank that required the cord blood collection tube be flushed prior to packing and sealing. She explained that the partner who was charged with this responsibility was confused with this technical requirement and so she assisted with flushing the tube. Nurses straddle both clinical practice and the commercial requirements of the private banks and do much of the unrecognized, yet necessary work required for a successful cord blood collection.

Once the cord blood is labeled and packaged, most often with the assistance of a nurse or midwife, partners often called a courier or a family member, to pick up the cord blood unit and take it to the private bank's laboratory. Some private banks require women and couples to use specific medical couriers to transport the cord blood, while other banks allow women to choose their mode of transport. In the case of one private bank, the medical courier they require transports the cord blood in a bag that contains a computer chip that monitors the temperature of the bag from the time it picks up the cord blood unit to the moment it drops it off at the laboratory. The information on this computer chip is downloaded onto a computer and the bank maintains a record of the specific temperature and temperature variation of the cord blood from the moment of pick up. Thus begins the highly technical process of transforming the cord blood unit to a bankable product.

## **Conclusion**

In her book, *More Work for Mother*, Ruth Cowan (1983) shows how industrialization of the home and the introduction of new "time saving" appliances, such as the microwave, actually increased, not decreased, women's domestic work. Private banks market cord blood banking as requiring very little, if any, work by women. However, unlike the marketing rhetoric of private banks that erase

women's work in banking, I show in this chapter how women are crucial to the successful collection of a cord blood unit. Moreover, I argue that women actively engage in coordinating work between the clinical practices and logics of the hospital and the commercial practices and logics of the private bank. I show how the insertion of commercial practices into a clinical space produces tensions and potential confusion among the various social actors and most often women and nurses step in to do the work needed to collect cord blood. I also suggest that private cord blood banking is another example of the domestication of health technologies or tools (Childerhose & MacDonald 2013) in which the work and responsibility for the use, or production, of the health tool is shifted from clinicians to laypeople and from exclusively inside the clinic to outside or multiple sites. Ironically, at the most crucial point of cord blood collection post-birth, women feel the height of responsibility and yet are least able to intervene physically. In spite of this physical challenge, they were actively engaged in ensuring the cord blood had been collected. Even when women were lying on a hospital bed, many having had their bodies surgically opened up to deliver their child, they spoke about asking about the cord blood and worrying about whether or not enough had been collected.

Science and technology scholars have studied the production of biological materials as research tools or objects for scientific research. Scholars have examined the cultural and scientific production of specific cell lines, such as the HeLa cell line, as scientific tools to study specific diseases (Landecker 2007), the procurement and use of female reproductive tissues for use in stem cell science (Waldby & Cooper 2008), and the transformation and standardization of entire organisms, such as the OncoMouse™, into research tools (Haraway 1997). In this Chapter, I have foregrounded the experiences of women to analyze their work in banking cord blood. In addition to the work of experts and technicians, I argue that women are key actors in transforming biological materials into valuable objects that are implicated in contemporary bioeconomies. In the next chapter, I follow the cord blood unit once it has been received at the private bank's laboratory and turn to a

detailed analysis of the socio-technical process of transforming the collected cord blood to blood stem cells that are cryopreserved for future use. I focus my analysis on the production, and loss, of value in the cord blood stem cells as it is produced into a potential therapeutic object.



## Chapter 4: From “Waste” to (Fool’s) “Gold”: The Unstable Biovalue of Cord Blood

*“Do anything but throw them [i.e. cord blood units] out.”*

Laboratory Director, Private Bank 4

### Introduction

The private cord blood banking industry exists because cord blood is thought to be a valuable biological material worth banking. According to biomedical discourse, cord blood is valuable because it has been shown to be therapeutically useful in treating a number of blood- and immune-based diseases. As a result, clinicians and scientists, among others, have described cord blood as being transformed from “waste” to “clinical gold” (Waldby & Mitchell 2006; Zacharias 2013). The metaphor of “gold” suggests that cord blood is a valuable resource and that to discard it would be a waste. As the Laboratory Director quoted above implies, there is a moral imperative against wasting something that is now thought of as valuable. Cord blood is considered to be “clinical gold” because of its blood stem cells that can be used to improve the health and vitality of people who are sick. However, it is also “financial gold” for the private cord blood banks that profit from its storage. While cord blood, in general, is valuable as a clinical treatment how a specific cord blood unit comes to be known as valuable involves social and technical production involving multiple social actors and forms of knowledge.

In this chapter, I examine the production of specific cord blood units as valuable and bankable biological object once it has been received in the private bank. I conceptualize biovalue in cord blood not as an inherent quality of the blood stem cells based of their ability to regenerate, but as produced by complex social and technical processes and consider what insights private cord blood banking can provide about contemporary ways of valuing new biological objects. First, I show that women who banked cord blood spoke about and understood cord blood as

valuable if they believed it could be clinically used in the future to treat their child if s/he were to become sick. I argue that the production of biovalue in cord blood is a social and technical process that can be stabilized and destabilized during the cord blood banking process. Second, I show that cord blood's potential clinical use is not an inherent stable quality of the blood stem cells biological capacities, but is unstable and at times contested. I follow the production of cord blood's biovalue by tracing the technical and knowledge processes of the cord blood unit once the private bank has received it. By detailing three particular instances or articulations of a cord blood unit's value – a “good sample,” a “low volume unit,” and a cord blood unit that is “completely useless” – I show how a cord blood unit's biovalue is unstable and how it is stabilized through various technical and knowledge forms. The biovalue of a particular cord blood unit is produced through negotiations between private banks and women, and through tensions in different forms of knowledge (clinical, technical, scientific/speculative, and lay) and power/knowledge relations. I make visible how the production of cord blood's potential use value is shaped by the tensions and negotiations between women and the private banks at the site of “low volume” units. I also show how under conditions when the potential use value of blood stem cells must be realized (i.e. when there is a diagnosed medical condition that could be treated with blood stem cells), the cord blood stem cells may be clinically useless and lose all biovalue.

Lastly, I argue that women are key actors in producing a cord blood unit's biovalue. Unlike some scholars who have responded to the fetishization critique of biovalue by pointing to the work of technicians and expert knowledge labour, I show that women, and laypeople, also play an important role in producing value in biological objects. The multiple social actors engaged with the production of a cord blood unit's value – women, private banks, and physicians – also have a different relationship with the cord blood as a social object and have different aims. For private banks, a cord blood unit is a profit-generating object. Banks increase their profits as long as the cord blood unit is banked and remains in a state of potential

use. Women view cord blood as a maternal object that ensures the health and well-being of her child and family. For women, the value of their cord blood unit is never an abstract consideration; it is always thought of in relation to its clinical useability to treat or cure a specific disease for a family member. Lastly, transplant or treating physicians are solely concerned with the use of cord blood as a clinical treatment. They apply a clinical logic to the use of cord blood and, in the end, determine whether or not its use value is realized.

I begin with a review of the bioeconomies and biovalue literatures specific to cord blood banking. Next I provide a detailed empirical account and analysis of the production and (de)stabilization of biovalue in cord blood at three specific articulations of value in the cord blood unit: the “good sample”, the “low volume” sample, and a sample that is “completely useless.” Lastly, I conclude with a summary of the key points and arguments in this chapter and reflect on the potential for cord blood to be “fool’s gold.”

### **The Bioeconomy of Cord Blood**

In Chapter 2, I discussed some of the broader points of the contemporary bioeconomy, biocapital and biovalue and some of the current debates regarding these concepts. In this section, I discuss in greater detail the bioeconomy of cord blood and its forms of value. The circulation of cord blood in a tissue economy can take two different forms: allogeneic or autologous circulation. Very simply, in allogeneic circulation, or transplant, the cord blood is removed from one person, undergoes biotechnological transformation, and is transferred or inserted into another person. This movement and use of cord blood from one person to another for the purposes of improving health is what Kent et al. (2006) suggest produces biovalue in biological materials banked for allogeneic transplants. Autologous circulation, on the other hand, does not involve the movement of cord blood from one person to another, but rather the removal of cord blood from one person and, following biotechnological transformation, the re-insertion of the cord blood back

into the same person. In autologous circulation, the “donor” and “recipient” are the same person. Because of the lack of movement or transfer from one person to another, Kent et al. (2006) question if biovalue might be produced differently in autologous circulation.<sup>35</sup>

Public cord blood banks store cord blood for allogeneic circulation<sup>36</sup> whereas private cord blood banks deal with both autologous and allogeneic circulation. While many private banks emphasize autologous use in their marketing and many commentators refer to private cord blood banking as autologous banking, most cases of privately banked cord blood use in Canada have been allogeneic transplants from one sibling to another. Thus, some private banks refer to their services as “family banking.” Still, private banks differ from public banks for their potential autologous circulation. Brown (2013) argues that both public and private cord blood banks are based on forms of exchange economy that produce exchange value in cord blood. Public banks participate in a global exchange network in which cord blood units are exchanged for money across national borders. In Canada, the health care system pays approximately \$42,000 for each unit of cord blood it imports (Komarnicki 2014) and the National Public Cord Blood Bank will charge other countries for every unit it exports. Private banks engage in an exchange economy with women and couples who pay to bank their cord blood; in this case, it is an exchange of money for processing and storage services.

Both public and private banks depend on methods of cord blood collection that are increasingly challenged with emerging reports of the benefits of delayed cord clamping (Brown 2013). Brown (2013) argues that the tensions between cord

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<sup>35</sup> Kent et al. (2006) view Waldby’s (2002) conceptualization of biovalue as depending on the movement of biological material from one body to another; thus, they argue that autologous circulation does not fit this model of biovalue production. They suggest that biovalue in the case of autologous circulation is produced through the *extra-corporeality* of bodies (rather than *inter-corporeality*) in which a body’s material is removed, transformed and re-inserted, thereby extending the corporeality of a body outside its boundaries for the purposes of improving health.

<sup>36</sup> It is not impossible, in theory, for autologous circulation to occur in a public cord blood bank, but highly unlikely for this to occur. Even if an autologous transplant were to occur this would not be known since all cord blood units in a public bank are anonymized.

blood collection and delayed cord clamping reflect a tension between two different use values for cord blood. Whether public or private, cord blood collection is premised on a *potential* use value for cord blood at some point in the future. Delayed cord clamping, on the other hand, is promoted for its *present* use-value that is made manifest through its immediate infusion into the newborn following birth to support the health of the newborn. Thus, according to Brown (2013) expectant parents in the UK considering banking cord blood experienced a tension between banking to invest in their child's future health or to delay cord clamping in order to contribute to their child's present health. The former is a potential use value that may be manifest in the future while the latter is a current use value for cord blood for their child's health.

Fannin (2013) offers a different view of the private banking economy by arguing that rather than an exchange economy, private tissue banks,<sup>37</sup> as operating as a hoarding economy and the person who banks as resembling Marx's "miser." Fannin (2013) argues that private tissue banks operate very differently from financial savings or investment banks. In the latter case, savings or investments in financial institutions operate through circulation. The financial institution pools the money that people have put into their savings account and re-invests it, putting it back into circulation to produce more money. This is possible because the specificity of a particular material bill does not matter. For example, any five dollar bill can stand in for any other five dollar bill since its symbolic value is what matters and not its specific materiality. Unlike money, in which the specificity of a material bill does not matter tissues, such as cord blood, are banked precisely for their specific biological materiality; thus, they cannot enter into circulation as financial savings do. The argument in favour of private cord blood banking is premised on the unique materiality of one's own specific cord blood and its irreplaceability by any other cord blood unit. Thus, Fannin (2013) argues that a private tissue bank

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<sup>37</sup> Fannin (2013) looks specifically at private banks for endometrial tissue or menstrual fluid (specifically for mesenchymal stem cells); however, her analysis can be extended to private cord blood banks.

“more closely resembles the form of proto-saving described as hoarding rather than the calculative practices of investment and saving” (36). While suggesting that privately banking tissues resembles hoarding, Fannin (2013) also challenges the psychological and economic views of hoarding as a crisis.<sup>38</sup> She considers the hoarding of biological tissues not as crisis, but as an example of people’s desire to place themselves at the centre of all forms of exchange as the “enterprising self” (36) (see Chapter 6 for further discussion of the “enterprising self” or “entrepreneurial subject”).

Scholars have applied economic concepts and theories to theorize contemporary bioeconomies. Discussions of theories or forms of value in biological materials or biovalue in cord blood have relied on application of economic models or theories to explain how and what type or form of value is produced. As I have reviewed above, these discussions and analyses have provided important insight into the bioeconomy and forms of value of cord blood. In this chapter, I offer an analysis of the value or (de)valuing of cord blood that focuses on the social processes by which specific cord blood units come to be known as valuable by the various social actors involved in private banking. Rather than beginning from the assumption that cord blood is valuable because of the regenerative capacities of the blood stem cells, I examine how private bank technicians, women who have banked, and clinicians come to know the cord blood unit as being valuable and bankable.

### **A “Good Sample”**

**CSR2:** So the lab, um, gets the sample they, um, will weigh that collection bag, um, we pride ourselves also in giving all of our clients feedback, telephone feedback within about 12 to 24 hours of receiving the sample here so they all get a phone call saying, “oh, Mrs. Smith, um, Dr. X was able to collect, you know, 85 milliliters of blood. That’s a very good sample and from that we’ve

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<sup>38</sup> Psychologists identify hoarding as a psychological disorder that arises in people as a response to fears of scarcity while economists view hoarding as a practice that can lead to market crisis (Fannin 2013).

got a wonderful stem cell yield of, you know, 750 million.” So they know, black and white, they know the quality they’re getting.

In the quote above a Client Services Representative is describing to me what a laboratory technician might say to a woman after the laboratory has received and assessed the cord blood unit. We were seated across the table from one another in a large room where she typically conducts Parent Education Sessions for prospective parents who are interested in banking with her company. She had just finished walking me through the collection kit and showing me how the doctor or midwife would have inserted a needle into the umbilical vein in order to collect the cord blood in the collection bag. Once the private bank receives the cord blood unit, laboratory technicians begin the work of transforming the collected cord blood into its bankable form. This involves a number of standardized steps including weighing the cord blood unit, separating the blood stem cells from other blood cells, and counting or estimating the number of blood stem cells provided. After processing and separating out the red blood cells and platelets, the remaining stem cells and factors in the cord blood unit are cryopreserved and banked in metallic cases. When a cord blood unit is received at a bank, a technician weighs the unit and calls the woman to advise her of the weight, and in some cases, a cell count of her unit. This is the first time women are told of the “quality” of their cord blood unit and women’s concerns about whether or not they “got enough” (described in Chapter 3) are ameliorated or not. As the Client Services Representative says in the quote above, private banks provide women with numerical measures of the volume and stem cell count as a representation of the “quality” of their cord blood unit.

In the first step of cord blood processing, private banks establish the quality of the cord blood unit through the application of technical knowledge and measurement. Quality, or a “good sample,” is defined by the volume of the cord blood unit and estimated cell count of the blood stem cells. The private bank’s main concern is that a sufficient number of cord blood stem cells have been collected and “quality” is known in technical, numerical terms. As I discussed in Chapter 1, one of

the key criteria for a clinically efficacious cord blood unit is a sufficient volume of cord blood. Thus, the clinical use of cord blood depends on having a sufficient amount of cord blood stem cells. According to Inception Lifebank's contract:

Inception's minimum acceptable volume for a cord blood collection is a total sample volume of 70 mL, comprised of 35 mL of umbilical cord blood and 35 mL of anticoagulant (already in the collection bag). Greater than 87% of collections exceeds or meets this minimum volume.

Inception's minimum acceptance criteria for a cord blood unit (CBU) are based on established therapeutic cell doses used by physicians for bone marrow transplants.

[https://www.inception.com/sites/default/files/pdf/61-0001-registration-package\(download\)-Feb-2013.pdf](https://www.inception.com/sites/default/files/pdf/61-0001-registration-package(download)-Feb-2013.pdf)

The contract goes on to say that based on a study of the correlation between the volume of a unit and the TNC (Total Nucleated Cell) count of a cord blood unit the bank has measured, greater than 99% of the cord blood units that have a volume of 70 mL or more have a TNC count that meets their "minimum acceptance criteria," 71% of cord blood units that have a volume of 60-70 mL meet the minimum, and 19% of cord blood units with a volume between 50-60 mL meet the minimum criteria.<sup>39</sup> Private banks establish their minimum volume criteria based on scientific and clinical knowledge regarding current cord blood use.

After the volume of cord blood is measured, technicians establish a TNC count followed by a blood stem cell count based on CD34 markers.<sup>40</sup> In addition to obtaining these measures, the red blood cells and plasma must be separated and extracted from the stem cells and factors in cord blood since they will not be cryopreserved. Key informants at private cord blood banks spoke about the blood stem cell count as the measure of "viability" or "alive-ness" of the cord blood unit

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<sup>39</sup> [https://www.inception.com/sites/default/files/pdf/61-0001-registration-package\(download\)-Feb-2013.pdf](https://www.inception.com/sites/default/files/pdf/61-0001-registration-package(download)-Feb-2013.pdf), downloaded Feb. 12, 2013.

<sup>40</sup> CD34 markers are proteins on the surface of blood stem cells. This measure provides a more specific count of the blood stem cells in the cord blood unit.



since it is a measure of the live blood stem cells. They translated numerical measures of the cord blood unit and cord blood stem cells to social or value terms such as “alive-ness,” “quality,” and “good.” At each stage of processing, technicians aim to maximize the number of live blood stem cells since a high cell count correlates with high quality. A Laboratory Director explained to me that processing cord blood always results in some loss of blood stem cells:

**I:** So what is considered a good yield?

**LD4:** If you read the literature you will see that a public bank which, um, most of the literature that’s published are public banks that are published. Private banks tend not to do that because you don’t want to expose yourself. If you read the literature from public banks that have been doing this a long time and has worked diligently, I would say 80 to 85% of cell recovery is what you should expect. And if you get higher than that, I would be suspicious, I think, that’s for what we call “total nucleated cells,” TNCs. For the stem cells which is a lighter cell, you can see 90 to 95% recovery.

In order for a cord blood unit to be considered a “good sample” and to be valuable, a number of important technical and social transformations occur. The cord blood unit is transformed from shared maternal/child embodied material to a quantified object produced through various separation and measuring techniques.

Determining that the cord blood unit is a “good sample” requires situating and interpreting these numbers within existing clinical and scientific discourses regarding the amount of blood stem cells needed for successful transplants. If these numbers meet the minimum amount used in current clinical applications, the private banks determine that a sample is “good” or useable. The reliance on current biomedical truth discourses challenges some of the work that suggests that private cord blood banking is based entirely on speculative hope and the promissory. For example, Brown (2005) suggests that private cord blood banking is organized by a *regime of hope* whereas public cord blood banks are organized by a *regime of truth*. A key distinguishing factor between these two regimes is the role of biomedical truth discourses based on current clinical practices. Brown (2005) argues that

private cord blood banks do not draw on current biomedical truth discourses, but rather on speculative, hope discourses of potential uses of cord blood stem cells. While promissory and speculative uses of cord blood stem cells certainly play an important role in promoting private cord blood banking, I show that private banks also draw on current biomedical discourses in establishing measures for bankable cord blood units. Thus, private banks rely on both current biomedical truth discourses (that provide the measures for a “good sample”) *and* promissory speculation (of potential uses and expansion techniques in cases of “low volume” units).

Designating a cord blood unit as a “good sample” produces and stabilizes the cord blood as valuable and useable. When a cord blood bank calls a woman to tell her that her sample is of good quality, this determination temporarily stabilizes and renders invisible the contingencies of current clinical knowledge, variations across different private banks, and ambiguities in counting techniques themselves. Many private cord blood banks rely on current clinical uses and knowledge to determine the minimum amount of cord blood stem cells that represent a “good sample” and understandably so since this is the best information that exists today. However, there is no guarantee that the amount they have banked today will be sufficient in the future. This is particularly important given the future orientation of private banking; women bank cord blood for future use and private banks emphasize future possibilities of cord blood use. In addition, there are a number of clinical contingencies, such as type of disease treated and the size of the patient that may influence whether or not the minimum amount will, in fact, be sufficient should it be needed in the future. While most banks have similar minimum volume criteria, there is some variability across banks since Health Canada regulations are silent on the minimum volume required for all private banks.<sup>41</sup> As I discuss in the section

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<sup>41</sup> A marketing strategy of many private banks is to suggest to women and clients that they have a great deal of flexibility and choice regarding what they might do with the banked unit in the future. For example, they say that women can move their cord blood unit from private bank to private bank or donate it in the future to a public bank if they choose to. However, the variation of minimum

below on “low volume” units, different private banks deal with cord blood units that do not meet the minimum amount in different ways.

Counting or quantifying techniques may also be ambiguous and do not necessarily provide an objective “black and white” representation of the quality of a cord blood unit, contrary to what the Client Services Representative said above. The Laboratory Director suggested this when she described how she might be suspicious of a very high percentage of blood stem cell recovery. As science and technology scholars argue, counting is not a self-evident or neutral technique. Martin & Lynch (2009) introduce the concept of “numero-politics” and show through historical scientific counting and measuring disputes how counting practices are political practices that act to stabilize natural and social orders. The rules and conventions around which objects get counted, which objects do not, and how things get counted are established within political and epistemic debates (Martin & Lynch 2009). Counting and measuring techniques and instruments are developed according to a particular epistemic paradigm and once established and accepted they assume a taken-for-grantedness quality (Bowker & Star 1999, as cited in Martin & Lynch 2009).

In the case of cord blood stem cells, measuring collected cord blood volume as a proxy for the number of cord blood stem cells in the unit and counting CD34 cells to obtain an approximate measure of live cord blood stem cells are techniques that use instruments devised with a particular counting paradigm. The cord blood stem cell count also depends on agreed upon average percentages of the various blood cells found in cord blood. For example, the TNC count refers to the cells in the cord blood that have nuclei. Cells with nuclei make up approximately 40% of the

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volume levels has implications for moving cord blood units from bank to bank or from a private to public bank. In addition, differing processing techniques across private banks may result in biological materials that may not be as compatible across banks as suggested. An Executive of a private bank explained that in principle they would accept a frozen unit from another private bank, but since they did not process and freeze the blood stem cells themselves, they would be less certain about the quality or usability of the cells. While this is a marketing strategy to encourage women to bank, according to key informants, cord blood units are not typically moved from one bank to another.

cells in cord blood; the other 60% is composed of platelets and mature red blood cells. Blood stem cells are one of 5 types of cells (others include: lymphocytes, monocytes, granulocytes and immature red cells) with nuclei and make up about 0.5-1.0% of all nucleated cells. Therefore, knowing the TNC count of a cord blood unit provides an estimate of the number of blood stem cells in the unit (from interview with Laboratory Director at Private Bank 4). These proxy and approximate measures are further complicated by differing cord blood stem cell extraction techniques that may lead to differing blood stem cell yields. In spite of these contingencies, a high numerical count for blood stem cells comes to stand as evidence of a “good sample.” Private banks make a categorical judgment – the cord blood unit is a “good sample” or not – based on this number and women come to know their cord blood unit as valuable or useable based on this judgment. Moreover, the use of numbers function to produce facticity (Seale et al. 2006); thus, women receiving reports from private banks with volumes and cell counts may understand these numbers as stabilizing and establishing as fact, the useability of their cord blood unit in the future.

After the laboratory technicians process the cord blood, most private banks send women written documentation regarding the volume and the blood stem cell count. The private banks share these numerical values with women and couples to confirm and stabilize the biovalue, or future useability, of their specific cord blood unit. Some banks, as the quote below shows, send women a certificate (see Fig. 1) with this information while other banks send this information in a letter to women. P9 explained to me how she received this information after she had banked her cord blood:

**P9:** ... Oh, and they [i.e. the private bank] phoned the next day [i.e. the day after she had given birth and the cord blood unit had been delivered to the laboratory] just to, like, confirm my birthday or something and then they phoned, they phoned to say that they had it, like, phoned to confirm, like, “We got the blood.” And then the next week, in the mail, I got a little, like,

certificate saying, like, “We have your blood, it’s useable,” ‘cause, you know, they say sometimes you don’t get enough. So they said how much it was, I don’t know how much it was, and um, something, like, the percentage viable or something? And it said, “It was good,” and “Anything above this is good,” and ours was, like, way above it. So, now we have this certificate. I should have brought it, I don’t even know where it is actually [laughs], to say, like, that, “We have it,” and how much it is, the quality, or whatever. So then that was it and I haven’t heard anything since. Like, it’s just there for good now, I guess.... It’s kind of funny. I kind of thought, ‘cause it’s a certificate! It looks like a diploma or something. I thought it would be just like a report, a medical report, or something. But it’s good to have, so now we have, like, evidence, or whatever. I don’t know, I thought it was kinda funny. It’s good to have.

In talking about the measures or “evidence” that the cord blood bank provided, P9 described her cord blood unit as “useable” and “good.” She also translated the abstract numbers provided in her certificate into clinical and social terms that were meaningful to them. None of the women I interviewed remembered specific numbers; they were not interested in understanding the details of the numbers they were given as long the numbers were above the bank’s minimum levels. Instead, women knew their cord blood units as valuable if they believed that it could be used as treatment for their child in the future. For women, the quality or value of the cord blood stem cells was directly associated with their aim to protect their child in the face of an uncertain future.



Figure 1: Certificate of Cryopreservation  
<http://www.progenicscryobank.com/en/whychoose/choose07.php>, downloaded March 15, 2013

The letter or certificate sent by private banks acts to further stabilize the biovalue of a cord blood unit. In the figure of the certificate above (Fig. 1), the numbers are printed and stand as evidence of the quality and value of the cord blood unit banked. Although P9 found the certificate somewhat humorous, as an object that stabilizes biovalue of cord blood it stands as a visual and formal reminder of an otherwise non-visible entity. The certificate may play on the conventions of stocks and bond certificates in traditional banking or viewed as similar to a diploma, the certificate is tangible evidence and recognition of achieving a certain value. The certificate also serves the important social function of maintaining a social connection between the woman and her family and the cord blood unit sitting in a liquid nitrogen tank many miles away. In maintaining this social connection, privately banked cord blood differs from most other forms of commodification of biological materials that rely on the severing of social relations between the “part” from the “whole.” Scholars have demonstrated how biological materials must be separated from social personhood in order to enter markets of exchange or research

circuits (Seale et al. 2006). For example, Pfeffer (2009) shows how the transformation of aborted fetal tissue to biological research tool requires social cleansing that removes all connections of the fetus as a social being. This includes erasing any social relations between a woman and her unborn. Anonymization of biological materials is an effective and important technique in erasing these relations. Private cord blood banks and other private tissue banks, however, function very differently since all social connections are not removed. Waldby & Mitchell (2006) have referred to this as “partial alienation” of body parts. I suggest that the maintenance of these social relations through written inscription techniques such as a certificate function to stabilize a cord blood unit’s value. The certificate acts as a reminder to women and couples that the cord blood is valuable, like their child is valuable. A certificate also serves as recognition that something valuable, or of quality, has been accomplished; in this case, a valuable cord blood unit has been banked.

In the case of a “good sample,” the cord blood unit is produced and stabilized as a valuable biomaterial by the confluence and agreement of various forms of knowledge. The cord blood unit is measured and counted as useable based on current scientific and technical knowledges. The private banks draw on current clinical uses and knowledge of blood stem cells to translate this numerical measure of value to social categorical terms of a “good” and bankable cord blood unit. Women use the numbers and technical knowledge provided by the private banks to proceed with banking the cord blood stem cells. These numbers provide women with a tangible measure of the abstract or potential use value of the cord blood in the future. Women know their cord blood unit(s) as “good” or having “quality” and thus, they stabilize its biovalue by banking it. These multiple forms of knowledge act in concert to reinforce and stabilize cord blood as valuable.

### **“Low Volumes”**

Not all cord blood units collected meet the minimum volume recommended by the private banks. When these units, referred to by some private bank staff as “low volumes,” are identified, they present an occasion in which the future useability of the cord blood unit comes into question:

**Ex1:** So when people register we ask them what they would like to do in the case of, we call them “low volumes.” So for whatever reason, you know, maybe there wasn’t enough blood in the cord which is very rare, or the health care professional didn’t leave the needle to let it drain enough, or whatever it is. Um, so what we do is we ask when you register what you’d like to be done with it in the event of a low volume and then we give criteria what a low volume would be so you kind of know. Do you want it banked, donated or discarded? So those are your options. If you want it banked, because for, um, self-use, the volumes don’t necessarily have to be as great as if you were banking for a public bank so they still could be very viable. Uh, donated, you could donate it to research or discard it, throw it away. So then at that point for any of the services that we’re not able to complete the client would be reimbursed.

As the Executive described above, private banks have a formal process by which they deal with low volume units. When women register they are asked to document what they would like to have done in the case of a low volume collection: bank, donate, or discard. This process seems clear and simple enough; however, in practice, when a low volume collection arises women described much more complex interactions with the private banks. With a low volume collection, the cord blood is not useable according to current clinical therapeutic uses because there are too few blood stem cells to be clinically efficacious. When this happens, private banks shift their focus from current clinical uses and knowledge to promissory or speculative claims regarding stem cell expansion techniques (i.e. a technique to increase the number of stem cells) and experimental uses of blood stem cells. Although private banks ask women to indicate what they would like to have done with a “low volume” unit during registration, when these cases occur many key informants at private



banks told me that someone from the bank will call the woman to ask her what she would like to do with her cord blood. It is in these discussions of specific cord blood units that negotiations between women and private banks occur and the minimum numbers used to determine value can shift down and low volume units can be re-valued as bankable.

Two women I interviewed had “low volume” units. In one case, P6 learned that her cord blood unit was well below the minimum recommended amount of 70 ml. At a volume of 49.2 ml, her cord blood unit was even below the lower limit of 50 ml. According to her contract, if her cord blood unit was 70 ml or above the bank would proceed with banking, however if it was between 50-70 ml she had indicated that she wanted the cord blood to be donated<sup>42</sup> and anything below 50 ml was to be discarded. She explains this in the following quote:

**P6:** It’s very possible. Because yeah, like, what she told me was, there’s this whole thing actually, this whole thing about the amount and what the nurse told me to do when I filled out my thing was agree that if, yeah, “if the total, um, sample volume for the cord blood unit is greater than 50 and less than 70,” [she is reading this off her contract] neither of which, mine wasn’t even 50 [laughs], um, I would donate it, I clicked “donate.” “I understand that if the total volume is between 50 and 70 you will contact me so that I will make, so that I can make a decision about what to do with it.” [she is reading this off her contract]. So that was what the nurse told me and I just made it, I just specified it [she had hand written this statement at the bottom of her contract in addition to checking the box for “donate”] here to make it clear. What the nurse told me is, “you should tick ‘donate’ because then they’ll call you and you can decide at that time.” Which is not cons-, you know, just the whole thing is kind of, “Really?” What if it’s less than 50? I thought that they’d told me that if it’s less than 50 they’d just throw it out.

P6 expressed surprise that the nurse had advised her to select the “donate” option so that the cord blood bank would call her if her cord blood unit did not meet the

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<sup>42</sup> Although private banks offer women the choice to donate “low volume” cord blood units, public banks have higher minimum volume requirements and these minimum levels are less flexible than private banks. This raises a number of questions including what is actually done with “low volume” units that are marked for donation. It is unclear what private banks do with these cases.

minimum recommended volume. The nurse's advice struck her as inconsistent given everything she has been told about minimum cord blood amounts leading up to that point. P6 continued to describe what happened in the case of her low volume unit:

**P6:** So they sent me a letter, which I could go get if you want. Um, they sent me a letter eventually, but I think that they first called me. I'm pretty sure they called me and I was led to believe that like, oh it's a blur now, they called me when I was in the hospital. Yup, it was in the hospital the day after she was born, 6:50 or whatever, that day I got a call I remember 'cause my husband wasn't there, but my mom was, and they said, "Do you still want us to go ahead with the processing? We'll send you a letter telling you about the quality and then you can decide whether you want to bank it." And I said, "Fine, whatever, go ahead with the processing." They're like, "We'll give you all the information we can about the, like, how viable it is." And then later I got the letter saying, "You decided to bank it." And I was like, wait a minute, I thought I just decided to have it processed to see how viable it would be for banking. But now, if I had been, like if I had been upset that they banked it and I didn't want to pay I would have just called them and said, "That's BS, like you never, you never got my consent to actually bank this." Um, but at that point it was sufficiently viable and I called them and got enough information to, to make me feel comfortable that it was sufficiently viable that I would just keep it, so I didn't care. So there was a bit of confusion around that actually.

Many women are required to negotiate with the private bank soon after giving birth because of the strict timeline private banks follow in processing the cord blood. According to AABB standards, banks that are accredited must process the cord blood units within 48 hours of collection. The imposition of this technical processing timeline on their post-birth recovery places added challenges on women who must consider what to do with their low volume cord blood unit. As P6 described, the pressure of having to make a quick decision following giving birth led her to be confused and misunderstand her options. She was frustrated and angry with the private bank for banking her cord blood when she thought she had not consented to

it; however, her anger was assuaged when she learned that her cord blood was considered “sufficiently viable.”

When I asked her what kind of information she was looking for when she learned that she had a low volume unit, this is what she said:

**P6:** I just remember sort of trying to get as much information as I could about like what I could do with this size of a sample and obviou-, like, they’re, you know, they’re trying to sell, they want you to bank your blood, the blood, and so, which I appreciated and I was like not blind to the fact that they’re, you know, trying to market their service, um, but they did say something about how future technologies will allow us to do something.

**I:** Expand?

**P6:** Yeah, like basically, yeah expansion of the cells into blood. “Who knows what we can do when you’re able to expand.” But I think they were, when I said, like, “Could it cure my cancer? Could it cure this? Could it cure,” like they

**I:** So you asked them really specific questions

**P6:** Yeah. They were like, “Well it probably wouldn’t, you need a certain number of stem cells per pound of body weight so as your child gets older, or for you, like it probably wouldn’t be enough, but with expansion therapies it might be,” kinda thing. So that, I was like, “*fine*.” At that point I was probably like so tired, like, so I was just like, “whatever.”

With low volume cases, private banks must negotiate with women in order to convince them that their cord blood is valuable and worth banking. In these negotiations there is a tension between the private banks use of technical knowledge (i.e. measures and counts) and promissory claims and women’s understanding of cord blood stem cell use as cure for specific diseases that could affect her child or family member. In other words, there is a tension between the private bank’s valuing cord blood as a profit-generating object and women’s valuation of cord blood as a maternal object in relation to their child and family’s health. Specifically, P6 wanted the private bank to translate the numerical knowledge of her cord blood unit to clinical knowledge about whether or not it could be used to treat cancer. If women do not consider their low volume cord blood unit to be clinically useful for their child and thus not bankable then the cord

blood unit also fails as a profit-generating object for the bank. In the negotiation, the private bank redirects focus to “future technologies” and speculative claims such as expansion techniques. If successful, these techniques would eliminate current limitations of cord blood use based on low volume or numbers. Expansion techniques are aimed at expanding or increasing the numbers of blood stem cells in cord blood in order to address some of the current limitations of its use in therapeutic treatments. As I explain in Chapter 1, given the limited number of blood stem cells available in cord blood, the units that are banked are only therapeutically efficacious in treating people who are 110 pounds and less (Bordet et al. 2010). However, P6 is less interested in abstract future possibilities and brings the discussion back to the present and asks the private bank about the ability of the cord blood stem cells to treat specific diseases. When she does this, the bank is forced to admit the current limitations of low yield blood stem cell collections. The tension between a cord blood unit’s value based on current clinical knowledge and applications versus its value based on speculative futures is an important component of these negotiations.

In the end, P6 decided not to object to her low volume cord blood unit being banked. However, she indicated a second tension in this negotiation in the quote above and that is that the private bank’s aim to capitalize on the cord blood unit may be at odds with women’s aim to protect their child and family’s future health. Private banks make money as long as the cord blood is banked; therefore, it is in their best interest to present the most favourable view of what might be possible with a low volume cord blood unit. P6 was aware that the private bank wanted her to bank and that they were trying to market their services. However, she was also relying on the bank to provide her with the information she needed to decide whether or not to bank. Many women I interviewed expressed this tension between being wary of the profit-making strategies of private banks and having to rely on the banks to provide them with the necessary information about their cord blood unit. This tension was apparent again when P6 shares with me the letter she received

from the private bank that advised her that her low volume unit was “sufficiently viable:”

**P6:** Oh, here it is. So yeah, so there’s, my child’s sample was that much [she is pointing to the number in the letter] and that’s the acceptable parameters [she is pointing to a second number in the letter] so it was within, barely within the acceptable parameters, but then it’s 91% viability so I remember calling and being like, “What the hell does that mean?” you know? Like is there 91% chance that it will cure all of our disease? You know, I was like, “What does that mean?”

**I:** Ok, so that would be Total Nucleated Cell Count [here I’m reading off the letter] so you would have had 150 million and they say 140 million is the minimum [i.e. the accepted parameter amount]

**P6:** Yeah, but see like normally they need 70 mls, but I only had 49.2 mls so I was like, “how is it possible that I have an acceptable number of cells with 49.2, but I guess sometimes the cells are dead or whatever, they’re not good cells. But there’s, it was just a dense, good dense sample. That was sort of the impression I got.

...

**P6:** Yeah so that’s 91%, I think they then said 91% of the cells in that sample of 150 million are viable.

**I:** Yeah, are alive

**P6:** So I was like, “Ok, well I have a lot of cells, I have an acceptable number of cells, and 91% are viable,” like I could, if I had 150 million and 60% were viable, then they would of still considered it acceptable to bank the blood [i.e. 60% viability was the minimum percentage of viability that was considered acceptable by the bank] so I was like, whatever.

After the cord blood was processed, the private bank provided P6 with numerical counts of her low volume cord blood unit. Since the concern with low volume samples is that they do not have enough cord blood stem cells to be clinically useful, P6 was particularly concerned with understanding what the numbers actually meant. P6’s efforts to understand these numbers demonstrate the confusion, tensions and challenges women experience in trying bring together different forms of knowledge that produce a cord blood unit as valuable. The counts represent a technical, scientific knowledge that provides an approximate measure of the number of blood stem cells and a percent or concentration of these stem cells in the overall

cord blood unit. This technical scientific knowledge does not address P6's clinical question and concern of curing disease. When she calls the private bank to clarify the meaning of these numbers she draws on a form of epidemiological risk knowledge. Epidemiological risk knowledge is used to predict the probability of disease incidence in a population based on exposure; however, in this case she is trying to apply a similar logic when she asks if 91% viability means that there is a 91% chance that the cord blood stem cells can cure a disease. She was attempting to translate the abstract number to a probability of curing a particular clinical condition. This is a very different way of knowing the value in cord blood stem cells than the abstract technical counts the private bank provided. P6 also translated the numerical counts to a lay knowledge or understanding of her cord blood unit as a "good dense sample." Interestingly, later in the interview she attributed this density and strength of the cord blood unit to the personal qualities of her daughter who she described as "small, yet strong."<sup>43</sup>

Later when I asked P6 why she said it was "fine" with regard to the misunderstanding between the private bank and her regarding processing and banking her cord blood, this is what she had to say:

**P6:** [Laughs] Because it meets their acceptable parameters. But what though, like what *that* means I have no frickin' clue. Like, their acceptable parameters could mean that it can cure one of the diseases on this list. Who knows, right? Um, but it's one of those things that it was just like sometimes, it's \$1300, or whatever, and I was like, you know, very, very, very hormonal and I couldn't give a rat's ass at this point [laughs], you know, so I just did it.

Again, P6 demonstrated the tension, or incommensurability, between numerically based knowledge of a cord blood unit's value and clinically based knowledge of its value when she tried to understand the private bank's numerical "acceptable

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<sup>43</sup> Historically, the afterbirth has been thought of as the child's "double" and thus performing specific post-birth rituals regarding the afterbirth have been thought to be critical to the child's future well being (Gelis 1991, as cited in Santoro 2011).

parameters” in terms of the cord blood stem cells’ ability to cure diseases. This tension between different forms of knowledge also exists for cord blood units designated as “good samples;” however, it is not made explicit because women are not required to engage with or reconcile these various ways of knowing the cord blood unit’s value. In cases of low volume units the useability, or biovalue, of the cord blood unit is destabilized and women are in a position of having to make a decision to bank or not. In spite of this tension, P6 ultimately decided to bank and accepted the private bank’s claim that the blood stem cell count in her low volume unit is sufficiently viable.

A second woman, P3, also had a low volume cord blood unit. In the quote below she describes how she learned of this and what she did to assess whether or not she should proceed with banking her cord blood:

**P3:** ... Um, we received a letter [i.e. from the private bank] saying that the sample was small, um, and that they were concerned and they gave us, um, a, ah, a measurement, something slash mols per litre, um, and wanted to know whether we wanted to continue with storing the sample because of its small size. So then I contacted my doctor and I said, “How did this happen?” and she said that it was, um, the way that they, the way that they got the sample from the umbilical cord, um, that they were given instructions in the kit to extract the sample this way and she didn’t agree with that way and that’s why they got a small sample. She would have liked to have used a syringe and pull out more, um, but that they weren’t supposed to do it that way, um, so, ‘cause I was angry, right? And I was like, “Why did this happen and who’s to blame?” So the, my doctor said, “Well it’s the method that we’re supposed to, how we’re supposed to collect the blood. It’s not the most efficient and we don’t get the best volume this way.” So then I started doing more research on the internet, like how valuable is a small size sample? And I found a guy, I don’t remember what his name is now, but he is some sort of cord blood expert, um, and, ‘cause I was, you know, “What am I gonna do with this sample? Is it of any use?” I should try to find the name of that guy for you, um, and so I sent him an email with the exact volume of stem cells that I had and I said, “Do I continue to save this or do I not?” His response was, “Of course it’s up to you, but we do have ways to multiply the cells now,” he goes, “You’re at the, right at the bottom, if it was any lower then you should just discard it, um, but you are a candidate for cellular multiplication to increase the volume of the sample.” He goes, “Should you ever need it you would need

a lot, you would need a, sort of a lead time 'cause we would need to do, increase the sample before you could do anything with it." He goes, "*But* it still has some value. So there's the information, now you do what you like." So given that, ah, we decided to continue to store it.

P3 consulted her doctor and an expert online to help her resolve the tension between numerical and clinical knowledges and to determine whether or not her low volume cord blood unit was valuable. Like P6, she was also concerned with understanding the abstract numbers the private banks provided in terms of clinical knowledge regarding whether or not her low volume cord blood unit could be used to treat disease if her child were to become sick. By consulting an expert, P3 was attempting to get a clinical answer to the question, "is the cord blood of any use?" The expert responded by drawing on future speculative technologies of cell expansion which deal only with the limitations of quantity and not of clinical utility. By drawing on the promise of expansion techniques, the expert lowered the lower limit for cord blood unit volumes and P3's low volume unit was re-constituted as valuable. However, expansion techniques are still in experimental stages and are not yet used in clinical practice. As I discuss below, it would turn out that for P3 the low volume of her cord blood unit would not be the reason for her cord blood to be useless.

Women who are in a similar position as P6 and P3 try to make sense of technical numbers by drawing on clinical and lay knowledges and they do so largely on their own. Although most private banks try to help women interpret these numbers if women ask, the private banks are not required to explain what these numbers mean and/or how to understand them. Even if banks were required to explain the numerical counts better, the issue of incommensurability of knowledges persists. The private banks frame the decision to bank low volume units as solely the woman's decision:

I: Right. So ultimately, who would make the decision that a cord blood unit isn't useable then?



**LD4:** It would be the parents. Yup, it's their decision. Even if it's 3 drops in a unit and they say, "no we still want to keep it," because I mean none of us can look in the crystal ball and say, "this will be completely useless." I mean I don't think it will be useful today and I can tell them my professional opinion, but if they say, "No, no, we want to do this anyway," we're gonna do it obviously.

**I:** Ok. So if a parent is in that situation where they may have a low yield and, and um, who would they speak to at the bank about what to do with it?

**LD4:** Yeah, they speak to, ah, one of our nurses, who's very experienced in all of this, or they can speak to me about that. And if it's, if they're kinda on the fence and they don't really know what to do and it's a stressful decision, I mean they've, they've thought long and hard of making this decision and now we're saying, you know, "ah, we don't think it's good enough." You know, that's a hard decision. So I usually advise them to keep it for, you know, couple of years and come back because the field is moving forward so quickly and what we can do today, you know, we might be able to do a lot more in two, three years, and then make the decision. Then when they, you know, they're new parents, a lot of things going on, maybe you don't want to make this decision right then to terminate, instead push it forward a little bit and then make the decision later. But then again, if it's a small sample, I would seriously advise them not to do it.

If a woman wants to bank a low volume unit, the private banks will oblige. In order for the cord blood unit to generate profit for the private banks, the banks must persuade women that the cord blood, even a low volume unit, is valuable. Although the Laboratory Director above suggested that the decision is entirely the woman's, as I show above in the cases of P6 and P3, women took the numerical knowledge of their cord blood that private banks provided and tried to translate this knowledge into their own understandings of clinical knowledge regarding the uses of cord blood. The private banks foreground promissory and speculative techniques and uses of cord blood stem cells in an effort to re-constitute low volume units as valuable for women. If a woman decides to bank a low volume unit she takes a gamble that her cord blood stem cells will be clinically useful in the future.

### **Cord Blood as “Completely Useless”**

Using the words of the Laboratory Director above, under some conditions specific cord blood units can be found to be “completely useless.” As long as conditions do not require the actual use of the banked cord blood stem cells, their value as a therapeutic object remains in their potential use. However, if the cord blood stem cells are needed for treatment – that is, their potential use value is to be materialized – the cord blood stem cells can be determined to be useless and their value lost. For P3, she learned that her cord blood stem cells were useless when her son was diagnosed with childhood leukemia. She had lost her brother to childhood leukemia when she was young and living with this loss kept concerns about her child’s future health in the foreground of her mind when she was pregnant. P3 recalled that even before she was pregnant she had heard about cord blood banking so that when she was pregnant with her first child she was quick to look into it.

**P3:** Um, well I knew it was, um, used for, ah, bone marrow transplants and um that they used it for other, um, sort of auto-immune type diseases and I remember looking at the website and they had varying numbers, but they were like, “oh well, you know, right now we can use stem cells to treat 23 known and we’re predicting in the future that it’s going to be, you know, double in the next 5 years.” Um, so those kinds of, um, sort of, little factuals I sort of tagged on to. Um, you know, as soon as I saw the word “cancer” I was like, oh yeah, you know, it’s gonna protect my son from, from cancer should he, you know, we have this back-up plan. Um, and then I thought, “oh all these other diseases, that’s just bonus,” right? That we can hold onto this sample, um, and treat anybody in the family, with, with, if anything else hits us, then we can use this sample to treat something else. And, um, and then the possibilities are just ballooning from there.

As described in the previous section, P3 had had a “low volume” collection and had decided to bank after an expert had advised her that expansion techniques would increase the number of blood stem cells should she need them in the future.

After making the decision to bank, P3 felt confident that the banked cord blood stem cells had the potential for clinical use until her son was diagnosed with leukemia:

**P3:** I didn't think much about it [i.e. banked cord blood] until [son] turned 4 and then [son] was diagnosed with leukemia. So there we are, worst case nightmare came true. And then I thought, "Oh I have this, you know, saving grace." Through, um, you know, your world is upside-down at the time, but I was just like, "You know what, we have [son's] cord blood banked." And they were like, "Well, let's not worry about that right now we have chemo to get through," and all that kind of stuff. Um, so we continued, of course we paid the fees to, to continue banking, it was a year of intense chemotherapy, um, and then, it ah, so he was 5 and it came time for us to renew and we were like, "OK are we gonna be using this, do we keep, you know, is this a possibility?" And then someone told us, "Well no, with leukemia you rarely, if ever, auto-transplant stem cells." I'm just like, "*What?! [her emphasis].*" Why did I save his stem cells if leukemia was what I was afraid of most of all anyways?" And then I'd already had a daughter [*her second child*] and it's just like, well what I needed was her stem cells.... Um, and they said, "Well his stem cells are useless anyways because he's got some sort of genetic marker for leukemia or for cancer, um, and they will never be transplanted into anyone."

**I:** So who told you that?

**P3:** The oncology department. Um, so at that point I started asking around to see if anybody was doing research on genetic markers, um, and if they wanted some stem cells from a known leukemia patient to do research on. So we tried that for a year.

When conditions arise for the use of the banked cord blood stem cells, several important shifts occur. In the instances of "good samples" and "low volume" units, the private banks and women who bank are the key social actors, drawing on multiple knowledges and promissory claims to establish that the cord blood unit is valuable and worth banking. When a child or family member becomes sick with a disease that could be treated with a blood stem cell transplant, the transplant or treating physician becomes the key actor in determining the therapeutic use of cord blood. The treating physician is the authority and current therapeutic knowledge of cord blood stem cell treatment trumps the private bank's technical knowledge and

speculative claims about the cord blood's potential use. At this point, the potential use value of the cord blood stem cells materializes or, as in the case of P3, it fails and is valueless. Only under these conditions can women get a clear and definitive answer to their question regarding the clinical value and utility of their cord blood unit.

It is in the interests of the private banks for women to bank and for the banked cord blood units to remain in a state of potentiality. That is, private cord blood banks make money as long as the cord blood units remain unused and in a state of uncertainty regarding whether or not they will be used. If, as in the case of P3, a physician determines that the cord blood will never be used, then the bank loses money because the woman no longer wants or needs to bank her cord blood unit. If a cord blood unit is used as a transplant therapy, the private bank again loses money because the cord blood unit ceases to generate profit. Private banks release banked cord blood units to transplant physicians at no extra cost to women who banked. The potential use value of the cord blood stem cells as a biomedical or therapeutic object is realized. The capitalistic logic of the private bank is to increase storage and encourage women and couples to hoard their cord blood for as long as possible; it is not a logic of circulation or exchange as Fannin (2013) argues. The private banks' marketing of banked cord blood as "biological insurance" (discussed further in Chapter 5), also relies on the non-realized, potential for cord blood stem cells to provide biological security against disease in the future.

Once the physician confirmed that the cord blood was useless as a clinical treatment, P3 turned her attention to finding a research laboratory that might be interested in using the cord blood unit for research:

**P3:** Yeah, yeah. So we saved it for a year 'cause I thought, "Oh my god, you know, we need it, we need it." And then they were like, "Nope. OK, he's in remission. It's all good." Um, and then I was finally able, you know, to come up for air and ask, you know, "Do we need these stem cells because the fees are due." And they said, "No. We will never need these stem cells for, for his treatment," right? That was the specific question, "Do we need these stem

cells for his treatment?” and the answer was, “Never.” So then I, yeah, so then I went to [private cord blood bank] and I said, “Listen, I am not will-, I am not, you know, we’re not using these stem cells for [son], um, but I want to find someone to donate them to. I want a research, um, facility to find out,” so they said they would look into it. But I also looked into it at the, at the hospital site too so I sent, um, emails to, um, the head of oncology at Children’s Hospital and said, “I have this sample that I would like to, is anybody doing research in this area? Could anybody use them before they get destroyed?” That went on for a year. So the status of sample was in limbo for a year. When it came time for another year of fees, now I’m back due a year of fees.

P3’s efforts to find a use for her cord blood as a research tool in a scientific laboratory is suggestive of efforts to salvage value, any value, in the cord blood unit that was determined to be therapeutically valueless. However, this proved to be much more difficult than originally suggested by the private bank at the time of registration. The challenges P3 faced when trying to donate the cord blood demonstrate the complexities and difficulties of moving a privately banked cord blood unit into the donation option. It also demonstrates the specificity of each of the uses of and final forms (e.g. scientific object or therapeutic object) that the cord blood unit takes. A research laboratory operates according to scientific standards and practices that differ significantly from the standards and practices of a commercial private bank.<sup>44</sup>

P3’s efforts to salvage value in the cord blood also provide some insight into the meaning and value of the cord blood for her. It is not difficult to consider how P3 might want to find a use for her cord blood since she had paid financially to have it banked. For P3, to have the cord blood be useless and discarded could feel like she had wasted her money to bank it. However, I propose that her concern is also more than a financial one. As I suggest above, women value the cord blood as a maternal object that provides security and assurance of health for their child’s future health.

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<sup>44</sup> For example, according to a conversation I had with a research scientist examining environmental toxins in cord blood, she explained that the cord blood used in her research had to be collected in glass vials, not plastic to avoid any possible contaminant leakage from the plastic. Cord blood collected for private bank storage is held in plastic bags similar to the bags used in blood donations.

They are concerned primarily with the cord blood unit's ability to cure particular diseases should their child or another family member be diagnosed with a disease. Moreover, inscription practices and textual documents, such as a collection certificate, serve to stabilize the social relations between a woman/family and the separated cord blood by serving as a visual reminder that the partially alienated biological material still "belongs" to the family. I suggest that as a maternal object, the clinical determination that the cord blood is "completely useless" means the loss of value in an object with social and familial significance. As such, P3's efforts to find a use for the cord blood can be viewed as an effort to salvage value in an object that was believed to provide security for her child and family in an uncertain future. If the cord blood is useless in treating my child, then maybe it can be of use in finding a treatment for someone else in the future. Unfortunately, P3 was unable to find any research laboratory that was interested in using her cord blood. There is a tragic irony in the complete uselessness, or absence of biovalue, in P3's cord blood unit after her son was diagnosed with leukemia. While private banks and popular and expert media consistently extol the value of cord blood as "clinical gold" and frame as wasteful the decision not to bank it, P3's cord blood was valueless for the private bank, clinicians, researchers and P3 herself. In the end, when she desperately wanted to salvage value in her cord blood, some of the same players who had formerly advised her to bank were now telling her to discard it.

## **Conclusion**

Stem cells generally and cord blood tissue specifically are considered to be valuable by social scientists (e.g. Waldby & Mitchell 2006; Fannin 2013), scientists and the lay media because of their self-generating properties. These properties allow these materials to be used in regenerative therapies and, thus, to potentially address a number of health conditions and optimize health. However, this property in and of itself is insufficient in ensuring that a specific cord blood unit is valuable. Producing and knowing a cord blood unit as valuable, that is a biological material

that can be used to ensure or optimize health, must be determined through the process of banking itself.

In this chapter, I have demonstrated the social and technical transformations of cord blood that produce it as valuable. Focusing on three specific articulations of the value of cord blood: a “good sample,” a “low volume” unit, and a useless cord blood unit, I argue that the production of cord blood as valuable is shaped by multiple forms of knowledge – technical, clinical, and speculative – and the tensions between them. In cases of “low volume” units, the process of producing cord blood as valuable requires women and private banks to negotiate and women are in the difficult position of having to reconcile or understand different and incommensurate ways of knowing if cord blood is valuable. What this demonstrates is that not only does the production of biovalue in specific cord blood units require the work of technicians and techno-scientific knowledge, but it also requires the work of women and prospective parents who engage in the process of saving their cord blood in a private bank. In “good samples” the numerical knowledge of the cord blood unit stabilizes its value for the private banks and the women because it coincides with the parameters of meaning established at the time of registration and it coincides with amounts needed for current clinical therapeutic uses of cord blood stem cells. In the case of a “low volume” unit, the numerical measurements for the cord blood unit destabilize the potential use value in the present and thus the private bank makes efforts to re-establish or revalue the low volume unit.

Lastly, I show how a cord blood unit can be “completely useless” in spite of the presence of live regenerative stem cells. This last case is particularly interesting and is the specific reason for the reference to “fool’s gold” in the title of this chapter. Fool’s gold is a mineral, iron pyrite, which visually resembles gold, but does not have the same desirable properties as gold. Miners believed they had found something valuable, only to learn that it was not the valued substance they thought it was. Like the gold miners who believed they had found something valuable, women too are sold the idea that cord blood is valuable. The private banks’ aim of producing profit

through the banking of cord blood provides them with no incentive to suggest that cord blood units may be “fool’s gold” and not useable. Women who bank or are considering banking cord blood must take on this real possibility of cord blood failure and the risk that it is useless. I consider this in greater detail in the following Chapter on cord blood as “biological insurance.”



## Chapter 5: Troubling Biological Insurance™



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### Benefits of Biological Insurance – 3i's

3 unique characteristics distinguish the Biological Insurance™ stem cells found in the umbilical cord and umbilical cord blood from other types of cells: intelligence, imagination, irreplaceability.



<http://cordbloodbankofcanada.com/benefits-of-cord-blood-banking/>

### Introduction

The storage facility of a private cord blood bank in Toronto is a large, cavernous room that holds several large liquid nitrogen tanks. Each of these tanks holds hundreds of carefully placed metal cassettes that contain the valuable hematopoietic stem cells extracted from cord blood. The only item that distinguishes one cassette from another is a unique barcode placed on each cassette. Stored at temperatures as low as -196 degrees Celsius<sup>45</sup> these frozen stem cells are the biological materials that are marketed by private banks as providing *biological insurance* to the women and families who have banked them. Cord blood has been marketed as biological insurance since the early days of the private banking industry in Canada. In 1999, Janet Hass published an article in the *Canadian Medical*

<sup>45</sup> <http://www.insception.com/frequently-asked-questions>, downloaded Nov. 19, 2013.

*Association Journal* quoting Ernest Stacey, then president of LifeBank Cryogenics, a private cord blood bank located in Burnaby, BC, as saying:

We have coined the term ‘biological insurance’ .... I’m not sure that’s preying on anyone’s fear, but it’s a realistic term. It’s an opportunity and it is not misleading because we’re telling people up front. We’re not deceiving anyone – we’re saying ‘here it is and yes, it may work or no, it may not work. And there’s no guarantee.’ (552)

The metaphor of cord blood as biological insurance is currently widely used by many expert and popular media articles on private cord blood banking, by many health professionals who use the metaphor as a shorthand when explaining private cord blood banking to expectant women and couples, and by private banks as a marketing strategy to promote their service. More recently, in an online article posted on November 14, 2013 comparing private and public cord blood banking in Canada, Clifford Librach, director of CReATe Cord Blood Bank in Toronto, ON, promotes private cord blood banking as “biological insurance”<sup>46</sup>. According to its website, the Cord Blood Bank of Canada’s (CBBC) has trademarked Biological Insurance™ to establish proprietary rights over the term itself.<sup>47</sup>

The appeal of the metaphor of biological insurance and its traction over the years is easy to understand. In the contemporary Global North, optional (e.g. travel cancellation insurance) and non-optional (e.g. auto insurance) forms of insurance are part of our everyday lives and something with which most people are very familiar. In North America, the 20<sup>th</sup> century saw a rise in insurance in both the private sector (for e.g. life insurance and private pensions) and the public sector (for

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<sup>46</sup> <http://healthydebate.ca/2013/11/topic/innovation/cord-blood-banking-in-canada>, downloaded Nov. 19, 2013.

<sup>47</sup> The trademark is an economic device aimed at establishing a form of private ownership over the use of these words or phrase. The CBBC’s trademark efforts point to the efforts of private banks aiming to maximize their profits through the selling of this biological service. Haraway (1997) recognizes the importance of the trademark as a symbol of branding and establishing proprietary rights. In the case of the OncoMouse™, a trademark established on a mouse transforms it to a capital and scientific object owned by Dupont.

e.g. social insurance and publicly insured healthcare in Canada) (Baker & Simon 2002). In theory, these financial forms of insurance protect the individual against unexpected and uncontrollable negative events such as poverty, unemployment, natural disasters and automobile accidents by calculating and spreading risk across a population. In other words, a population, or group of people, pool money and this money is distributed to individuals when an adverse event, such as a car accident in the case of car insurance, occurs. The purpose of this form of insurance is to provide financial protection to an individual who experiences an adverse life event. Baker & Simon (2002: 7) write, “Because almost everyone, at least in the developed world, has so much experience with insurance – buying auto, life, and homeowners insurance; consuming medical services covered by health insurance; paying social insurance taxes; and so on – insurance is a category that people tend to believe they understand.”

In this Chapter, I examine “biological insurance” as a metaphor for private cord blood banking beginning from the accounts of women who banked. I examine what women had to say about biological insurance by identifying and analyzing key themes that emerged from their discussions around privately banked cord blood as biological insurance.<sup>48</sup> I focus on four themes for analysis and discussion: biological insurance and fear, biological insurance as guilt insurance, biological insurance and risk, and the failure of biological insurance.

First, women were prompted to buy “biological insurance” out of fear and discomfort that their child might be sick in the future. Unlike much of the social science literature on cord blood banking and molecular bioscience and medicine that emphasizes hope and promissory expectations (e.g. Brown 2005; Novas 2006), women spoke much more about fear and anxiety than hope in new biotechnologies. I argue that the production of a need for biological insurance involves a vision of an uncertain and fearful future that inspires feelings of fear, anxiety and discomfort in

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<sup>48</sup> In this chapter, I use “biological insurance” to refer specifically to privately banked cord blood. Other types of biological insurance exist (for example, banking of menstrual blood or ova), however the analysis and discussion in this chapter are specific to cord blood banking.

women. Second, women spoke about cord blood banking as providing them with “guilt insurance.” I explore and consider the ways in which buying biological insurance comes together with moral language and normative framework of maternal responsibilities. I suggest that the maternal moral imperative to buy biological insurance as “guilt insurance” demonstrates an expansion of maternal responsibility over the health of their children and family members. Third, women spoke about biological insurance as similar to life insurance and I reflect on the ways in which “biological insurance” is not an insurance technology, like life insurance. I argue that private cord blood banks do not operate according to the same logic as life insurance companies. I provide a detailed account of one woman, P3, for whom the metaphor of “biological insurance” does not hold. I present her account as an exemplary case of the failure of the promise of health security and demonstrate the social and clinical complexities of the use of banked cord blood stem cells. In doing so, I bring to the foreground the risk that is taken with banking cord blood privately. Private banks have effectively marketed private cord blood banking as “biological insurance” by offering women the promise of their child’s future health security. I suggest that the need for “biological insurance” is produced by inspiring fear and hope in women and coincides with women’s anxieties about their child’s future health and their desire to be good, responsible mothers.

I begin this chapter with a discussion on analogical or metaphoric reasoning and comparison. I follow this with a review of the social science literatures on “biological insurance” and financial forms of insurance. Next, I discuss the four areas mentioned above: biological insurance and fear, guilt insurance, biological insurance as life insurance, and the failure of biological insurance. I conclude with a review of the key arguments and discuss the trouble with biological insurance.

### **Metaphors and Analogical Reasoning**

Hofmann et al. (2006) write that experts and lay people use analogies to handle challenges related to new technologies. Beginning from the premise that the

ontological status, uses of, how to know and understand new technologies are not self-evident, the authors argue that experts use analogies to provide explanation, order to, and understanding of new technologies (49). For example, the authors ask: is cord blood cells, tissue or organ? Is it blood or not? What it is will determine how it is governed and what is or is not permissible to do with it. Some of these questions have been settled. In Canada, Health Canada regulates cord blood as a transplantable biological material and not as a blood product. Clinical and scientific discourses have settled the question of to whom the cord blood belongs by determining that genetic match should be the primary criterion for belongingness. A range of analogies are deployed to speak about and frame cord blood banking including: waste and gold, a natural resource, organ transplantation, a gift, gambling, and the metaphor that is the focus of this chapter, insurance. Metaphors and analogies are not only useful analytic tools to understand the normative framework of new technologies, but they also have a normative effect themselves (Hofmann et al. 2006: 52). For example, the metaphor of biological insurance presents a normative framework for private cord blood banking.

An important feature of metaphors or analogies is that they are necessarily incomplete. Hofmann et al. (2006) write that “analogies are not exhaustive. Individually they are not able to deal with the full complexity of challenges that may emerge within a technology-driven field such as biobanking” (52). The use of analogical reasoning is a form of comparative analysis or reasoning. That is, deploying an analogy to deal with issues in cord blood banking is to compare and determine that a familiar form, object, or “thing” is similar to the novel technology under consideration. This raises questions and challenges related to comparison of two different things, objects, or forms.

Writing on the challenges of ethnographic narrative and comparative analysis, Strathern (1991) describes the limitations, and productive work, of analogies. She writes:

To draw a comparison, or make an analogy, is not necessarily to impute connection: it may indicate a resemblance, rather than a relation, and the resemblance may be fantastic, rather than real, 'magical' (Jackson 1987). Yet the very act of comparing also constitutes a making of connections, and evokes a metaphorical relationship. Michael Jackson (1987:21) notes: "[T]he fact that things are used on the basis of magical similitudes does not preclude their having intellectual and therapeutic value." Conversely, using the similitudes gives things a value: comparison — intellectual, therapeutic — creates their multiplicity. (Strathern 1991: 51)

A metaphorical relationship is necessarily a “partial connection,” according to Strathern (1991). For the purposes of this project, what I take from Strathern’s work is that the characterization of metaphors as articulating “partial connections” speaks to the incompleteness or partiality of knowledge and metaphorical strategies. However, despite their partiality, metaphors can also give shape to and direct actions and relations among people, institutions, and systems of governance. For example, as my review of Rei’s (2010) work below shows, framing cord blood as “biological insurance” places it within a commercial industry and thus allows it to be governed more liberally than if it were framed as a clinical or health service.

### **Literature on Biological Insurance**

To date, there has been little social science literature that examines “biological insurance.” While many social scientists writing in the field of cord blood banking acknowledge or make reference to the popular metaphor, few have examined it in much detail. Three exceptions include the work of Geransar (2010), Rei (2010) and Brown & Kraft (2006). Geransar (2010) considers the use of biological insurance as a metaphor for private cord blood banking in her dissertation on public cord blood banking in Canada. While not the focus of her research, she documents and discusses how some women drew on the metaphor of biological insurance to explain reasons for banking. When women spoke about biological insurance, they did so in relation to the private banking option. That is, they thought of private cord blood banking as providing biological insurance for

their child. In two cases, women spoke about donating cord blood to a public bank as providing insurance; however, Geransar (2010) noted that these women had donated to a public bank that was part of a much larger private bank and thus, she wondered if they may have been influenced by the advertising of the private bank. Considering biological insurance as a metaphor, Geransar (2010) cautions that while metaphors may be helpful to explain new and unfamiliar practices, they can also be misleading and/or elicit emotional responses rather than enable clear understanding. In another study, Rei (2010) examined how the private cord blood bank's use of the metaphor of biological insurance influenced private cord blood bank governance in Taiwan. She argues that the adoption of the biological insurance metaphor frames private cord blood banking as a commercial, for-profit business rather than a health issue resulting in a more lenient governance structure for the industry. Like Geransar (2010), Rei (2010) is also critical of how the widespread adoption of this metaphor might mask the scientific uncertainties of cord blood stem cells and could limit people's understanding of their uses. Both authors are critical of the ways in which the deployment of the metaphor of biological insurance can have a framing or limiting effect at the levels of both the individual and state policy.

Brown & Kraft (2006) also reflect on private cord blood banking as providing a form of *corporeal insurance* or *corporeal indemnity*. They note that private banks market their service as a form of insurance and the authors recognize the opening up of a moral space for people considering banking. In their study, participants explained that they had banked cord blood, in part, to avoid feeling regret in the future. Brown & Kraft (2006) contrast the different indemnity logics that organize private versus public banking pointing out that in private banking the cord blood is directed to the depositor (or any other person the depositor chooses). In public banking, the authors write that the corporeal investment is not directed to any individual, but pooled for the "general good" or general population (323).

## Sociological Literature on Insurance

Foucauldian scholarship on insurance theorizes it as a governance technology (Ewald 1991). A technology has a specific goal or purpose, has a particular way of knowing or understanding how to achieve its goal, and applies specific methods, tools, and techniques to achieve this goal. Many governmentality scholars theorize life insurance and other types of financial insurance as rationalizing technologies activating calculable risk techniques. Calculable risk emerged with the rise of actuarial science in the late 19<sup>th</sup> century (Ewald 1991). As a rationalizing technology, insurance is disinterested, calculating and free of morality and moral regulation. With the rise of actuarial science, Castel (1991) identifies several transformations in governance technologies associated with the “shift from dangerousness to risk,” including separation of “risk” from “danger” and the end of the “subject” or “real individual” and its replacement with a collection of risk factors based on the population. As I noted earlier, the goal or purpose of insurance is to pool or spread individual risk across a population and thus, provide security against possible financial ruin should an adverse event, such as death, occur.

Ewald (1991) identifies four characteristics of insurance as a social object (197-198). First, he writes that insurance can refer to the *institutions* that provide insurance. These institutions vary and provide different kinds of insurance. For example, some insurance companies offer life and home insurance to individuals who pay for insurance coverage. Private insurance companies operate as for-profit businesses and market their services in an effort to generate paying customers. On the other hand, social or public insurance institutions operate very differently. Health insurance in Canada is a social, non-profit form of insurance that is paid for by the government on behalf of all Canadians in order to ensure that everyone in the population has access to healthcare. Second, Ewald explains that what is common among different insurance institutions is that they all use an *abstract technology* based on actuarial science and calculable risk. In theory, the technology of insurance is about combining different social and economic elements in a specific way. He



writes that each insurance institution is a unique combination of these elements. Thus, life insurance combines the social event of death with economic or financial payout through pooling and redistributing money. Third, according to Ewald, insurance institutions are more than the application of a technology, thus they are not all uniform. Instead, he writes that there are different insurance *forms* (for example, private versus social insurance or mandatory versus optional insurance forms) that are informed by different *insurantal imaginaries*, the fourth characteristic of insurance. This refers to the social context, ideas, discourses that make possible the adoption and development of a particular form of insurance. Building on the work of Ewald, Baker & Simon (2002) define insurance imaginaries or visions as “ideas about and images of (or, alternatively, discursive practices regarding) insurance that animate the development of insurance technologies, institutions, and forms” (9). Insurance visions are involved in making possible the production of the market for a particular insurance form.

Baker (2000) challenges the abstract characterization of insurance as an amoral technology that dominates in the governmentality and economics literatures. He argues convincingly that the emphasis on insurance as a rationalizing technology presents more of an economic and less a sociological view of insurance. Contrary to the work of Ewald and colleagues, Baker (2000) shows that moral regulation has been an integral part of insurance technologies and systems since the 19<sup>th</sup> century through to the present. According to Baker’s review of documents produced by insurance companies in the late 19<sup>th</sup> century, many companies were concerned with “moral hazard” and the character of people who might buy insurance and make fraudulent claims. Insurance companies felt it was their duty to maintain a moral order by providing insurance to “good” people and denying insurance to “bad” people. Moreover, when an insurance claim was made it was the duty of an insurance adjuster to scrutinize the character of the claimant to determine whether or not s/he was an honest person and thus trustworthy not to make a fraudulent claim. The occurrence of a “bad event,” or risk, was thought to be not only the result

of fate and the external world, but also to people of “bad” character (Baker 2000: 566). Baker (2000) argues that within the counter-story of insurance in which it functions as a moralizing technology, this technology fits within a disciplinary framework and not solely an actuarial one (560).

Writing about insurance in neoliberalism, Ericson et al. (2000) argue that private insurance companies, while ostensibly thought to pool risk across a population, in practice “un-pool risk” by increasingly segmenting people such that the “pool” becomes ever smaller (533). The effect, they argue, is that private insurance companies increasingly individualize risk since there are fewer people across which risk is shared. Empirical studies of private financial insurance also show that insurance technologies deviate from their idealized forms. For example, Ericson & Doyle’s (2006) ethnography of private and public insurance shows that deception is institutionalized in private life insurance companies. Thus, they argue, ironically, private insurance as it operates in neoliberalism requires policyholders to take *on* risk since the policies they hold may not provide the protection they believe it will. The authors also challenge the assumption of the calculability of risk in life insurance arguing that, in practice, many life insurance companies exercise speculation in calculating risk since they rarely have all the information required. Ericson & Doyle (2006) write that the “veneer of calculability” of risk allows private life insurance companies to market their products as providing more protection and security than they actually might. Ericson et al. (2000, 2006) and Baker (2000) demonstrate that insurance, in practice, can deviate from its abstract, technical form. In the remainder of this Chapter, I analyze how women speak about banking cord blood as “biological insurance” and consider the partiality of this metaphor by comparing what privately banked cord blood provides with a specific understanding of insurance in sociological literature.

### **Biological Insurance and Fear**

All the women in this study described banking cord blood as buying “biological insurance” without any specific questions or prompts from me. In their interviews, they talked about buying biological insurance to avoid a possible tragic and insecure biological future for their children and families. Private banks encouraged women to imagine their child becoming sick in the future and women spoke about the fear and discomfort they felt when imagining this. Their discussions of the peace of mind and assurance that banking cord blood brought them was inseparable from anxiety and discomfort about the future. Consider the following quote by P11:

**P11:** Um, it means, the first word that kind of came to my mind is, sort of a sense of relief, I don't know why. That, kind of, an assurance that there's something that if, god forbid, [son] were to come down with a list of different potential illnesses or diseases that there's something that we could provide him with, help him with. Um, not that that's a guarantee that that would work or, I mean that, you know, but that that's something that we can look to as an option. I think it provides more options for us at that point. Um, so there's a sense of relief around that and a sense of we're providing good care for him and doing the best that we can for him. Um, and a sense of fear that that could be something that he would have. You know, I think that, I wonder sometimes if people don't do this because they want to avoid it, right? “He's not gonna get that. I don't want to think about it. And so I'm not gonna bank 'cause I don't want to think about that.” So by going through the process you're also acknowledging that he could come down with these different illnesses and that's a scary thought. Um, so you know, it's, it's mixed I guess, um, 'cause avoidance, ah, isn't, as a therapist I know it's not the best approach [laughs], um, but it can be helpful when you don't want to think about things. Um, and so by doing this you can't avoid it. You can't avoid the fact that you're thinking about the possibility of that. Um, but pleased, like I feel, I'm really glad that we did it....

The imagined tragedy of a child's early death from a disease that could be treated is a necessary condition that contributes to the production of the need to save cord blood for one's child and family. As P11 explains, banking privately involves women and parents producing and engaging with this fear and thereby sustaining and

engaging with a fearful vision of the future. The sense of relief, assurance, and hope that biological insurance provides depends on the production of fear and anxiety about biological health. The need for biological insurance not only depends on people imagining the body as a site of disease and illness, but also on their viewing the body as providing the biological material for regeneration and cure. This vision of fear and anxiety is promoted through the marketing materials of the private banks. The Cord Blood Bank of Canada (CBBC) lists a total of 104 diseases that blood stem cells can be used to treat currently or potentially in the future.<sup>49</sup> Presenting this extensive list not only exaggerates<sup>50</sup> the therapeutic uses of blood stem cells, but also raises alarm and concern in many parents and parents-to-be since each condition or disease listed is a potential harm from which their child might suffer. The banks also produce a sense of urgency about saving cord blood. The CBBC states on its website, “You only have one chance to collect your baby’s Biological Insurance™ stem cells. They must be collected at birth or they are lost forever.”<sup>51</sup> The list of diseases presented by the private banks prompt women interested in banking to imagine a future in which their child is sick with a potentially terminal disease that can be cured with cord blood stem cells (see Chapter 1 for a discussion of current and future therapeutic uses of cord blood). According to the private banks, banked blood stem cells can save their child and provide security against this fearful future. Mixed in with this fearful vision of the future are images of cord blood stem cells as “perfectly matched” to the child and “unique”.<sup>52</sup> The CBBC encourages imagining cord blood stem cells as the child her/himself personifying these cells with traits such as: intelligence, imagination and irreplaceability.

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<sup>49</sup> <http://cordbloodbankofcanada.com/medical-uses/>, downloaded Nov. 21, 2013

<sup>50</sup> Critics argue that private cord blood banks make hyperbolic claims about the clinical uses of cord blood stem cells. Private banks do not highlight the low likelihood of contracting many of these diseases nor do they clarify which conditions are treated by allogeneic, not autologous, transplants.

<sup>51</sup> <http://cordbloodbankofcanada.com/benefits-of-biological-insurance-irreplaceable/>, downloaded Nov. 21, 2013.

<sup>52</sup> <http://www.insception.com/why-bank-cord-blood>, downloaded Nov. 22, 2013.

The private bank's efforts to produce this fearful vision of the future were not lost on the women I interviewed. For example, P12 was particularly troubled by what she viewed as the private bank preying on the vulnerability of pregnant women:

**P12:** I hadn't really given it that much thought. She's [a friend who did not bank cord blood] a very, she errs on the side of natural everything, and, and it sounds like it's [delayed umbilical cord clamping] hugely beneficial and her argument was, "We already know that this is beneficial. Cord blood banking might never benefit you or anybody else." Um, so I agreed with that. The only thing that gets, gets me is that it's like a bit of a, I can't remember what the word is, it's like they [the private banks] find women at their most vulnerable, most vulnerable spot in life, they give you all this information that are like, "If your kid has leukemia, like this could solve the problem." And you're like, "I'll do anything! Whatever you need me to do!" So that, I think, is like, my beef with it. I don't love that about it, but and that's why I stopped them, I was like, "Please don't pitch me. Like, I don't need a sales pitch." I made this decision for my reasons, but like, I don't need lists of all the wonderful things that can be done with it....

Later in the interview, P12 discussed further her view of the problems associated with the production of a vision of fear by for-profit private cord blood banks:

**P12:** Because you're *so* sensitive and *so* raw with this hypothetical life that you've built in your head. You're like, "I'm gonna have this beautiful baby and it's gonna be so wonderful and they're gonna grow up to be a President of the United States [she is originally from the USA]." And then [private bank] is like, "But if they get leukemia," and you're like, "I'm worried as it is." It's like they pull on your paranoia to make people that might be on the fence, do it. And I don't like that, just, it really grosses me out. Um, and I feel that way across the board. I have a friend who, ah, lives in the States, and again it's really different in the States, she's got cancer, she's my age and she can't get some of the cancer drugs she needs because the pharmaceutical companies are specifically trying to create supply and demand. And they are only releasing batches of this drug, even though they have the formula, they have the facilities, they could just make as much as they need to fix all these people's problems and she can't get what she needs. To me, like, pharmaceutical companies that behave like that are, like, infuriating. And I think that these people [i.e. private banks] are basically pharmaceutical companies. I mean

it's, to be more specific, it's by, you know, science or whatever it is, it's the same concept. So I don't like that. And I don't like being sold to when I'm in a vulnerable spot. You know, they came by again, I'm actually just remembering this, I don't know if it was the [private bank] woman or if it was just someone in the hospital, it must have just been someone in the hospital, when I was in that early labour, like, the scariest day of my entire life, I had all these specialists coming to tell me, like, what could happen if my baby were born that day and they, someone was like, "Did you do cord blood banking?" And in that moment, if you're about to have a baby that early, you might really need that cord blood one day and, so if you couldn't afford it, you might at that point say, you know, like, "We won't pay our mortgage. Let's get this done." Like, when people asked me that I was scared.

The vision for biological insurance is not one that adds only hope to the optimistic images parents hold for their future child, but as P12 describes, it also prompts fear that disrupts the hopeful visions that women hold for their children in the future. This fearful vision is presented during a time of heightened caution and concern for many pregnant women. As P12 recounts and as I describe in Chapter 3, many women have birthing experiences that are unpredictable and often involve a number of unexpected or unplanned biomedical interventions such as, labour inducement or caesarian section deliveries. The insertion of fearful visions of a child's future health by asking about cord blood banking during labour contributes to the stress and anxiety that many women are already experiencing when they are giving birth. Moreover, the sense of urgency promoted by private banks advertising claims that collecting cord blood is a "once in a lifetime opportunity" come together with the culture of urgency in an acute-care hospital setting adding to women's feelings of stress and anxiety. For many women, visions of a fearful future are produced at a time when they are dealing with a great deal of social and cultural pressure to care for their child according to normative standards.

Women experienced feelings of fear, discomfort and anxiety<sup>53</sup> when imagining future visions of their child becoming sick. As Brown & Kraft (2006) point

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<sup>53</sup> In examining women's experiences of emotions, I conceptualize emotions as a sociological construct and not as a psychobiological fact. Emotions were largely absent from sociological

out, biological insurance is a future-orienting technology in which people make decisions in the present in order to provide security for the future. The accounts of women in this study present an emotional orientation to the future that differs from much of the literature on contemporary biotechnologies and medicine. To date, social science scholarship on molecular medicine and cord blood banking has primarily emphasized hope. In this broad body of scholarship, scholars have examined hope as the object of study (e.g. Novas 2006) and as key to shaping research and investment in genomics and contemporary biotechnologies (e.g. Gottweis 2005). Novas' (2006) study on the political economy of hope and patient activist groups organized around a genetic disease builds on the work of medical anthropologist, Mary Delvecchio-Good and colleagues (1990). Delvecchio-Good et al. (1990) examined hope discourse in American oncological practice and introduced the concept of a "political economy of hope." Drawing on qualitative interviews with practicing oncologists, Delvecchio-Good et al. (1990) describe how hope plays an important role in the physician-patient relationship and physicians aim to encourage hope in their patients because of its influence in the patient's experience of having cancer. Moreover, in introducing the "political economy of hope," they suggest that hope, which inspires and sustains the idea that cancer is curable, is key

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scholarship until the late 1970s and the work of Hochschild. Hochschild aimed to develop a sociology of emotion that foregrounded emotions as an object of sociological study and offered a concept of the self, *the sentient self*, that is capable of conscious feelings and emotions (2003). Moreover, Hochschild argued that feelings and emotions were organized according to social patterns and structures introducing the concepts of *feeling rules* and *emotion work*. Through her qualitative study of flight attendants, Hochschild (1983) argues that flight attendants are involved in emotion labour when they work to manage the emotional state of travellers as well as their own emotions. She examined the ways in which one's gender and class positions are associated with one's conscious experiences of emotions and obligation to perform particular kinds of emotion work (Hochschild 1979; 1983; 2003). Social and cultural anthropological work also offers an alternative to a bio-psychological view of emotions in which emotions are thought to be "natural" and derived from an "interior self." This view of emotions renders them pre-social and pre-cultural (Lutz 1986). As an alternative to this view, Lutz (1986) and colleagues (Abu-Lughod & Lutz 1990) suggest examining emotions as discourse, or "emotion talk," which includes how emotions are talked about, what can be said about emotions, and who can express what and when. Emotions have long been feminized and they have been considered as secondary and thus less deserving of scholarly attention than rational or objective thought (Hochschild 2003; Lutz 1986).



to generating money for cancer research. Novas (2006) draws on Delvecchio et al.'s (1990) work and examines the political economy of hope in patient activism and genomic science and medicine. In his qualitative study of a patient group organized around a genetic condition, pseudoxanthoma elasticum (PXE), he examines how the group's hope and expectation of a cure for this condition lead to their activism and work to generate money and provide the genetic material for research on this disease. In analyzing and describing the political economy of hope, Novas (2006) conceptualizes "hope" as more than an emotion and as having material and political dimensions. The political activism of the patient group, he argues, demonstrates the shift in contemporary biopolitics in which individuals know themselves in biological terms, form biosocial groups and shape biotechnologies and genetic knowledge (Novas 2009: 290).

Scholars have also examined how hopeful speculation is integral to new forms of biocapitalisms (Rajan 2006) and how emotions such as hope are playing an increasing role in the governance of genomic technologies (Gottweis 2005). Rajan (2006) argues that contemporary biocapitalisms and bioeconomies are characterized by an orientation to the future and an emphasis on promissory claims. New biotechnology companies that have yet to produce anything that has use value attract investors by producing hype and hope around what they will produce in the future. Hope, Gottweis (2005) argues, also plays an increasingly important role in genomic governance since decisions around genomics at the policy and individual levels must be made in uncertainty. By uncertainty, he refers to a constellation of uncertainty including the uncertainty resulting from a lack of scientific knowledge about genomics. Gottweis (2005) argues that because of this uncertainty, decisions cannot be made through calculation and thus emotions play a larger role. For example, ethical debates and discussions about the uses of new genomic technologies often rely on stories of compassion or suffering of people with a genomic condition, and discourses of hope are drawn upon to encourage support for new avenues of genomic research. Many scholars writing on new biotechnologies



use hope as synonymous with speculative, promissory expectation and as the key explanatory emotion leading to the advancement or adoption of new biotechnologies. Thus, I characterize this body of scholarship as “hope literature.”

There is no doubt that hope plays an important role in contemporary biotechnologies and medicine; however, I suggest that the strong emphasis on hope in the literature has resulted in a partial picture of the articulation and growth of new biotechnologies that is heavily skewed towards the optimistic. As I have shown above, fear and anxiety featured prominently in women’s narratives of cord blood banking. Women spoke about the fear that their child may become sick in the future and that if their child were to become sick, they might not be able to find a blood stem cell match to treat the disease. Women oriented to the future not in a solely optimistic hopeful manner, but also with discomfort and uncertainty about the future. I suggest that the production of a need for biological insurance depends on the production of an insurance imaginary in which women must engage with the possibilities of a fearful future and the belief that cord blood can protect against this negative future. Thus, women’s hope and optimism regarding the future possibilities of cord blood follows the generation of anxiety and concern over the future.

### **Guilt Insurance**

In addition to feelings of fear and discomfort in imagining a future in which biological insurance would be needed, women also spoke about banking cord blood and saving it for their child as a form of “guilt insurance.” The women I interviewed considered banking cord blood privately not only to be a means of protecting their child against the risk of future ill health, but also a way to protect them from future guilt and regret as mothers. The decision to bank privately was a moral one for women and it was shaped by normative views of maternal responsibility. For example, P6 describes a discussion with a pregnant friend of hers about cord blood banking as providing insurance against guilt:

**P6:** Well, one of, yeah, one of my friends was pregnant around the same time as me. She was 3 months ahead of me and she'd already, I think, signed up and made the decision to do it. And so, she's also a lawyer, and her big thing was about, this feeling, it's like the guilty mother complex, you know? Like if I don't do this and something happens and the doctor says, "Oh it's too bad that you didn't bank the cord blood," I would, like, put a knife through my heart, I'd feel so guilty, right? So she said it's, it's, what did she call it, like "insurance for my guilt," or some-, like "guilt insurance," or something. Um, it's like buying insurance, in a way, I guess.

The care of children and management of their health and development is highly gendered with strong cultural expectations around motherhood and women's responsibilities in caring for their child. With cord blood banking, however, the responsibility has expanded to include mothers having to be prepared for their child's future therapeutic treatment. The moral imperative that women felt as mothers and the ways in which they spoke about their guilt or regret if they did not bank suggests that for some, banking cord blood was less an option and more of an obligation. The weight of this obligation is evident in P6's comment about how she would react if she had not banked cord blood and her child needed it:

**P6:** Like for me, I'd probably shoot myself in the head. I'd just feel so terrible because that's kinda like the wreck that I am. Some people they'd be like, "Oh well, too bad." You know? They just have more perspective on these things.

P10 also spoke about banking privately out of fear and to avoid feelings of guilt:

**P10:** ... So, um, but again, I just, I would never be able to, I wouldn't be able to look at myself in the mirror if I were, um, if he [son] needed it and I didn't do it. So I think, unfortunately, a little bit out of fear. You also never know.

Women's discussion of maternal responsibility for the health of their children and biological kin is not new. Women as mothers are held responsible for the health of their child even before their child is born. Pregnant women are encouraged to

engage in some activities (e.g. watch their diet) and prohibited from others (e.g. drink alcohol) to ensure a healthy child. Recently, biomedical experts have suggested that the dietary practices of a woman while pregnant are associated with whether or not her child will be obese (i.e. “unhealthy”) in the future (Maher et al. 2010). P6 lists the various practices she had adopted to prevent her child from becoming sick in the future:

**P6:** Um, I guess it's peace of mind. Whatever that's worth. That if something were to go wrong I would have done everything I could have to, you know, in addition to giving her organic food and feeding her breast milk and using frickin' green cleaner, you know, whatever, all these things you do, right, because you want to protect your baby's health and ensure that they don't get cancer when they're 50, um, or whatever, or when they're 10, um, I'll have done that and that's like, you know, I did as a mother. I, like, loved her enough to do everything I, you know, and I thought of enough to do everything that I possibly could. That's, I think, primarily what it means to me.

The family has long been a site of health management and mothers given the responsibility of ensuring their family's health (Foucault 1997); however, new biotechnologies and increasing medicalization of pregnancy and parenting has expanded what women and parents are responsible for in terms of their child's health. For example, the application of predictive genetic tests for breast and ovarian cancers has expanded the temporal range, to include both the present and future, in which women must exercise responsibility over others' health. Predictive genetic testing produces knowledge about genetic risk and susceptibility prior to the display of any symptoms. Hallowell (1999) demonstrated that women managed their genetic risk for these diseases because of a responsibility they felt for the future health of their daughters and other family members. Along with this expanded responsibility is an increased sense of obligation. Although proponents of predictive genetic tests argue that knowing one's genetic risk would be empowering and increase options and control for women, Hallowell (1999) showed that women also felt their options were limited because of their concern for others. Women, in

her study, chose to forego the right not to know their genetic risk because they felt that this information might be important to share with their daughters and other biological kin. Moreover, some women who learned they had an increased genetic risk for breast or ovarian cancer decided to have prophylactic mastectomies and/or oophorectomies because of the moral responsibility they felt as mothers to remain alive for their children (Hallowell 1999).

As Hallowell (1999) writes, “[g]enetics is not about individuals, it is about biological relationships” (606). For the women she interviewed, the empowerment they felt by knowing their personal genetic risk was constrained by their maternal responsibility for others. Other scholars, such as Konrad (2005), have also shown how predictive genetic tests increase the moral and maternal burden on women. Private cord blood banking is also about biological relationships. Specifically, private cord blood banking prioritizes a biologized view of kin relations at the molecular level of HLA types.<sup>54</sup> Many private banks refer to their services as “family banking” on the view that family members who are genetically related can potentially use the banked cord blood stem cells. However, unlike predictive genetic tests for a specific and clearly targeted genetically related disease such as breast cancer or Huntington’s Disease, private cord blood banking for many women is far less targeted. Thus, I suggest, the moral imperative to bank cord blood is an expansion of maternal responsibility regarding familial health not only in terms of the temporal, but also in terms of *what* they are expected to act to ensure. For example, P12 spoke about protecting her children:

**P12:** Because I believe in protecting my children to the best of my means and we had the money so I did it. Like, it, there are a million other, we don’t have a ton of money and there are a million other things I could have done with a thousand dollars, for sure. We need a lot of stuff. Babies are so expensive. We

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<sup>54</sup> HLA, or human leukocyte antigen, tests are conducted on cells of the “donor” and “recipient” to test for tissue compatibility. The closer the match the less likely a graft-versus-host reaction will be triggered in which blood stem cells from the donor generate an immune response against the host cells.

could have put it in an education savings plan which in reality would probably be more likely to be used and helpful in the long run and that could be half of a semester for them to get their PhD one day, whatever it is, you know what I mean? Like, that could be really helpful. Um, but it could save my kid's life and I think as a parent you have to do everything within your means to set your kid up to be as successful as possible and that includes overcoming a horrible illness, so yeah, so we did it.

As P12 described, the potential for cord blood to save a child's life seemed to trump everything else for the women who banked. For the women in this study, if they *could* bank – that is, if it was within their means – then they *should* bank. If they did not, the guilt and regret of not doing so would be too great to overcome. P12's quote further demonstrates the expansion of maternal responsibility in her description of the “everything” that parents are now responsible for. In the past, setting one's child up for success might have meant a very wide range of things such as: establishing an education savings plan, introducing them to a number of different activities and lessons, and feeding them healthy foods. Now, parental responsibilities have expanded and “includes [their child] overcoming a horrible illness.” This expansion of parental responsibilities that women spoke about did not pre-exist private cord blood banking, but emerged from the growth of private cord blood banks and the option to bank.

The guilt that women talked about was great enough that the low likelihood of cord blood use did not matter. In other words, the “guilty mother complex” and the fear of their child's premature death overrode what might have made more rational or financial sense:

**P11:** A little bit, but um, but in any, you know, if it's 2 per-, if you have a chance of needing it, what if you were that 1 percent or 2 percent or 3 percent? Where you, your child did develop a condition that the cord blood banking or that, you know, stem cells could help with? Wouldn't you be kicking yourself and feeling awful that you hadn't done that? Um, so the insurance of that and having the safety of that, it wasn't a deterrent for us, but I would certainly see it being a deterrent for some, especially if you haven't had, you know, with my friend [name] who has aplastic anemia and my father

with leukemia, my grandfather with non-Hodgkin's lymphoma and my cousin with, you know, there's a number of people in my family and so, if you don't have that kind of connection I could see it feeling really distal and not being important. I'm sure there's things for me 'cause, you know, we haven't had family members with other illnesses like diabetes, you know, if there's a preventative thing for diabetes I may be less connected to it because that's not an illness that we have had to experience as a family. So that percentage was certainly not a deterrent for us.

P11 was clear that even if the chances of her child needing cord blood were as low as 1, 2 or 3 percent,<sup>55</sup> she would bank cord blood because no chance is too small to take when it comes to her child. Some women, like P11, had had personal experiences of living through diseases with close friends and family members and thus, they were able to imagine readily the loss and guilt that might come of not having banked cord blood. Even though their child was not at any increased risk for getting any of these diseases, these women banked in part to insure themselves against maternal guilt.

I have shown that women felt morally compelled to manage their child's health by acting to ensure that they are healthy in the future through banking, or hoarding, biological materials. This, I argue, is an expansion of maternal responsibility for their children's health through encouraging healthy lifestyle and activities. Women feel a moral burden to provide the corporeal materials to make their children healthy in the future.

### **Biological Insurance as Life Insurance**

Many women explained that they thought of biological insurance as analogous to life insurance. For example, P15 explained that banking cord blood brought "peace of mind" and was like an extension of her and her husband's life insurance:

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<sup>55</sup> As noted above, according to clinical literature there is a 1 in 2000 to 1 in 200,000 chance that someone will need a blood stem cell transplant (Nietfeld et al. 2008). This means that the percent likelihood that W11's child would need a transplant would range from 0.05% to 0.0005%.

**P15:** It's just a, it's just a piece of security. It's just a peace of mind. I don't think about it a lot. I don't, um, it's just a kind of checks and balances, checks that you have in place to, you know, my son was born and we upped our life insurance policy. Um, and so it's just an extension of, it's just, things you put in place as insurance policies and you hope you never need to use them, but you're comfortable paying into them for what they might be if you ever find yourself in the unfortunate spot when you need them.

Life insurance is about managing death (Zelizer 1979). Specifically, life insurance as a formalized profit-making business that emerged in the 19<sup>th</sup> century was intended to relieve the economic burden on surviving family members, primarily women and children, when a person died (Zelizer 1979: xiii). The introduction of life insurance in North America in the early 19<sup>th</sup> century was initially met with resistance because of religious and moral beliefs that considered buying life insurance to be setting a financial price (profane) on a man's<sup>56</sup> life (sacred) (Zelizer 1979). However, Zelizer (1979) shows that changing social and cultural ideas that associated money with life/death from one of gambling on life (an immoral act) to providing economic security for widows and children (a moral act) enabled the widespread growth of life insurance. In theory, life insurance today continues to act as a financial form of insurance that provides economic protection for surviving family members by sharing the risk of financial loss through death across a population.

In talking about private cord blood banking as similar to life insurance, women were using analogical reasoning:

**P12:** ... Ultimately, I think even before I did the research I knew that I was gonna do it because to me, I have life insurance for my husband, I have life insurance for me, why wouldn't I have life insurance for my baby? And this is not like insurance that you would benefit on the other side, this is like, it literally saves their life, hypothetically. It also could save my nephews' lives or something like, or they cord blood banked and they can, it can save my baby's life so to me, I already thought that, like, 'cause we're in the financial place, I don't ever want to wake up 15 years from now and be devastated that

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<sup>56</sup> The initial introduction of life insurance in the 19<sup>th</sup> Century was intended to ease the financial hardship on a woman and her child/ren should her husband die.

I just didn't spend the 1,200 dollars or whatever it was. To me, like, thank god we were in the place, in the financial place that we could make that decision. So then I did all the research and by the time I got to the [private bank] office at [location], she started on her sales pitch and I said, "You don't even, you don't even need to pitch me, like, I'm here because I've already filled out my forms. I'm ready. Just sign me up"...

P12 makes a distinction between life insurance that provides a payout to the surviving benefactors of the person who died and the potential "payout" of cord blood as biological insurance that can be used to "save the life" of the person from whom it came. For P12, banking cord blood is like buying life insurance for her and her husband, only better. Cord blood could actually save her child's life. According to P12, unlike life insurance which provides financial protection for survivors of the deceased, cord blood is a form of life insurance that can provide life for the "policy holder" her/himself. As it is with analogical reasoning, the terms are not the same but similar enough to make partial connections and to have an important framing effect.

Only a partial connection exists between biological insurance and life insurance. Both promise future security; however, biological insurance is not an insurance technology like life insurance. Biological insurance is not organized according to the same rationality and logic of financial forms of insurance such as life insurance. Unlike life insurance companies, the private cord blood banks do not use actuarial science nor do they function to share risk associated with a negative event across a population. Although Ericson & Doyle (2006) point out that in practice the population is increasingly shrinking, the logic of insurance remains unchanged. The individual is protected from future harm by pooling resources with a larger population. Thus, Ewald (1991) describes insurance technologies as organized around a "solidarity paradigm." Private cord blood banking, on the other hand, ostensibly protects the individual (i.e. child or family) from future harm by saving the biological material for one's own use. People who buy "biological insurance" are protected through individual hoarding and not by sharing resources



among a population.<sup>57</sup> Privately banked cord blood promises future security to the person who banks through the exclusive use of the individual cord blood unit. Hofmann et al. (2006) ask if advertising private cord blood banking as biological insurance is even correct. They write:

Moreover, it is worth noting that insurance is based on well-known probabilities, and that it is monoaxiological: it focuses only on economical value (including the economic value of uncertainty). This appears to be different with biobanking: the probabilities that you will need knowledge resulting from biobank research are not well known, and the values involved when you need it are certainly not only economic (or easily exchangeable to economic values). These aspects may make the gambling analogy more suitable. (Hofmann et al. 2006: 54)

They suggest that gambling might be a better analogy for private cord blood banking:

The gambling analogy highlights aspect of uncertainty in the same way as the insurance analogy, however, without necessarily quantifying the uncertainty. A gambler enters the game because of desire for the outcome (and for the fun of it) but seldom on the basis of risk-spreading calculations. Hence, one can enter cord blood into a biobank in order to hopefully win the big prize (life and health or important knowledge). (Hofmann et al. 2006: 54-55)

I agree with Hofmann et al. (2006) that gambling is a better metaphor for private banking. Framing it as biological insurance emphasizes security and assurance. It frames private cord blood banking as a relatively risk-free venture. The metaphor of gambling, however, alerts women to the uncertainties of private cord blood banking

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<sup>57</sup> In terms of mutual dependence among individuals who pool resources, a public cord blood bank operates more similarly to insurance than does a private cord blood bank. The public cord blood bank receives donations of cord blood, banks it, and makes it available to anyone who might need it and is an HLA match. Thus, the person who donates is pooling her/his resources with a larger group and is protected against future harm through mutual participation. I am not suggesting that public cord blood banking is an insurance technology. There are key differences between public cord blood banking and private insurance. For example, in the case of the former, the population is everyone whereas in the latter, the population is only those who have also bought insurance. However, I argue that as a metaphor, the public banking model is more similar to insurance than is private banking.

and the risk that they must take on. As I show below, the person who banks must take on the risk that the cord blood unit s/he banked may not be therapeutically useable when it is needed.

### **An Insurance Policy “Full of Holes”**

In this section, I present in detail P3’s experiences of banking cord blood and finding it to be useless, or an insurance policy “full of holes” when she needed it for her son. She takes on the risk of private cord blood banking and is in the unfortunate situation of losing. In the previous chapter, I focused analytically on cord blood as a social and biomedical object and discussed how P3’s banked cord blood stem cells were constituted as useless and not valuable. Here, I discuss P3’s experiences with and thoughts on cord blood as biological insurance. Her experiences provide an exemplary case of the trouble with “biological insurance.”

When P3 was a child she lost a sibling to childhood leukemia. Her personal experiences of losing her brother alerted her to the promises of cord blood banking and the use of blood stem cells to treat leukemia well before she was ever pregnant. When I asked her what interested her about cord blood, this is what she said:

**P3:** Um, fear [*pause*] was my main motivator. Um, I had a sibling die of leukemia and, um, in my mind at that point, my worst nightmare would have been my son getting diagnosed with leukemia. And for some reason I was sure that having stem cells banked would be some sort of insurance policy for my son. And that’s how I had connected all those dots together, was, you know, “leukemia, well they’re making major breakthroughs with stem cells, I wanna have his stem cells ready just in case this bad thing ever happened,” and so it was really, like, once I figured out the ‘how,’ money was no object. It was, I needed this to feel safe.

She had heard that banked cord blood was like having a biological insurance policy against leukemia so she registered with a private bank to save her son’s cord blood stem cells. She thought of privately banked cord blood as a “back-up plan” for her son should he get cancer and she was assured from the private bank’s website that

his blood stem cells could be used to treat cancer and a number of other diseases. Although she had been advised by her family physician that her brother's death from leukemia did not increase the likelihood of her own children getting leukemia, the experience of losing her brother made her aware of this possibility and she was prompted to privately bank cord blood. As I discussed in the previous chapter, P3 experienced first-hand the insecure security provided by banked cord blood:

**P3:** For, immediately after, I felt safe, then I got the letter [the letter from the private cord blood bank stating that she had a "low volume" collection] and I felt unsafe again. I worried that our sample was inadequate. And then, um, did more research and then when I found out, "Oh yeah, the sample can be multiplied," there was a feeling of security for a few years. And it felt, it felt good to know that these cells were safe somewhere. And then it all came crumbling down at age 4.

Initially, P3 described feeling secure and assured from having biological insurance; however, these feelings did not last long. When her son was four years old, P3 described noticing that her son became extremely fatigued after simple everyday activities like walking to school. He also seemed to get sick frequently. She began to record her son's symptoms and shared this information with his physician which eventually led to her son's diagnosis of leukemia. When she was told by the doctors treating her son that his leukemia could not be treated with an autologous stem cell transplant, she was incredulous, "I'm just like, "What?! Why did I save his stem cells if leukemia was what I was afraid of most of all?" Later in the interview, she described again the security she thought she had with the banked cord blood stem cells:

**P3:** Well as soon as he's diagnosed with leukemia. But, I mean we asked during our, um, you know, that meeting room that the doctor's take you in, right, and they sit down and give you the bad news, we were like, "Cord *blood, we're good! We're safe!*" [her emphasis]. And they were like, "Let's not talk about that right now. It's not, it's not in the treatment plan." ....

Although P3 initially thought that banking her son's cord blood would provide greater assurance of his health, she learned that her son's cord blood stem cells could not be used to treat his leukemia *because* they were his own. What had not been made clear to P3 when she banked cord blood was that an autologous transplant would not be used to treat leukemia. Her son had a form of leukemia with a genetic association and thus his cord blood stem cells were not a treatment option for him. On the one hand, this can be thought of an example where clearer information about the uses and limitations of cord blood transplants may have been useful. On the other hand, even if a woman knows of the limits of cord blood when she banks, she must take on the risk of the failure of cord blood when she banks. If cord blood fails to be therapeutically useful, neither the bank nor clinicians are held responsible for the failure.

During her son's treatment she continued to keep the cord blood stem cells at the private bank; however, when he was considered to be in remission she sought medical advice regarding what to do with the banked cells:

**P3:**... Ah, in one visit at the hospital I just laid down the line and I said, "you know what," um, [son]'s oncologist had been promoted to the head of oncology at [name of hospital] and so we had him as our doctor, had a rapport and a relationship with him and I just said, "listen, I've got [name of private cord blood bank] wanting 3 years worth of storage fees from me, I need to know if these cells are useful to anyone." And he said, "No. Just destroy them."

Even though her son was not treated with a blood stem cell transplant and is currently in remission, the possibility remains that he may need blood stem cells in the future:

**P3:** No. Um, that is, a stem cell transplant will be probably the first line of defense if there's ever a relapse. So it still is looming, that fear of, of needing

stem cells, um, is still looming, but again, it would never come from him, it would come from a relative or from a public bank.

In spite of her son's remission, P3 describes a fear that continues to loom. If her son's leukemia returns, he may need an allogeneic blood stem cell transplant. As she continued to talk, P3 reflected on the need for a robust public cord blood bank and considered how a public bank might provide better future health security than a private bank.

Reflecting on her experiences of banking cord blood privately, this is what P3 had to say:

**P3:** Well, as I mentioned at the beginning of the interview, it was fear of [son] getting leukemia, right, and losing him. And it's, it's something that you can't control, right? You don't, we don't get to say whether our children get sick or not, so um, you know, it was like a facade of having control over it or an insurance policy against it. And now, looking back at it, I see, I see that it was full of holes, full of holes...

**P3:** Well I felt, I felt that the whole process was fraud. Um, but I also felt guilty, like it was, I felt like I had done an inadequate job of researching it. Um, and then, you know, when you calm down you realize that my decision making process was entirely emotional. So there's, you know, guilt that I've wasted resources and money, um, and um, and this, this, this fraudulent feeling that I had, I thought I was safe and yet I wasn't. I had purchased this safety net and yet it wasn't, it had big holes in it. So, um, anger I guess at [private cord blood bank], um, you know. I don't know, especially after they called and kept asking me for money, then I started to get angry...

In hindsight, P3 considers biological insurance as providing the "façade of having control", to be an insurance policy "full of holes", and to be a fraudulent process. Having experienced the risk-as-loss, that is, the failure of the banked cord blood to deliver on what she believed it was promised to deliver, P3 is angry, feels deceived, and is left with cord blood that is useless and a bill for outstanding fees. Some might consider P3's experiences to be a cautionary tale. That is, her experiences can be viewed as an example that encourages women to research cord blood stem cells in

greater detail, to understand the therapeutic limitations, and to pay greater attention to the “fine print” in order to avoid what happened to her. This view, however, is too narrow and focuses only on individual responsibility. On this view, women must be better, more responsible, consumers in order to avoid the pitfalls of relying on an insurance policy that may be full of holes. Moreover, this view does not consider the limitations to how fully any woman or person would be able to inform her/himself in the first place. Not only does this view place greater responsibility on women to have enough scientific and clinical knowledge to understand the details of the potential uses and limitations of cord blood, but there are also limits to the scientific and clinical knowledge that exists in a developing field such as stem cell science and regenerative medicine.

The metaphor of biological insurance minimizes and obscures the biomedical complexities that determine whether or not it is, or can be, used. P3’s experiences with the failure of biological insurance demonstrate these complexities well. The use of cord blood stem cells therapeutically is, in the end, a clinical decision. In P3’s case, her son’s specific leukemia strain and diagnosis determined relatively early on that his stem cells would not be used in his treatment. However, whether or not cord blood stem cells are therapeutically useable depends on a number of other important clinical contingencies including, but not limited to: the specific disease diagnosis, available therapeutic options, the treating physician’s familiarity with cord blood stem cell transplants, and the size and weight of the person diagnosed with the disease. A woman cannot know or consider these clinical contingencies when she is considering banking cord blood privately. Even if P3 had asked all the “right” questions and had done more research, she would not have known what kind of leukemia her son might have nor would she have known if his treating physician would choose to use cord blood stem cells. In the end, the physician makes the decision whether or not the cord blood stem cells will and can be used in treatment. P3’s experiences demonstrate the risk-as-loss that women take on when they bank privately. While the need for biological insurance is produced by inciting fear and

encouraging visions of life-threatening disease in the future, the risk that the cord blood stem cells may *not* be therapeutically useable when needed is obscured.

The metaphor of biological insurance frames cord blood banking as a prudent activity that provides protection and security against future harm. This metaphor directs women's attention towards the potential harm of their child becoming sick in the future and directs attention away from the potential risk that the banked cord blood unit may not be useable. The metaphor of insurance also has a normative effect. A good mother is a mother who banks her child's cord blood. Applying the metaphor of gambling to private cord blood banking would frame the practice very differently. The metaphor of gambling would direct women's attention to the possibility of the cord blood unit's failure. Perhaps, more significantly, a gambling metaphor does not have a normative effect and mothering discourses that incite women to buy biological insurance would function very differently, if at all, with "biological gambling." That is, mothers would be less likely to feel compelled to gamble out of guilt since gambling has a negative moral valence that buying insurance does not.

## **Conclusion**

In this Chapter, I have examined biological insurance beginning from the experiences and accounts of women who have banked cord blood. Unlike the hope and hype that scholars have focused on in the contemporary biotechnologies literature, I show that the need for biological insurance involves imagining a fearful future. Women spoke about feelings of fear, anxiety and discomfort when they imagined their child becoming sick in the future and banking cord blood for some women meant engaging with these uncomfortable thoughts. While women did speak about hope and security provided by biological insurance, they did so in a way that was inseparable from anxiety and fear. The emphasis in the literature on hope and hype presents a partial picture of contemporary biotechnologies in which the field develops through optimistic expectations. In the case of private cord blood

banking, I show that negative expectations are key to women's uptake of new biotechnologies and are necessary to produce a need for "biological insurance." Women also spoke about cord blood banking as providing them with guilt insurance. They drew on moral discourses of responsibility and avoiding maternal guilt and described doing everything they could for their child's success. I suggest that "everything" has expanded to include ensuring health through the banking of biological materials. I argue that women take on risk when they buy "biological insurance" and describe the experiences of one woman whose cord blood was clinically useless when she needed it for her son. The risk that women take on is obscured by the metaphor of insurance and women and their families may find themselves with an "insurance policy full of holes." I suggest, along with Hofmann et al. (2006) that "biological gambling" may be a more accurate metaphor for private cord blood banking.

I have focused on one example or type of "biological insurance," cord blood banked in a private bank, however there are other types. For example, social egg freezing, or the freezing of eggs by women in their reproductive years who want to bank their eggs for future use, is referred to by its proponents as a type of insurance. Supporters suggest that freezing one's eggs provides the assurance that a woman will be able to have biological children in the future regardless of age and other potential biological and social obstacles (e.g. Inhorn 2013). Following the American Society of Reproductive Medicine's removal of the "experimental" designation in 2013 on the practice of egg freezing, some commentators point out that the door has been opened to allow for-profit companies to offer this service to women (e.g. Urist 2013). Another example of "biological insurance" includes banking stem cells in menstrual blood.<sup>58</sup> I suggest that it is not unlikely that new types of "biological insurance" will arise as new biotechnologies and advancements in molecular medicine allow for the preservation and use of additional tissues and cells.

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<sup>58</sup> <http://www.cryo-cell.com/menstrual/stem-cells>, downloaded May 22, 2014.



## Chapter 6: The Precautionary Actor at the Site of Private Cord Blood Banking: Problematizing the Neoliberal Medical Subject

*P13: I'm a large believer in sometimes the less you know about the details, the better when you're trying to not get anxious or stressed...*

### Introduction

Women presented complex accounts of cord blood banking and making the decision to save their cord blood for their child and family. They expressed feelings of anxiety and stress and acted with some skepticism and irony. They described practices and decisions made under conditions of uncertainty and insecurity and talked about cord blood banking as a way to hedge their bets against an uncertain future. Women talked about fitting cord blood banking into busy work and life schedules, and about struggling to manage the many medical appointments and prenatal classes required. What emerged from their accounts was an actor at this empirical site that challenges the dominant Foucauldian theorization of the active subject in health. In this Chapter, I provide an in-depth examination of women's accounts of private cord blood banking and offer a re-characterization of the social actor produced at this empirical site.

Foucauldian scholars characterize the active subject in neoliberalism, or the neoliberal medical subject, as a calculating, rational, enterprising and informed decision-maker concerned with optimizing his or her own health. The neoliberal medical subject takes up expert biomedical knowledge and is incited to self-govern through operations of productive power (Novas & Rose 2000; Rose 2007). Contemporary health governance literature emphasizes this singular characterization of the active subject and focuses almost exclusively on the operations of productive power.<sup>59</sup> Examining the subject at the site of private cord

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<sup>59</sup> For an important critique on the reduction of all forms of power to productive power see Singer & Weir (2006); Mykhalovskiy (2010).

blood banking, Waldby (2006) argues that the *entrepreneurial subject* is produced at this site. Drawing on women's experiences, I show that the social actor at the site of private cord blood banking differs from the Foucauldian active or entrepreneurial subject. I suggest that the *precautionary actor* is a more accurate characterization of the social actor of neoliberalism and argue for a revision of the active neoliberal medical subject in contemporary post-Foucauldian scholarship.

I show that unlike the neoliberal medical subject, the precautionary actor does not act solely according to the norms of entrepreneurship or the enterprising subject, but draws on emotions and emotional forms of reasoning; she does not engage primarily in rational calculation with the aims of prevention, but acts in uncertainty and exercises precaution; and rather than engaging hopefully in biotechnology futures, the precautionary actor is cautious about science and expresses anxiety as she faces an uncertain future. I argue that women's accounts demonstrate that for them, private cord blood banking, which many scholars and commentators conceptualize as a promissory biotechnology offering greater control over health, is a site of uncertainty and tension. Women's banking accounts, I suggest, contribute to the critique of rational decision-making in the sociology of health literature. Lastly, I argue that women who bank privately are in a bind in which the belief that they can exercise some control over their child's future health obligates them to do so.

This chapter begins with a review of the social science literature on the Foucauldian active subject and the entrepreneurial subject. I follow this with a discussion of the social actor and how this concept differs ontologically and epistemologically from the subject produced in rationalizing, expert discourses. In doing so, I highlight what an examination of the social actor contributes to the scholarship on contemporary health governance. Next, I provide a detailed discussion of the empirical data and demonstrate the key features of the precautionary actor in neoliberalism. Specifically, I show how women manage expert knowledge, their cautious view of science, how they speak about making an

emotional decision and using emotional forms of reasoning, and the relationship between control and fear at the site of private cord blood banking. Lastly, I conclude with a discussion of the precautionary actor of neoliberalism.

### **The Active Subject**

According to Foucault, the subject as a discursive form is produced in and through rationalizing, expert discourses and power/knowledge relations (Foucault, 1978; 1983). The active subject is a historical figure that came to prominence in advanced liberalism and succeeds the welfare subject of the welfare state. Rose (1999) describes the active, or free, subject in advanced liberalism as governed through freedom and responsabilizing, individualizing discourses. This subject is produced and governed through a productive power that operates by inciting the individual to participate in techniques or governance of the self rather than through repressive or negative forms of power (Rose, 1999). In advanced liberalism, the active subject wants to be healthy not because of the norms of social solidarity (i.e. I must be healthy so that I can contribute to my social community), but because of individual responsibility (i.e. I must be healthy because I am responsible for my own health). The active subject is an enterprising subject who is governed increasingly through internalized forms of self-governance or practices of the self (Rose 1992). Thus, the active subject manages her or his own health through self-governance by taking up rationalized and expert discourses and acting in enterprising and calculating ways. The subject is assumed to exercise rational decision-making.

The work of Rose and colleagues has been instrumental in shaping the Foucauldian and post-Foucauldian work on the contemporary active subject. In the context of genomic medicine and biopolitics in the 21<sup>st</sup> century, Novas & Rose (2000) describe the active or neoliberal medical subject as “free yet responsible, enterprising, prudent, encouraging the conduct of life in a calculative manner by acts of choice with an eye to the future and to increasing self well-being and that of the family” (490). In their article, “Genetic risk and the birth of the somatic individual,”

Novas & Rose (2000) argue that there has been a shift in personhood (i.e. the somatic individual) in genomic medicine:

New genetic languages and techniques thus come into an association with all the other shifts that are assembling somatic individuality, with the norms of enterprising, self-actualizing, responsible personhood that characterize 'advanced liberal' societies, and with the ethics of health and illness that play such a key role in their production and organization. (Novas & Rose 2000: 488)

Produced in medical or clinical discourse, physicians and genetic counselors encourage the somatic active subject to know oneself through their specific, individual genetic or corporeal make-up and to engage in managing their genetic risks in responsible ways. The active subject is incited to self-govern in order to manage, enhance and optimize her/his own health. Rose argues that in contemporary biopolitics in which state sponsored programs aimed at ensuring the health, or fitness, of the population are increasingly being replaced by private for-profit industry and private insurance companies encouraging individual responsibility and investment into one's health, the somatic individual acts as an enterprising subject investing in one's corporeal self.

In their article, Novas & Rose (2000) are responding to a specific critique of geneticization as well as making a broader argument about a new form of active subject or personhood in contemporary biopolitics. On the first point, they challenge the geneticization critique made by feminist and critical scholars (such as Lippmann 1991 and Nelkin & Tancredi 1994) who were concerned about genetic determinism and the potential controlling and limiting effects on people who received predictive genetic testing. Novas & Rose (2001) argue that genetics and genomic medicine, rather than limiting and repressing people, open up new ways of thinking about, knowing oneself and self-actualizing as genetic individuals. Thus, they argue that the genetic or somatic subject is an active subject for whom managing her/his genetic risk and responsibility is inseparable from ethical self-

actualization and self-knowledge. This subject, who is genetically-at-risk and responsible, also has a hand in shaping the direction of science. Novas & Rose (2001) provide examples from online postings of a support group for people who have been genetically tested for Huntington's Disease (HD):

The responsible-genetic subject becomes active in the shaping of the enterprise of science. This takes the form of placing one's hope in finding a cure for HD. It entails posting promising new research findings in the webforum. Materially, it often implies donating parts of one's income towards finding a cure for HD, engaging in various fundraising activities to support the search for a cure, and a willingness to take part in experimental clinical trials for potential therapies to cure HD. People do not passively await the development of new treatments: they come to have an active stake in the development of biomedicine (Rabinow 1999; Rabeharisoa and Callon 1998). (Novas & Rose 2000: 506)

Somatic individuals, or neoliberal medical subjects,<sup>60</sup> come to form new biosocial groups through shared corporeal or biological make-up and actively participate through biological and financial investment in moving science forward. They are optimistic about science and its potential to provide new treatments and cures in the future. In formulating the active somatic subject in contemporary health, Novas & Rose (2001) make several important contributions. They emphasize that power in genomic medicine operates to activate and not repress, they challenge a genetic determinist or essentialist argument, and they provide an example of how one group of somatic individuals participate in enterprising ways to produce scientific and clinical knowledge.

Scholars have applied this particular conceptualization to empirical sites beyond genomic medicine, including private cord blood banking. According to Waldby:

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<sup>60</sup> Throughout this chapter, I use the terms "somatic individual," "active subject," and "neoliberal medical subject" interchangeably because scholars use these terms this way. The active subject of contemporary medicine is also known as the neoliberal medical subject and/or the somatic individual.

In my analysis, private cord blood banking is one of the technologies and industries that call [the neoliberal medical] mode of subjectivity into being. Its form of investment appeals not only to a generalized parental prudence and credulity, but also to these new norms of entrepreneurship, risk management and collaboration with the future of biotechnology. Doubts about the current clinical value of a cord blood account are outweighed by its potential, speculative value, as a source of autologous tissue that might be profitably deployed in relation to new stem cell or genetic techniques. (Waldby 2006: 67)

Based on secondary analysis of published empirical research on people who have banked cord blood, and analysis of published popular media accounts and private bank advertisements, Waldby (2006) argues that the appeal of private cord blood banking for prospective parents is not only based on exaggerated risks of future disease in children, but also on providing people an opportunity to participate in the promises of future biotechnologies (59). Private cord blood banking, she argues, is consistent with neoliberal values “around the virtues of private property, entrepreneurial investment and technocratic progress” (Waldby 2006: 59). The entrepreneurial subject is produced at the site of private cord blood banking as women and couples invest in the speculative promises of future biotechnologies. Thus, while Waldby agrees with critics of private cord blood banking, she explains people’s participation in banking by their incitement to act as neoliberal enterprising subjects.

This formulation of the active subject in neoliberalism dominates in the scholarship on contemporary health and biopolitics and scholars have applied it with little analytic or empirical critique. I am not arguing that these scholars (Rose & Novas and Waldby) are necessarily in favour of, or support, new biotechnologies nor am I arguing that they are in favour of neoliberalism. What I am arguing, however, is that the conventional understanding of the active subject – that is, as a calculating, rational, self-actualizing investor who participates in the advancement of science – is analytically flat and does not provide a complete account of social

actors in health governance and contemporary biopolitical strategies. This analytic flatness, is in part methodological since Foucauldian methods emphasize examination of expert, rationalizing discourses and ontological in its conceptualization of the subject as produced in discourses and power/knowledge relations. When the discursive subject stands in for the social actor, this elision reduces the experiences of the social actor to an abstract discursive formulation and does not provide an account of the social relations, meanings and embodied experiences of the social actor. The social cannot be reduced to discourse and the social actor cannot be reduced to the discursive subject thus, I maintain a distinction between the *discursive subject* and the *social actor* in this Chapter. In contrast to the abstract active subject, social scientists conceptualize the social actor as embodied, embedded in social relations and acting in relation to others, and identifying with social groups and categories with varying social effects (e.g. Weir 2010) (see Chapter 2 for further discussion). A consequence of the dominance of the conventional formulation of the active subject described above is a lack of critique in the literature since one could argue that there is little concern to be had about self-actualizing, responsible individuals, participating in the optimistic futures of biotechnologies and medicine. This is the subject scholars understand as produced in discourse. In many ways, this presents a view of contemporary biotechnologies that is, at best, positive and, at worst, benign. This positive or neutral view of contemporary biotechnologies is certainly the view promoted by dominant popular and scientific discourses.

### **Critique of the Active Subject**

In the sociology of health literature, Lupton and colleagues, writing in the late 1990s were concerned with what, at the time, was an emphasis on surveillance and disciplinary powers by Foucauldian health scholars and a focus on production of the “docile body” through the clinical gaze. They argued that the medical encounter incited patients to act and medicine produced an active, not a passive subject, who

self-governed by taking up technologies of the self. Lupton (1997), however, was also critical of the limitations of Foucauldian work that focused on expert, rationalizing discourses. She writes:

In their focus on the disciplinary regimes and apparatuses that surround the body in the medical or institutional context, there is little discussion in many Foucauldian accounts of the phenomenological body, or how people respond to the external discourses and strategies that attempt to discipline them. Nor is there much discussion of how these responses are mediated through such factors as gender, age, social class, sexual identity and ethnicity. While it is clearly important to trace the discourses and practices of medicine and to demonstrate shifts as well as continuities over time, it is equally important to investigate empirically the ways that members of the lay population respond to the clinical gaze, to 'bring them alive' rather than represent them simply as docile or passive bodies constrained at every turn by hegemonic discourses. (Lupton 1997: 102-103)

While she applied her critique specifically in order to consider the ways in which people are activated in medical encounters, she also cautioned against the assumption of the active subject as one who is "always consciously aware of what she or he is doing, who is engaging in a reflexive evaluation of the situation and responding accordingly to maximize her or his life changes, who approaches life as if it were a rational enterprise" (105-106). Lupton (1997) was critical of reproducing the active subject as the rational actor and argued for a sociology of lay experiences and phenomenological accounts to examine the social actor at specific empirical sites.

Several scholars working in the field of contemporary biosciences and medicine have shown through empirical work that people, in their everyday lives and practices, do not necessarily conform to abstract active subject form or somatic personhood produced in discourse. For example, Callon & Rabearisoa (2004) show through their qualitative in-depth interview with one man, Gino, that people resist genetic personhood and knowing themselves through genetic forms of knowledge. Gino has limb-girdle muscular dystrophy, a genetic condition, and the researchers



interviewed him as part of their broader study on muscular dystrophy. Callon & Rabeharisoa (2004) describe how Gino demonstrated three refusals: he refused medical care (i.e. he did not see a doctor when symptoms of muscular dystrophy arose since he could identify his condition from knowing the experiences of family members), he refused to participate in the local muscular dystrophy support group and organization (i.e. refused biosociality), and he refused genetic testing thereby also not providing his genetic information to his family. The authors explain Gino's refusal "as the rejection of a form of agency and subjectivity, in which the individual is considered as an autonomous subject forced to choose between a number of pre-established options and responsible for the consequences of his choices" (1). Thus, Gino demonstrates a form of active personhood that does not conform to genetic somatic personhood.

Anthropologists, Lock (2009) and Konrad (2005) show how people take up information about their genetic risk to Alzheimer's Disease (Lock) and Huntington's Disease (Konrad) in complex ways that challenge the singular production of the genetically-at-risk subject. Lock's (2009) ethnography of the genetics of Alzheimer's Disease shows that people who are genetically tested for the disease and found to have an increased susceptibility do not necessarily re-frame their lives and activities and know themselves as genetically-at-risk. She critiques Novas & Rose's (2001) broad claim of a shift to genetic or somatic personhood and shows how people respond in diverse ways to their genetic information, in some cases ignoring or forgetting the results of their predictive genetic test, and do not necessarily behave in genetically "responsible" ways by managing their genetic risk. Lock (2009) suggests that knowledge of one's increased genetic susceptibility to Alzheimer's Disease did not necessarily transform people to identify as genetic individuals, in part because of the lack of cure for Alzheimer's and uncertainty in disease progression. Thus, the uncertainty of the disease and clinical treatments played an

important role in how people responded to their genetic information.<sup>61</sup> As a final example, Konrad (2005) challenges the claim that the new genetics has led to an epochal shift to the molecular. She shows in her ethnographic study on predictive genetic testing for Huntington's Disease that in some cases the predictive genetic test for a disorder identifies people who are pre-symptomatic and thus, in theory the genetic test reveals the person as "pre-symptomatically" ill. She argues that the dominant epistemic shift associated with genetic testing is not a shift from depth to flattened ontology, but to a form of divination in which the genetic test aims to make a prediction about an unknown future. In calling predictive genetic tests a form of divination, Konrad (2005) links the present with former cultural practices of future-telling that implicitly have some amount of uncertainty. Konrad (2005) explores how predictive genetic testing brings ethical complexities to the home regarding genetic (non) disclosure and testing. She demonstrates the struggles and tensions of genetic responsibility and the challenges testing raises for people who have been tested and the kinds of *potential* futures they must now consider.

Private cord blood banking is, no doubt, a practice that is organized by very different logics than that of predictive genetic testing discussed above. Saving cord blood for one's own personal and familial use is not based on a logic of revelation or discovery and the production of new forms of identity or self-hood. Rather, it is primarily thought to be based on a logic of neoliberal risk calculation and investment. Thus, the entrepreneurial subject produced at the site of private banking emphasizes the rational risk management and investment practices of the active subject (Waldby 2006). Fannin (2013), however, challenges Waldby's use of

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<sup>61</sup> On the matter of predictive genetic testing for single gene disorders, Miller et al. (2005: 2542) show that there is a paradox whereby increasing specificity of genetic diagnostic technology produces greater uncertainty about disease diagnosis management in the clinic. Genetic tests have changed the way in which some diseases are diagnosed and a predictive genetic test can identify the presence (or absence) of a particular disease prior to any display of symptoms. Miller et al. (2005) show that genetic counselors who advise people undergoing predictive genetic testing experience clinical uncertainty since people who test positive for a genetic disorder may present as "pre-symptomatic."

investment logic as providing an explanatory function in private cord blood banking. She writes:

The desire to save without circulating that characterizes the figure of the miser in Marx's political economy also characterizes the desire to store one's stem cells in an autologous stem cell bank account. This desire may appear more obscure than that of the rational individual invited to calculate her future corporeal risks. Yet it is this very obscurity that suggests a need to reconsider how much explanatory power is ascribed to the call to become a calculative, risk-aware individual. Does the explanation that stem cell banking responds primarily to a neoliberal logic of self-investment not inadvertently affirm the centrality of the 'rational' subject that is the object of critique? (Fannin 2013: 47)

Fannin makes an important distinction between investment, which circulates, and hoarding, which does not enter circulation and argues that private cord blood banking is an example of hoarding and not investing (see Chapter 4 for detailed discussion). Using economic theory and analysis, she challenges the entrepreneurial subject as rational investor and argues that the entrepreneurial subject at the site of private cord blood banking is a "mad capitalist," or miser, who hoards the substance for transformation (53). Fannin (2013) questions the reproduction of the rational subject and the assumption of investment logic in private cord blood banking. In doing so, she offers an important critique on the work in private tissue banking specifically, and the active subject more broadly. In the remainder of this chapter, I contribute to the scholarship that critically examines the active subject through detailed empirical analysis of the social actor produced at the site of private cord blood banking.

### **Managing Expert Knowledge**

The neoliberal medical subject is an informed subject. In order for this subject to engage in practices that maximize life and health, s/he must be informed. For example, being informed might include knowing one's genetic risk for breast

cancer or knowing what kind of exercise regime or dietary choices might reduce one's risk for a particular medical condition, such as heart disease. Acting as an enterprising and informed investor who is able to weigh the pros and cons of investing in new biotechnologies requires the subject to skillfully use available information and expert knowledge. This model of the subject assumes s/he will seek out information thoroughly in order to act rationally and responsibly.

Women's accounts, however, did not conform to this model of information seeking and gathering. Women in this study described engaging in selective research and limiting the amount of information they researched about cord blood banking.

Consider what P15 had to say about how she researched cord blood banking and, specifically, how she limited her research:

**P15:** ... You know what, I didn't wanna, I didn't, 'cause I kinda had the voice of my best friend in the background, the whole, not wanting to, I just kinda, I didn't put a lot of emphasis in what they did and why, I just kinda like, "OK, I want my cord blood banked. These are credible facilities. Oh, these guys do something extra? It's not that much more money? OK, let's just do it. Let's just see what comes of it in the future. At least we have it." So it was kind of, um, I'm usually someone who goes, you know, looks at things very meticulously, but there was, there was also that slight, that slight uncomfortable-ness of what this means if you ever need to use it. So in a way I kinda detached myself from that and just said, "OK, that's good enough." Like, "Yes, this is a good facility, they do something extra? Sure. Let's just do it." You know? So, yeah, I do, it's very, it was very uncharacteristic 'cause when I, I usually do research to ad nauseam. I almost become a little obsessive about it. But in this case I took a very, kind of, back off stance to it.

Like most of the women I interviewed, P15 described managing information about cord blood banking by limiting how much research she did. Many women described limiting their information to learning the "how-to" of banking cord blood in a private bank, the cost, and whether or not cord blood banking posed any clinical risks to

their child.<sup>62</sup> Most women I spoke to were less concerned with learning the specifics about what cord blood is and, somewhat surprisingly, specific information about the medical conditions that cord blood can treat.

P15 also avoided in-depth research and investigation, in part, because she wanted to avoid the discomfort of imagining her child as sick:

**P15:** Yeah, especially when it's such a small part of it, right? And it could be something that helps meet the needs of women who are banking more because it is kind of this idea that the institution is here and they are providing you that service and there's not that many, there's not that much competition out there so you're just, kind of, put your faith in them. And that's a little disconcerting. Like I said, you never know if these, if you've chosen the right one. You never know if it's a greedy owner and there's gonna be a scandal. At the end you're not protected by any kind of government agency behind you, but you put your faith in it and you, like I said, it's the one thing in my life where I didn't put an extensive amount of thought in 'cause I couldn't deal with being, didn't want to just get into that mind space of what it meant if, if you needed it. So it was just kinda like, "I'm just gonna do this. It's just gonna be there. I don't want to think about it. What do I need to do?" So, yeah.

As I discussed in Chapter 5, some women explained that banking cord blood required them to engage with the uncomfortable thoughts of their child becoming sick in the future. For women like P15, the discomfort of projecting a future in which their child is sick also led them to limit the amount of research they did on cord blood banking. Moreover, she did not limit her research because she trusted the private bank; rather, she acted in spite of her reservations and skepticism about for-profit private banks. P15 took a "leap of faith" not only in banking cord blood, but also in choosing which bank to use.

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<sup>62</sup> Women took a narrow view regarding the risks, or harms, of cord blood banking by considering only their child and not concerns for themselves. According to current clinical knowledge and practice if the child is born full-term with no known medical conditions, clamping the umbilical cord immediately after birth and collecting cord blood is thought to present no clinical risk to the child. However, Dickenson (2007) points out that the clinical risks to the mother are often overlooked. Cord blood is collected in the third stage of labour which is an active phase of labour for women in which she is at greatest risk for hemorrhaging (see Chapter 1 for further discussion).

Some women also described managing or limiting their research to only positive information about private cord blood banking and literature in support of it. P12 described how she was selective in her research:

**P12:** ... Um, I was researching, you know, sort of uplifting stories about when it had worked and people that had been saved and things like that. Um, I kind of steered clear of, like, news, um, that comes out from the negative, um, like, whatever, there are a lot of people that are scientifically against it for whatever reason. I didn't really go down that road because I didn't agree with it and, like, most times when you do research you're doing research because you don't know what answer you want. I already had kind of made up my mind, but I was doing research just to make sure that it was the right thing for me.

Like many women I interviewed, P12 had already made up her mind to bank even before she had begun researching blood stem cells and private cord blood banking. Women did not limit their information because they were unaware of the normative expectation to conduct research, nor did they limit their research because they were not familiar with how to conduct research. Several women work in fields that they described as requiring a great deal of research (e.g. law, social science, para-healthcare) and many explicitly stated, such as P15 above, that their lack of research into cord blood banking was an anomaly. P6, a lawyer, described feeling somewhat embarrassed that she had not researched cord blood banking more thoroughly:

**P6:** I did. You know, surprisingly for someone so, so [starts to laugh], like I consider myself quite diligent, I didn't do *that* [her emphasis] much research. Um, I just thought, I mean there's no downside except for the cost and I was prepared, like, it's mainly a one-time cost and then beyond that, it's sort of like a storage fee which is not significant per year. And so there didn't seem to be really a downside from my perspective and so I didn't do that much research and in retrospect I might have done a little more, but I'm not sure that my decision would have been different. I don't know. I didn't look into it that much. I'm embarrassed to say. I just kinda went for it.

P6 described herself as a diligent researcher in other areas of her life and her embarrassment stems from knowing the normative expectation that she should have researched cord blood banking more thoroughly. She is casual and light in tone regarding her decision to bank because she is able to afford the financial cost easily. For some women, the guilt and moral imperative to bank overrode other potential concerns such that the only cost of banking as they saw it was the financial cost. Other women I interviewed spoke about limiting information because they simply did not have the time to research cord blood banking in addition to their employment and all the additional work required to prepare for a new child.

Lastly, several women explained that they limited their research on cord blood banking because of their lack of expertise in the fields of stem cell science and cord blood. For example, P12 described how she dealt with information on cord blood banking:

**P12:** ... They're all comparably priced 'cause they're competitive with one another so I just wanted one that was like, I didn't do a ton of research on the facility that was gonna hold the blood or how they, because I don't know enough to do a comparative analysis. I was like, "That sounds high tech to me. Take care of my blood." I didn't know enough to say, like, "You do one thing and you do another thing and I want the way you do it." It was more important to me that they would have a relationship [i.e. relationship between the bank and the hospital] and make sure that it happened.

P12's admission that she felt limited in the kinds of questions she could ask the private banks because of her lack of expertise raises an important point regarding lay understandings of contemporary bioscience. At the level of the individual, P12's reflection on her lack of scientific knowledge addresses of what she feels is a limitation in her ability to ask informed questions. She responds to her lack of expertise by continuing with the process of banking based in part, I suggest, on a level of trust that she has with medicine and the hospital and the extension of this trust to the private bank. More broadly, P12's lack of scientific expertise and the

difficulties this poses for understanding the details of banking is not unique to private cord blood banking.

Questions of what it means to be informed and how informed one can be are increasingly salient given the complexities of regenerative medicine, stem cell science, and contemporary biotechnologies. Not only is the scientific information complex, but the sheer volume of information (some of it contradictory) available online and in print makes the imperative of being responsibly informed a daunting task. Social scientists have shown how laypeople are not solely passive recipients of expert knowledge who simply take up this knowledge, but that they bring their own lay knowledge to health and science issues (e.g. Callon 1999). Scholars have demonstrated the tensions and negotiations between expert and lay forms of knowledge in health (e.g. Armstrong, 2005; Epstein, 1995). Popay & Williams (1996) argue that public health efforts and policies would be improved by incorporating lay knowledge and expertise. They challenge established epistemological privilege of biomedical knowledge and argue that people's experiences with illness and disease can provide valuable knowledge regarding theories of illness causation and prediction. Prior (2003), on the other hand, challenges the concept of the "lay expert" and argues for a distinction between lay knowledge and expert biomedical knowledge. She draws on her empirical research with multiple groups (Down's Syndrome, brain injuries, and the elderly) to argue that lay experiences can provide descriptive knowledge of symptoms and conditions, but differs from the expert knowledge of clinicians. In some cases, she argues, lay knowledge can be wrong. In the area of health decision-making, Mykhalovskiy (2008) critiques the rational model of decision-making as assuming a discrete individual rationally considering biomedical information to come to a decision (143). According to biomedical discourse, rational decision-making is a linear and normative process. Mykhalovskiy (2008), however, shows how persons living with HIV/AIDS engage in particular health practices not primarily through rational consideration of neutral biomedical knowledge, but by integrating and



understanding this knowledge within their own social lives and experiential knowledge.

The disjuncture between the informed subject in expert discourse and women's actual practices in being informed suggest women have a more complex relationship to scientific knowledge, the future, and new biotechnologies than is accounted for by the neoliberal medical subject. I suggest that women's accounts of limiting their information challenge the assumption of rational decision-making in the neoliberal medical subject. Similar to health decision-making, women who banked cord blood oriented to the information in ways that were shaped by their particular expectations of the future, their experiences of illness in the past, their level of comfort with scientific information, the time they had available, and what they viewed as the relative cost of banking.

### **An Emotional Decision**

Most women I interviewed described their decision to bank cord blood as an emotional one. Situating hope language and discourses within the broader field of emotions and molecular science and medicine, Gottweis (2005) argues that reasoning based on emotions are replacing rational reasoning given the incalculable uncertainty that exists in genomic science. Although emotions have been largely absent from accounts of the active subject, women who banked cord blood drew on emotions as explanations when talking about their decision to bank. Not only did some women draw on emotional talk of fear and discomfort to explain why they limited their research on cord blood banking, as described above, many explicitly described their decision to bank as an emotional one:

**P11:** No [laughs], to be very honest with you. Um, you know, it's interesting, like, depending on what things are, sometimes I *really* [her emphasis] read through and *really* [her emphasis] educate myself on it, um, and do my due diligence in terms of researching, you know, check out MedLine [an online medical database] or, you know, all that, like I kind of, I'm a researcher [she's a PhD candidate in psychology]. Um, and for whatever reason I didn't do that

with this

**I:** Why do you think that you didn't?

**P11:** I don't know why. I think it was probably, I knew enough of what I needed to know, I knew that it wasn't going to harm [son] and that it could help him. So *very* [her emphasis] basic. Um, that was all I needed to know, which is interesting because normally I would need more. Um, I think it was also kind of an emotional thing for me so, um, I reacted on more emotion as opposed to, like I reacted more with my emotional brain as opposed to my, kind of, practical, scientific researcher brain, um, that I kinda didn't give a shit about that. As long as it was O.K., that was what was important to me, which is actually in contrast to my personality for a lot of other things. Um, but it is what it is, you know? Um, I certainly knew enough about leukemia and all that piece of it so I knew what could be the negative that could come from it, that was enough information for me, I think.

As a researcher in her professional life, P11 knows well the methods of research and rational reasoning. She is familiar with the online database for medical journals, MedLine; however, when she was making the decision to bank cord blood she did not draw on these methods. Instead, she described her decision to bank as an emotional one and drew on her experiences of losing her father to cancer in explaining her decision. Earlier in the interview, P11 had told me about her experiences with her father who had been diagnosed with leukemia and had had a bone marrow drive to find a stem cell match. A match had been found and he had been treated with a bone marrow transplant, but he had died recently after his cancer had returned. When P11 described how deciding to bank was an "emotional thing" for her and that she used her "emotional brain," she was drawing on her experiential knowledge to determine whether or not she would bank. She was motivated not by rational tools of calculation and weighing of the scientific and clinical information, but by fear and a desire to avoid a tragic outcome with her son that she had experienced with her dad.

Drawing on Gottweis' work, I suggest, that P11's use of emotional reasoning is not the absence of rational reasoning, but the use of an alternative form of reasoning. Gottweis (2005) argues that the prevalence of emotions and emotional discourses in genomics is not an absence of rational reasoning, but is an alternative

form of reasoning itself. Emotional reasoning draws on different “tools” and a different logic than rational reasoning. In emotional reasoning, people use the “tools” of feelings, emotions and experiential knowledge instead of calculation and expert knowledge to guide a certain set of actions. With rational reasoning people use calculation and expert knowledge to come to a decision (Gottweis 2005).

P6 also spoke about making an emotional decision to bank cord blood and contrasted this with a rational, calculated decision. Like P11 above, her discussion demonstrates that she is aware of both:

**P6:** Because, I just, it's, it's, I just think, what would I do if someone told me in 10 years that I should have banked my baby's cord blood, you know? I just, it just felt like if the option is there and it's not prohibitively expensive, it's like, it's like, I don't know, I'm trying to think of an analogy, but [pause] I don't know, but it just seemed like, why not, right? And like, you never know, I guess, if there's a one in one million chance that we'll need this, is it worth it from a rational perspective? No. But from a pregnant mother's emotional, hormone clouded perspective it probably is, right? So, so you do what you do.

In explaining her decision to bank, P6 begins by projecting herself into a regretful future; she imagines a future in which she should have banked, but had not. Thus, it is from a future orientation of regret that she makes her decision. As she struggles to provide an explanation for how she came to bank cord blood she draws on various discourses to do so. She draws on clinical discourse of likelihood of cord blood use and the language of odds to establish that she knows the low probability of use. If she were to strip the clinical odds (i.e. one in a million) of social meaning and context and consider them only as numbers, private banking does not make rational sense. However, she draws on discourses of motherhood and emotions which call to mind ideas of maternal responsibility. This provides a specific social context for the low numerical odds of cord blood use that provides social meaning and explanation for banking. Interestingly, P6 draws on biomedical discourse to explain her use of emotional reasoning. When she refers to, “a pregnant mother's emotional, hormone clouded perspective,” she explains emotional reasoning

through biomedical discourse of hormonal (i.e. biochemical) changes associated with pregnancy. In doing so, P6 both challenges and takes up biomedical discourse in a way that is useful and meaningful for her. Thus, the social process of deciding to bank involves more than rational calculation and economized discourses of investment. When numbers and calculation are considered, they are done so within frameworks of social and emotional context and meaning.

I recognize that the separation of emotional and rational reasoning and rationale that women discussed and that I reproduce in my analysis is, to some extent, problematic and rooted in a history of Cartesian dualistic thought. Feminist philosophers, such as Grosz (1994) and Diprose (1994), challenge the separation between mind/brain and body/emotions and the gendered associations of the male mind and female body. Along with the gendering of the mind and body is the epistemological hierarchy that situates rational thought as superior to emotional knowledge. Contemporary feminist materialist scholars in science studies have been particularly effective in arguing against the dualistic separation of mind and body. For example, Wilson (2004) shows through her empirical work on hormones and the gut the ways in which biology and the mind or psyche are inseparable. In my own analysis, I have maintained a separation between rational and emotional reasoning for heuristic purposes to demonstrate the ways in which different discourses and logics inform women's decision to bank. I also do so to demonstrate the separation that women make in explaining their decisions.

Lastly, women's use of emotions and emotion talk to explain their decision to bank is prompted by the private banks. In their marketing materials, several private banks encourage women and prospective parents to have an emotional response to banking. The few private banks that have released cord blood units to successfully treat a child share highly personalized accounts of these uses in order to encourage women to imagine their child as the one who might need cord blood. Consider P7's account of reading these stories:

**P7:** ... So, um, no, my questions were basically, you know, is, has it been used? Is this one of those crazy cryogenic technologies that they hope they'll be able to do something? Um, so the website that they had was really, really useful. So there was, there were lots of resources online so that basically my questions were answered even before I knew I had them. So reading the F-A-Qs, I'm like, "Oh I never would have thought to ask that and now I know the answer" .... I read about, like, they have those stories about how, you know, this little girl her life was saved because they were able to do this. And so I read a couple of those and even though statistically the odds of like my kid having anything like that were very low, I just couldn't imagine being a parent in that position and thinking, "I had an opportunity to have done something and I said no." So that was, it wasn't a particular question, it was just that emotional kind of, which I'm sure they totally, it's there.

While the private banks use research studies and biomedical discourse to provide "fact" based arguments for cord blood banking, the strength of their marketing to women is based less on scientific fact and rational calculation, and more on emotional appeal. As discussed in Chapter 1, the scientific and clinical research in favour of private cord blood banking is contested and ambiguous. Thus, on their websites, many private banks use "success stories", visual images of happy couples with healthy babies, and long lists of potentially treatable diseases to elicit particular emotional responses in pregnant women and prospective parents. For example, two figures below show the main home page (Figure 2) and a personal story of one family's use of banked cord blood stem cells (Figure 3) for Inception Lifebank, the largest private cord blood bank in Canada.

PRICING EVENTS LOCATIONS OUR COMPANY BLOG Français 中文

Call now to speak with a clinical consultant **1-866-606-2790**

**Register**

Why bank cord blood? Why choose Inception Lifebank? Family Stories Ready to bank with Inception Lifebank? Health Care Professionals

**I Will... ..protect you no matter what**

**Video Gallery**

**Latest News**  
**Medical Leaders Use CordMatch To Help Patients Find Cord Blood Samples**  
 An innovative web platform is making waves across Europe and the US to help match ...

**Special Offers**  
**\$98 per month**

**Request Info**

Figure 2: Inception Lifebank Webpage (<http://www.inception.com>), downloaded May 21, 2014

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Call now to speak with a clinical consultant **1-866-606-2790**

**Register**

Why bank cord blood? Why choose Inception Lifebank? Family Stories Ready to bank with Inception Lifebank? Health Care Professionals

**Get to know Devon.**

**How my daughter saved my son's life.**

Devon was born on December 23, 2003. When Devon was two, we took him to see our family doctor for a routine check-up. When he listened to Devon's heart he thought that something wasn't quite right and that maybe he might have a heart murmur. The family doctor referred us to a Pediatrician and sent us for blood work. The results came back completely abnormal and we were sent to McMaster Children's Hospital immediately. With a platelet count of only 6 (normal range 150 - 400) Devon was in desperate need of a platelet transfusion.

**Our Transplants**  
 Who else have we helped? See a wide variety of families

**Barrett's Story**  
 Because of a decision his parents made 13

**Say Hello to Leo**  
 Leo was born in Toronto in 2007 and

**Meet Jesse**  
 It is incredible the umbilical

**Request Info**

Previous

Question

Offline - L

Figure 3: Inception Lifebank Webpage (<http://www.inception.com/devons-story>), downloaded May 21, 2014

The picture of Devon and his sister personalize the story for people viewing this webpage. The story told through the voice of a parent encourages the reader, or prospective parent, to imagine her/himself as the parent of a child who might need cord blood stem cells. Lastly, the unexpected and unpredictable nature in which Devon's condition was identified places all expectant women and couples in a position in which their child could also unpredictably need a cord blood transplant. Through the pictures and personal stories, women and couples are encouraged to imagine their child as Devon and to respond with emotions to his story.

### **Caution and Uncertainty**

According to Waldby (2006), the entrepreneurial subject participates in the optimistic futures of new biotechnologies through biological investments made in the form of biological banking. Some women, however, expressed a skeptical or uncertain view of science and the private banks themselves. For example, consider what P15 had to say about institutions and scientific studies:

**P15:** Um, I mean assuming that the credibility of these institutions is good. All you need is one scandal to come out and you go, you know, which you always consider as a possibility. It could happen, um, trusting these things to private institutions. Even Canadian Blood Services had a big problem at one point in history. Um, I've heard of the health benefits of cord, delayed cord clamping, so that would be a really, a really tough decision. Um, you know, I don't know, I don't know what the qualities of the studies is either, ah, which always comes to, how do you, how do you, you base some of these big life decisions on other people's conclusions. You just hope that they've done the research well and they found the appropriate statistic and they haven't buffered things to make them look better than they are, you know? That they've included all the data in their analysis, um, and that their sample size was large enough.

Private cord blood banking exists in the shadow of the "tainted blood scandal" and the subsequent Royal Commission of Inquiry on the Blood System in Canada, or the Krever Inquiry, in Canada (Commission 1997). In the 1980s infectious viruses were



in Canada's blood supply leading to serious illness for people who received these blood products. In response to this health crisis, the federal government ordered a Royal Commission and instituted several recommendations including new regulations regarding the collection, testing, and storage of blood products intended for clinical use. These new Health Canada regulations extend to the collection, testing and storage of cord blood in both private and public banks.<sup>63</sup> One of the effects of this "crisis" in the national blood supply was the loss of public confidence in the institutions that regulated and provided blood products. P15 carries some of this mistrust to the institutions that bank cord blood privately. Moreover, she demonstrates skepticism in the very science that is ostensibly aimed at providing expert authority on the best clinical uses of cord blood.

In addition to questions related to the veracity and methods of scientific research that might inform women about cord blood stem cells, some women also expressed concerns about the bioethics and controversies regarding stem cell science itself. P1 discussed her reservations about potential uses of stem cell science in general, but explained her choice to bank based on maternal concern for her child's health:

**P1:** I feel those things too. I was thinking about this this morning before you came over as well, there, you know, the phrase "stem cells" like conjures up a lot of things for people and I'm not, ah, an expert on the, like it's not, like I've read articles in the newspaper and whatever, but I'm not like in any way an expert about how stem cells are used, but I know that it is for lots of people like a pretty controversial area. Um, you know, I'm not, I'm not really interested in seeing a human being get cloned, I'm not like, the places where I see potential, like the little bit that I know the places where I see for it to be like abused feel frightening to me. Um, but on the flip side and it's like again if you, you know, worst case scenario, if our daughter were diagnosed with something where her own stem cells could be put to use to save her life, like, I wouldn't hesitate, you know what I mean? So it feels like a tiny bit

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<sup>63</sup> In Canada, there are gaps in regulations regarding cord blood stem cell collection, testing and storage. First, Health Canada regulations deal exclusively with therapeutic allogeneic use and are silent on autologous use. Second, banked cord blood stem cells could potentially be used for non-therapeutic purposes such as research and in experimental clinical applications.



hypocritical maybe just in that it feels like it fits into like this spectrum that, like, at one end is very, like, is maybe technically messy kind of scary and a bit unknown, but I feel like where, the place in the spectrum where she fits, where her little bank of stem cells fits feels pretty, like, OK.

In this case, P1's uncertainty and concern about stem cell science is not about whether or not it will advance, but she is uncertain about, and concerned with, what the science might be used for. Thus, she too does not hold a wholly optimistic or hopeful view of science. In making the decision to bank, P1 draws on her maternal concerns for her child and she justifies what she refers to as the possibly "hypocritical" act by providing a nuanced consideration of a spectrum of possible uses of stem cell science. Later in the interview, P1 again situates cord blood banking within a controversial science:

**P1:** ... Obviously not everybody has the money to spend to bank cord blood, um, so that part aside, like, she [her daughter] may be one less person who needs to ask somebody else for that. Not that I would discourage anybody being a donor, but you know what I mean. So there's that part. Um, and it was at the time within our means to do it so the financial stretch of it, you know, it wasn't a financial decision that we took lightly, but we did have the money at that time so it was kind of like, this isn't gonna be, like we don't have to look around for the money right now, so. Um, yeah, so it means, it means good things, but it, you know, I acknowledge that it's connected to like a broader sort of field of science that's maybe a bit fraught and controversial.

In her ethnography of IVF and prenatal genetic diagnosis (PGD), Rapp (2000) developed the concept of "moral pioneers" to describe the complex moral and ethical terrain through which women navigate when making decisions around pregnancy and PGD. She demonstrated how women, when faced with the difficult decision of what to do when a genetic test indicates that the unborn child may have a genetic disease, engage in the difficult and complicated task of decision-making that involves "judg[ing] the quality of their own fetuses [and] making concrete and embodied decisions about the standards for entry into the human community" (Rapp 2000: 3). I suggest that in a similar way, women who bank also engage in a

complex moral and emotional calculus that is informed by the particular situation of cord blood banking on the frontiers of stem cell science. Women do not bank simply as enterprising subjects believing naively in the truth of science, but as skeptical actors who are aware of the uncertainties of science. At the frontiers of stem cell science are the limits of current expert scientific and biomedical knowledge and it is under these conditions that women must act. They are required to take a “leap of faith” in science and do so to hedge their bets.

Women who banked cord blood engaged in complex moral questions that are embedded in a controversial and uncertain stem cell science. Women considered their family’s financial resources, the ethical controversies of stem cell science, the moral explanation that banking privately may free up cord blood for someone else, and the promise of future health for her child. Women are making decisions in the present facing an unknown future. The future is unknown for women in at least two key ways. First, women do not know if their child will be diagnosed with a condition that can be treated by cord blood stem cells. None of the women interviewed had children who were at increased clinical risk for any of these treatable diseases. Second, the clinical uses of cord blood stem cells in the future are unknown. As I point out in Chapter 1, current uses of cord blood stem cells are quite limited and although many private banks advertise a much longer list of diseases that blood stem cells may treat in the future, whether or not these experimental uses will be successful and lead to wider clinical applications is unclear.

### **Controlling an Uncertain Future**

Proponents of private cord blood banking suggest that saving cord blood in a private bank offers prospective parents control over their child’s future health. Control is often thought to be a “good” thing and many women who banked privately spoke about control in positive terms:

**P10:** Um, I think it's just knowing that I've done everything as a parent that I can. There's so much that's out of my control, that I feel like there's one little thing that I can control and so it gives me a little bit of peace of mind...

Some women also spoke about the importance of controlling, or having agency over,<sup>64</sup> their cord blood when comparing private with public cord blood banking. For example, P1 explained that she had decided to bank her cord blood privately because she could control what happens to her cord blood and have it available for her daughter:

**I:** Yeah. Earlier you'd mentioned that you had some concerns about public cord blood banks where you donate and it enters a general pool. Do you remember what some of those concerns were?

**P1:** Um, to be honest it was about like feeling in control and feeling like, "OK so we're putting this out there and," it was, it was very selfish [sigh]. Um, just like, I want to know exactly what we have, where we have it. Um, and yeah, you know, on a totally, totally personal level, like that's, that's something that, you know, I'm being honest about but that I also feel a little bit ashamed about. But it's truthful.... So in the same way with the public banking I just felt like, you know, I kinda wanna, my impulse to do it was not about the greater good. My impulse to do it was about her [daughter's] good.

Ideas of control, that is, what is controllable, who should or has control, and thus, who is responsible when control fails or is not exercised, are formed in power/knowledge relations. Private cord blood banking claims to offer prospective parents a type of control that in the past was unthinkable. The development of appropriate biotechnologies makes it possible to save biological materials for future therapeutic use and this possibility of control reinforces and is reinforced by

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<sup>64</sup> In describing women as "having agency over" their cord blood, I draw on Strathern's (2005) understanding of "having agency over" bodies and parts. She argues that the ability to control over or to have a right to say what can or cannot be done to biological material is a social science definition of ownership that offers an alternative to legal definitions of ownership. Property ownership, when defined in legal terms, cannot apply to biological materials and therefore no one can be said to "own" their own (or others) bodies and/or body parts. This legal prohibition of bodily ownership extends to the arena of private tissue banking. However, women speak about their cord blood as if they "own" it insofar as they have control or agency over when and for whom it can be used.

normative discourses of parental responsibility to control. While women expressed that saving cord blood provided them with feelings of security, I suggest that women also experienced this responsibility as a burden to control. Private cord blood banking contributes to the belief that parents can exercise greater control now, over their child's future health, than what was previously thought possible. If future health *can* be controlled then the women I interviewed thought they *should* exercise this control. The effect of this moral imperative that women *should* control their child's future health places a burden to control on women by limiting their ability to choose not to control.

A physician who has been in family practice for 35 years had some thoughts on the issue of control and private cord blood banking:

**D1:** And I also think as a clinician, um, we've had to be very, very careful not to, ah, imply or suggest to any couple that by failing to do this they would have jeopardized or put their, *yet to be born* [her emphasis] infant at risk. Because I think if you do that, um, you have really set up what I think is unconscionable, um, consequences in terms of what would a couple have to do should they have a child with leukemia if in fact they had not banked that damn cord blood. So, I would just never, I would never want that. I mean I've been in practice 35 years and I have never had anyone with childhood leukemia in the practice. You know, it doesn't mean that I won't turn around next week and have one 'cause I look after the kids that I deliver too. So, I just, I wouldn't want it on my head that I had not suggested or had told a couple that this was valuable to them, but I think that's implied, ah, that's certainly implied when you're talking to couples about why would they want that. They say, "Well, um," "What are you worried about? In terms of, can you afford it? And you want it?" And they say, "Well just, you know, if there's a problem and we don't have it." I say, "What problem do you think there will be?" So they, they don't get it. I mean, parents don't get that, you know, when they are about to have a baby, especially if it's their first, you know, they want everything for that baby. And they want all, everything covered. They have, they have no idea of risk hazard. They have no idea that, you know, I mean, life is whimsical and has bumps and around issues like childhood leukemia, I would never want any couple going, going into the process of having a family to think that the responsibility for making sure they had the means to treat *their* [her emphasis] child's leukemia was in *their* [her emphasis] hands before that child was born. Give me a break! But they do. They do because

they think they *can* [her emphasis] control everything. It's all about, "nothing will happen to my child because I'm here to make sure I can control everything." And it takes having that child and raising that child to know you can control very little, you know?

Like many clinical organizations (such as the Society of Obstetricians and Gynaecologists of Canada) the physician recognized the very low likelihood that cord blood would be needed and used by the women and couples who bank it privately. As a family physician, she was concerned with the implications of prospective parents feeling that they are responsible for controlling the outcome of their child's future health. In her view, the idea of control and the expectation that cord blood can ensure a child's health is an unrealistic expectation that places increased pressure on parents to exercise this control. According to the physician, private cord blood banking reinforces a façade of control over a future that is uncontrollable. Moreover, the pressure or burden of placing this control or responsibility on individual parents struck the physician as highly problematic:

**D1:** Um, I ask them how, how guilty they are [laughs]. Because, because it really is, I mean it, the specific application to them as a couple is *so* [her emphasis] rare that I say, you know, "What do you need this for?" [laughs]. "If you think that you actually may need or may have the child that is that one in 300,000 that is going to need it," I said, "If you really thought that this was the only way you could actually save your child's life," I said, "that would be a *terrible, terrible* [her emphasis] thing to go into any kind of pregnancy with, is that it was *all* [her emphasis] in your hands. That we couldn't save your child, you know, from grievous harm, if you did not do this *one* [her emphasis] thing." I said, "There will be a hundred thousand things that you will have to be guilty for that you fail to do raising this child, but" I said, "this is not one that you should put all of your money and effort into as a reassurance." So I'm very clear with them that this is, this is really about something quite different, um, and quite odd from my perspective.

What the physician finds "quite odd" is a shift to the individual as the locus of control and the assumption that the individual *can* and *will* control. She explains this further:

**D1:** 'Cause I think that's what, I think that's what young couples have. I mean, I think they have hope, but what they really have is they think they control, they think they have control of their own lives, like they're gonna have control over labour and delivery [laughs], like they're gonna have control over not needing an epidural. "Of course not. I'm not gonna have an epidural." OK, well, but 98% of the couples do. "Um, well that's not me." "I know that's not you, but", "that's the other 98%." So it's, yeah, I mean, that's it's, it's way more than hope. It's that control, that assumption that you will control.

According to the doctor, women and couples have a false belief that they can control biological and health matters. She views private cord blood banking as less about assuring future therapeutic treatment and more about parental efforts to exercise control. The implications of changing ideas of controlling the future health through biology are significant for women and couples who consider banking privately. If future health is believed to be controllable by individuals, then if (or when) health fails the responsibility for that failure will fall increasingly on the individual.

Private cord blood banking demonstrates an expansion of the realm of maternal or parental responsibility to manage or control future disease and health. As the physician explained, private cord blood banking is about more than hope, it is about the assumption of control. P3's experience of private banking as providing a "façade of control" (see Chapter 5) and the doctor's observation of this assumption of control raise an important point about the question of control. In part, the hope and hype surrounding stem cell science and regenerative medicine is related to the promise of greater control over health in the future. Proponents of stem cell science and new biotechnologies, such as biotech companies, venture capitalists, and some clinician-scientists, argue that the new molecular frontiers of science and medicine will lead to more specific targeting of treatments (e.g. pharmacogenomics), greater prediction (e.g. genetic testing), and assurance of biological treatments through banking cells and tissues (e.g. cord blood banking) and harnessing the regenerative capacity of stem cells. In spite of the promise of greater control, social scientists have shown that in many instances greater targeting, prediction, and personalized

healthcare have not materialized (e.g. Hedgecoe 2004; Lock 2009). Although this greater control has not materialized as promised in many clinical sites, the expectation of control persists and some women bank cord blood privately, in part, based on a belief that they can exercise control over their child's future health. I argue that, ironically, women bank cord blood stem cells under conditions of significant uncertainty and not greater certainty and control as promised.

### **The Precautionary Actor**

Drawing on women's experiences of private cord blood banking, I have shown the complex ways in which they orient to expert information, the ways in which they are skeptical and uncertain about stem cell science and cord blood use, their use of emotional reasoning in decision-making, and the imperative they feel to control an uncertain future. In exploring their experiences, I argue that they do not conform to the conventional understanding of the abstract neoliberal active subject in expert discourse. In arguing this, I do not suggest women are not active nor do I suggest that they are not rational. Women in this study described experiencing the tensions of increasing responsibility as mothers to exercise control over their child's future health while simultaneously questioning the science and clinical uses of cord blood. They drew on multiple discourses to explain their decision to bank, recognizing that private banking did not necessarily make rational sense if one were to base the decision entirely on calculated probability of use. Women are both incited to act and limited in their actions through moral discourses and shifting ideas of control. The social actor of neoliberalism challenges the entrepreneurial subject and its narrow focus on the subject in financial or economic terms. I offer the concept of the *precautionary actor* as a revision to the entrepreneurial or neoliberal medical subject produced at the site of private cord blood banking.

Drawing on the work of economic sociologist, Francois Ewald (2002), I suggest that women who bank privately exercise precaution and do not act as risk-calculating entrepreneurs. Ewald (2002) writes that the *precautionary principle*

“does not target all risk situations but only those marked by two principal features: a context of *scientific uncertainty* on the one hand and the *possibility of serious and irreversible damage* on the other.” (p. 283-284, italics added). Precaution differs from risk in that the former is activated under conditions of uncertainty whereas the latter is activated under calculable conditions. Precaution is typically applied to stop action; that is, the threat is so great if action were to be taken that one must not act (Ewald, 2002). However, I suggest that the precautionary principle can apply also to private cord blood banking in which the threat of non-action is so great – that is, the potential death of a child – that one must act. Thus, I argue that private cord blood banking satisfies Ewald’s conditions presented above. There is a great deal of scientific uncertainty in the field of blood stem cell science and its application and for women who bank, the possibility of their child having a life-threatening disease is a serious and irreversible damage.

Gottweis (2005) suggests that risk governance is not the only form of governance operating in genomics and stem cell science. Rather, he suggests that these fields of science and their related fields of medicine are organized by both risk and uncertainty. Gottweis (2005) argues that genomic governance, by which he means governance *of* genomics as well as governance *by* genomics, demonstrates a shift from risk governance to governance by uncertainty.<sup>65</sup> When uncertainty dominates, emotion talk and emotional reasoning replace rational calculation. For example, proponents of genomic research draw on the emotion talk of hope and make moral appeals of helping those who are suffering with a particular disease rather than drawing on scientific evidence to gain support for experimental genomic research (Gottweis 2005). At the site of private cord blood banking, women were

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<sup>65</sup> Gottweis (2005) argues that uncertainty can be thought of as the limits of scientific knowledge, but is also more than the limits of this knowledge. Uncertainty also includes social and political uncertainties. Social uncertainties refer to disrupting the boundaries between the social and science that anthropologists and science studies scholars have written about. For example, ambiguity between human and the technological in the figure of the “cyborg” (Haraway 1991). The line that demarcates “the social” from “the scientific” is increasingly blurred and uncertain. Gottweis (2005) refers to political uncertainty as debates waged in the public regarding the direction of and uses for genomics and stem cell science.



well aware of the limits, or uncertainty, of scientific knowledge in stem cell science. They also chose to remain uncertain about the specifics of cord blood banking and cord blood use by limiting their research. Thus, in the case of private cord blood banking, uncertainty features in the incalculability of knowing whether or not one's child will become sick in the future or if the cord blood will be useful in the future. Under these conditions, women drew on emotions and emotional reasoning when making their decision to bank.

I suggest that the concept of the precautionary actor gestures to broader shifts in health governance in the context of molecular and regenerative medicine and that it opens up new avenues of study and critique. First, women did not engage in rational calculation, in part, because risk technologies are not activated at the site of private cord blood banking. The neoliberal medical subject engages in risk calculations and thus risk technologies are thought to dominate in all health domains. Governance cannot be reduced to risk nor can all forms of power be reduced to a singular form of productive power (Mykhalovskiy, 2010; Singer & Weir, 2006; Weir, 2006). Risk technologies are certainly important in health governance; however, as I show through women's accounts above risk technologies cannot be assumed to operate in new areas of contemporary medicine. I agree with scholars (e.g. Bharadwaj 2002; Gottweis 2005) who argue that greater analytic attention must be paid to non-risk technologies, such as uncertainty, that operate at these sites. Whether or not uncertainty is a specific technology and how it functions requires further theoretical and empirical study.

Second, building on my argument in Chapter 5, the precautionary actor responds to feelings of fear, discomfort, and guilt that are inseparable from hope and optimism in future biotechnologies. The focus on hope in much of the social science literature fails to consider the ways in which new biotechnologies and contemporary medicine inspire greater anxiety together with the added burden of controlling an uncertain future. The detached investor characterized by the entrepreneurial subject is silent on the place of emotions in banking and on the cost exacted from

women who bank cord blood privately. Women are encouraged to imagine fearful futures and many feel obligated through gendered moralizing discourses to engage in banking cord blood. This is not the positive image of the subject optimizing health or maximizing investments. I argue that greater attention and critique must be paid to the costs on people at the frontiers of new biotechnologies and molecular medicine.

### **Conclusion**

In this chapter, I have drawn on women's experiences to examine the social actor produced at the site of private cord blood banking. I began by outlining the characteristics of the neoliberal medical subject, the subject form that has dominated in scholarship on health and governance. I argue that women who bank cord blood are constituted as a different actor form, the "precautionary actor." The precautionary actor differs from the neoliberal medical subject in a number of key ways. First, the precautionary actor is not the fully self-possessed, rational subject that the neoliberal subject is understood to be. The precautionary subject does not have the degrees of control that the neoliberal subject is assumed to have and instead acts within limits and constraints. The precautionary actor must navigate moral complexity and responsibilities and in doing so, responds to limits placed on their actions. Second, the precautionary actor responds to fear, anxiety and uncertainty along with hope and promissory expectation. The hopeful neoliberal medical subject is replaced by the uncertain precautionary actor. In a context where people are held increasingly responsible for future health while the state is retracting and the for-profit market expanding in health services, and science is uncertain and questioned, the expectation that people should control an uncertain future is one that fills them with fear and anxiety. Third, the precautionary subject is a skeptical and ironic subject. She is skeptical of the market, wary of the promises made by for-profit companies, and banks cord blood with a sense of irony. With this skeptical view she engages in a complex moral calculus in which she weighs the

moral responsibility and guilt against her own discomfort and questioning of the market. In the end, she must take care of herself and her children's and family's health.

## Chapter 7: Conclusion

In this Chapter, I provide a brief review of the key arguments of this study and discuss feminist and sociological critiques of private cord blood banking that emerge from these arguments. I follow this with a discussion of several health policy implications for private cord blood banking that come from my research. I conclude with some final thoughts on private cord blood banking and contemporary biopolitics.

I began my analytic chapters by providing a detailed account of women's work in banking cord blood (Chapter 3). In this Chapter, I demonstrated how the women in this study learned about cord blood banking, registered with a bank and obtained the collection kit, coordinated and managed healthcare providers and family members to assist with cord blood collection, and organized transport of the cord blood unit to the private bank's laboratory. I have also shown the challenges of cord blood collection immediately following labour and birth and women's concern with collecting a sufficient volume of cord blood and the tensions that arose between clinical and commercial logics and practices. Women's labour, I argue, is critical to the successful collection and banking of a cord blood unit. In addition to the work of women who banked cord blood, healthcare providers were also instrumental in ensuring cord blood collection. Most notably, labour and delivery room nurses increased their workload and assisted women and their partners in the latter stages of collection and packaging of the cord blood unit. I propose that this additional work is not recognized because it is outside the domain of clinical nursing practice and is not accounted for by the banks.

In Chapter 4, I picked up where I left off in Chapter 3 and followed the social and technical production of cord blood into a bankable or clinically useable unit. The cord blood unit undergoes social and technical transformation to be produced into a valuable unit that is cryopreserved and banked. In the case of cord blood, I have shown that biovalue is its potential clinical use value in the future and that this

value is highly unstable. The cord blood unit's value is stabilized through various techniques and forms of knowledge. The different forms of knowledge – clinical, numerical/technical, and lay – that are used to identify a cord blood unit as having potential use value can align or not. When they align they all constitute a cord blood unit as useable. However, when the different knowledges are misaligned, one form of knowledge may indicate the cord blood is not useable while another does. Under these conditions women and private cord blood banks have different interests that conflict. Women are concerned about the future clinical use of the cord blood unit, while the private cord blood bank is primarily concerned with cord blood's current profit-generating capacity. The power relations between a woman and a bank are such that a woman is dependent on the private bank for knowledge and information about her specific cord blood unit and whether or not it will be useable. As I have shown with the experiences of one woman, a banked cord blood unit can become totally unstable and useless. Private banks have a vested for-profit interest in banking as many units as possible and thus, can encourage the banking of units even when their clinical utility may be questionable.

In spite of the uncertainty and instability of a cord blood unit's future use value, private banks market their services as providing “biological insurance” to prospective parents (Chapter 5). Cord blood that is saved in a private bank is not an insurance technology; however, private banks have successfully applied the metaphor of “biological insurance” to cord blood banking. All the women in this study referred to banking cord blood as buying “biological insurance” for their child. The metaphor of insurance has an important framing effect that acts to shape a particular understanding of private cord blood banking. I show that the need for “biological insurance” is implanted by acting on women's fear and anxiety about their child's future health. The option of private cord blood banking has made possible the expansion of women's responsibility to include ensuring health through private tissue banking. Women spoke about banking cord blood to avoid feeling guilty in the future should their child need it and they had not banked. I suggest the

private cord blood banks' marketing strategy is particularly effective because it draws on changing ideas of control of future health. I argue that the metaphor of insurance frames cord blood banking as providing assurance while minimizing the possibility of the failure of cord blood as a clinical therapy. Like, Hofmann et al. (2006), I suggest that gambling may be a better metaphor for private cord blood banking.

Lastly, in Chapter 6, I have shown women's stance as the precautionary actor in private cord blood banking. Fear, anxiety, and emotional reasoning incite women to bank cord blood. They bank in order to exercise precaution against the potential harm of their child having a disease in the future that requires cord blood for treatment. In deciding to bank, women did not act as a rational decision-maker. Instead they used emotional reasoning, drawing on past experiences with illness and loss and their feelings for their child when making the decision to bank. They did not act as rational investors in the future promises of biotechnology, but as skeptical and ironic actors trying to hedge their bets and to act responsibly as they face an uncertain future. I argue that women's experiences of private cord blood banking challenges the conventional understanding of the Foucauldian and post-Foucauldian active subject of neoliberalism. This subject is characterized as a rational, calculating decision-maker who has a hopeful and optimistic orientation to science. According to Foucauldian scholars, the entrepreneurial subject of private cord blood banking invests in the future promises of contemporary biotechnologies. By examining women's experiences, I have shown that women, as social actors, orient differently to private cord blood banking and contemporary biotechnologies than is suggested by the active subject.

### **The Erasure of Women in Private Cord Blood Banking**

In Chapters 3 and 4, I aimed to make visible the work and contribution of women in producing a bankable cord blood unit and producing biovalue in a cord blood unit. By foregrounding the work of women who bank, I have contributed to

feminist scholarship that addresses the erasure of women as providers of biological tissues for contemporary biosciences and medicine. The issue of the erasure of women in private cord blood banking is an important feminist concern and requires further discussion. I suggest that women are erased or minimized in private banking in two very significant ways: one, at the level of practice, women's work in organizing and managing all the necessary steps for cord blood banking is minimized if not obviated; and two, at a more abstract level, women are denied from having any legal claims to cord blood.

The erasure of women's work in the process of private cord blood banking is a problem for a number of reasons. As I have shown, many women described the process of private cord blood banking as additional work and stress to the already stressful experience of giving birth. Several women in this study had very difficult childbirth experiences and still felt responsible for ensuring that a sufficient amount of cord blood had been collected. Immediately following birth, when women were unable to ensure that all the necessary steps for cord blood collection were completed, many nurses provided the extra work necessary. When this labour of women and nurses is made invisible, there is no need to improve on the process since it eliminates the recognition of any problems. For example, two women in this study had a difficult time obtaining a maternal blood sample following the birth of their child. They had to make arrangements with various people in their family or take their child with them to the laboratory to give a sample. While these women were able to successfully give a blood sample, this may be an obstacle for other women who lack social resources or are physically unable to give blood 5-7 days following birth. I argue that it is important that women understand clearly the expectations and requirements of cord blood collection without minimizing the work they must do. For nurses who assist with cord blood collection, their labour is completely erased. Unlike some physicians and midwives who are paid by private cord blood banks, nurses receive no financial compensation. The work of nurses that is required to set up the cord blood collection kit, seal the collection unit, and

pack up the cord blood is not recognized by the private banks. They provide this support in addition to all the clinical work for which they are responsible during labour and delivery. Cord blood collection occurs in the third phase of labour when the largest clinical concern is maternal hemorrhaging. As one nurse explained to me, after a woman gives birth nurses are very busy managing the woman post-birth. I argue that nurses' labour in assisting cord blood collection must be recognized and accounted for.

Cord blood is clinically and legally recognized as belonging solely to the child and not the woman who gave birth. This legal "ownership" or right is based on genetic match between the cord blood stem cells and the child. Currently, women have no legal claims to cord blood. In Chapter 3, I explained that women sign the contract with the private bank to store cord blood on behalf of her child since the cord blood is considered to be the child's. Also, as I discussed in Chapter 2, genetic match is only one way of establishing personal claims to biological materials. An alternative basis for establishing "ownership" of biological materials is to consider whose labour contributed to the production of the tissues. In the case of cord blood, both the woman and child's bodies contribute to its production and thus both would share claims to the cord blood. The question of legal claims to cord blood is more than an academic one. Although there have not been any published legal disputes regarding the status of cord blood or whose it is, I suggest that questions or disputes may arise in the future.

In Canada, the first banks opened in 1996 and thus the first set of contracts that were signed for 18 years will expire in 2014. Women signed the initial contracts on behalf of their child and now the children who are legal adults must sign themselves. When I asked an Executive at a private cord blood bank what might happen if there is a dispute between a child who does not want to continue to bank and a mother/parent who does, she did not have a clear answer. She explained that this is a legal matter that the bank's lawyers must deal with, but suggested that the parent might encourage the child to sign with the understanding that the parent



would continue to pay storage fees. This raises the question of how long might someone bank cord blood for? Another question is, what if the child dies before s/he is 18 years old? The parents may want to keep the cord blood for a genetically related sibling, but what are the legal implications if the child whose cord blood was banked has deceased? Finally, families are social arrangements and it is highly likely that many of the couples that bank may not be together several years later. People may have children with other partners and these children could potentially need the cord blood that was banked. My point in raising these different scenarios is to demonstrate various legal questions that may arise in the relatively near future. When these legal questions arise, women may be affected by their lack of legal claim to the cord blood. Adding to this complexity would be paternal claims to cord blood. One can imagine that if, as the private banks suggest, cord blood becomes an effective treatment for conditions such as Alzheimer's Disease and cardiac disease, many more people may want and need access to cord blood. I argue that cord blood is shared biological material between women and child and the question of legal claims to cord blood must be examined and attended to carefully.

### **Sociological Critique of Private Cord Blood Banking**

The legal questions I raise in the previous section assume that cord blood is and will be clinically useful in the future. However, throughout this dissertation I have demonstrated that cord blood's potential use value is far more unstable than private banks and many commentators make it out to be. As I pointed out in Chapter 1, many clinical organizations recommend against private cord blood banking because of the low probability of clinical use based on low incidence rates of the diseases currently treated by cord blood. What I have shown is that the cord blood unit itself may not be useable based on its low volume and/or the limitations of autologous use for diseases such as leukemia. In addition to these clinical limitations, private cord blood banking has important social implications. For example, I have demonstrated that private cord blood banks market their services

by amplifying women's concerns and anxieties about their child's future health. Women who banked described their discomfort at imagining their child as sick in the future. Some described feeling a tension and conflict about participating in a for-profit industry that they did not necessarily support because of an obligation and responsibility they felt as a mother to care for her child. Private cord blood banks are made possible in part by changing ideas of future control that is associated, I argue, with stem cell science and the promises of regenerative medicine. Changing ideas of control over the future have a normative effect such that women feel an obligation to bank in order to ensure their child's future health and to be a "good mother."

Private banks have a for-profit aim that puts their interests at odds with the interests of women. This is particularly a concern when the potential clinical use value for cord blood is under question, such as when low volume units are collected. As I have shown in Chapter 4, women who have a low volume collection depend on the information and knowledge provided by the private banks to determine whether or not to bank. Women must make this decision under strict time pressures. When private banks receive a low volume unit, many advise women of the promissory possibilities of cord blood use in the future and the immanence of expansion techniques that will, they hope, make it possible to use the small volume in therapeutic treatments. Thus, the minimum recommended volume of cord blood can be ever lowered. I am not making a strong argument that the private banks intentionally set out to deceive people. In fact, many of the Laboratory Directors I interviewed were thoughtful and aware of the current limitations of cord blood. However, as a general course of action, private banks draw on scientific discourse in favour of banking and emphasize the future possibilities of clinical cord blood use to increase their profits. At an institutional level, the private banks have a fiduciary responsibility to its investors to produce profit; thus, private banks aim to encourage as many women to bank as possible. The less people need cord blood and the longer it takes for science to develop new uses and therapies with cord blood,

the more money the banks make. The problem, then, is when women rely on the private banks to provide the necessary information to determine whether or not bank a low volume unit. There is, I propose, a conflict of interest since the private banks have a responsibility to their investors and not to women. They make a profit when women bank regardless of whether or not the cord blood is ever used or is even useable. If a cord blood unit is needed and proves to be clinically useless, the bank loses nothing except for some lost revenue from storage fees. Women, on the other hand, lose a great deal including the failure of cord blood to assure their child's future health.

Private cord blood banking also reasserts the biologization of kin relations. Women made the decision to bank cord blood for the security of their child's future health. The decision itself is a social one in which a mother/parent makes the decision on behalf of her child. The women in this study did not bank to ensure their own health, but rather acted out of a deep sense of maternal responsibility and sacrifice. While cord blood banking is an example of the disaggregation of individual bodies as live tissues are banked outside the body, it is also simultaneously a case of the biologization or geneticization of kin relations. The person who banks is an individual-in-relation to a broader network of genetic kin bound together by cord blood. Some private banks promote their services as "family banking" because there is a higher probability that the cord blood will be a genetic match for people who are genetically related. In other words, the cord blood is more likely to be useful to genetically related kin, thus reasserting the importance of genes or biology to determine who does or does not "belong" to a family. The familial or genetic kin group is now also very relevant where there are moral responsibilities that one has for the others in the genetic kin group. As I have shown, moral language of responsibility feature heavily in women's accounts of banking. Women did not speak about or know themselves as genetic individuals in relation to cord blood banking, but primarily as "mothers" in relation to their children and also as biological or genetic kin to their family.

### **Health Policy Implications**

There are several health policy implications regarding private cord blood banking that flow from my research. Broadly, I recommend greater regulation and oversight of private cord blood banking. The lack of regulation over private cord blood banking is consistent with the lack of regulation in other for-profit industries dealing with fertility and assisted reproduction (see Cattapan 2014). I propose that oversight of the private cord blood banking industry could be provided in part by international organizations that govern the industry, such as the AABB or Net-Cord FACT. In addition, professional clinical organizations such as the SOGC, Canadian Nurses Association, Canadian Association of Midwives, and Canadian Fertility and Andrology Society might also provide some leadership, guidance and input into how the industry might be better regulated. Lastly, Health Canada as a national regulatory body should also play a role in developing regulations that not only focus on the safety of cord blood for recipients, but also the efficacy of cord blood and safety to cord blood providers/donors.

One, I suggest that there is a need for greater oversight regarding the content and information provided by private cord blood banks to women and couples. As critics and I have pointed out, private banks emphasize the potential uses of cord blood and focus on the possibilities for use. Many women I interviewed did not understand clearly the limitations of cord blood use. In particular, most women were unaware that most leukemias would likely not be treated by autologous cord blood transplants. They were also unclear on the current limitations for clinical use of the relatively small amount of cord blood collected. Although most women in this study were not interested in knowing all the details of cord blood banking and limited the information they sought out, I argue that it is important that women be given clear information about the current limits of cord blood use.

Two, I suggest that there is a need for greater oversight regarding how information about cord blood banking is delivered. On this matter, I propose that

industry governing bodies and professional clinical organizations might play a role. Currently, there are no specific regulations or standards that govern how health-related information regarding cord blood banking is provided by private banks. At minimum, I recommend that private banks require women and/or couples to speak with a third party either in person or over the phone to ensure that potential clients understand the limitations and uses of cord blood. This third party should be someone who is not paid by the private banks, such as a prenatal instructor or other healthcare professional; however, the third party should have received instruction about private cord blood banking from a source other than a private bank. Currently, private banks are the primary source of information and training for healthcare professionals including physicians and prenatal instructors. Many private banks offer in-person and online information sessions and are available to speak to women over the phone, but women are not required to attend any sessions or speak to anyone before registering. Given the complexities of cord blood use and the work women must do to bank cord blood, I suggest that it would benefit women and couples to speak to someone prior to registration.

Three, I recommend greater oversight over advertisements of private banks in hospitals. As I argue in Chapter 3, the strong presence of private cord blood banks in some hospitals led women to believe that the private bank was working together with the hospital. Although Inception LifeBank does have a formal association with hospitals, the nature of this association is unclear. I suggest that strong advertising in hospitals by private banks sends a message to potential clients that the hospital endorses the private bank. Such an endorsement might provide what I call a “hospital halo effect” which leads women to extend the trust that they have for hospitals and healthcare providers to the private cord blood bank. The two institutions are highly different and are governed by very different regulations, aims, and logics. Women cannot assume that the private bank will care for their needs as hospitals do.

Four, I suggest that stricter regulations be placed on minimum levels of cord blood banked in private banks. This will provide some protection for women regarding the future useability of the cord blood unit and the tendency for private banks to bring down the lower recommended minimum volume of cord blood that can be banked. This may also make it possible for privately banked cord blood units to be transferred to a public bank. Although private banks indicate that women can move their cord blood from a private bank to a public one if they choose, the standards for a public bank are much more rigorous than a private bank. Thus, a public bank would not accept a cord blood unit that falls below its minimum required level.<sup>66</sup>

### **Study Limitations**

This study has several limitations. One, the sample of women I interviewed was largely homogeneous so there is little diversity of experiences based on women's social locations in this study. All the women I interviewed were White, educated, middle- to upper-socioeconomic status, in a long-term relationship, and live in an urban setting. It is difficult to get a clear demographic picture of women who participate in private cord blood banking because private banks do not share this information. However, several key informants in private banks indicated that most of the women who banked were of middle- to upper socioeconomic status and were educated. All the banks I visited were in urban cities and thus, I suggest it is fair to assume that most women who participate live in urban settings. Although private banks advertise that they can bank cord blood collected anywhere, not only must women have the financial and social resources to bank, but healthcare providers must also be familiar with collection techniques. One woman I interviewed explained that her mother, who is a nurse in a rural town in British

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<sup>66</sup> The National Public Cord Blood Bank (NPCBB) likely has numerous strict regulations governing the cord blood units that can be banked so transfer of a cord blood unit from a private bank to the NPCBB will likely be very difficult if at all possible.

Columbia, told her that no one in her hospital had ever assisted with cord blood collection or even knew what it was. Thus, the homogeneity of my sample may be consistent with a relatively homogeneous population of women who bank. Ethnicity, however, may be one social category that may provide some interesting insight. Some private banks (and the national public bank) target ethnic minorities by emphasizing that large international public registries are less likely to have a cord blood match for non-White people. Thus, private banks suggest that the children of non-White women and couples may have a more difficult time finding a match in a public bank.<sup>67</sup>

Two, I interviewed only women who banked in this study and not partners or women who did not bank.<sup>68</sup> Interviewing partners would provide important insight into any differences between maternal and paternal views of private cord blood banking or birth mother and non-birth mother views. I chose to focus on women who banked for my study because of time and logistical constraints. For example, it would potentially be more difficult to try to arrange to interview couples together or one at a time. Interviewing women who looked into private banking, but did not bank would also offer important information on reasons why women decided not to bank.

Three, it is possible that the women who chose to participate in this study did so because they felt they had something to say about private cord blood banking. That is, there may be some concerns regarding self-selection bias. Self-selection bias refers to a biased sample that poses a problem with probability sampling. As a qualitative study in which I do not claim to have a representative sample, this concern is less significant. However, there is the possibility that women in my research had a particularly difficult or negative experience with private cord blood

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<sup>67</sup> The National Public Cord Blood Bank also has as one of its mandates the aim of obtaining cord blood donations from non-White women and couples. One of the arguments for the establishment of a NPCBB in Canada is the country's multi-ethnic population and the need to have cord blood matches for the population.

<sup>68</sup> I interviewed two women who did not bank, but did not include them in my analysis because I did not think their interviews provided enough data for a comparative analysis.

banking and thus wanted to share their experiences. In response, I would say that not all the women indicated that private banking was a difficult or challenging experience. Even if this is the case that the women shared exceptional experiences, I argue that it does not take away from the data generated from the interviews and the arguments I make.

### **Final Thoughts**

Foucault wrote that biopower marked a shift in political power in which the sovereign's right to "*take* life or *let* live was replaced by a power to *foster* life or *disallow* it to the point of death" (Foucault 1978: 138, emphasis in original). In other words, "*let* live, *make* die" was replaced in modern biopolitics with "*make* live, *let* die." Contemporary biopolitics in the 21<sup>st</sup> century Global North is considered to have changed in scale from the molar to the molecular (Rose 2007). Political governance is now not only concerned with optimizing individuals and the population through measures of health and life, but also in governing the very material substance and production of life at the genetic or corporeal level. In neoliberalism, the individual is increasingly responsible for self-governance and managing and optimizing one's own health through practices and technologies of the self, what I term "being healthy."

Reflecting on changing notions of health in the 21<sup>st</sup> century, I propose that there has been an expansion from "*being* healthy" to include "*ensuring* health." Throughout this dissertation, I have conceptualized private cord blood banking as a strategy for health. However, private cord blood banking differs from other forms of health practices in that it is not about maintaining a particular lifestyle to avoid disease, managing symptoms, or engaging with biomedical interventions. In other words, it is not about "being healthy," or acting to maintain or achieve a state of health. Instead, it is about participating in practices that ostensibly ensure one's future health by storing biological resources for potential treatment. This differs from blood donation since private tissue banking is aimed at hoarding for the



individual, or is organized by an “individualist paradigm.” Blood donation involves pooling a biological resource (i.e. blood) and redistributing based on need. This model of donation follows a “solidarity paradigm” (Ewald 1991). If contemporary biopolitics in the Global North has extended personal responsibility from “*being* healthy” through lifestyle and activities to “*ensuring* health” through corporeal transformation and accumulation, then private cord blood banking is an exemplary case of a contemporary biopolitics. Under these conditions, in which the imperative to “ensure health” is both ubiquitous and normative, expectations about what can be controlled and sacrifices that should be made to accomplish this health ideal can easily be glossed over for the greater good of “health.”

As I have shown, private cord blood banking is a highly social practice. From the shared corporeal materiality of cord blood between mother and child to the social practices that require a mother to make decisions on behalf of and to stand in as “donor” for her newborn, private cord blood banking involves more than the individual. There is a cost beyond the financial for women who bank: they must do the work involved in banking cord blood, they must take on the responsibility and stress of ensuring an adequate collection, they must sit with the tension and discomfort of participating in a for-profit industry, they must set aside their skepticism of stem cell science in order to provide for their child’s future health, and they must engage with the fearful possibility that their child may become ill. The promise that stem cell science offers women the ability to exercise some control over their child’s future health provides them with some precarious assurance; however, women also experienced a moral burden and responsibility to bank. My aim in emphasizing the costs to women is to draw attention to the ways in which women’s experiences challenge much of the scholarship in contemporary biopolitics with its explanatory emphasis on the active neoliberal subject’s rational and calculative investments. The concern, I suggest, with this dominant characterization is that it presents a partial picture of private cord blood banking that continues to erase people’s experiences of taking up biopolitical strategies and thus, this

literature is lacking in the empirical specificity for which critical anthropologists, such as Lock (2005), argue. Although women in this study might be considered to be a privileged group insofar as they all have relatively high levels of financial, educational and social resources, their narratives demonstrate a much more complicated account of engaging with stem cell promises and how it is taken up in people's everyday lives than is suggested in conventional biopolitics literature. I challenge biopolitics scholarship that presents an over-generalized, acritical account of contemporary biopolitics and argue for greater analytic and empirical attention to the everyday lives and experiences of people who engage in health optimizing strategies. With the growth of private tissue banks and promises of regenerative medicine and stem cell science to ensure future health, I argue that there is a strong need for a critical biopolitics.

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## Appendix A: Cord Blood Banks in Canada

(As of July, 2014)

<b>Name of Bank</b>	<b>Province</b>	<b>Private or Public</b>
Inception Lifebank	Ontario and British Columbia	Private
Progenics	Ontario	Private
Cells for Life, Ltd.	Ontario	Private
Victoria Angels Registry of Hope	Ontario	Public (affiliated with Cells for Life, Ltd.)
CReATe Cord Blood and Peristem™ Stem Cell Bank	Ontario	Private
Cord Blood Bank of Canada	Ontario	Private
Stemsciences Inc.	Ontario	Private
Healthcord Cryogenics Corporation	British Columbia	Private
Canadian Cord Blood Registry	Alberta	Private
Alberta Cord Blood Bank	Alberta	Public (affiliated with Canadian Cord Blood Registry)
Hema-Quebec	Quebec	Public (for Quebec residents only)
National Public Cord Blood Bank	Ontario, Alberta, and British Columbia	Public (for all Canadian residents)

## Appendix B: ELSI Literature

Like the SOGC, most international clinical organizations, including the American Pediatric Association, the Royal College of Obstetrics and Gynaecology (UK), the Royal College of Midwives (UK), and the EU Ethics Committee do not recommend private cord blood banking. Some countries, such as France and Italy, have outlawed private cord blood banking (Ballen, Barker, Stewart, Greene & Lane 2007). The French government considers private cord blood banking to be at odds with their public health care system and to be a form of commercialization of body parts which they oppose on ethical grounds (Katz & Mills 2010). Katz & Mills (2010) point out, however, that national laws prohibiting private banks have limited effectiveness since there are no legal restrictions regarding banking in a private bank internationally. The absence of private cord blood banks has generated a form of “medical tourism” as women and their partners in France pay to have their cord blood extracted and banked privately in countries that allow private banks (Katz & Mills 2010). Canadian private banks also advertise that they will bank cord blood collected in any country as long as they can receive the cord blood unit within 48 hours of collection.

Opponents of private cord blood banks argue there is a lack of clinical evidence for the efficacy of autologous blood transplants (Samuel, Kerridge & O’Brien 2008), private banking is not cost-effective given the low likelihood that an autologous blood transplant will be needed (Ballen et al. 2007; Kaimal, Smith, Lavos Jr., Caughey & Cheng 2009), the possible conflict between public and private banks, the lack of social value of private banks (Flegel 2009), and the uncertainty of potential regenerative or therapeutic uses of stem cells in cord blood (Katz & Mills 2010). Interestingly, the issue of uncertainty of potential regenerative therapies derived from cord blood is also used as the main argument *for* private banks. Hollands & McCauley (2009) argue that since we do not yet know what the potential for cord blood is, this is all the more reason that we should bank it privately now. Proponents of private cord blood banks emphasize the future potential of cord blood

based on ongoing research rather than current clinical uses (Chen 2006) and claim opponents of private banking are making ideological or paternalistic arguments (Roberts 2008).

The ethical issues involved with cord blood banking include questions of ownership, practices of obtaining informed consent, issues of confidentiality, and in the case of private cord blood banking issues of equity of access and equity of care (Samuel & Kerridge 2007). Currently, the consensus statement by Americans, Sugarman, Kaalund, Kodish, Marshal, Reisner, Wilfond & Wolpe (1997) is taken as the standard approach in most North American jurisdictions. They suggest that cord blood is analogous to a tissue in organ donation and, drawing on a biomedical definition, that cord blood should be thought of as belonging to the child based on genetic identity. As such, Sugarman et al. (1997) suggest that consent for cord blood banking can be provided by the mother on behalf of the child. Although this is the standard practice taken up in Canada and in many other jurisdictions, Hofmann, Solbakk & Holm (2006) point out that ontological questions regarding “what cord blood is” and normative questions of “whose it is” have yet to be adequately addressed. As Saginur et al. (2004) pointed out, these questions remain legally ambiguous. Questions of legal ownership in Canada remain to be settled in the courts.

Bioethicists have also expressed concerns with the informed consent process for public and private cord blood banking (Hofmann et al. 2006). Several key concerns include when to obtain informed consent (i.e. how far in advance to labour and delivery should consent be obtained), who is consenting to what (i.e. research, therapy, storage), and given that cord blood is banked for some future use how and what is considered to be adequate information when future research and/or therapeutic uses are yet unknown. Related to questions of providing adequate and correct information, bioethicists have raised concerns over mis-information provided by private cord blood banks in their marketing strategies (Rosell & Virt 2004). Specifically, several commentators have expressed concern over what they



consider to be hyperbolic promises that private cord blood banks make regarding the future therapeutic uses of cord blood to take advantage of parental concerns for their future child's health (Rosell & Virt 2004). Some bioethicists suggest that these concerns can be addressed through greater regulation of private cord blood banks and better information provided to parents (Rosell & Virt 2004; Saginur et al. 2004)

An international survey (Canada, USA, Turkey and Italy) of the literature that examines pregnant women's perspectives shows that most women know very little about cord blood and cord blood banking; that they often under-estimate the likelihood of finding a match in a public cord blood bank and over-estimate the likelihood and the conditions for which private cord blood will be used; and that they would like information from health professionals (Dinc & Sahin 2009; Fernandez, Gordon, Van den Hof, Taweel & Baylis 2003; Fox, Stevens, Ciubotariu, Rubinstein, McCullough & Chervenak 2007; Rucinski, Jones, Reyes, Tidwell, Phillips & Delves 2010; Salvaterra, Casati, Bottardi, Brizzolara, Calistri, Cofano, Folliero, Lalatta, Maffioletti, Negri & Rebullà 2010). Most of these studies conclude with recommendations aimed at increasing public awareness and information to pregnant women and their partners. Salvaterra et al (2010) recommend producing an information brochure for women, Dinc & Sahin (2009) suggest that nurses should be trained to inform women on cord blood banking during prenatal care, and Kharaboyan et al. (2006) write that all obstetricians should provide information on cord blood banking to their patients. One area of particular focus by proponents of public cord blood banks involves the recruitment of non-White donors in order to increase the likelihood of matches for non-White recipients (Rucinski et al. 2010). Silversides (2009) argues that Canada's genetic heterogeneity is an asset to public cord blood banks with the implicit suggestion that the non-White population in Canada should be encouraged to donate.

## Appendix C: Interview Guide – Women

Can you tell me how you heard about cord blood banking?

- What did you do to get more information about UCB banking?
- Who initiated getting information about UCB banking?
- What interested you about cord blood banking?
- What kinds of questions did you have when you were thinking about cord blood banking?

How did you come to bank cord blood?

- Listen for how they made the decision to bank or not bank; what were important/relevant factors or considerations and why?
- At what point in your pregnancy did you know you were going to bank cord blood?
- How did you come to go with the bank that you did?

Can you tell me what you did to bank cord blood?

- Can you walk me through what you did?
- Can you tell me about your experiences beginning with going into labour?
- Probe for specific sequence of events/practices
- Listen for any unexpected events; listen for expectations around labour and delivery
- Probe for how the process of extracting cord blood fit with the process and experiences of labour and delivery - who was present during labour and delivery?

Can you tell me about your interactions with the cord blood bank after giving birth?

What surprised you about cord blood banking?

- Listen for assumptions about cord blood banking
- Women can answer this as broadly as they'd like; i.e. surprise can be in terms of the actual practice of banking cord blood or what cord blood can be used for or how many/few people bank cord blood, etc.

What does it mean for you to have banked cord blood?

What would you tell someone who's considering cord blood banking?

## Appendix D: Interview Guide - Key Informants

Can you tell me what you do in this bank/company?

Can you tell me about your bank/company?

- I.e. size, history, relation to other cord blood banks, location (I will be more specific based on the information that I have about the specific bank)

When and how do women hear about your bank?

- Who is normally their first point of contact in your organization?

Can you tell me about what happens to the cord blood unit when it arrives at your bank?

- What kinds of tests are done on the cord blood unit when it arrives at your facility?
- What happens to the cord blood unit if you're not able to extract enough? Who decides?
- What are the regulations that determine what tests must be done?
- What happens with the results of the tests? Do you share the information with women/parents if there is a positive test result?
- What happens to the cord blood unit if it doesn't meet the testing standards? Is it still banked? Is it used for research? Who decides?
- Are there regular visits or checks of your facility by CSA or any other regulatory body?

Can you tell me what happens when someone needs their cord blood unit?

- What's the process of retrieving their sample to use therapeutically? Do you have any direct interaction with clinicians when this happens?
- What are the regulations that guide what can and can't be done to/with banked blood?
- What happens if someone defaults on payments (for private banks)?
- Can someone choose to "give" their cord blood unit to another person? A "non-family" member? That is, what can someone do/not do with the cord blood they've banked privately?
- Do women/families contact you about their cord blood unit?
- What happens to the cord blood after 18 years? (i.e. most contracts with private banks are only good for 18 years)

What is the relationship like with your bank and other banks? With hospitals? With research labs?

What do you foresee as the direction of the cord blood banking field?

- I.e. Do you think more people will bank? Do you think the private banks will eventually close? Do you think private banks will grow as the clinical and research science develops?
- What's your opinion of a national public cord blood bank?
- What do you think might be the impact of the national public cord blood bank on the private banks?
- What kind of relationship do you think the national public bank and private banks will have with one another?

## **Appendix E: Interview Guide – Key Informants: Scientific/Laboratory Directors**

Can you walk me through the process of what happens to the cord blood unit once it arrives in your lab?

- Who does what to it? How long does the processing take?
- What is cryopreserved?
- How many people are involved in the processing of cord blood?
- Why 48 hours time limit for cord blood sample to arrive at lab?
- What's the difference between cord blood unit volume and stem cell viability? How do you test viability?
- What kind of stem cell yield are you looking for? What's the minimum amount? How does this differ from the min. CB volume (50-100 mL)?
- How are these standards set?
- How much variability is there in the processing and preserving of CB units? How many units do you get a week? Are there unexpected events or things that happen when you're processing?

How are the cord blood units categorized/organized so that they remain identifiable with the woman who banked?

- How do you label and identify the different cord blood units? (i.e. with labels, codes, biological markers, checks and balances in the system)
- How does HLA typing work? How is this associated with race or ethnic background?

Can you walk me through the process of what happens when you release a cord blood unit?

- Who does what?
- What do you do with the unit?
- Are there any tests that you have to do? Who does the test? Your lab or the transplant physician/centre?
- Do people ever contact you about the CB unit after it's been processed and preserved? How long can CB be cryopreserved for?

What happens in the case of "unusable" cord blood units?

- How do you identify "unusable" CB units? What makes them "unusable"?
- Do cord blood samples go to research labs?

What are the regulations or regulatory bodies that you have to comply with?

- How often are their labs inspected by regulators?
- What training do their technicians receive?

Where do you see the field headed?

**Appendix F: Interview Guide – Healthcare Professional: Nurse**

Can you tell me how long you've worked as a labour and delivery nurse?

Can you tell me what a typical work day for you is like?

What is normally done with the placenta and umbilical cord after delivery?

- I.e. is the cord, cord blood or placenta used for anything else after? Are samples taken for anything else?

Have you ever been involved in a delivery when a woman is privately banking her cord blood?

If yes, can you walk me through an example or case (beginning with labour)?

- When are you told about banking cord blood?
- When does the woman/couple give you the cord blood kit? Who normally gives it to you?
- Do you do anything with the cord blood after it's been collected?
- Have parents asked you for help?
- When is the cord blood collected? (before or after placenta is out?)

Has there ever been a case when there were problems with collecting the cord blood?

Is it something that is quite common? Have you noticed a change in the number of women who are banking cord blood?

Has collecting cord blood changed how you do things during labour and delivery?

- I've heard that some hospitals (e.g. Sunnybrook) allow the cord to continue to pulse after the baby is born; do you do this? Does this pose any conflicts or problems with banking cord blood?
- Has this changed what you do after a baby is born?

What do you think about private cord blood banking?

What are the women normally like when they tell you about the cord blood kit?

- I.e. are they anxious? Nervous? Worried? Calm?

**Appendix G: Interview Guide – Healthcare Professional: Physician**

How did you hear about cord blood banking?

Do women ask you about CB banking?

Do you talk to women who are pregnant about cord blood banking? If yes, how long have you been discussing it in your practice?

- At what point in their pregnancy do you talk to them about it?
- Do most women who are interested in it bank or do you see many women who are on the fence about it?

Can you walk me through what you do when you collect cord blood?

In your experience, has there ever been a case where there were problems when cord blood was collected?

- If yes, what happened?
- What happens if something goes wrong with cord blood banking in the delivery? Who is responsible/liable? The doctor? The hospital?

Do you have pamphlets of CB banks in your office?

- What do you think of CB banks putting pamphlets in doctors' offices?

What do you think of private cord blood banking? (given the earlier clinical critiques of it)

- What do you recommend to your patients?

In your opinion, are there any concerns with cord blood banking?

What do you think about delayed cord clamping versus cord blood banking?

- I.e. are they in conflict with each other? Can you do both?

I've heard that some doctors get paid for banking cord blood. Do you think this is an incentive for physicians to assist with banking cord blood?

## Appendix H: Informed Consent Form

### Informed Consent Form

**Study Name:** A Sociological Study of Umbilical Cord Blood Banking in Canada

**Researcher:** Jennie Haw, PhD Candidate, Sociology, York University, jhaw@yorku.ca

**Purpose of the Research:** This research studies public and private cord blood banking in Canada. The objectives of my study are to give an overview of cord blood banking practices in Canada and to examine the experiences and practices of women who are considering banking or have decided to bank cord blood. In order to do this I will interview people who work in the cord blood banking field, health care professionals who have some experience with cord blood banking, and 10-15 women who are considering banking or have decided to bank cord blood. This research will be written up as a dissertation manuscript in accordance with the requirements of the doctoral program in the Department of Sociology and the Faculty of Graduate Studies at York University.

**What You Will Be Asked to Do in the Research:** You will be asked to participate in a semi-structured interview of up to two hours' duration. You will be asked questions related to your work and/or experiences with cord blood banking.

**Risks and Discomforts:** You may experience some distress or discomfort discussing your experiences of your pregnancy, health and the future health of your child/ren. If you feel uncomfortable during the interview you may refuse to answer any question(s) and/or terminate the interview at any time.

**Benefits of the Research and Benefits to You:** I do not foresee any direct benefits of the research to you, but you may find it interesting to discuss your involvement in cord blood banking.

**Voluntary Participation:** Your participation in the study is completely voluntary and you may choose to stop participating at any time. You have the right to refuse to answer any question. Your decision not to volunteer will not influence the nature of your relationship with York University either now, or in the future. No incentive is offered to you for your participation.

**Withdrawal from the Study:** You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

**Confidentiality:** Recordings and notes from the interviews will not be associated with identifying information. All information you supply during the research will be held in confidence and unless you specifically indicate your consent, your name and the name of the cord blood bank will not appear in any report or publication of the research. The data will be collected through handwritten notes and a digital recording device. Your data will be safely stored in a locked facility and/or on a password-protected computer and only research staff will have access to this information. The data will be stored for ten years and then destroyed by shredding of all paper files and permanently deleting all computer files. Confidentiality will be provided to the fullest extent possible by law.

**Questions About the Research?** If you have questions about the research in general or about your role in the study, please feel free to contact me, Jennie Haw, by email (jhaw@yorku.ca). You may also contact my Graduate Program, York University Sociology Department, 2075 Vari Hall, 4700 Keele



Street, Toronto, Ontario, Canada M3J 1P3, 416-736-2100 Ext. 33913. This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5<sup>th</sup> Floor, York Research Tower, York University (telephone 416-736-5914 or e-mail [ore@yorku.ca](mailto:ore@yorku.ca)).

**Legal Rights and Signatures:**

I \_\_\_\_\_, consent to participate in "A Sociological Study of Umbilical Cord Blood Banking in Canada" conducted by Jennie Haw. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

**Signature** \_\_\_\_\_  
Participant

**Date** \_\_\_\_\_

**Signature** \_\_\_\_\_  
Principal Investigator

**Date** \_\_\_\_\_

## Appendix I: Participant List

### Women Who Banked

	<b>Year(s) banked</b>	<b># CB units banked</b>	<b>Occupation</b>	<b>Province/State</b>
P1	2010	1	Teacher	Ontario
P2	2009	1	Manager	New York
P3	2003	1	Researcher (M.A.)	British Columbia
P4	2006, 2009	2	Manager	Ontario
P5	Did not bank			
P6	2011	1	Lawyer	Ontario
P7	2006, 2010	2	Lawyer	Ontario
P8	2010	1	Stay-at-home mom	Ontario
P9	2011	1	Support Worker	Ontario
P10	2011	1	Manager	Ontario
P11	2011	1	Researcher (Ph.D.)	Ontario
P12	2010	1	E.C.E. Teacher	Ontario
P13	2008	1	Researcher (Ph.D.)	Ontario
P14	Did not bank			
P15	2010	1	Chiropractor	Ontario

### Key Informants

	<b>Occupation/Title</b>	<b>Private Bank</b>	<b>Province</b>
CSR1	Client Services Representative	1	Ontario
LD1	Laboratory Director	1	Ontario
Ex1	Executive Director	1	Ontario
CSR2	Client Services Representative	2	Ontario
SD3	Scientific Director	3	Ontario
LD4	Laboratory Director	4	British Columbia
D1	Physician	N/A	Ontario
N1	Nurse	N/A	Ontario
N2	Nurse	N/A	Ontario

**Appendix J: Analytic Codes**

Banking process  
Biotech – future  
Biovalue  
Birth  
Capitalization – discomfort  
Capitalization – for profit  
Cord Blood unit – ownership  
Cord Blood unit  
Control  
Cord blood bank – marketing  
Cord blood bank  
Cost  
Ethnicity  
Family – form  
Family – opinion  
Fear  
Friends – opinion  
Future  
Health concerns  
Health professionals – opinion  
Hope  
Hospital – Bank Association  
Imagining illness  
Insurance  
Investment  
Laboratory (research) – Bank Association  
Media – advertisements  
Moral – discomfort  
Moral – judgment  
Parenting  
Peace of mind  
Public Bank  
Public-private relationship  
Regulations – AABB and FACT  
Regulations – Health Canada  
Regulations – lack of  
Research – CB bank  
Research – use of hematopoietic stem cells  
Testing (of the CB unit)  
Uncertainty  
Work – partner