



This item was submitted to Loughborough's Institutional Repository (<https://dspace.lboro.ac.uk/>) by the author and is made available under the following Creative Commons Licence conditions.

 **creative commons**  
C O M M O N S D E E D

**Attribution-NonCommercial-NoDerivs 2.5**

**You are free:**

- to copy, distribute, display, and perform the work

**Under the following conditions:**

 **Attribution.** You must attribute the work in the manner specified by the author or licensor.

 **Noncommercial.** You may not use this work for commercial purposes.

 **No Derivative Works.** You may not alter, transform, or build upon this work.

- For any reuse or distribution, you must make clear to others the license terms of this work.
- Any of these conditions can be waived if you get permission from the copyright holder.

**Your fair use and other rights are in no way affected by the above.**

This is a human-readable summary of the [Legal Code \(the full license\)](#).

[Disclaimer](#) 

For the full text of this licence, please go to:  
<http://creativecommons.org/licenses/by-nc-nd/2.5/>

Ref. Saukko, P. (2004). Genomics, susceptibility testing and pregnancy: Something old, something new, New Genetics and Society, 23, 3, 313-325.

Version accepted for publication.

GENOMIC SUSCEPTIBILITY TESTING AND PREGNANCY: SOMETHING OLD,  
SOMETHING NEW<sup>1</sup>

Keywords: genetic testing, genetic thrombophilia, factor V Leiden, genomics, preventive genetics, prenatal testing

---

<sup>1</sup> The author would like to thank “Ann”, Professor Stephan Moll, Deborah Okner-Smith, the two anonymous reviewers, the Egenis-team and participants of the “The Meanings of Genomics” international seminar (Exeter, November, 2003) for useful comments. The support of ESRC is gratefully acknowledged.

## ABSTRACT

This essay explores how testing for common and complex or genomic, as opposed to genetic, susceptibility to deep vein thrombosis both challenges and consolidates old social discourses on genes, gender and pregnancy. The nexus between genetics and reproduction usually crystallizes in the moral dilemma of selective termination. This essay examines on-line discussion among women with a genomic predisposition to deep vein thrombosis, which is associated with miscarriage and stillbirth. It explores the women's exchanges on what to "do" in order to safely carry to term a foetus, which may always also have the genomic susceptibility. Interpreting DNA not in terms of predicting fate but of suggesting how to modify one's behaviour in order to give and care for life blunts its eugenistic edge. However, this interpretation also shouldered discussants with the complicated and laborious responsibility of modifying themselves, their life-styles and the life-styles of their families—all of which falls within women's traditional labour of love in the privatised age of bioindividuality.

Genetics and pregnancy usually come together in prenatal testing, technology designed to detect genetic “defects” in the foetus that raises the moral and social dilemma of selective termination. In the case of testing for the common, complex and low risk susceptibility to deep vein thrombosis pregnancy and genetics come together in an unusual way. Women who are pregnant or planning to get pregnant may be recommended to have the genetic test in order to take actions to prevent clots developing in the mother, the foetus or the placenta during pregnancy, labour and post-partum. Thus, in this case genetics works to help women to carry to term a foetus, which always may have a genomic susceptibility.

In this essay I explore on-line discussions on pregnancy among women, who have tested positive for genetic thrombophilia. I also analyse a webpage associated with these discussions. I examine the way these discussions and the webpage both challenge and consolidate traditional discourses and practices around genes, gender and pregnancy. Feminist scholarship on prenatal testing has drawn attention to the way in which it often articulates a friction between the individualist discourse on choice and the gendered principle of care (Rothman, 1994, Rapp, 2000, Ettore, 2002). The test for genetic thrombophilia confounds this scenario in that women on the discussion-list interpret the test in terms of helping them to give and care for life.

Reading the on-line discussion against feminist and general social scientific literature on genetics draws attention to two developments. First, thrombophilia illustrates a genomic, as opposed to genetic, approach to DNA. This approach does not view DNA as determining an immutable “fate” but sees it as a malleable template, which can be transformed by changing life-style, avoiding certain drugs and taking others (see

Rabinow, 1996, Novas and Rose, 2000, Taussig, Rapp and Heath, 2003). Most of the discussion on the on-line list focused precisely on what to “do” about the genomic susceptibility and whether pregnant participants should take anti-coagulants to avoid clots in themselves or the baby. Interpreting genomics in terms of helping to safely carry a baby to term blunts its eugenistic edge. This became into particularly sharp relief, when a post on the list queried whether one should abort a foetus, if it were homozygous<sup>2</sup> for one of the thrombophilia markers, which was unanimously rebutted by the participants, many of whom were homozygous themselves.

However, the genomic or flexible approach to DNA not only overcomes crude determinism but also invites individuals to embark on a programme of genomically modifying themselves and their life-styles by making complicated decisions about testing, medications (with major side-effects) and health-care, introducing changes to diet, exercise, holidaying, contraception, making love and having children.

Commentators have noted how this “self-reflexive” (Giddens, 1990) or “entrepreneurial” (Rose, 1999, Novas and Rose, 2000) approach to life is becoming dominant in the current historical moment, emphasising people’s ability and responsibility to become active subjects who take charge of their lives and health, rather than end up passive objects of top-down institutions, such as medicine. Genomics introduces this “do it yourself” attitude to the way in which we relate to our genome. However, the commentators present the entrepreneurial attitude to the self, health and life as a universal phenomenon. Against this, the second point the essay makes is that genomic modification of life-style has specific and significant implications for women. The on-line discussion on how to

---

<sup>2</sup> Homozygous=inherited the allele from both parents; heterozygous=inherited the allele from one parent. Heterozygosity is associated with low risk of deep vein thrombosis; homozygosity is associated with more significant risk.

inject anti-coagulants and closely monitor oneself during pregnancy and on what foods, leisure-pursuits and drugs families should avoid and which ones they should prefer highlights that the everyday work on life-style largely falls within women's traditional labour of love in the increasingly privatised world.

### Feminist interpretations of genetics and reproduction

Before moving on to the on-line discussion on thrombophilia and pregnancy, it is useful to contextualise the issue against and within feminist literature on genetics and reproduction. Much of this literature focuses on gendered contradictions between caring and choice. In her landmark ethnography on amniocentesis Rayna Rapp (2000) argues that it is predicated on a tension between feminist movement's struggle for women's reproductive choice and a eugenic project of detecting and eliminating "defective" foetuses. Rapp documents how this tension interacts with women's traditional sense of themselves as carers and further with diverse ethnic, religious and class-based ethics and realities. On one hand white middle-class women having the test noted they would terminate the pregnancy, if the foetus was found to have Down's Syndrome, yet condemned themselves for being "selfish". On the other hand, religious women who decided to have a disabled child could count on their religious community not only for moral but also practical support in taking care of the child.

Rothman (1994) has noted that the decision women have to make about whether to abort a defective or "in-valid" foetus is not a choice but a tragedy. Women have to either take the responsibility of having a disabled and possibly suffering child or a responsibility of ending the life of the foetus. Hallowell (1999) has observed how caring

for their daughters also informs women's decision to take a predictive test for breast cancer, limiting their choice and directing them to taking preventive actions, such as removal of ovaries and breasts, with ambiguous clinical benefits. These conundrums produced by the new medical technologies raise the old feminist questions: Is caring for others, such as the unborn foetus or daughters, a feminine value that goes unacknowledged by masculine individualism? Or does caring for others, such as a disabled child or daughters, hamper women's ability to attain autonomous individuality and self-direction? (e.g. Gilligan, 1993, Ginsburg, 1998/1989)

Feminist have aimed to undo these starkly oppositional questions by drawing attention to the way in which caring is framed as a value and a practice that belongs to the private sphere of nurturance. This framing presents women contemplating selective termination with a seemingly existential personal choice between selfishness and self-sacrifice and obliterates the fact that these choices are shaped by the social context, such as the logic of prenatal testing, the gendered ethos of care and the availability of social and material support for having a child with a genetic "defect" or susceptibility.

However, the meanings and consequences of genetics are currently changing. Rabinow (1996) has argued that we are moving away from socio-biology, which modelled societies according to apparently natural differences and inequalities, and towards biosociality, which models nature in terms of society or as a socially constructed artefact. Heath, Rapp and Taussig's (2003) work illustrates how both sociobiological and biosocial agendas interlace the interactions between the medical community and Little People of America most of whom have achondroplasia, a genetically-based dwarfism. On one hand, little people fear that advances in prenatal testing will make aborting dwarf

foetuses into a norm. On the other hand, women with achondroplasia benefit from medical advice on how to manage their high-risk pregnancy, which affirms the value of dwarf babies.

Thus, current genetics is characterised by an intermingling of sociobiological notions of genetics in terms of eliminating defects and an emerging biosociality, where DNA no longer spells a fate or a tragic choice but invites individuals to adapt their behaviour informed by their unique genomic predispositions. This article explores the new as well as old gendered possibilities and problems embedded in the emerging biosocial practices.

#### Thrombophilia as a genomic condition

The new understanding of the genome as a malleable template is particularly relevant when studying thrombophilia, because it is the only common, polygenic and complex condition that is currently being tested for in mainstream medicine in the US and UK.<sup>3</sup> The most common gene alteration, factor V Leiden (FVL), which increases an individual's susceptibility to deep vein thrombosis, is present in one out of twenty-five individuals in Caucasian populations. Therefore, it is an example of one the blips or SNPs<sup>4</sup> that we all have in our genome. Moreover, unlike monogenic conditions, such as achondroplasia, which are relatively straightforwardly caused by a single gene alteration, thrombophilia is associated with approximately a dozen known and probably many unknown genetic factors that increase an individual's chance of developing a deep vein thrombosis (DVT). Furthermore, thrombophilia is a complex condition in that not only

---

<sup>3</sup> The test for factor V Leiden is one of the most common genetic tests in the UK and the US (see Hellman et al 2003, UK Genetic Testing Network, 2004).

<sup>4</sup> Single nucleotide polymorphism.



genetic but also biological and environmental factors play a major role in increasing an individual's susceptibility to DVT. Age is a significant risk-factor; environmental factors include, for example, the use of oral contraceptives, hormone replacement therapy, pregnancy, surgery, immobility, smoking and obesity.

The complexity of thrombophilia is illustrated by the fact that the presence of factor V Leiden increases an individual's chance of having a DVT 4-fold, and taking the Pill increases a woman's chance of having a DVT the same 4-fold. However, the risk-factors behave synergistically, so that a woman, who has FVL and is on the Pill, has a 30-40 fold increased chance of having a DVT, even if this chance is still small in absolute terms (see Middeldorp, 2001, Bauer, 2001). The main reason why individuals are referred to the test for FVL or the other thrombophilia markers is to avoid situations where several risk-factors coincide, such as advising people with the predisposition not to go on the combined Pill and to take special precautions in high-risk situations, such as during long flights, or during and after surgery or pregnancy. Some of the preventive measures people with genetic susceptibility to DVTs can take are useful and harmless, such as wearing special stockings during flights. However, to further complicate matters the use of anti-coagulants (blood thinners) is associated with the potentially fatal risk of internal bleeding and is not, therefore, recommended for people with thrombophilia, who have not had a clot. The jury is still out on whether women, who are heterozygous for FVL but have no history of clots or miscarriage, should inject anti-coagulants during pregnancy (Bauer, 2001).

These facts about thrombophilia highlight two issues. First, they illustrate the multidimensionality of the condition, which is not reducible to a linear, causal reasoning

where there is a gene “for” something (see Moss, 2003). Second, the complex and interactive nature of thrombophilia renders it a condition that can be modified by avoiding certain medications, taking others and changing life-style. However, this modification involves assessing and manipulating complicated, interacting and uncertain risks and benefits—not necessarily an easy task.

### Visions of genes and life

The Internet listserv for people with genetic thrombophilia<sup>5</sup> is a forum where participants exchange information on how to manage the complexities of the condition. Based on an analysis of a total of 3600 posts (all posts belonging to a thread of three posts or longer) exchanged during a six-month period in 2003 the most popular topic on the list was the general use of anti-coagulants (900 posts), the second most popular topics were symptoms and experiences of DVT and pregnancy (300-400 posts each), followed by expressions of emotional support and uplift (250 posts) and life-style advice (150 posts). The most popular topics indicate that the participants are most interested in information on what to do, particularly what medications to take, to prevent clotting.

This essay will focus on the discussion on pregnancy; I have discussed the general use of anti-coagulants elsewhere (Saukko, 2004). Pregnancy is one of the most frequently discussed topics on the list, but it also brings into particularly sharp relief the gendered nature of the discussion and condition. Thrombophilia is equally common in men and women. However, the gendered nature of the risk situations (pregnancy, contraception, hormone replacement therapy) account for the fact that the vast majority

---

<sup>5</sup> The discussion list monitored is the main on-line group for people with genetic thrombophilia. It has approximately 1,000 subscribers, most of them American women. The list is associated with informational web-pages. The list can be found at: <http://www.fvleiden.org> (July 2004).

of the participants of the list are women and, based on our off-line study, 80% of the referrals (n = 567) for the factor V Leiden test in an English regional molecular genetics laboratory during a 28 month period were for women. Acknowledging and exploring the gendered nature of the test and prevention is important, as discussion on new scientific technologies, from IVF to foetal surgery and stem cell research, often obliterate the fact that these technologies operate through women's bodies, pain and labour (Van Der Ploeg, 2004, Roberts and Throsby, 2004).

Pregnancy was a major topic on the list, because women have a risk of developing deep vein thrombosis either during or after pregnancy. Blood clots can also develop in the foetus and placenta, and genetic thrombophilia is associated with both early and late miscarriage and stillbirth. Women, who have had recurrent pregnancy losses, may be referred to the test, so that they may decide to take anti-coagulants during pregnancy to prevent miscarriage. As said earlier, women who are heterozygous for FVL but do not have a personal history of clots or miscarriage are not routinely prescribed anti-coagulants during pregnancy.

Many of the threads on pregnancy on the list were started by a new member of the list, who was either pregnant, planning to get pregnant or a mother of a pregnant daughter, who queried whether it would be a good idea to take Aspirin or Lovenox during pregnancy.<sup>6</sup> Most of the time the participants encouraged the new members to go on the "proper" anti-coagulant, Lovenox and during the observation period several women asked their doctor to prescribe them the daily injections. Other topics included women posting about their concerns about getting pregnant, fearing complications; these women

---

<sup>6</sup> Aspirin, a common and relatively harmless drug is used to prevent arterial problems, such as heart disease; it is not considered effective to prevent deep vein thrombosis. Lovenox (a low molecular weight heparin) is one of the "proper" anti-coagulants that both treat and prevent DVTs. Lovenox is injected daily.

were frequently and emphatically encouraged by other participants to “go ahead”. At one point several personal stories of stillbirth triggered threads where women mourned the loss of “our little angels” and suggested inventing healing memorial rituals and places.

Space does not permit an analysis of the conversation on pregnancy in detail. Rather I focus on a particular posted story, which is not necessarily typical, but is rather an “intense” case (Patton, 1990), which condenses themes and emotions that are addressed on the list. The story was posted by Ann (a pseudonym), who responded to a query about whether taking Aspirin was sufficient to prevent clotting during pregnancy:<sup>7</sup>

Just from my own personal experience, I had 3 pregnancies. I took baby aspirin thru all of them. My sister had a full term stillbirth and at the time, there was no test for FVL. My first 2 babies were fine. But with the last one, born 10 months ago, I had a complete placental abruption at 38 weeks. The baby died, and I almost did as well from the massive blood loss. The physical recovery took 5 or 6 months and I still have some female problems from this. The emotional scars may never heal for my family.

If I were to get pregnant again, I'd be on Lovenox shots and induction at 36 weeks. To me, I wouldn't chance it with just the baby aspirin. The mother and baby's life is much too important to play around with. If I were you, I'd get another opinion and do the lovenox shots with early induction. You have to be so

---

<sup>7</sup> Ann has agreed for her story to be used in this context. I have posted to the group about the study (the response was unanimously positive) and worked in consultation with the moderator (Deborah Okner-Smith) and Dr Stephan Moll from University of North Carolina's Thrombophilia Center, who advises the discussion-group (on research ethics in e-context, see Eysenbach and Till, 2001).

forceful with your medical care sometimes, the drs just want to do things their way.

Ann

Ann's post can be read in (at least) two main ways. It can be interpreted as a strong testimony on personal loss intended to advise other women what to do in order to avoid further tragedies. However, it can also be read as an instance where a participant emphasises the genetic risk of illness/clotting, while not mentioning the risks of preventive treatments. The tendency to emphasise the genetic risk and downplay the risks of preventive measures has also been observed in a qualitative study on women with genetic predisposition to breast cancer (Hallowell, 1999).

However, what is interesting, as well as unusual, about Ann's post is that it contained a link to web-pages that she had constructed in memory of the stillborn baby, Thomas. These pages are a moving display of scanned images from Ann's sonograms at several stages of gestation, striking baby-pictures of Thomas, dressed-up in a pretty baby-outfit, appearing as a beautiful newborn albeit with a bluish hue. There are also pictures of mother and father holding him and pictures of family-members, including the other children of the family in the funeral. The web-pages contain a link to the list-serv's informational pages so that "other tragedies will be avoided" as well as a link to an organization that campaigns for issuing birth certificates for stillborn babies, legally acknowledging the "birth" and individuality of the "beloved baby". The website powerfully witnesses, and weaves together, contradictory visual discourses and social agendas that come together at this touching node between new medical and

communication technologies. Two strong themes emerge from the web-pages, which also reflect general trends on the discussion on pregnancy on the list.

### Life worth living

When I initially started analysing Thomas' web-pages, I was reminded of a presentation by a clinical geneticist I attended not too long ago. The presentation was constructed around a series of slides depicting foetuses with genetic "defects". Each of the images focused on a "defective" part of the bodies of the foetuses, such as missing limbs or extra fingers. They also heavy-handedly constructed the foetuses as clinical objects, de-individualizing them so that, for example, the head and face of the foetus were in some cases covered with a white sheet. Much has been written about the "ocular" fixation of medicine, which defines truth as something that is seen from a universal, objective point of view (e.g. Haraway, 1988). In the early twentieth century this ocular quest manifested itself in the various theories about the correspondence between bodily shape and physical and psychological qualities and genetic make-up, often backed up by extensive photographic galleries of bodies of distinctive "kinds" (see Sheldon, 1940). The practice of looking for difference still applies to clinical genetics, this time backed up by biomolecular evidence of a correspondence between physical appearance and DNA-markers.

The images of Thomas disrupt this discourse. The main photograph of Thomas, where he appears in a classical funeral posture, as if sleeping but with his little hands crossed on his chest, states underneath: "He was perfect". This statement may be seen to affirm the normality of Thomas (and thereby the abnormality of some Other foetuses),

however, in the context of a genetic condition it removes Thomas from the sphere of pathology. The web-pages erase any reference to genes as an inherent or defining quality of either Thomas or Ann. Rather genes appear in much more processual role, a source of the tragedy of Thomas' death, which could have, however, been averted.

An event on the list underlines the wider meaning and importance of this understanding of babies and genes. Around the time of Ann's post an expecting couple posted, worried about what to do as a doctor had advised them to terminate the pregnancy, if the foetus was found to be homozygous for factor V Leiden. The post received a flurry of responses, many from people, such as Ann, who were themselves homozygous, testifying, how they had had healthy children, and lived happy and healthy lives, being "63 now", and advising the couple to think twice. This incidence calls attention to the pivotal ethical question of whether the new technologies redefine what we consider the quality or quantity of life worth living or letting live (Is sixty-three years long enough?) (see Rothman, 2001: 186). The supportive emails from participants illustrate how the community-ethos of those people carrying the genetic marker emphasising the caring for life, and bearing witness to its meaningfulness, may have an important role to play challenging the eugenic use of the technology.

However, the images of Thomas also speak about or against the grain of another visual and social discourse or a lack of it. When one first looks at the web-pages, it comes as a shock to realize that the beautiful baby in the images is dead. One then realizes that one rarely sees these kinds of images in our culture. Medical visualization technologies, such as the sonogram, account for the prominent visual presence of the foetus in both private lives of expecting women or couples as well as in the public sphere.

At the same time, as noted by Layne (2003), miscarriage and stillbirth remain a visual taboo. All the pregnancy-manuals, whether mainstream, alternative or feminist, are dotted with evocative images of new mothers with wrinkly newborns in their arms and on their bellies. In all of these manuals the (short) section discussing miscarriage and stillbirth is void of images.

As Layne (2003) states the silence that surrounds these intensely sad events makes it much harder for women to bear and find support in bearing these painful experiences. Thomas' beautiful, bluish baby-pictures alone and in the arms of a mother and a father make a statement about Thomas' individuality, standing in opposition to the clinical tendency to define miscarriages and stillbirths as "events" and something to get over. The webpages claim that Thomas' birth was a "real birth" and honours the deep embodied grief of women, who have carried these babies, and other family-members confronting the loss.

The discussions and images on pregnancy and loss on the list work to disarticulate the associations of genes and foetuses from the galleries of pathology and to recover stillborn babies from a visual void. However, these articulations not only interrupt previous taboos and discourses but by making thrombophilia visible and speakable as a preventable condition they fortify other familiar discourses.

### Caring in the age of privatization

The most prominent sensibility on the list-discussion on pregnancy as well as on Thomas' webpages is a gendered cherishing of caring for life. This caring is communicated by frequent soliciting and giving advice on how to take care of one's own



and one's family's health as well as by expressions of sympathy and support for participants, who have experienced miscarriage or stillbirth or have fears and concerns. A sense of understanding and togetherness is particularly important for women who have experienced stillbirth, often considered an unspeakable taboo (Layne, 2003). Giving advice on anti-coagulants for women who have experienced a pregnancy loss may also be literally life-saving (Gris et al., 2004), even if the same is not necessarily so true for women with thrombophilia, who have not had miscarriages.

However, the discourse on caring for life particularly in the context of pregnancy is also a double-edged sword as pointed out by feminist research in the area. This research has, for example, analysed how sonogram images of the foetus present it as an independent or transcendental entity (often as if floating in deep space or eternity), obliterating the fact that the foetus always exists within a woman's body (Hartouni, 1992, Stabile, 1993, Franklin, 1997). These images, familiar from pro-life and health-campaigns, may construct the mother as opposed to the foetus, threatening it with termination, smoking, drug use and so on. Going back to Thomas' pages they do not juxtapose the baby and the mother. However, they also constitute Thomas as an object of the medical discourse or the baby, who could have been saved via new technologies with the aid of the mother, who subjects herself to a regime of daily injections of anti-coagulants, close surveillance, induction and so on. This discourse frames the woman as responsible for doing everything within her means to guarantee the health and well-being of the unborn child. In the case of genetic thrombophilia this means presenting the woman with a "choice" to make in the face of complicated and uncertain knowledge

about risks and benefits of tests and medications in a situation where women often feel particularly vulnerable.

However, the care does not stop there. As illustrated by the daily exchanges between women on the list, it extends into making continuous complicated decisions about medications, health care, insurance, adjusting diet, exercise and holiday-making and providing practical and emotional support for those near and far from newborn babies with potential problems to elderly parents, who have had a fall and become dangerously immobilized and risking clotting. While the gendered repercussions of prenatal testing has been acknowledged and examined in social scientific literature, the gendered dimension of preventive and life-style genetic testing has not been addressed. However, activities falling under the rubric of “life-style”--such as preparation of food, monitoring and maintaining health, taking medications, planning and preparing for leisure-activities and holidays and taking care of vulnerable groups, such as children and the elderly--fall mostly within women’s traditional labour of love. While this caring takes responsibility of others, it may also consolidate a notion that caring for health is the responsibility of the private sphere of gendered nurturance in the face of diminishing public services and support and mounting concerns about discrimination by insurance companies.

#### On bioindividuality and beyond

To conceptualise these issues and agendas that interlace testing for genomic susceptibility to deep vein thrombosis it is useful to return to Rabinow’s discussion on socio-biology and biosociality. The query about whether a pregnancy should be

terminated, if the foetus turned out to be homozygous for FVL, reminds that the socio-biological principle of categorizing people based on their intrinsic or genetically based nature as able or unable and liveable and unliveable still looms at the background of genomic testing. The notion of biosociality or the idea that nature, like society, can be redesigned and modelled is close to the way in which participants on the list relate to genetic thrombophilia: as a condition we can “do” something about. The emancipatory or more humane nature of this understanding becomes apparent in contrast with the socio-biological interpretation.

Biosociality may not, however, be the right term to describe the current situation, as what seems to be emerging is bioindividuality, which models nature not according to society but according to a customised individual, designed to make the most out of its unique genomic dispositions and to live up to its individual desires. Rather than bestow people with a genetic fate this notion allows people to shape or “choose” their lives or fates (even though some of these “choices” may be the “damned if you do and damned if you don’t” type). Yet, the invitation to “be all that you can be” embedded in the bioindividualist discourse also easily plays into the neo-liberal policies that shoulder individuals, rather than the society, the responsibility of taking care of their health and also lands the (self-)blame on the individual’s door, in the case of unhappy endings (also Novas and Rose, 2000).

Despite this individualism genetics is still also always social, as it binds family-members together via genes, establishing lines of commonality and responsibility, which also extend beyond “real” kin to individuals with the same genetic conditions, such as the women gathering on the listserv (Rabinow, 1996, Novas and Rose, 2000, Callon and

Rabeharisoa, 2004). The discussion on the listserv, nevertheless, demonstrates that bioindividuality and biosociality may have different implications for different groups. Discussions on genetic testing and life-style are often oblivious of the way in which managing life-style mostly happens in the private sphere, where women care for families' diet, health, reproduction and daily activities. Thus the work entailed by managing both bioindividuality and biosociality, at least in the case of thrombophilia but most likely more widely (see Rapp, Heath and Taussig, 2001: 398), refers to women's labour.

Still, caring may also develop from private nurturance into public solidarity, fostering a biosociality that takes common concerns into public arenas. Members of the list have recently been involved in setting up a patient advocacy group, which wants to pressure for more affordable medicines, for better treatment, for banning discrimination by insurance-companies and employers and for distributing and improving information about the condition. Social scientists have examined these new forms of "genetic citizenship", either noting how they provide opportunities for patients to have a say on science, medicine and policy (e.g. Heath et al 1999) or lamenting that they reinforce the idea that it is individuals' responsibility to take care of their health (Petersen, 2003).

The agendas voiced on the listserv and in the advocacy group--such as universal access to health-care and bans on discriminating individuals based on disability, susceptibility or previous illness--not only concern people with thrombophilia but resonate across different social groups. Genomics has promised to overcome the genetic fixation on genes and to present a multidimensional understanding of disease and life. Maybe a genomic reinterpretation of biosociality would link the specific concerns of the genetic interest groups to wider social issues and agendas they form a part, such as the

need for good public or affordable services and health care as well as gender equality.

Such a politics would move beyond the gendered modification of the self and family and introduce the old idea of public responsibility for citizen's health and well-being into the new forms of biosociality.

## References:

- Bauer, K. (2001). The thrombophilias: Well-defined risk-factors with uncertain therapeutic implications, *Annals of Internal Medicine*, 135, 5, 367-373.
- Callon, M. and Rabeharisoa, V. (2004). Gino's lesson on humanity: genetics, mutual entanglements and the sociologist's role, *Economy and Society*, 33, 1, 1-27.
- Ettorre, E. (2002). *Reproductive genetics, gender and the body*. London: Routledge.
- Eysenbach, G. and Till, J. (2001). Ethical issues in qualitative research on internet communities, *British Medical Journal*, 323, 1103-05.
- Franklin, S. (1997). *Embodied progress: A cultural account of assisted conception*. London: Routledge.
- Giddens, A. (1990). *Modernity and self-identity*. Stanford, CA: Stanford University Press.
- Gilligan, C. (1993). *In a different voice: Psychological theory and women's development*. Cambridge, MA: Harvard University Press.
- Ginsburg, F. (1998/orig.1989). *Contested lives: The abortion debate in an American community*. Berkeley, CA: University of California Press.
- Gris, JC, Mericer, E, Quere, I, Lavigne-Lissalde, G, Cochery-Nouvellon, E, Hoffet, M, Ripart-Neveu, S, Tailland, ML, Dautzat, M. and Mares, P. (2004). Low molecular weight heparin versus low-dose aspirin women with one fetal loss and a constitutional thrombophilic disorder, *Blood*, January, [Epub ahead of print]
- Hallowell, N. (1999). Doing the right thing: genetic risk and responsibility, *Sociology of Health and Illness*, 21, 5, 597-621.
- Haraway, D. (1988) *Situated knowledges: the science question in feminism and the privilege of partial perspective*, *Feminist Studies* 14, 575-99
- Hartouni, V. (1992). *Fetal Exposures: Abortion Politics and the Optics of Allusion*. *Camera Obscura*, 29:130-49.
- Heath, D., Koch, E., Ley, B. and Montoya, M. (1999). Nodes and queries: Linking locations in networked fields of inquiry, *American Behavioural Scientist*, 43, 3, 450-463.
- Hellmann, L. Leslie, ND, and Moll, S. (2003). Knowledge and educational needs of individuals with the factor V Leiden mutation, *Journal of Thrombosis and Haemostasis*, 1, 2335-2339.

- Layne, L. (2003). Unhappy endings: a feminist reappraisal of the women's health movement from the vantage of pregnancy loss, *Social Science and Medicine*, 56, 1881-1891.
- Middeldorp, S., Meinardi, J., Koopman, M., Van Pampus, E., Hamulyak, K, van der Meer, J., Prins, M. and Büller, H. (2001). A prospective study of asymptomatic carriers of the Factor V Leiden mutation to determine the incidence of venous thromboembolism, *Annals of Internal Medicine*, 135, 5, 322-327.
- Moss, L. (2003). *What genes can't do*. Cambridge, MA: MIT Press.
- Novas, C. and Rose, N. (2000). Genetic risks and the birth of the somatic individual, *Economy and Society*, 29, 4, 485-513.
- Patton, MQ. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage
- Petersen, A. (2003). The new genetics and "citizenship". Available at: <http://www.lse.ac.uk/collections/BIOS/docs/AlanPetersen.pdf> [Accessed August, 2004]
- Rabinow, P. (1996). Artificiality and Enlightenment: From socio-biology to biosociality. In P. Rabinow. *Essays on the anthropology of reason* (pp. 91-111). Princeton, NJ: Princeton University Press.
- Rapp, R. (2000). *Testing women, testing the fetus: The social impact of amniocentesis in America*. London: Routledge.
- Rapp, R., Heath, D. and Taussig, K-S. (2001). Genealogical dis-ease: Where hereditary abnormality, biomedical explanation and family responsibility meet. In S. Franklin and S. McKinnon (eds.). *Relative values: Reconfiguring kinship studies* (pp. 384-412). Durham, NC: Duke University Press.
- Roberts, C. and Throsby, K. (2004). Discarded, wasted or spare: Human embryos in the new biotech economies. Paper presented in the 1<sup>st</sup> International Cesagen conference, Royal Society, London, March, 2-3, 2004.
- Rosendaal, F.R. (1999). Venous thrombosis: a multicausal disease, *Lancet*, 353, 1167-1173.
- Rothman, B. K. (1994). *The tentative pregnancy: Amniocentesis and the sexual politics of motherhood*. London: Pandora.
- Rothman, B.K. (2001). *The book of life: A personal and ethical guide to race, normality and the implications of the human genome project*. Boston: Beacon.

- Saukko, P. (2004). From transmission to tangle: Complex mode of risk communication on Internet discussion on genomic thrombophilia. Paper presented in the 1<sup>st</sup> International Cesagen conference, Royal Society, London, March, 2-3, 2004.
- Sheldon, W. (1940). *The varieties of human physique: An introduction to constitutional psychology*. New York: Harpers.
- Stabile, C. (1993). Shooting the mother: Fetal photography and the politics of disappearance, *Camera Obscura*, 28, 179-206.
- Taussig, K.S., Rapp, R. and Heath, D. (2003). Flexible eugenics: Technologies of the self in the age of genetics. In A. Goodman, D. Heath and M.S. Lindee (eds). *Genetic nature/culture: Anthropology and science beyond the two-culture divide* (pp.58-78). Berkeley, CA: University of California Press.
- UK Genetic Testing Network (2004). A list of tests offered by UKGTN laboratories. Available at: <http://www.dh.gov.uk/assetRoot/04/07/66/92/04076692.pdf> (accessed July 2004)
- Van Der Ploeg, I. (2004). "Only angels can do without skin": On reproductive technology's hybrids and the politics of body boundaries, *Body & Society*, 10(2-3), 153-181.