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NECESSARY SUBJECTS: THE NEED FOR A MANDATORY NATIONAL DONOR GAMETE DATABANK

Naomi Cahn¹

INTRODUCTION

Donor eggs, donor sperm, donor embryos—and adoption—are means of creating families in which children are not genetically related to one or both of their parents. Although the offspring in each of the differently-formed families may know of this lack of genetic connection, they may not have access to information about their biological progenitors.

Like the reproductive technology field, adoption law has faced numerous issues concerning children's access to information about their biological progenitors,² even though each field has a different history of protecting confidentiality. It was not until the early twentieth century that adoption records were sealed from a prying public.³ States allowed members of the adoption triad access to these records until the latter half of the twentieth century. While this secret, closed system is a relatively recent phenomenon in adoption, the secrecy of donor sperm dates to its earliest known uses.⁴ On the other hand, the history of secrecy in the donor eggs' context is also fairly recent (indeed, the use of donor eggs has only been possible since the successful development

¹ John Theodore Fey Research Professor of Law, George Washington University Law School. Thanks to Christina Ayiotis, Nanette Elster, Susan Crockin, Madelyn Freundlich, Tony Gambino, Joan Hollinger, Wendy Kramer, and all of the organizers of the DePaul University College of Law Health Law Institute's Tracking Changes Symposium.

² See Nanette Elster, *All or Nothing? The International Debate Over Disclosure to Donor Offspring*, *Inst. On Biotech. & the Human Future* (conference materials), avail. at:

http://www.thehumanfuture.org/commentaries/assisted_reproductive_technology/art_commentary_elster01.html

³ Elizabeth Samuels, *The Idea of Adoption: An Inquiry into the History of Adult Adoptee Access to Birth Records*, 53 RUTGERS L. REV. 367, 369 (2001).

⁴ Professor Gaia Bernstein reports that it was not until 1909 that the first publication concerning donor sperm appeared, discussing "an 1848 case in Philadelphia involving a forty-one year old merchant and his wife . . . [who was inseminated with] semen collected from the best looking member of the medical school class . . . Neither the merchant nor his wife knew what was done. The physician confided in the merchant after the fact. The merchant was delighted but arranged for his wife to remain in ignorance." Gaia Bernstein, *The Socio-Legal Acceptance of New Technologies: A Close Look at Artificial Insemination*, 77 WASH. L. REV. 1035, 1056 (2002). It appears that the resulting child never knew, either.

of IVF thirty years ago); donor eggs initially involved known donors, although today, egg providers are more likely to be unknown and promised confidentiality. The pressure for allowing donor-conceived children access to identifying information about their gamete providers is analogous, although less legally well-developed today, to that in the adoption context.⁵ The private Donor Sibling Registry has taken the lead in helping families formed through donor gametes voluntarily find each other, but the Registry's success has occurred without supporting laws.

The history of secrecy in adoption stems from a variety of sources that are comparable to those in the donor gamete situation. Keeping donor sperm or adoption secret has facilitated a couple's appearance of fertility and may have helped with the acceptance of the resulting children, who were not "strangers" within their new families.⁶ Unlike adoption, which, although surrounded by secrecy, involves legal procedures and multiple parties outside the newly formed family, using donor sperm simulated the expected familial relationships because it requires no public involvement. In his 1964 book, Dr. Wilfred Finegold, the Head of the Division of Sterility at the Planned Parenthood Center in Pittsburgh, explained the advantages of artificial insemination: "The husband's infertility is a secret in A.I. To his friends, the husband has finally impregnated his wife . . . In A.I., the child is never told."⁷ The donor's characteristics should be, he observed, similar to those of the husband's and the two men must be of the same religion.⁸ Further, Dr. Finegold explained that "all" physicians require an anonymous donor and listed a series of precautions for preserving the sperm provider's anonymity.⁹ These

⁵ The analogies and comparisons between adoption and reproductive technology are not entirely synchronous. See MADELYN FREUNDLICH, *ADOPTION AND ETHICS: ADOPTION AND ASSISTED REPRODUCTION* (2001); Naomi Cahn and Madelyn Freundlich, Evan B. Donaldson Institute: Old Lessons for a New World (forthcoming 2008) (draft on file with author); Melanie B. Jacobs, *Procreation Through ART: Why the Adoption Process Should Not Apply*, 35 CAP. U. L. REV. 399 (2006) see infra for further discussion of the utility and limitations.

⁶ See, e.g., June Carbone, *The Role of Adoption in Winning Public Recognition for Adult Partnerships*, 35 CAP. U. L. REV. 341, 357-359 (2006).

⁷ WILFRED FINEGOLD, *ARTIFICIAL INSEMINATION* 25 (1964). Alan Guttmacher wrote the introduction.

⁸ *Id.* at 40.

⁹ *Id.* at 33-35. In her keynote address at the Symposium, Professor Lori Andrews discussed this history as well. Lori Andrews, Keynote, Tracking Changes Symposium

mechanisms provided “cover” for the recipient family so that only the doctor would know for sure.

This article first discusses secrecy in the adoption context before turning to issues involving confidentiality in the donor context. After analyzing the issues involved in maintaining the secrecy of donor gametes, the article ultimately recommends the establishment of a national information databank (or registry), similar to that in place in numerous other countries, to keep track of the numbers of children both through donor egg and sperm and the identities of the gamete providers. Participation in the databank would be mandatory for anyone involved in supplying donor gametes. Once donor-conceived offspring reached the age of 18, they would be able to receive identifying information about their donor, and the donor could file a statement indicating his/her lack of interest in being contacted.

Allowing offspring access to this information involves a series of complicated issues, beginning with the question of informing children of their donor origins so they can seek out this information. Second, what information—beyond identity—would be collected? Third, what information—beyond identity—would be released? As discussed at the symposium, the information collection and dissemination issues are highly complex; for example, should genetic samples be preserved for all donors?¹⁰ Should donors and the children conceived through their material be tracked for purposes of follow-up concerning medical issues?¹¹ As a related matter, because any change in the current system requires additional counseling for all involved, how should those protocols be developed and implemented?¹²

Finally, and more pragmatically, beyond satisfying the needs of many donor offspring and their families to find connections, a national databank would prevent the same donor from providing gametes to numerous banks and numerous families. Existing limits within banks are unenforceable across banks unless donors are identified. A registry

¹⁰ As Dr. Hughes noted at the Symposium, testing of all samples at the time of collection does not necessarily mean that all genetic diseases can be screened. Mark Hughes, Medical Issues (presentation, Tracking Changes Symposium).

¹¹ See generally, William Heisel, *Registry May Track Egg, Sperm Donors*, L.A. TIMES, p. B3, Jan. 3, 2008; Jennifer Schneider, *It's Time for an Egg Donor Registry and Long-Term Follow-Up* (Nov. 14, 2007), avail. at: <http://geneticsandsociety.org/article.php?id=3820>.

¹² Indeed, the existing levels of counseling are problematic as well. See Susan Crockin's paper for this symposium; *Julie Derek, Confessions of a Serial Egg Donor* (2004).

might even help with sharing critical medical information between donor-created families.

I. THE ADOPTION/ART ANALOGY

To be sure, the analogies between adoption and reproductive technology are only that: analogies. There are numerous differences between them, beginning with the regulatory structure and continuing with the relational context. First, adoption has historically (since the mid-nineteenth century) been subject to state oversight, and there is even an international treaty in the area; the child abuse and neglect/foster care system, which is closely related to adoption, is highly regulated by both state and federal laws. State adoption laws explicitly focus on decisionmaking that is in the best interest of the child and that considers the fitness of the parents, and there are laws that clearly specify the rights and obligations of biological and adoptive parents.

States have well-established regulatory systems to protect the integrity of the adoption process. An adoption can only be finalized pursuant to a court order; the rights of biological parents must be terminated (either voluntarily or involuntarily) before the child becomes available for adoption; adoption agencies must be state-licensed; and, although agencies may charge fees for certain expenses, including those related to the biological mother, there is a clear prohibition on the sale of babies (the special situation of surrogacy is beyond the scope of this Article, although it too is highly regulated).

On the other hand, the regulation of reproductive technology is far less unified and coherent. While adoption requires a judicial recognition of each new parent-child relationship, and provides clearly defined legal right for all parties, there need be no public aspect of any part of assisted reproduction. Donors' interests are protected by contracts and by laws directly address parenthood through assisted reproduction, although the coverage and scope of these laws vary from state to state. Gametes are obtained through a private market with little oversight. Over the past twenty years, the federal government has become involved in regulating the safety of gamete handling and in preventing deceptive practices by clinics concerning the success of their procedures.¹³ The Centers for Disease Control publishes an

¹³ The Fertility Clinic Success and Certification Act, 42 U.S.C. § 263a (2008 *see* Lori Andrews & Nanette Elster, *Regulating Reproductive Technologies*, 21 J. LEG. MED. 35, 49 (2000)).

annual report summarizing success rates; the report does not include statistics on sperm donation, and there are no legal sanctions on clinics for failing to report their data.¹⁴ While other countries limit the numbers of times one person can donate sperm or eggs, or the numbers of embryos that can be implanted in one woman, or the payments that can be made for gametes, there are no comparable binding federal limits on these issues in the United States (although a few states have provided some limits in these areas). While the industry's own self-regulatory organizations, such as the American Society for Reproductive Medicine (ASRM) and the American Association of Tissue Banks, do offer guidance on many of these issues, their recommendations are influential, but they are not mandatory.¹⁵ Through their own initiative, individual clinics have also developed and implemented their own standards.

Second, the interests of the family members involved in reproductive technology and in adoption are overlapping, but not identical. Children conceived through donor gametes (aside from those conceived through donor embryos) typically live with one biologically-related parent and perhaps even with related siblings, while the typical adoptee (outside of the significant number of children adopted by family members) does not live with – or have contact with – anyone to whom he or she has any genetic connection. Consequently, while adoptees may wonder about why their biological parents could not keep them, donor offspring do not have to face this particular set of issues.¹⁶ Adoptees typically learn at a young age that they are adopted, but donor offspring are far less likely to learn of their status, and a majority of parents do not disclose this information to them. Moreover, while there is an increasing amount of research on biological parents who have relinquished their children for adoption, there is far less research on gamete donors.¹⁷

¹⁴ Department of Health and Human Services Centers for Disease Control and Prevention, *2005 Assisted Reproductive Technology Success Rates: National Summary and Fertility Clinic Success Rates* (2007), figure 49, p. 61, available at <http://www.cdc.gov/ART/ART2005/508PDF/2005ART508.pdf>

¹⁵ See, e.g., the ASRM ethics reports available at <http://www.asrm.org/Media/Ethics/ethicsmain.html>

¹⁶ See Naomi Cahn and Jana Singer, *Adoption, Identity, and the Constitution: The Case for Opening Closed Records*, 2 U. PA. J. CONST. L. 187 (1999) (exploring similarities and differences); Ellen Waldman, *What do we Tell the Children?*, 35 CAP. U. L. REV. 517, 533-34 (2006).

¹⁷ See Freundlich, *supra* note 5.

Nonetheless, both donor-conceived children and adoptees experience the same lack of connection with at least one-half of their genetic heritages. Writer A.M. Homes describes what it was like to learn that she and her biological mother shared certain habits as “this indescribable subtlety of biology.”¹⁸ It is this lack of knowledge about their biological progenitors, and the emotional needs for this knowledge that many adoptees and donor offspring articulate, that has motivated advocates within each movement to push for disclosure, and that motivates this article’s call for a national, mandatory databank.

II. CONFIDENTIALITY AND ADOPTION

Until the past several decades, many social workers (and others) involved in adoption have reinforced the belief that a biological connection has no role to play once an adoption has occurred. Whether it be in the context of open adoptions, through which a biological parent retains some contact with the adoptee, or open records, such that an adoptee has access to her original birth certificate, this approach viewed adoption as a complete substitute for any blood ties, and was thus generally against allowing any type of tie between adoptive and biological families. In an effort to “overcome” any connections engendered by the biological relationship, experts attempted to deny it completely. Accordingly, biological mothers were frequently assured that, following the birth, they would be able to move on with their lives as though nothing had happened. Adoption records were sealed so that the adoptive family became “the same” as the biological family (and legally, this was true). The biological tie was considered erased for both the birth mother and the adoptee. When the first “modern” adoption statutes were enacted around the middle part of the nineteenth century, they focused on legitimizing the practice of adoption and protecting the welfare of the child.¹⁹ These statutes did not address secrecy or confidentiality. Adoption evolved over the next century, becoming more bureaucratic and professionalized, and ultimately, more confidential.

During the 1930s and 1940s, states began issuing new birth certificates to adopted children. The purpose of these new birth certificates was *not* to prevent adoptees from accessing their original birth certificates but instead, this was an effort to improve the

¹⁸ A.M. HOMES, *THE MISTRESS’S DAUGHTER* 102 (2007).

¹⁹ See Naomi Cahn, *Perfect Substitutes or the Real Thing?*, 52 DUKE L.J. 1077 (2003).

collection of children's vital statistics as well as to reduce the stigma of illegitimacy. As these children became adults, during the 1970s, they brought lawsuits seeking access to their original birth records, and in the 1990s, their efforts resulted in some successful court cases and referenda.

Two states—Kansas and Alaska—never sealed their records, and, over the past dozen years, another six states have opened their adoption records and made them available: Alabama, Delaware, Maine, New Hampshire, Oregon, and Tennessee.²⁰ In almost a dozen additional states, there is limited access to this information: adult adoptees born during specific time periods do not have the right to access their birth certificates, while those who were born either before or after that time period are able to access their records.²¹

Other states have developed different approaches when it comes to the determination of whether adoptees should have access to identifying information, and some have enacted legislation establishing mutual voluntary registries or confidential intermediary systems.²² Mutual voluntary (or passive) registries require the existence of consents for disclosure of the relevant information from both the adoptee and the biological parent before any information can be released. States have not adopted a uniform approach to the procedures for mutual consent registries. Most systems require a consent from at least one biological parent and the adult adoptee (adoptive parents may be able to consent if the adopted person is still a minor), before the disclosure of any identifying information. The Donor Sibling Registry is an example of a mutual consent registry in the gamete world that is already in existence and that works in a similar way—the key is voluntary registration by the two (or more) parties that produces the matches.

At least another six states have established a mechanism for a confidential intermediary system, which authorizes a third party to help find the biological family members to determine if they will consent to

²⁰ Evan B. Donaldson Adoption Institute, *For the Records: Restoring a Legal right for Adult Adoptees* at 3 (2007), available at http://www.adoptioninstitute.org/publications/2007_11_For_Records.pdf [hereinafter Donaldson, FOR THE RECORDS].

²¹ Donaldson, FOR THE RECORDS, *supra* note 20, at 11 (there are 11 states in this category).

²² EVAN B. DONALDSON ADOPTION INSTITUTE, ADOPTION REGISTRIES AND INTERMEDIARIES BY STATE (2008), http://www.adoptioninstitute.org/resources/openrecord_stratergies_intermediary_programs.pdf (last visited Apr. 29, 2008).

the release of information.²³ Confidential intermediary systems are more active than the mutual consent registries because an adoptee can initiate the process which might result in contact, and need not wait for the biological parent to indicate a willingness to be identified.²⁴ Today, in approximately 30 states, adoptees do not have access to their original birth certificates or to records from their adoptions.²⁵ Adoptees can, however, petition a court for identifying information and, for good cause shown, the court may grant access.²⁶

III. CONFIDENTIALITY AND DONOR GAMETES

Confidentiality protections in the donor gamete context come from various sources: statutes, private contracts, case law—and many participants' expectations. The Uniform Parentage Act of 1973, in a section dealing with parentage in the context of donor insemination, provides:

All papers and records pertaining to the insemination, whether part of the permanent record of a court or of a file held by the supervising physician or elsewhere, *are subject to inspection only upon an order of the court for good cause shown.*²⁷

The UPA was enacted in 18 states; it has now been superseded by the 2002 UPA, which contains no such language in the provisions governing assisted reproduction using donor gametes.²⁸ Few other states have established even minimal record-keeping requirements.²⁹

²³ CHILDREN'S BUREAU, U.S. DEPT. OF HEALTH & HUMAN SERV., ACCESS TO ADOPTION RECORDS: SUMMARY OF STATE LAWS (2006), available at http://www.childwelfare.gov/systemwide/laws_policies/statutes/infoaccessapall.pdf (last visited July 18, 2008).

²⁴ Naomi Cahn & Jana Singer, *Adoption, Identity, and the Constitution: The Case for Opening Closed Records*, 2 U. PENN. J. CONST. L. 150, 165 (1999) <http://www.bastards.org/activism/access.htm> (last visited Apr. 29, 2008).

²⁵ ACCESS TO ADOPTION RECORDS, *supra* note 24.

²⁶ Cahn & Singer, *supra* note 25, at 154; Samuels, *supra* note 3, at 427-29; CHILDREN'S BUREAU, U.S. DEPT. OF HEALTH & HUMAN SERV., CHILD WELFARE INFORMATION GATEWAY, Access to Adoption Records (2006), available at http://www.childwelfare.gov/systemwide/laws_policies/statutes/infoaccessap.cfm (last visited Apr. 29, 2008).

²⁷ Uniform Parentage Act, §5(a) (1973). See also COLO. REV. STAT. § 19-4-106 (2008) (Example of enacted state statute). (Emphasis added.)

²⁸ Uniform Parentage Act §700 (2002), available at

Indeed, few cases involving donor identity disclosure have reached the courts. In perhaps the most famous, *Johnson v. Superior Court*,³⁰ the disclosure of the genetic parent's identity was incidental to the tort claims being brought against the clinic that had provided the allegedly defective sperm. The court did, however, consider the UPA to determine whether the contract between the recipient parents and the bank protecting confidentiality of the donor controlled the issue of whether the donor could be compelled to appear at a deposition. The court noted that there were no reported decisions concerning the UPA's "good cause" standard, and ultimately held that "insemination records, including a sperm donor's identity and related information contained in those records, may be disclosed under certain circumstances."³¹ This was not a case where donor offspring sought access to information; consequently, the court was not called upon to decide the circumstances under which a court would disclose such information to a child pursuant to the UPA. Nonetheless, the court did not foreclose such a possibility, opining:

And enforcement under all circumstances of a confidentiality provision such as the one in Cryobank's contract with the Johnsons conflicts with California's compelling interest in the health and welfare of children, including those conceived by artificial insemination. There may be instances under which a child conceived by artificial insemination may need his or her family's genetic and medical history for important medical decisions.³²

<http://www.law.upenn.edu/bll/archives/ulc/upa/final2002.htm>. See also WASH. REV. CODE § 26.26.011 (2002) (Example of state that enacted the Uniform Parentage Act of 2002). The 2002 UPA has been enacted in seven states.

²⁹ See Elster, *All or Nothing?*, *supra* note 2, at 3-4 (listing New York and Ohio, and noting that the ASRM recommends maintaining permanent records. About half of the states have established laws concerning the supervision of sperm banking. Dawn R. Swink & J. Brad Reich, *Caveat Vendor: Potential Progeny, Paternity, and Product Liability Online*, 2007 BYU L. REV. 857, 872 (2007).

³⁰ *Johnson v. Superior Court*, 80 Cal. App. 4th 1050, 1057 (2d Dist. 2000), *modified*, 101 Cal. App. 4th 869 (2d. Dist. 2002).

³¹ *Id.* at 1066.

³² *Id.* at 1067.

No other court has interpreted this provision, although the term “good cause” has a long history in the adoption context when it comes to courts’ allowing the disclosure of birth records.³³

In another context, Minor J sued his mother, Diane J., to find out the identity of his biological father.³⁴ Minor J was born in 1989 to Ms. and Mr. J. His parents were divorced in 1995. Although both Minor J and Mr. J had assumed that Mr. J was the biological father, DNA tests after the divorce indicated that there was no biological connection between the two. Minor J sued his mother in 2006, seeking to require her to reveal the identity of his biological father. Both the trial and appellate courts refused to allow the case to proceed because of the marital presumption: the strong assumption that a child born into a marriage is the legal child of the husband and wife.³⁵

In yet another sperm identity case, again not involving a child’s effort to determine identifying information about a sperm donor, “Michael Hayes” sued an Oregon fertility clinic to determine if his sperm was mistakenly used to inseminate a stranger rather than, as he had intended, his fiancée. M.H., as he is known in the court papers, wanted to establish a relationship with the child who might have been born. The woman who received the sperm—who had not revealed whether she gave birth to a child—wanted to be left alone, without revealing her identity (in the court papers, she is known only as “Jane Doe”).³⁶ She alleges that she was forced to take a morning-after pill, and even offered a free abortion. The judge prevented M.H. from finding out whether he is a biological father, again using the marital presumption to shield the woman and her husband from further scrutiny.³⁷

While donor offspring have not yet organized in the same manner concerning the need for disclosure as have adoptees, the donor movement is beginning to place pressure on the gamete industry for

³³ For courts’ interpretation of good cause in the adoption context, see, e.g., Samuels, *The Idea of Adoption*, supra note 3, at 427-429; Cahn and Singer, supra note 16, at 161-62.

³⁴ *Sutton v. Diane J.*, 2007 Mich. App. Lexis 754 (2007).

³⁵ Murray Davis, *Child Should have Right to Know Genetic Information*, Detroit Free Press, Mar. 6, 2007, at 9; Christina Stolarz, *Teen Fighting to Find Real Dad*, Detroit News, Nov. 20, 2006, at 1B.

³⁶ Elizabeth Suh and Ashbel S. Green, *Who Gets the Baby?*, The Oregonian, Sept. 22, 2006, at A1.

³⁷ Ashbel S. Green, *Judge Rules in OHSU Sperm Sample Mix-Up*, The Oregonian, Apr. 17, 2007, at B2. (Article only provides courts holding but not its reasoning as the citation seems to indicate)

more disclosure. The Donor Sibling Registry has operated a voluntary mutual internet-based registry for matching, but there are no comparable state-mandated procedures. The donor movement could learn from adoption rights advocates about the reasons for requiring disclosure.

In addition, given that one man is capable of providing sperm for numerous children (the Donor Sibling Registry reports as many as 64 half-siblings from one man's sperm), information release will provide two additional services: first, it may prevent half-siblings from marrying each other; and second, it may allow for limits on the numbers of children created through one person's donation. In England, for example, there is a limit of no more than 10 families per gamete donor, although the potential number of children per family is unlimited.³⁸ The ASRM has suggested guidelines for limitations on donations; however, they are not binding.³⁹

Issues related to the importance of sharing or withholding information in assisted reproduction arise in numerous contexts, as is the case in adoption. As professional organizations and social workers involved in assisted reproduction begin to recommend disclosure (whether it be of the fact of donor conception or additional identifying or non-identifying information),⁴⁰ adoption can provide instruction on best practices concerning the legal and psychological methods of disclosure and follow-up. In many cases, the bases for these recommendations in gamete donation track the same reasons for disclosure in the adoption context: allowing offspring the opportunity for knowledge, satisfying emotional and psychological needs, and providing genetic information.

There are, of course, various possibilities for using legal language to frame these issues. In the comparable context of adoption, advocates have typically made five distinct, albeit interrelated, legal arguments for disclosure:

1. Adult adopted persons have a fundamental "right to know" personal information about themselves.

³⁸ See HFEA, *Infertility: the HFEA Guide* 31 (2007), avail. at <http://www.hfea.gov.uk/docs/Guide2.pdf>

³⁹ ASRM, 2006 Guidelines for Gamete and Embryo Donation, 86 *Fert. & Ster.* S38 (2006); see Naomi Cahn, *Accidental Incest* (unpublished manuscript on file with author).

⁴⁰ ETHICS COMMITTEE REPORT OF THE AMERICAN SOCIETY FOR REPRODUCTIVE MEDICINE, *INFORMING OFFSPRING OF THEIR CONCEPTION BY GAMETE DONATION* (2004), Available at http://www.asrm.org/Media/Ethics/informing_offspring_donation.pdf

2. States do not have a legitimate role in withholding birth and/or adoption information from adopted persons once they are adults.
3. Withholding birth and/or adoption information from adult adopted persons violates legal equal protection guarantees by denying them the same rights as other persons.
4. Placing the decision on release of this information in the hands of courts has resulted in inequitable decision-making.
5. Adopted persons should not be bound by decisions on anonymity made by birth parents and adoptive parents at the time of the adoption.⁴¹

The corresponding legal arguments against disclosure include protection of the rights to familial and reproductive privacy, of the right to prevent disclosure of information, against a violation of adoptive parents' privacy, and of equal protection.⁴² Each of these translates into the gamete donation context. Courts have not yet decided these issues in the ART context, so it is difficult to predict which set of arguments will be more successful within the legal system. Based on the adoption analogy, courts are likely to uphold as constitutional laws requiring the disclosure of information;⁴³ what is less clear is courts' receptivity to arguments compelling the release of information.

Beyond consideration of these legal rights—and regardless of the outcome of court cases—however, there are additional reasons to require a databank respecting the interests of donor-conceived offspring,⁴⁴ the recipient parents, and the donors themselves. Even though banks increasingly allow their clients to choose either identified or anonymous donors, there is no obligation on donors to provide accurate information to banks and no obligation for one donor not to donate repeatedly. A national databank might help with the veracity of information because donors would know that they may be accountable not only to the bank, but also to future offspring, and that the banks will be keeping track of how many times they donate.

⁴¹ *For the Records*, *supra* note 19, at 12.

⁴² *Id.* at 17. For an information privacy analysis of donors' interests, *see, e.g.*, Sunni Yuen, Comment: *An Information Privacy Approach to Regulating the Middlemen in the Lucrative Gametes Market*, 2 U. PA. J. INTL. L. 527 (2007).

⁴³ *See* Jennifer A. Baines, Note: *Gamete Donors and Mistaken Identities: The Importance of Genetic Awareness and Proposals Favoring Donor Identity Disclosure for Children Born from Gamete Donations in the United States*, 45 FAM. CT. REV. 116, 126 (2007).

⁴⁴ *See, e.g.*, Cahn, *Test Tube Families* (chapter 12) (forthcoming 2009).

Given the importance to many parents of having a genetic connection to their child, it should be unremarkable that children are themselves interested in learning about those to whom they have a genetic connection. In the case of gamete provision, where couples establish a genetic attachment between one of them and a child, it should not be surprising that children would want to know about other aspects of their genetic heritage. Professor Mary Lyndon Shanley explores the irony:

Secrecy and anonymity suggested that the identity of the donor involved in begetting the child *was* important: if the genetic tie had no significance whatsoever, it would not need to be hidden. . . .

But many people who used donated sperm or eggs to conceive a child who was genetically related to one parent attributed a different kind of significance to their genetic link to the child. Having a child genetically related to one member of the couple gave a sense of continuity.⁴⁵

This kind of continuity, with both the future and the past, is, understandably, important to many donor offspring.

One of the major concerns about removing confidentiality is the question of what would happen to the supply of donor eggs and sperm. Indeed, studies have repeatedly shown that about half of both egg and sperm donors would not participate if anonymity were removed—that the other half would continue to provide gametes.⁴⁶ Early studies from countries that have moved towards mandatory donor identification similarly showed that donors were less willing to provide gametes if they knew their identity would be disclosed.⁴⁷ Even the

⁴⁵ MARY LYNDON SHANLEY, *MAKING BABIES, MAKING FAMILIES: WHAT MATTERS MOST IN AN AGE OF REPRODUCTIVE TECHNOLOGIES, SURROGACY, ADOPTION, AND SAME-SEX AND UNWED PARENTS* 89 (2001).

⁴⁶ See Eric D. Blyth, Lucy Frith, and Abigail Farrand, “*Is it Possible to Recruit Gamete Donors Who Are Both Altruistic and Identifiable?*,”

FERTILITY & STERILITY JOURNAL 84 (2005): S21, Supp. 1, http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6T6K-4H88108-1T&_coverDate=09%2F30%2F2005&_alid=451336191&_rdoc=1&_fmt=&_orig=search&_qd=1&_cdi=5033&_sort=d&view=c&_acct=C000031558&_version=1&_urlVersion=0&_userid=1193445&md5=6289394e3d8fced9e1f6f37fa5acc030. Found article online but you have to purchase the pdf – DePaul does not have a subscription to the journal.

⁴⁷ See June Carbone and Paige Gottheim, *Markets, Subsidies, Regulation, and Trust: Building Ethical Understandings into the Market for Fertility Services*, 9 J. GENDER, RACE & JUST. 509, 540 (2006); K. Daniels and O. Lalos, *The Swedish Insemination*

future possibility that a law will require such disclosure may have a dampening effect.⁴⁸ Indeed, after Sweden enacted legislation in 1985 that required the release of information concerning gamete providers when the child reached the age of 18, there was some concern that the legislation had caused a severe decline in the number of sperm donors.⁴⁹

On the other hand, allowing for the limited release of donor identity might result in the development of new methods to recruit donors.⁵⁰ Moreover, the publicity associated with new laws may encourage different types of donors to come forward. By changing advertising techniques to emphasize helping others rather than the amount of payment, banks may be able to recruit donors who care less about money and more about facilitating the creation of families. As one physician at a fertility center in England explained, "we need to change our strategies to target older men in established relationships. Since it appears they are likely to offer help for altruistic purposes, we must . . . increase public knowledge of the need for donors up to the age of 40."⁵¹ Payment does seem to remain a critical component; when Canada outlawed payment for sperm donors, the sperm supply decreased dramatically.⁵²

In the comparable context of adoption in the United States, leaving the original birth certificates unsealed has not compromised the integrity of the adoption process nor served as harsh limits on the number of children adopted. Indeed, in the two states which never closed their records, there were higher than average rates of adoption.⁵³

Act and Availability of Donors, 10 HUMAN REPRODUCTION 1871 (1995). (DePaul has a subscription but it's from 1996-present. I will request article on interlibrary loan)

⁴⁸ June Carbone and Paige Gottheim, *Markets, Markets, Subsidies, Regulation, and Trust: Building Ethical Understanding into the Market For Fertility Services*, 9 J. GENDER, RACE & J. 509 (2006).

⁴⁹ K. Daniels and O. Lalos, *supra* note 43; F. Shenfield, *Privacy Versus Disclosure in Gamete Donation: A Clash of Interest, of Duties, or an Exercise in Responsibility?*, 14 JOURNAL OF ASSISTED REPRODUCTION AND GENETICS 371 (1997); A. Lalos, K. Daniels, C. Gottlieb, and O. Lalos, *Recruitment and Motivation of Semen Providers in Sweden*, 18 HUMAN REPRODUCTION 212 (2003).

⁵⁰ See, e.g., Ken R. Daniels and Darel J. Hall, *Semen Donor Recruitment Strategies – A Non-Payment-Based Approach*, 12 Human Rep. 2230 (1997).

⁵¹ <http://www.oxfordjournals.org/eshre/press-release/nov051.pdf>.

⁵² "Sperm Donor Shortage Hits Canadian Fertility Clinics," CBC News (Dec. 19, 2006), <http://www.cbc.ca/health/story/2006/12/19/sperm-shortage.html>.

⁵³ See Naomi Cahn and Jana Singer, *Adoption, Identity, and the Constitution: The Case for Opening Closed Records*, 2 U. Penn. J. Con. L. 150, 187 (1999).

It appears then, that the requirement that children receive access to donor information will not necessarily result in a dramatic decrease in donors. It is their interests, and, in many cases, the interests of their parents, which are respected through a disclosure regime.

IV. RECOMMENDATIONS FOR DISCLOSURE.

There are numerous issues – and potential solutions -- to the questions surrounding the development of a databank. Once the decision is made to develop a databank, the first question is what purposes it will serve. Next, there are two dimensions with respect to the databank itself: mandatory or voluntary, private or public. The term “voluntary,” in turn, has two different aspects: clinics can participate voluntarily and choose whether to provide information; and/or donors/offspring can participate voluntarily, so that matches occur only when there is a mutual desire for contact, without any required disclosure of identity when, for example, the offspring reaches a certain age.

These can, in turn, be expanded to four specific options on how to proceed:

1. do nothing, and continue with the private system that we have (kudos to Wendy Kramer and the Donor Sibling Registry);
2. establish a national voluntary databank with standards, and with an administrative board composed of stakeholders, including donor offspring, donors, recipients, and the fertility industry, with private funding;⁵⁴
3. develop a state-based voluntary or mandatory databank; or
4. develop a national mandatory or voluntary databank.

Within this set of choices, I believe that the optimal outcome is the final one, the development of a national mandatory databank, where offspring over the age of 18 can obtain access to information, and to which gamete banks and fertility clinics must contribute information, including live births.

Congress should enact legislation requiring that fertility clinics, sperm and egg banks, and physicians’ offices maintain records for each child born through donor gametes and guaranteeing that gamete offspring have the right to access those records. While the fertility

⁵⁴ At the conference, Dr. Charles Sims circulated a proposal for a national voluntary registry. See also DSR, Draft Proposal for a National Donor Gamete Databank (unpublished, on file with author, 2008)(co-authored by Christina Ayiotis, Naomi Cahn, and Wendy Kramer)(counter-proposal).

industry has a strong stake in ensuring the effectiveness of such a registry, and an interest in administering it, there are numerous other stakeholders who must be involved. Governmental mandates can ensure widespread participation, and can sanction entities that do not report. There is also the concern, as expressed by Wendy Kramer at the symposium, that “[a] national registry that is set up, run, and governed by the sperm banking industry is only a fearful reaction to the possibility of the FDA imposing its own regulations and will only serve to protect this industry’s own best interests.”⁵⁵ Indeed, the federal government exercises some oversight already over the fertility industry. The Centers for Disease Control collects and publishes information annually on the pregnancy rate of individual fertility clinics pursuant to the Fertility Clinic Success Rate and Certification Act of 1992⁵⁶; the most recent report weighed in at 574 pages.⁵⁷ The federal Food and Drug Administration (FDA) has issued extensive regulations governing the testing and safety of gametes.⁵⁸

One alternative to either the fertility industry or the federal government operating the registry might be state implementation.⁵⁹ There are, however, four problems with this approach. First, even if uniform legislation is developed, states might modify the legislation prior to enactment, so the registration and disclosure requirements could vary dramatically. Second, children might not know the state in which their parents obtained gametic material and underwent fertility treatment, and so might need to engage in searches of multiple state registries. Third, even if states attempted to coordinate their databank systems, this would require yet another oversight body to ensure the necessary cooperation. Finally, rather than establishing one system for information collection and retention, all 50 states would have to set up their own systems, causing a potentially overwhelming amount of duplicative work. A federal-level structure could more efficiently and effectively implement any large-scale collection of information and oversight of the process.⁶⁰

This right to know includes two interrelated parts: the right to know that one has been conceived through donor gametes, and the right

⁵⁵ Wendy Kramer, Donor Sibling Registry, <http://www.donorsiblingregistry.com/chicagotalk.pdf> at 6.

⁵⁶ 42 U.S.C. §263a-1 (2008); see 70 Fed. Reg. 5187 (2005).

⁵⁷ See Assisted Reproductive Technology Success Rates, *supra* note 14

⁵⁸ 21 Fed. CFR 1271 et seq. (2008).

⁵⁹ See, e.g., Baines, *supra* note 44.

⁶⁰ See *infra* nn. ___.

to know who the donor is.⁶¹ Requiring that parents tell their children of their donor-conceived status is highly problematic; not only is it difficult to enforce, but it is highly intrusive of intrafamilial relationships.

There are, however, other methods to ensure that children know that their biological and legal parents are different people. One option is for birth certificates of children conceived with donor gametes to be stamped with “by donation” next to the mother and/or father’s name.⁶² Although this places pressure on parents to inform their children of their biological origins, it also ensures that, regardless of whether parents inform their children, the children will know. Or, babies might receive two birth certificates, one that becomes part of the public record which does not include this information, and a second one, which would only be available once the child turns 18 and which would include identifying information about the donor.⁶³ This allows a child’s origins to be kept secret until she turns 18.

A comparable system is already being considered in Britain. In late 2007, some members of the British Parliament suggested that birth certificates indicate the donor status of a child with a special stamp or by including the words “from donor.”⁶⁴ Children born after 1990 can already petition the British Human Fertilisation and Embryology

⁶¹ Lucy Frith, *Beneath the Rhetoric: The Role of Rights in the Practice of Non-Anonymous Gamete Donation*, 15 *Bioethics* 473,476 (2001).

⁶² *See id.*; See also a report from the Ethics Committee of the American Society for Reproductive Medicine on the topic of disclosure:

Clinicians, mental health professionals, academics, and children themselves have in recent years called for more openness in donor conception in order to protect the interests of offspring. Because of persons’ fundamental interest in knowing their genetic heritage and the importance of their ability to make informed health case decisions in the future, the Ethics Committee supports disclosure about the fact of donation to children. It also supports the gathering and storage of medical and genetic information that can be provided to offspring if they ask. It recognizes, however, that disclosure is a personal matter to be decided by the participants....

Ethics Committee of the ASRM, *Informing Offspring of their Conception by Gamete Donation*, 81 *FERT. & STER.* 527, 530 (2004).

⁶³ See Alison Motluk, *Okay, So Who’s Really Your Daddy?*, *TORONTO STAR*, Feb. 16, 2008, at D6, available at 2008 WLNR 3054678.

⁶⁴ Caroline Jones, *The Changing Face of Families: A Controversial New Proposal Would Mean a Special Stamp on the Birth Certificates of Babies From Donor Eggs or Sperm. How Will This-and Other New Laws-Affect Families?*, *THE MIRROR* (London), Jan. 10, 2008, at 40, available at 2008 WLNR 502950.

Authority (HFEA) to disclose whether they are donor-conceived.⁶⁵

Changing current law will be difficult. A variety of interests – clinics, some recipients, some children, and many past, present, and future donors – are opposed to at least some aspects of a mandatory donor gamete databank. The culture of gamete use has come to value secrecy or, at least, the *choice* of identity release. In the analogous context of open records for adoption, advocates have laboriously proceeded state-by-state, using lawsuits, lobbying, and referenda in an ongoing effort to change the existing closed records situation. On the other hand, as technology enables the donor world to obtain more information through genetic tests and internet registries,⁶⁶ existing practices are clearly being challenged.

Others have suggested model legislation that would require the state to maintain records concerning the identity of gamete donors and recipients, but would permit donors to choose to remain anonymous⁶⁷ or that would require the release of medical and genetic information, but not identifying information.⁶⁸ Depending on how these information requirements are administered – if, for example, there is a national mandatory databank -- these proposals might guard against donor siblings marrying each other, and might also prevent one donor from creating more than a specified number of children. Such a national registry could also be used to prevent one person from becoming the biological progenitor of countless offspring (there are numerous reasons to limit the number of offspring from any individual donor, ranging from the possibility of transmission of various diseases to the potential unwillingness for any individual donor to be identified to multiple offspring).⁶⁹ Without a central information repository, even if an individual bank imposes a limit, nothing prevents the donor from offering his or her services elsewhere; a national, mandatory registry could protect against this outcome.

⁶⁵ But see IFFS Surveillance Table 9.2, *Specific Modifications to Anonymity*, FERT. & STER., highlighting variations in national programs for release of gamete donor information.

⁶⁶ For discussion of this, see, e.g., Swink and Reich, *supra* note 27.

⁶⁷ Sara Cotton, et al., *Model Assisted Reproductive Technology Act*, 9 J. GENDER RACE & JUST 55, 79-80 (2005).

⁶⁸ Pino D'Orazio, *Half of the Family Tree: A Call for Access to a Full Genetic History for Children Born by Artificial Insemination*, 2 J. HEALTH & BIOMEDICAL LAW 249, 267 (2006).

⁶⁹ See Naomi Cahn, *Accidental Incest: Drawing the Line – or the Curtain – in the Donor Gamete World* (2008) (unpublished manuscript on file with author).

On the other hand, these proposals do not go far enough in recognizing the offspring's needs for information, nor the donors' and recipients' needs for closure and connection.⁷⁰ It is important to acknowledge that genetic ties may be important for a variety of reasons. Without essentializing the notion of genetic connection, children may still want to know where they came from.

The British Human Fertilisation and Embryology Authority (HFEA) provides one model of a national, mandatory system where clinics must report information on all cycles involving donor eggs, sperm, and embryos, beginning with identifying information concerning the donor and continuing through to the outcome of the treatment.⁷¹ Additional countries are similarly confronting changes in their laws concerning donor anonymity.⁷²

Actual implementation of the registry could be modeled on the HFEA, which operates pursuant to an enactment of the British Parliament.⁷³ While the HFEA is administered by the government, a US national registry could be administered through federal funding and mandate with a board composed of all stakeholders. Information would remain private, except to the donor, the offspring, and the gamete recipients. The HFEA system allows children to check whether they result from donor gametes. Donors might also be required to update their information when the child turns 18. When children turn 18, they should be able to receive identifying information about their donors. The "no contact" statement would be helpful as children considered what to do with the information.

Allowing for the release of a donor's identity recognizes that biology is not everything, but that a child's identity develops through multiple sources. Releasing this information does not change the

⁷⁰ While this is admittedly a self-selected group, messages posted on the Donor Sibling Registry message board by mothers of donor children repeatedly mention issues of "community."

⁷¹ <http://www.hfea.gov.uk>. The HFEA model cannot, of course, be transferred entirely to the US context. For commentary on the British model, see, e.g., Mary Foster Reilly and Richard A. Merrill, *Regulatory Reproductive Genetics: A Review of American Bioethics Commissions and Comparisons to the British HFEA*, 6 *Colum. Sci. & Tech. L. Rev.* 1 (2005); Alicia Ouellette, et al., *Lessons Across the Pond: Artificial Reproductive Technology in the United Kingdom and the United States*, 31 *Am. J.L. & Med.* 419 (2005).

⁷² See Howard W. Jones, Jean Cohen, Ian Cooke, and Roger Kempers, IFFS [International Federation of Fertility Societies] Surveillance 07, 87 *Fert. & Ster.* S1, S8-13, S33-36. (April 2007).

⁷³ <http://cop.hfea.gov.uk/cop/COPContent.aspx?M=0&S=71&SM=83&P=58#content>.

identity of the child's parents. In this connection, the law must guarantee that donors cannot assert parental rights based on their status as donor; in the case of known donors, if the donor signs a contract providing for contact with the child, or if there is some other basis – such as functional parenthood – then, of course, the donor may be able to use these other legal mechanisms for establishing rights.⁷⁴ Legal certainty concerning the rights – or lack thereof – of donors must accompany the establishment of a registry in order to protect the interests of the recipient parents in the stability of their new family and to clarify the donor's responsibilities to any resulting child.

Adults created through gamete provision have a strong interest in having access to information about their biological origins. Regardless of whether anyone involved actually seeks this information in any particular situation, there are a variety of justifications to make it available and to mandate a national mandatory registry that would not only include stakeholders, but that would also involve public, governmental oversight. For the now-grown child, this information may be critical to a sense of identity, satisfying emotional and psychological needs.⁷⁵ Moreover, the private nature of the process, keeping the donor's identity confidential, does not accord with the realities for many recipient families, as shown by the enormous success of the Donor Sibling Registry in helping biologically-related families find one another. Offspring, as well as their families, often want connections. Once offspring learn information about their donors, they can search for others who share the same genetic heritage. The numbers of donor-conceived offspring is increasing. In 2005, the most recent year in which data is available, there were more than 15,000 cases of egg donation and more than 6,000 babies born, and, while there are no reliable data, estimates of the total number of donor-conceived children born each year range from 30,000-60,000. As these offspring learn of their origins and the lack of knowledge available to them, they will create additional pressure to mandate the maintenance and disclosure of accurate information about their donors.

A final issue concerns the retroactive/prospective nature of a registry. It is important to acknowledge that permitting access may disrupt the expectations of some donors and recipients who have relied

⁷⁴ See NAOMI CAHN, TEST TUBE FAMILIES: WHY THE FERTILITY MARKETS NEED LEGAL REGULATION, chapter 12 (forthcoming 2009).

⁷⁵ These issues were insightfully discussed by Andrea Braverman and Jean Benward at the Tracking Changes Symposium; see Keith Griffith, *Who Am I? Your Right to Know* (2008)(unpublished paper on file with author).

on continued secrecy. Nonetheless, as in other areas of family law, the interests of adults and their settled expectations are subject to override based on public policy concerns, including a child's best interests or other reasons underlying the change in controlling law.⁷⁶ And, going forward, a new system could guarantee that all involved in the donor process are aware of the changing aspect of disclosure through mandated counseling. All donor records would still remain sealed, except in the limited circumstance of allowing an offspring access to information.

For multiple reasons, the United States should move towards a mandatory registry that would collect information on donor gametes. All clinics and sperm banks should be required to report certain data. Sperm banks should provide information on each donor, including number of "donations," as well as identity. Clinics should provide comparable data on egg and embryo donors (they already provide data on the number of pregnancies and births).⁷⁷ To ensure the security of this information, the registry would be required to establish sophisticated encryption protocols. Second, donors could keep their identity secret, but only until any future offspring reached the age of 18, at which time the offspring could be granted access to the identifying information. In recognition of the donors' interests, donors could file a non-binding no contact preference form; in recognition of the offspring's interests, the identifying information would nonetheless be disclosed (together with the existence of the no contact form). Finally, the United States should mandate limits on the number of offspring produced by any one donor's genetic contributions.

Private mutual registries already exist. The next steps should be regulation to protect the best interests of the donor-conceived children. Taking those next steps will require the involvement, participation, and cooperation of multiple stakeholders both within and outside of the donor world.

⁷⁶ See *Johnson*, 80 Cal. App. 4th at 1057; *Uniform Parentage Act* §§700 et seq. (2002); Cahn and Singer, *supra* note 16.

⁷⁷ As Susan Crockin points out, there may be no need to include explicitly egg and embryo banks or recruiters because use of eggs or embryos requires a clinic's involvement. See Susan Crockin, Remarks at Tracking Changes Symposium

