Half of the Family Tree: A Call for Access to a Full Genetic History for Children Born by Artificial Insemination

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Introduction

Joedy and Ute Cook each carried the gene for cystic fibrosis. Rather than risk the one in four possibility that one of their children may inherit the disease, they sought an artificial insemination procedure. But when one of the couple's triplets developed the disease, speculation turned toward the sperm clinic's artificial insemination procedure. The Cooks charged that the sperm bank and genetic testing facility failed to adequately screen the donor for the genetic disorder.

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2 More than 10 million Americans carry the defective gene, many without knowing it, and it is the most common inherited disease among Caucasians, affecting about 30,000 American children and young adults. Id. When both parents carry the defective gene, their baby stands a one out of four chance of developing the disease, and it is estimated most babies who develop the disorder are born into families unaware that they were at risk. Cystic Fibrosis, supra. Since there are approximately 100 mutations of the cystic fibrosis gene, genetic testing is not 100% accurate. Id. However, testing can rule out 90% of mutations, and guidelines call for minimal testing of the 25 most common mutations. Id.

3 Ginsberg, supra note 1, at 830.

4 Id. One of the triplets developed the disease, despite the clinic's guarantee that the donor
Such implantation of genetically flawed gametes is not as rare as some think. Documented cases of the transmission of wrong or defective gametes have occurred in California, Michigan, New York, and the Netherlands, among others. Against the backdrop of these unfortunate events arise the issues of whether the offspring of a donor has a right to access his or her genetic origins and, subsequently, whether the donor enjoys substantive rights to protect his identity.

sample would be screened. Id.

5 See Denise Grady, As the Use of Donor Sperm Increases, Secrecy Can be a Health Hazard, N.Y. TIMES, June 6, 2006, available at http://www.nytimes.com/2006/06/06/health/06opin.html. (last visited November 29, 2006). (discussing various problems that have arisen from anonymous sperm donation). See Raizel Liebler, Are You My Parent? Are You My Child? The Role of Genetics and Race in Defining Relationships After Reproductive Technology Mistakes, 5 DEPAUL J. HEALTH CARE L. 15, 25 (Summer 2002) (discussing various problems that have arisen from anonymous sperm donation). The implantation of wrong embryos from donors other than one chosen by parents may suggest the possibility that genetically defective embryos could be passed. Id. See also Mary Lyndon Shanley, Collaboration and Commodification in Assisted Procreation: Reflections on an Open Market and Anonymous Donation in Human Sperm and Eggs, 36 LAW & SOC'Y REV. 257, 258 (2002) (arguing against anonymous sperm donation). The term gamete refers to a cell that contains half of the material necessary for procreation. Id. A gamete can refer to a sperm or an egg, but will generally imply a sperm in this discussion since far more procedures involve donor sperm. Id.; See also Philippa Taylor, Donor Anonymity: Or Rights for the Offspring of Donor Insemination? THE CENTRE FOR BIOETHICS AND PUBLIC POLICY 1 (May 2003), available at http://www.bioethics.ac.uk/publications/donor-anonymity.pdf. (last visited November 29, 2006). (claiming far more children are born as a result of sperm donation than egg donation). The most common form of AI results from the sperm donor inseminating the woman on her expected ovulation date. Ginsberg, supra note 1, at 825-26.

6 See infra note 58 (discussing Johnson v. Superior Court of Los Angeles County). See Grady, supra note 5. A Michigan donor whose sperm produced eleven offspring passed defective genes to five of those children, leaving them susceptible to leukemia. Id. A donor in the Netherlands who was later found to have a serious neurological disease fathered 18 offspring. Id. See Anita M. Hodgson, The Warranty of Sperm: A Modest Proposal to Increase the Accountability of Sperm Banks and Physicians in the Performance of Artificial Insemination Procedures, 26 IND. L. REV. 357, 359-60 (1993) (discussing documented instances where wrong gametes used to inseminate women). Fred and Julia Skolnick of New York City were the victims of the implantation of wrong gametes. Id. at 357-58. In 1985, Fred deposited his sperm into a sperm bank after discovering he had a form of cancer which could inhibit his ability to father children in the future. Id. at 357. Julia was inseminated with what she thought was Fred's sperm a year later. Id. Once the child was born, however, the Skolnick's, who are both Caucasian, were shocked to learn that their baby was biracial, proving that Fred's sperm was not used in Julia's insemination procedure. Hodgson, supra, at 357-58. See also Ginsberg, supra, note 1, at 829-30. Dr. Cecil Jacobson, a physician at a sperm clinic, inseminated up to 75 women with his own sperm. Id. See also St. Paul Fire & Marine Ins. Co. v. Jacobson, 48 F.3d 778 (4th Cir. 1995); United States v. Jacobson, 4 F.3d 987 (4th Cir. 1993).

7 See Guido Pennings, The Right to Privacy and Access to Information About One's Genetic Origins, 20
Despite the recent “clear evolution from secrecy and anonymity towards openness,” courts and legislatures have rarely intervened in the area of genetics and anonymity in artificial insemination. This Note argues that a child created through artificial insemination should not be required to wait until a major health problem arises before he or she is granted access to information about the donor's genetic history. Part I of this Note will focus on the increasing importance that our genetic history and makeup have on daily health decisions. A discussion of how the unregulated assisted reproduction industry in the United States retards donor offspring's access to a complete genetic history will be analyzed in Part II. Finally, Part III will examine various ways in which the government can encourage access to donor information through regulation, and will discuss the problems and concerns that may arise with such steps.

I: The Growing Importance of Genetic Information and Family Medical History

The importance in understanding our own genetic inheritance is becoming increasingly plain as knowledge of genetic makeup is becoming more common and necessary in making medical treatment and personal health decisions. Doctors often

MED & L. 1, 11, 15 (2001) (analyzing how to balance right to privacy and right to access information about oneself). The issues of donor anonymity and the donor child's right to information about the donor are two of the most pressing issues facing the assisted reproduction industry today. Id. See Pasquale Patrizio et al., Disclosure to Children Conceived With Donor Gametes Should be Optional, 16 HUMAN REPRODUCTION 2036, 2037 (Oct. 2001). United States law foresees the possibility of stripping the donor of his anonymity when the “essential interests” of the child are endangered. Pennings, supra note 7, at 1. When referring to “genetic makeup” or “genetic history” in this Note, the author is implying the person's individual genetic makeup and the genetic history of the individual's family. Early detection and a special diet can prevent mental retardation of a child from phenylketonuria (PKU). See Lori B. Andrews & Nanette Elster, Adoption, Reproductive Technologies, and Genetic Information, 8 HEALTH MATRIX 125, 126 (Summer 1998) (discussing important role of genetics and governmental response). Access to information about a donor's family history is vital in leading to the early detection of certain diseases. See Lucy R. Dollens, Artificial Insemination: Right of Privacy and the Difficulty in Maintaining Donor Anonymity, 35 IND. L. REV. 213, 232 (2001) (analyzing recent developments in donor's right to privacy). This is especially true when dealing with hereditary diseases that develop later in life and can be fatal if not properly diagnosed. Id. Further compelling interests would arise in a case where the insemination recipient was in need of a bone marrow or organ transplant, where it is vital to find as many biological relatives as possible. Id. This Note, however, is not arguing for identifying information of the donor, which would be necessary if the donee were to actively seek out the donor and ask for the transplant. See Mark Henderson, Should Kids From Donated Gametes Have the Right to Trace Their Real Parents? TIMES UK, Jan. 29, 2005. Even disorders that the layman would not consider genetically linked, such as alcoholism or drug abuse may render a person predisposed due to family history. Hollace S. W.
advise individuals with a history of family problems to alter their behavior, diet, or habits to reduce the risk of diseases or disorders they may be predisposed toward.\textsuperscript{10} Some proponents believe that an analysis of the individual's DNA discounts the importance of that individual's knowledge of his family's genetic history as well as his individual physical genetic makeup.\textsuperscript{11} For example, an individual with a history of heart disease in the family would be advised to pay particular attention to their weight, fat and cholesterol intakes.\textsuperscript{12} A woman with a family history of breast cancer may undergo mammogram screening on a more frequent basis.\textsuperscript{13} Daily advances in the use of family history and genetic science will continue to reveal new information about the ways in which genes contribute to our health, behavior, and personality.\textsuperscript{14}

As science discovers more genetically-linked disorders, individuals will demand information about their genetic history in order to make informed decisions about their future health.\textsuperscript{15} These choices include important decisions concerning an individual's

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\item Swanson, \textit{Donor Anonymity in Artificial Insemination: Is It Still Necessary?} 27 COLUM. J.L. & SOC. PROBS. 151, 174 (1993) (supporting adoption of laws for better record-keeping). Therefore, a person with a family history of alcoholism or drug abuse would be well advised to be particularly careful in dabbling with these substances. \textit{Id.} The author also recognizes the importance of a full genetic and family history in the early detection of diseases. \textit{Id.}
\item Swanson, \textit{supra} note 9, at 174.
\item See Henderson, \textit{supra} note 9. The benefits of mapping the human genome will not depend only on people's individual genotypes or raw genetic data. An understanding of phenotypes - the actual characteristics that genes produce - will often be just as important. You need to know not only that you have a certain gene but that your father had it too, and developed bowel cancer at 50. Unless donors' anonymity is lifted, it is hard to see how their descendants could get a hold of such information, which could prove critical to their health. \textit{Id.} at 2. "The likelihood of the availability in the not too distant future of health/genetic profiles through testing of individuals, e.g. 'DNA chips', will reduce the need for reliance on the reported health history of biological parents and relatives." \textit{Id.} See also Patrizio, \textit{supra} note 8, at 2038.
\item Swanson, \textit{supra} note 9, at 174.
\item Id.
\item Henderson, \textit{supra} note 9, at 1.
\item Ruth Landau, \textit{The Management of Genetic Origins: Secrecy and Openness in Donor Assisted Conception in Israel and Elsewhere}, 13 HUMAN REPRODUCTION 3269 (1998) (discussing various approaches of secrecy and openness). Genes greatly determine an individual's predisposition to illness. See Claudia Kalb, \textit{In Our Blood}, NEWSWEEK, Feb. 6, 2006, at 46. The Founder effect occurs when populations with genetic susceptibilities from small ancestral groups breed within their own community, thus creating a higher risk of passing the defective genes among the group. \textit{Id.} Examples include the Amish, who are more likely to inherit extra fingers or toes from a polydactyly condition, and Gaucher and Tay-Sachs diseases, which are more common in Ashkenazi Jews. \textit{Id.} Kalb also points out the importance of the presence of recessive genes, where the donor offspring could be unaffected, but his children would be susceptible. \textit{Id.} An example is an individual who inherits the Tay-Sachs condition, who remains unaffected but
prospects for future procreation. The role of genetics in procreation decisions is reflected in the fact that many individuals choose to undergo an insemination or adoption procedure to prevent the passing of known genetic disorders.

In the artificial insemination context, the donor child’s reliance on an abstract family and medical history provided by the donor is an insufficient gauge for determining future health. Although the donor’s family history should not be whose offspring would have a 25% chance of inheritance. Kalb, supra. See also Taylor, supra note 5. Regular checkups and dietary or lifestyle changes can be implemented with a proper understanding of one’s genetic heritage. Id. “There will be demands from children (and indeed from parents) to know their full genetic history if they develop a major health problem and it will become increasingly difficult deliberately to deny children such crucial information.” Id.

16 See Ginsberg, supra note 1, at 849-50. The child needs to know for purposes of future procreation whether or not the donor has passed a genetic disease. Id. See Landau, supra note 15, at 3269. “Secrecy and anonymity can also be a problem for donor offspring when they come to have children of their own. Without reliable knowledge of their paternity and maternity, they can make no prediction of the risk of transmitting a wide range of genetic disorders, particularly those recessive conditions which may be manifest only when a defective gene is passed from both parents.” Id. Consideration must be taken into account “whether it is good medical practice to set up a situation where a future patient . . . will not have access to half their genetic or family health history and that this is a state of affairs which will last throughout their lives and affect the genetic history of their children.” See A. McWhinnie, Gamete Donation and Anonymity: Should Offspring From Donated Gametes Continue to be Denied Knowledge of Their Origins and Antecedents? 16 HUMAN REPRODUCTION 807, 815 (May 2001). See also Kalb, supra note 15 (discussing types of recessive genes); see also Swanson, supra note 9, at 175-76 (discussing how knowledge of genetic history will help prevent passing defects to own children).

17 Ginsberg, supra note 1, at 827-28.

18 See Kristin E. Koehler, Artificial Insemination: In the Child’s Best Interest? 5 ALB. L.J. SCI. & TECH. 321, 330-31 (1996) (supporting donor offspring’s right to know donor information). Supporters of more access to donor information note that medical histories of donors are “superficial, incomplete, and extremely outdated.” Id. at 331. The author also cites the importance of accurate medical history in preventative and diagnostic treatment. Id.

It is sometimes claimed that a family history is simply genetic information in a different guise, and therefore that a genetic test result is no different than a known family history. Yet, family history is abstract knowledge that has been tainted by bad or failing memories, lack of accurate data about why someone has become ill or died, and by an absence of understanding about the pattern of disease in a family pedigree. In contrast, genetic test results can offer a high degree of specificity, both in terms of predicting the likelihood of disease in other family members and in terms of putting flesh on the bones of a suspicion that has heretofore been unconfirmed. Specific information bring with it a number of realities that can include a degree of “certainty” about future ill health or even the mode and manner of one’s own death. These realities can impact an individual’s self-perception in ways that family history cannot, for, with the latter, one has the comfort of having lived with an abstract threat that has always manifested to someone else.

Graeme T. Laurie, Challenging Medical-Legal Norms: The Role of Autonomy, Confidentiality, and Privacy in
The argument that has emerged to the forefront in support of granting donor offspring access to donor information is the donor child’s need for a complete genetic and medical history to make health decisions. Donor children have access to half of their genetic lineage; in essence, fifty percent of the family tree. The rising number of donor offspring, coupled with the increased importance of genetic science, will only add pressure to grant these individuals access to donor information. Naturally, with an increase in donors, the risk of passing a genetically-linked disorder will grow, adding to the immediate need for regulation in this area.

While doctors and patients have placed

Protecting Individual and Familial Group Rights in Genetic Information, 22 J. LEGAL MED. 1, 3-4 (2001) (distinguishing between family history information and specific genetic information).

Laurie, supra note 18, at 3-4. Specific knowledge of one’s own genetic constitution, especially when it is accompanied by knowledge of future ill health, requires individuals to reassess themselves and their position within a family unit and to look with fresh eyes upon their family history, which will have suddenly become very unfamiliar. Specificity of knowledge can deprive us of the ostrich’s “head in the sand,” which can sometimes serve as a valuable psychological coping mechanism. Id. at 4.

Josephine Johnston, Mum’s the Word: Donor Anonymity in Assisted Reproduction, 11 HEALTH L. REV. No.1, 51, 52-55, available at http://law.ualberta.ca/centres/hli/pdfs/hlr/v11_1/johnsonfrm.pdf. (last visited October 8, 2006) (discussing proposed Canadian legislation that addresses donor anonymity). In the past 20 years, the presumption in favor of secrecy of the donor has been challenged and replaced with calls for the donor child having information about their gamete donors. Id.

Laurie, supra note 18, at 3-4. See also McWhinnie, supra note 16, at 807-17. See also Shanley, supra note 5, at 267 (arguing anonymity would not be maintained if it was not significant).


Bauman, supra note 22, at 214.
more emphasis on family genetic history as a means of testing for and preventing
diseases, more extensive genetic screening is viewed as purely optional for parents
involved in insemination procedures. More incomplete and outdated donor medical
histories mean that donor children have to settle for incomplete or inaccurate
information. More extensive genetic testing would also benefit the donor in detecting
unknown or ignored genetic predisposition.

Finally, perhaps the strongest indication that a donor's genetic history is
important to the donor child is reflected by the budding efforts of donor children to
access donor information themselves. It may become impracticable to sustain donor
anonymity in the United States as genetic science and the population of donor offspring
continue to develop in tandem. Approximately 30,000 to 40,000 children are born
annually from artificial insemination, and the needs of the coming generations of donor
offspring ought to be addressed as the population continues to expand.

24 See Ginsberg, supra note 1, at 836. See Koehler, supra note 18, at 330-31.
25 Bauman, supra note 22, at 216-17. A donor child's knowledge of certain predispositions could
improve his chances for a cure through early detection. Id. The author argues that even a slim
chance that disclosure will help the donor child justifies access to the donor's genetic
information. Id. at 217.
26 Swanson, supra note 9, at 176.
27 See Amy Harmon, Concept of Family Evolves as Sperm Bank Children Find and Meet Siblings, N.Y.
times, November 20, 2005, available at 2005 WLNR 18781069 [hereinafter Concept of Family]
(analyzing use of internet in tracking down genetic relatives). The Donor Sibling Registry allows
parents and offspring to search for each other by donor number and sperm bank, as well as
provide contact information. Id. See Kalb, supra note 15, at 47. See Interview by Jonathan Mann,
Deborah Feyerick with Dr. Dorothy Mitchell-Lee, Fertility Specialists, Reproductive Biology Associates. CNN
INTERNATIONAL: Insight, Anonymity for Sperm Donors, January 2, 2006, Transcript available at 2006
WLNR 77624 [hereinafter Mann]. Submitting genetic information for analysis could become as
routine as a physical. Ian Sample, Teenager Finds Sperm Donor Dad on Internet: Boy Uses Genealogy Site
to Find Genetic Father Result May Spell End for Donor Anonymity in US, GUARDIAN (UK), November
3, 2005, available at 2005 WLNR 17726349 (discussing fifteen-year-old boy used swab from cheek
to match Y-chromosome with donor father on online genetic database). FamilyTreeDNA.com
has a database of 45,000 Y-chromosomes and The Sorensem Molecular Genealogy Foundation
promises a database of 500,000 people with lineage going back four generations. John Von
Radovitz, Anonymity Fears After Boy Traces Donor Dad Online, WESTERN MAIL (UK), Nov. 3, 2005,
available at 2005 WLNR 17838344 (discussing boy who found father online via genetic database).
28 Ginsberg, supra note 1, at 850. Full disclosure of all medical information is "one of the most
important aspects of a regulated sperm donor system." Id. The argument that advances in
 genetic technology is a valid reason for disclosure of a donor's genetic information is off base. Id.
Advanced genetic screening in the fertility industry will correlate into less risk for donor
offspring. Id.
29 See Bauman, supra note 22, at 196. Approximately 30,000 children are born in America
annually from artificial insemination by donor. Id. However, the nature of the unregulated
II: The Dearth of Artificial Insemination Law in the United States

Anonymous sperm donation, for a wealth of reasons, has been the de facto practice in the United States for the vast majority of artificial insemination's history. The current environment in the United States places the donor offspring in the unfortunate position of having no control or input over the consequences resulting from the process that created them. In the lawmaking context, the time has come to seriously consider the donor offspring's interests in accessing this information. The astoundingly minimal presence of state or federal regulation of the sperm donor industry has given way to a patchwork of non-binding professional guidelines and individual clinical discretion.

industry makes it clear that clinics are unaware of the number of such children born or their respective location. See Concept of Family, supra note 27. See Harmon, supra note 22 (noting rough industry estimates put number of children born from artificial insemination at 40,000 annually in United States).


[Nondisclosure] is seen as a way to ensure that the non-genetic parent be perceived as equally connected to the child, to ensure that the child grows as a strong bond with that parent as with the genetic parent, to maintain the appearance of a 'normal' family, to avoid distressing the child with the truth of his/her origin, and to allow the nongenetic parent's infertility - a condition that usually carries a negative stigma with it - to remain unknown to others. See McGee, supra note 22, at 2034. Doctors traditionally have supported anonymity because it freed the donor of legal, physical, and moral responsibility to the child. See Shanley, supra note 5, at 266. Recipient couples could also remain impossible to differentiate from parents. Id. The desire to sustain a continuous supply of donors is a main argument "in favor of the status quo." See Taylor, supra note 5.

31 Johnston, supra note 20, at 52. "[D]onor offspring have no control over the secrecy about either the mode of their conception or the identity of their gamete donor(s). They are, in effect, at the mercy of their birth parents, their gamete donors, and the [artificial insemination] system when it comes to knowing about their genetic heritage." Id.

32 Id.

33 See Helen M. Alvare, The Case for Regulating Collaborative Reproduction: A Children's Rights Perspective,
A. A Self-Regulated Industry

The government's apparent lack of interest in the industry has allowed individual clinics to impose their own regulations for screening standards, the number of donations per donor, recipient age limits and price. Only a handful of private and government studies have actually analyzed the artificial insemination industry, and these studies have exposed difficulties in the areas of genetic screening and medical record keeping.

40 HARV. J. ON LEGIS. 1, 29 (2003) (discussing possible reasons for absence of significant legislation for collaborative reproduction). "The federal foray into regulation has left the clinics largely unfettered, with the exception of a requirement to report accurate success rates." 40 Id. See also Chung, supra note 30, at 263, 267 (recognizing that four out of five largest sperm banks in the world are based in the United States and rely on voluntary guidelines). The FDA has passed regulations requiring screening of cell and tissue donors for "risk factors for, and clinical evidence of, relevant communicable disease agents and diseases." 40 Id. at 277 (quoting Eligibility Determination for Donors of Human Cells, Tissues, and Cellular and Tissue-Based Products, 69 Fed. Reg., 29,789 (proposed May 25, 2004)). Gamete donation should be conducted "in ways to promote the best interests of offspring in learning the facts of their conception while respecting the privacy interests of donors and recipient parents." 40 See Informing Offspring of Their Conception by Gamete Donation: Report by Ethics Committee of the American Society for Reproductive Medicine, 81 FERTILITY AND STERILITY no.3, 527, at 527-31 (March 2004) [hereinafter Ethics Committee] (providing suggestions and guidelines for assisted reproduction industry). The Committee suggested that it "may benefit children by protecting their interests in knowing their genetic heritage and in securing accurate information about potential health problems." 40 Id. at 528. The report also recognized the impracticability of guaranteeing donor privacy due to possible new laws or the need to open medical records in certain circumstances. 40 Id. The American Medical Association calls for permanent files with donor's non-identifying and identifying health and genetic screening information. 40 Id. at 529-30.

34 Alvare, supra note 33, at 31. No state or federal law limits the number of donations per donor, though some clinics do so voluntarily. 40 Id. Laws do not impose age or health qualifications on recipients, regulate advertisement, limit the price for donations, or constrain the grounds on which recipients can choose donors. 40 Id. See Chung, supra note 30, at 278.

35 See Ginsberg, supra note 1, at 830 citing Martin Curie-Cohen, et al. Current Practice of Artificial Insemination by Donor in the United States, 300 NEW ENG. J. MED. 585, 588 (1979). Martin Curie-Cohen's study is dated 1979, but the author claims it is still telling of the industry today. 40 Id. Ginsberg points out that the study's findings indicate physicians tend not to screen for genetic diseases because of the "exceptional donor pool" made up of medical students or residents. 40 Id. In the study, 96% of responding physicians asked donors if they had a history of genetic disease, but rarely asked for information beyond the superficial questioning regarding known defects in the donor's family. 40 Id. The recommendation of the study was to establish uniform genetic traits that should be screened and increased training and education about genetic disorders. 40 See Ginsberg, supra note 1, at 830 (discussing Congressionally-commissioned study of artificial reproduction industry). The 1988 study, commissioned by the Office of Technology Assessment, found broad inconsistencies among those in the industry to uniformly and consistently screen for
The voluntary guidelines implemented by organizations such as the American Fertility Society and the American Association of Tissue Banks do not carry the binding force that strict, mandatory guidelines would impose. For example, The American Fertility Society recommends genetic screening for high risk donors and recommends access to a donor's non-identifying genetic information upon the request of the donor child. Additionally, The Ethics Committee of the American Society for Reproductive Medicine has advised sperm clinics to take steps in anticipation that donor children will seek information about their donors in the future. The problem with said guidelines and recommendations lie in their voluntary nature and inability to create uniformity within the industry.

Granted, fertility clinics test for genetic defects in donor samples despite the absence of mandatory national screening standards. Clinics screen for HIV and STDs, genetic disorders. Id. While most banks tended to comply with professional guidelines, the inconsistencies among sperm banks nationally still exists. Id. The study did find, however, that most sperm banks and physicians favor the implementation of national standards for donor screening. Id. "Several surveys have found considerable inadequacies and inconsistencies in fertility clinics' screening of donor materials." See Alvare, supra note 33, at 27. See Ginsberg, supra note 1 (analyzing inadequacies in industry regulation and suggesting industry is "ripe for reform").

36 See Andrews, supra note 9, at 136, citing The Ethics Committee of the American Fertility Society, Ethical Considerations of the New Reproductive Technologies, 46 FERTILITY AND STERILITY 1s, 83s-45s (Supp. 1 1986). American Fertility Society Guidelines recommend freezing semen for 180 days to allow retesting for the HIV virus. See Eggen, supra note 30, at 672. Recommended testing also includes screening for genetically transmitted diseases and common sexually transmitted diseases. Id. The American Fertility Society ("AFS") established guidelines in 1990 to address inadequate donor screening. See Ginsberg, supra note 1, at 835. Ginsberg's main contention with the AFS's guidelines is that compliance with the recommendations is voluntary. Id. The AFS's Ethics Committee recommends medical follow-up visits for donors, while preserving the anonymity of the donor. See Ginsberg, supra note 1, at 835 (listing specific genetic disorders the 1990 AFS Guidelines suggest screening for). The American Association of Tissue Banks recommends screening donors for certain medical conditions that "present contraindications for donation." Eggen, supra note 30, at 673. Guidelines implemented by professional medical organizations "lack the teeth of a penalty for noncompliance." Id. at 668. New issues arise in rapidly progressive technologies that cannot be cured by self-regulation. Id.

37 See Andrews, supra note 9, at 136. No provisions exist in the guidelines for updating donor information. Id.

38 Ethics Committee, supra note 33, at 529. The Committee suggests the implementation of programs that "consider sharing with inquiring offspring who have reached 18 years of age the information that would be available to the recipient parents, such as details about the gamete donation process and non-identifying information on file about the donor." Id.

39 See infra notes 47-51 (discussing current regulation).

40 Hodgson, supra note 6, at 359-60 (arguing that risk of defects could be significantly reduced
as required by the Food and Drug Administration, conduct genetic tests for disorders such as cystic fibrosis and Tay-Sachs disease, and examine the medical histories of their donors. However, a CDC report from 1999 found that 59% of labs reported testing sperm for syphilis; 50% tested for Hepatitis B; 44% tested for HIV I; 29% tested for HIV II; 41% tested for Hepatitis C; and 11% to 27% tested for diseases like chlamydia, gonorrhea, herpes, and rubella.4

Despite the existence of professional guidelines that recommend the preservation of records, the fertility industry has historically fostered a culture marred by inadequacy of record keeping, even to the point of condoning the destruction of a donor's medical records.43 Physicians in the fertility industry have traditionally contributed to the culture of donor anonymity by keeping poor records, therefore making it difficult to link sperm donors to their recipients.44 The unwillingness of health professionals to maintain proper genetic records appears to stand in sharp contrast with the general trend of doctors to rigorously record and preserve all medical through more extensive screening, but the cost to clinics discourages such efforts). See also David Plotz, Who’s Your Daddy? Sperm Banks, INTERNATIONAL HERALD TRIBUNE, May 20, 2005, at 1 (claiming clinics compete “vigorously” with each other to satisfy customers’ insistence on health and safety). Plotz offers an optimistic view on the sperm clinic’s efforts to screen donors and calls government efforts to regulate sperm safety a “late and largely unnecessary obsession.” Id. Plotz also points out that California Cryobank, as the leading U.S. sperm collector, boasts that less than 5% of donor applicants pass their rigorous screening process. Id. Note that this sperm collector is the same Cryobank company that Brittany Johnson used when she contracted kidney disease from an anonymous donor. See infra note 74. See also Amy Shelf, A Need to Know Basis: Record Keeping, Information Access, and the Uniform Status of Children of Assisted Conception Act, 51 HASTINGS L.J. 1047, 1062-63 (2000) (describing inconsistency in genetic screening between sperm and ovum donors). Shelf describes the ovum donations as more likely to be subject to rigorous testing and more in-depth medical history analysis. Id. at 1063. She attributes this to the “plurality of potential side-effects from fertility drugs.” Id.

41 Plotz, supra note 40, at 2. The FDA requires screening for HIV and several other communicable diseases. See Harmon, supra note 22.

42 Alvare, supra note 33, at 10-11, n. 54.

43 Koehler, supra note 18, at 335. Koehler describes the classic scenario as involving the youthful male medical student walking into the sperm bank with the understanding that his identity will forever remain anonymous. Id. at 334-35. The author states that the practicing physician will typically advise the donee couple to keep the procedure a secret. Id. at 335. The physician may also informally influence the maintenance of anonymity over the recipient couple and the donor. Id. See also Eggen, supra note 30, at 703.

44 See Swanson, supra note 9, at 154-55 citing Martin Currie-Cohen et al., Current Practices of Artificial Insemination by Donor in the United States, 300 NEW ENG. J. MED. 585, 589 (1979). About 36.9% of doctors kept records of children born from artificial insemination and 30.4% kept donor records. Id.
documentation of their patients. Finally, it must be noted that financial expenses do discourage clinics or insemination recipients from conducting more in-depth genetic testing.

B. State and Federal Government Inaction

The government has been slow to follow the steps that professional medical organizations have taken to attempt to regulate the artificial insemination industry. Federal regulation of assisted reproduction has been at best problematic, leaving a tarnished "legacy of inaction and inattention." No statutory attention has been focused on the health of the donor or a donor offspring's rights to obtain information about the donor. Simply put, donor offspring lack a legal right to know information about their donor because courts and legislatures have not addressed whether such a right exists.

45 Swanson, supra note 9, at 155.
46 Hodgson, supra note 6, at 360 (estimating extra $800-$900 to pay for additional testing is small compared to total cost of raising child with genetic defect).
47 Eggen, supra note 30, at 667. Government action has only focused on narrow, ad hoc problems as they arise rather than addressing broader issues in the assisted reproduction industry. Id.
48 Eggen, supra note 30, at 687.
50 The international trend is to base the claim on identity rights or ethical grounds. 

See Chung, supra note 30, at 288. Arguments in favor of openness are generally made on ethical grounds, i.e. the child has a right to know where he/she came from, but in other countries, a clear legal right exists to support openness arguments. Id. The privacy rights of the donor are constantly invoked to protect anonymity, but little regard is given to the offspring's privacy when others control important genetic information. See Laura Shanner, Viewpoint: Legal Challenges to Donor Anonymity, 11 HEALTH L. REV. no.3, 25, 25-27, available at http://www.law.ualberta.ca/centres/hli/pdfs/hlr/v11_3/06shannerfrm.pdf. (last visited September 30, 2006)
The state laws that address assisted reproduction tend to focus on domestic relations issues like paternity and legal parentage. Most state statutes require screening for the obvious dangers, such as HIV, but do not adequately address the duty of sperm banks to guarantee that offspring are free from genetic diseases passed by the donor, resulting in an industry that is at liberty to set its own rules regarding most aspects of the AI process. Several states do permit disclosure of donor information upon a showing (analyzing legal principles and donor anonymity in Canada). The right to control one's own body is a fundamental human right. See also Lisa Shields, Consistency and Privacy: Do These Legal Principles Mandate Gamete Donor Anonymity? 12 HEALTH L. REV. no.1, 39, 41 (2004), available at http://www.law.ualberta.ca/centres/hl/pdf/hl/v12_1/07_Shields.pdf. (last visited September 30, 2006) (discussing Canadian legislation concerning artificial insemination by donor). It is the right to anonymity that has been a constructed right. Id. Shields goes on to say that control over one's body is more fundamental than donor anonymity and should be codified into law. Id. Efforts have also been made to fashion artificial reproduction laws after adoption laws. See Chestney, supra note 49, at 366, 375. The situation of the donor child and the adopted child is similar, i.e. absence of one or more genetic parent, but there are still significant differences. Id. at 375. Nevertheless, as openness in adoption continues to grow, the same should be expected in the artificial reproduction sphere. Id. at 376. From the perspective of the child, there are similarities between adoption and artificial insemination, i.e. the presence of another genetic parent in addition to the custodial parent(s). Id. at 366. See Lucy Frith, Beneath the Rhetoric: The Role of Rights in the Practice of Non-Anonymous Gamete Donation, 15 BIOETHICS n.5/6, 473, 479-80 (2001) [hereinafter Beneath the Rhetorich] (discussing international trends, various ‘rights’ arguments, and policy considerations). But see Shields, supra note 50, at 40. The author warns of a danger to construct gamete donor laws after adoption laws, while recognizing the law is moving toward openness and keeping current practice in place would go against legal consistency. Id. Gamete donor laws should begin to recognize growing importance of openness. Id.

Eggen, supra note 30, at 682-83. The primary focus of most artificial insemination by donor statutes is the legitimization of offspring by providing that the husband of the inseminated woman is considered the legal parent of any offspring produced as a result of the insemination, provided that the husband consented to the insemination procedure. While the thrust of most of these statutes involves the domestic relations interests of the state, some statutes do attempt to regulate the procedure of artificial insemination by donor. Id.

Ginsberg, supra note 1, at 836. Ginsberg cites statutes in Ohio that mandate genetic testing for non-spousal donors, and statutes in Delaware and Illinois that require banks to register with the State Health Department. Id. The 1987 survey found that 26% of insemination practitioners would accept sperm from a donor with a family history of Huntington’s disease. See Megan D. McIntyre, The Potential for Products Liability Actions When Artificial Insemination by an Anonymous Donor Produces Children With Genetic Defects, 98 DICK. L. REV. 519, 523 (1994) (discussing congressionally sanctioned report of assisted reproductive industry). The offspring of an individual with Huntington’s disease has a 50% chance of contracting the condition. Id. The study found that 94.7% of practitioners would reject a donor with Tay-Sachs disease, but less than 1% of those practitioners actually tested donors for Tay-Sachs. McIntyre, supra, at 523 citing Martin Curie-
of "good cause," such as an adequate showing of medical need or psychological trauma. The "good cause" standard was codified in the Uniform Parentage Act and has been adopted by at least eighteen states. Yet, despite the reality that over a dozen states permit the disclosure of donor information for such purposes, many fertility clinics routinely destroy documentation once the insemination procedure is complete. Only a handful of states have taken the simple step of enacting laws which require the preservation of any records relating to the insemination process, with a notable few specifically requiring the preservation of donor records.

C. Limited Case Law

Very few cases have directly addressed the rights of donor children; the vast majority of cases deal with issues of paternity, intestate succession, and other issues that do not involve donor children's rights. The most significant case addressing an


Andrews, supra note 9, at 137-38. See also Bauman, supra note 22, at 198 (citing Uniform Parentage Act's "good cause" exception that allows for disclosure of donor's identity). See Dollens, supra note 9, at 216-17. At least eighteen states have codified the good cause exception; courts tend to weigh the interests of the parties in an effort to determine if good cause exists. Id. See also Shelf, supra note 40, at 1071. The author offers two alternatives to the Uniform Parentage Act. Id. The first is an absolute right to receive detailed identifying information about the donor, including names, social security number, driver's license number, and the last known address. Id. The second is codification of the "good cause" standard and access to the identifying information. Id. The author suggests destruction of one's own medical records or the discovery of a disease is sufficient for good cause. Id.

See Dollens, supra note 9, at 216-17.

See Bauman, supra note 22, at 199. It is "general practice" to destroy records in an effort to help maintain anonymity of donor and recipient couples. Id. This practice is encouraged by a deep belief in the thoroughness of the genetic screening process. Id.

Alvare, supra note 33, at 31. Fourteen states have laws concerning the preservation of records relating to artificial insemination. Id. "These laws do not always guarantee that the rearing parents, the donors, or the children will be able to identify important medical history or one another in the future. For the most part such statutes only regulate record keeping about husband's consent to the [artificial insemination] procedures, though a noticeable few do require retention of some donor information." Id.

Penick, Give the Child a Legal Father: A Plea for Iowa to Adopt a Statute Regulating Artificial Insemination by Anonymous Donor, 83 IOWA L. REV. 633, 638 (1998) (discussing the need to regulate artificial insemination industry). The paternity of the child conceived from the procedure is the most commonly litigated issue. Id. Shelf argues that the Uniform Status of Children of Assisted Conception Act of 1989, while excluding donors from parenthood responsibilities, fails to adequately improve existing state law or address offspring's interests. Shelf, supra note 40 at 1057-59. Shelf also points to the inadequacy of tort claims on this issue...
attempt to pierce the donor's anonymity was decided in 2000, and was expected to have a great impact on the evolving legal issues in this area. The plaintiffs in the Johnson case successfully convinced a court to disclose the identity of a donor who had passed a genetic kidney disease to the child. To date, though, Johnson has not been precedent-setting, and it enjoys little state or federal significance. Because they are decided too narrowly. Id. at 1048-49, 1067. The Uniform Parentage Act does not address such issues as keeping records of the genetic information of donors, nor does it decide when donees should be granted access to such information. Id. at 1448-49. The act creates no legal obligation to maintain records that preserve identifying and non-identifying information of the donor, and gives no statutory treatment of a donee's access to this information. Id. See also Swanson, supra note 9, at 156-62 (discussing the development of artificial insemination issues at common law).

58 Johnson v. Superior Court of Los Angeles County, 95 Cal.Rptr.2d 865, 875, 877 (Cal. Ct. App. 2000) (holding that in an action against an artificial insemination clinic, the state had a compelling interest in requiring a party to comply with the discovery request to disclose the sperm donor's identity). See Dollens, supra note 9, at 229-36. In Johnson, Donor 276 disclosed his individual and familial medical history to the sperm bank, including the possibility that autosomal dominant polycystic kidney disease was present in Donor 276's family. Id. at 867-868. The Johnson's signed a confidentiality agreement that provided for the donor to “forever remain anonymous” and reserved the right of the sperm bank to “destroy all information and records” pertaining to Donor 276's identity. Id. Despite assurances from the bank that the sperm was healthy, the child was diagnosed six years later with the very disease that Donor 276 was at risk for. Id. Bauman concludes that the Johnson court properly found that sustaining the donor's anonymity was outweighed by the state's interest in protecting the health of the donor child. See also Bauman, supra note 22, at 218. She goes on to predict that the decision will compel sperm banks to scrutinize donors more rigorously. Id. Finally, in noting society's acknowledgment of the importance of genetics in individual health decisions, Bauman questions the industry's commitment to sustaining anonymous donation. Id. See also Bauman, supra note 22, at 216. The sperm donor in the Johnson case, Donor 276, had donated 320 sperm specimens to the sperm bank. See Johnson, 95 Cal.Rptr.2d at 877. While unlikely, Bauman suggests that it is possible that Donor 276 fathered that many children. See Bauman, supra note 22, at 216. In Johnson, the sperm bank informed Donor 276 that he no longer could donate due to his genetic disease. Id. Bauman argues that the sperm bank should also be obligated to tell Donor 276 that his medical information might have to be disclosed to any donee who contracts the disease. Bauman, supra note 22, at 216.

59 See supra note 58.

60 See Bauman, supra note 22, at 214. Johnson will “serve as a reminder that this era of technological advances means priority must still be placed on the health and safety of the children.” Id. See also Dollens, supra note 9, at 217, 234-35. Johnson has “tipped the scales in favor of the offspring.” Id. Dollens predicts that the anonymity of the donor will not be protected by a court if it finds the interests of the donor offspring are more compelling than the interest of the donor in maintaining his or her anonymity. Id. Dollens predicts that less compelling interests than preserving the discovery process may be enough to justify disclosure and the case will lead to a reduction in the transfer of genetic defects by forcing more donors to be screened for defects. Id. Finally, the author credits Johnson as an important step in holding
D. Where We Are Today

Commentators and scholars have attributed the dearth of United States regulation in this area to anything from out of court settlements aimed at maintaining the industry’s integrity, to the difficulty of creating a set of durable rules for a complex industry in constant flux. Significantly, much of the dialogue in favor of ending donor anonymity has ignored the need for genetic information and has focused on the personal and psychological issues of the donor child. As stated above, donor offspring may be

sperm banks accountable for negligence. Dollens, supra note 9, at 217, 227-28, 324-25. The California “right to privacy” that the Johnson court interpreted is broader and more protective than the Supreme Court’s implied federal right. Id. The author attributes the court’s analysis of California’s right to privacy as a signal that similar decisions are likely to occur in other states. Id. The Johnson case has set a relatively low bar for future determinations regarding intrusions into donor privacy. Jennifer Foster & Barbara Slater, Privacy and Assisted Human Reproduction: A Discussion Paper, HEATH L. REV. 11 n.1, at 56, 59, available at http://www.law.ualberta.ca/centres/hli/pdfs/hlr/v11_1/fosterfrm.pdf. (last visited November 29, 2006). (discussing privacy issues in Canada). Johnson may open the door to a “far less anonymous future for sperm donors.” See Jessica Reaves, So Much For That No-Strings-Attached Stop at the Sperm Bank, TIME MAGAZINE, August 24, 2000, available at http://time.com/time/nation/article/-0,8599,53347,00.html. (last visited November 29, 2006).

61 See Alvare, supra note 33, at 24 (referring to the non-existence of legislation as the “dearth” and noting that U.S. laws do not address anonymity). Id. at 32. See Ginsberg, supra note 1, at 828, 836. Hodgson suggests it is more likely that the lack of legislation arising from problems with artificial insemination is attributable to out of court settlements that are designed to remain quiet and under the public’s radar. Hodgson, supra note 6, at 357-60. The Skolnick case against a sperm bank and attending physician ended in a no-fault settlement. Id. The “precise issue” of record keeping in AI procedures has not been litigated. See also Shelf, supra note 40, at 1067-68. Case law dealing with sperm banks and genetic testing tend to be tort cases that were narrowly decided. Id. The tort remedy is inadequate for plaintiffs, while the threat of such suits does not sufficiently compel the industry to conduct genetic testing and keep adequate records. Id.

62 See Naomi Cahn & Jana Singer, Adoption, Identity, and the Constitution: The Case for Opening Closed Records, 2 U. PA. J. CONST. L. 150, 185-86 (1999) (discussing that donor identifying information mostly aids in the personal and emotional development of offspring). See Lucy Frith, Genetic Donation and Anonymity: The Ethical and Legal Debate, HUMAN REPRODUCTION, 16 n.5, 818, 819-824 (2001) [hereinafter Ethical and Legal Debate] (discussing the arguments for and against anonymity in England). The two most common arguments for abandoning anonymity are that it is essential to human well-being and the individual has a right to know the truth about his or her origins. Id. See Johnston, supra note 20, at 52-55. Anonymity hinders important rights, including one’s right to know one’s origins, one’s right to identify with genetic relatives, one’s right to form an identity with certain information, and one’s right to satisfy their own curiosity. Id. Johnston argues that the real controversy revolves around these moral issues. Id. “The importance of knowing one’s genetic heritage for health reasons, particularly in light of the growing focus on genetic causes of disease, is less often contested than its relevance and importance in terms of social and identity issues.” Id.
forced to rely on an incomplete or inaccurate medical history of the donor, which might seriously undermine the offspring’s capacity to make potentially vital healthcare and lifestyle choices. Some have argued that the industry benefits from anonymity by masking accountability – but this assertion ignores the resulting inability for donor offspring to obtain critical genetic and medical information.

A major current problem with anonymity is that there is no way of knowing exactly how many children are born as a result of one particular person’s sperm donation. The sample from the more appealing donors will likely be used to inseminate a greater number of offspring. Thus, the number of donees potentially affected by the undetected genetic disorder of one donor is quickly compounded. Even in countries that restrict the number of children one sperm donor can produce, the number of children who can be born from one donor is as high as twenty-five or more. There is no incentive for sperm banks to limit the sales of their most popular donors. Since the bank is making more money on a particular donor’s sample, it may be less likely to spend money intensively screening that sample; the bank will hesitate too before looking for something that would render the sample incapable of transfer.

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64 Harmon, supra note 22, at 1. The Harmon article notes that there are no guarantees that the donor is the person who the clinic says he is. Id. Harmon quotes Hilary Hanafin, a Los Angeles psychologist specializing in counseling infertile couples, who says, “Frankly I think it’s just easier for the industry to do it anonymously. If you’re in total control of the information, it’s more efficient and less work.” Id.

65 See Chung, supra note 30, at 282. A survey conducted in 1977 found that fertility doctors in the United States admitted they used the same donor repeatedly, sometimes fifteen or more times. Id. Some donors deposit samples several times a week over extended periods of time, making it possible for donors to be responsible for the births of dozens of children. Id.

66 Shelf, supra note 40, at 1065. Donors with the best physical characteristics or intellect are the most sought after by potential donees and customers. Id.

67 Chung, supra note 30, at 275-76. Denmark limits 25 live births per donor, England limits ten, and France limits five. Id.

68 Harmon, supra note 22. Without verification of the number of children one donor could have, the number of offspring could be in the hundreds. Id.

69 See Hodgson, supra note 6, at 363 citing Kathryn Venturatos Lorio, Alternative Means of Reproduction: Virgin Territory for Legislation, 44 L.A. L. REV. 1641, 1651, n. 48 (1984). The common use of medical students in the procedure alleviates pressure to perform extensive genetic testing because of the assumption that medical students “realize the importance of certain family genetic details and know what information is crucial to the safety of their sperm . . . the process spares the expense of performing a series of expensive tests on every donor.” Id. See Hodgson, supra
Furthermore, suppose an insemination recipient learned that he or she contracted a disease or disorder and found strong evidence that the disorder was a result of the genetic contribution of the sperm donor.\(^7\) If inadequate records are kept, a sperm bank may be hindered in its ability to notify the donors who may be at risk, and may not be able to immediately discontinue the use of that at risk donor’s sperm.\(^7\)

**III: Regulatory Scheme**

The assisted reproduction industry has proven that it is incapable of tackling the issues of donor anonymity and access to genetic information through self-regulation.\(^7\) Strides must be taken now to contend with a future in which a significantly large number of children born from assisted reproductive technologies will ask questions about their

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\(^7\) Swanson, *supra* note 9, at 176.

\(^7\) Id.

\(^7\) The lack of regulation in the United States does not mirror the growing international trend toward openness and disclosure. Chung, *supra* note 30, at 274. International trends may be reflecting the attitudes of a generation of insemination-created children who are looking for more disclosure of relevant donor information. *Id.* It is becoming increasingly common internationally for donor anonymity to be regulated by law. *Id.* European trends “penetrate anonymity” by allowing the donor offspring access to information about the donor. *Id.* In The Netherlands, donor children can legally obtain the donor’s identity upon reaching age sixteen, and sperm clinics are barred from accepting anonymous donations. Chung, *supra* note 30, at 274. In England, donor children who reach age eighteen can trace information about those who donated after April 1, 2005. *Id.* In 1984, Sweden was the first country to completely abolish donor anonymity. See Ethical and Legal Debate, *supra* note 62, at 819. In 1992, Switzerland added language to its constitution which granted donor children access to identifying information about the donor. *Id.* A 1994 Ministerial Committee in New Zealand recommended that donors should not remain anonymous, and clinics now primarily accept non-anonymous donations. *Id.* Though relatively less regulatory, Iceland passed a law in 1996 giving donors the choice between anonymity and disclosure of identifying information. Ethical and Legal Debate, *supra* note 62, at 819. The Netherlands passed a law in 2000 obliging all sperm clinics to recruit non-anonymous donations. *Id.* Anonymity for semen donors has been abolished in Austria, Germany, and Switzerland. Landau, *supra* note 15, at 3270. In Sweden, full information about the donor is available to children once they reach the age of eighteen. *Id.* England has taken steps to grant access to genetic information, but not the identity of the donor. *Id.*
genetic heritage. State and federal governments must set up a system where genetic information is disclosed to the offspring, while the fundamental anonymity of the donor is preserved. Some may argue against the government becoming involved in this sensitive area, but government has a strong interest in promoting the health of the donor offspring and in preventing the spread of communicable and genetic diseases.

Many commentators advocate access to information about the donor’s medical and genetic history in times of medical necessity. Others specifically categorically dismiss

Ginsberg, supra note 1, at 836-39, 847-50 (claiming government regulation, federal and professional guidelines, and adjudication have not responded adequately).

See Ginsberg, supra note 1, at 839-50 (supporting federal regulation of assisted reproduction industry). Ginsberg proposes a comprehensive, four point proposal for regulation of the nation’s sperm donor industry: federal regulation of a national sperm donor system through the Food and Drug Administration (“FDA”); a national system of sperm donor centers; heightened standards for genetic screening; and relaxed standard for the disclosure of non-identifying donor information. Id. The author discusses the derivation of the federal government’s power to regulate a national sperm donor system, including regulation of interstate public health via the Commerce Clause. Id. at 839-40. The proposed national system of sperm donor centers would consolidate sperm samples into “official” centers monitored by the FDA. Id. at 841-42. Ginsberg suggests that a couple seeking a procedure would still be able to see a private physician for the procedure, but that the semen sample would come from an FDA monitored center. Ginsberg, supra note 1, at 841-42. This process would maintain the convenience of the procedure, and provide uniform, national screening for the semen samples. Id. at 842. The author further suggests separating donor centers according to genetic diseases that the recipient might be at risk for. Id. at 844. The theory behind this is that certain diseases are a risk only if present in the donor and the recipient, such as recessive genes, and the system would match donors with recipients that lack the corresponding recessive gene. Id. at 844-46. Aside from these proposals, Ginsberg advocates more rigorous testing of the donor's medical and family history. Ginsberg, supra note 1, at 845-46. The author's final point concedes that even the most in-depth testing will not eliminate the risk of passing a genetic disease from donor to offspring. Id. at 847. Therefore, Ginsberg advocates for more access to information among all parties, better record keeping, and disclosure of non-identifying information when deemed appropriate by the proper authorities. Id. A national registry should be created and barriers to donor information should be reduced. See Plotz, supra note 40, at A7. Voluntary standards should be replaced with national mandatory standards for donor screening. See also McIntyre, supra note 52, at 546. The author acknowledges the practical problems of setting up a complicated and comprehensive system from scratch, but promulgates the imposition of minimum standards. Id at 546-47. These standards will help physicians and the courts, thereby reducing the risk of passing genetic disorders to AI offspring. Id. at 547.

Eggen, supra note 30, at 701. The state should be involved in regulation since it would typically have an interest in preventing the spread of infectious diseases, encourage the practice of preventative medicine, and promoting accurate family histories. See Swanson, supra note 9, at 184.

allowing access to identifying information, such as the name and physical characteristics of the donor.77 This author does not advocate disclosure of a donor’s identifying information, per se, but instead supports the right of the donor child to access his donor’s non-identifying genetic and medical information.78

77 Chung, supra note 30, at 288-89. The justification [behind calls for anti-anonymity laws] appears to be based on ethical grounds and perhaps assumptions about the psychological frailty of children who never learn their donor’s name. While well-intentioned, laws that require donors to reveal not just their medical history but also the donor’s name have deterred donors who wish to remain anonymous…. Anti-anonymity laws hinder open reproductive markets and lack a solid justification. First, children do not have a fundamental right to know the exact name of the person from whom their genetic material originated ... Nor do gamete recipients have a right to know the name or identifying information about the donor. The interests of recipients and [artificially] conceived children can be just as easily met by acquiring detailed medical histories.... Id.

78 Swanson, supra note 9, at 187. The potential medical necessity for non-identifying donor information justifies disclosure of the donor’s medical and genetic profile. Id. Swanson supports mandatory record keeping, bifurcated levels of information, unrestricted access for donor children and limited access by the recipient couple, physician and donor. Id. at 185-90 (proposing recommendations for regulation of fertility industry). “Upon reaching the age of majority, someone created with transferred genetic material should have the right to learn, although not be compelled to learn, the identity of the provider, not simply medical facts or DNA profile.” Shanley, supra note 5, at 268.
A. Genetic Registries

In order to allow access to medical and genetic information of gamete donors over time, efforts must be made now to preserve genetic information safely and anonymously so as not to completely scare off donors with the prospect that their information can be manipulated or exploited by third parties. Preserving donor information in a government or privately-run registry is clearly an issue for discussion in the drafting of any legislation on the matter. In Victoria, Australia, for example, the government created the Infertility Treatment Authority. The Authority oversees and collects information on donors and recipients, which the donor offspring can access at age 18. Registries should keep genetic information available for an amount of time that allows donor offspring the ability to access donor information decades after the insemination procedure. Access to the donor’s genetic history will give the donor child the ability to avoid a false assumption that the genetic history of his custodial parents is the same as his own.

79 J.V. McHale, Regulating Genetic Databases: Some Legal and Ethical Issues, 12 MED. L. REV. 70, 75 (2004) (discussing controversies surrounding clinical genetic databases). “Part of the controversy [of genetic databases] relates to the fact that they involve the use and storage of an individual’s genetic material and genetic information . . . use and storage [of] which may be undertaken over a long period of time. This may be regarded as particularly sensitive information and material which individuals . . . may not be at all happy about being seen to give up control of.” Id. Publicly operated storage facilities would raise privacy concerns, but would reduce the burden on the clinics themselves to store and maintain the records. See Shelf, supra note 40, at 1071 (supporting state run warehouses for storage of medical records).

80 McWhinnie, supra note 16, at 815. See also Adamson, supra note 76. A national donor registry should be created to allow tracking of the donor if a medical need arises. Id. See also Ginsberg, supra note 1, at 838-50. The author favors registering genetic databases with the Federal Drug Administration, the purpose of which would be for offspring to trace their genetic origins. Id. Ginsberg calls for an improvement in the maintenance of donor records in fertility clinics and a release of FDA-approved non-identifying information. Id. at 847.

81 Beneath the Rhetoric, supra note 50, at 476.

82 Id.


84 McGee, supra note 22, at 2034. False assumptions of one’s own genetic history may lead to missed opportunities to take advantage of preventative steps and important medical care. Id. at 2035. Donor children may unknowingly ignore certain tests or forego treatment believing they are not at risk. Id.
B. The Need to Update Information

Currently, few provisions exist for updating a donor's health information beyond what is given at the time of donation. Since genetic disorders are constantly being discovered, a mechanism should be imposed to test samples over time for new genetically-linked diseases and disorders. Provisions must also be made to update the health information of the donor over time, especially in cases involving donors with a family history of a late-onset condition that may not be present at the time of the donation. Specific parameters that limit tests to known genetic disorders should also be implemented to avoid potentially intrusive and unduly expansive testing into a donor's genetic material. Finally, the individual clinics and physicians that actually perform the procedures should be given some incentive to follow a regulatory scheme that might be imposed upon them.

C. Problems and Concerns

Essentially, this author's recommendation is for the creation of a system that allows access to a donor's genetic background, while still maintaining the anonymity of the donor. To minimize legitimacy, paternity, and other possible legal challenges

85 Johnston, supra note 20, at 52. This is despite the increasingly obvious implications that late-onset conditions and a donor's family history could have on the offspring. Id.
86 Foster, supra note 60, at 60. "Ongoing disclosure may permit a donor to contact a donor child upon his discovery of a relevant health issue." Id.
87 See Mann, supra note 27, at 5. A doctor being interviewed by Mann appreciated the health benefits but believes parameters are necessary. Id.

Q: Is there ever a compelling medical case where someone would really profit, where their health would really benefit from knowing more about their medical history, their ancestor's medical history?

A: Yes, there might be some genetic problem that could be delineated, but it sometimes would have to be done so far ahead that even the individual themselves might not know it ... from a medical standpoint, yes, it would be important, but I think we would have to have specific parameters to know which diseases we're looking at. Id.

88 Koehler, supra note 18, at 334. Sperm banks and the physicians working in the industry must keep full and accurate records for such a system to work. Id.
89 See Ginsberg, supra note 1, at 838-50. Fears of donor liability and fears that the donor will be obligated to develop a relationship with the child are off base, and statutes have all but eliminated financial and paternal responsibility by declaring the husband of the donor recipient the child's father. See Landau, supra note 15, at 3268-73. England created a registry where individuals above 18 years of age can check whether they originate from donor material or were conceived by in
against the donor, the child should not know the donor's identification. Such a system would reflect similar trends in adoption laws. This approach would not only help quell fears of a severe drop in donor numbers, as discussed below, but will be less controversial and avoid multiple legal fights over privacy rights.

One of the greatest concerns with allowing disclosure laws to take effect is the fear of a severe drop in the donor pool. Evidence from other countries has

vitro fertilization. Id. The donor's identity cannot be revealed and the individual must actively seek the information in the registry; the government will not seek the donor child out. Id. In her proposed statute, the author states the following:

- In order to protect the privacy of the parties as well as to match the donor's characteristics with the husband's, the statute should require the physician to provide the woman, and her husband, if married with genetic and family medical history, race, age, hair and eye color, height and weight, and any other information that the donor agrees to provide. The statute should require that information identifying the donor be kept by the doctor who performs the insemination, or by the lab which collects the sperm, for a limited period of time such as five years. Thus, if any genetic defects occurred, the donor could be traced. This information would be obtainable only upon court order, and only if necessary in order to give a child medical treatment or remove a donor with genetic disorders from a sperm donation test. Only licensed doctors should be to perform artificial insemination by donor, and they should be required to test the sperm for general health, blood type, Rh factor, and genetic history.

Rice, supra note 49, at 1076.

90 See Ginsberg, supra note 1, at 848. Many statutes have made the issue moot and eliminated any financial responsibility of the donor by declaring that the husband of the donor recipient is the child's legal father. See Virginia Linn, Donor ID: More Openness in Terms of Identifying Fathers Comes to the Sperm Donation Process, PITTSBURGH POST GAZETTE, August 24, 2005, available at 2005 WLNR 13305990. Most recipients in search of donor disclosure just want a picture of the donor or more details regarding medical history. But see Shanley, supra note 5, at 268 (arguing that donor offspring should have the right to learn, although not be compelled to learn, the identity of the donor, not simply medical facts or DNA profile).

91 See Cahn, supra note 62, at 186. Adoption laws are mandating disclosure of anonymous genetic information, while easing up on calls for the disclosure of identifying information. Id. See Marilyn Gardner, Sperm Donors No Longer Bank on Anonymity, CHRISTIAN SCIENCE MONITOR, March 30, 2005, at 2 available at 2005 WLNR 4904727. If their identities were released, many donors fear the "knock on the front door" that may occur later in life. Id. But see Johnston, supra notes 20, at 51 (citing a New Zealand study that found 68% of sperm donors surveyed were agreeable to their identity being made available to their donor child).

93 Johnston, 11 n. 1 at 51.
demonstrated drops in donor applicants after the implementation of openness laws.94 Building on this concern, those who oppose disclosure have argued that the fertility industry in the United States would crumble with any changes toward openness in donor information.95 However, this argument appears to be archaic in nature, as trends in countries with relaxed anonymity laws have shown a rebound in donor numbers over time.96

94 See Donor’s Crisis Over Anonymity, DAILY MAIL, November 10, 2005, available at 2005 WLNR 18194474 (citing fertility experts in England who attribute drop in donor pool with ban on anonymity implemented April, 2005). The Newcastle Fertility Centre reported a drop of 175 donor applicants in 1994 to only 25 applicants in 2003. Id. Britain’s disclosure law did not come into effect until 2005, but the article claims anticipation of the legislation contributed to the drop in donors. Id. See also Shortage of Sperm Donors at Clinics as Law Changes, NEWSQUEST MEDIA GROUP, November 10, 2005, available at 2005 WLNR 18153943 [hereinafter Shortage of Sperm Donors] (arguing growing awareness of change in law as cause for rapid decline in sperm donors in UK since 2000). The avoidance of a future legal duty to the donor child is the primary reason donors want anonymity. See Koehler, supra note 18, at 333. It is unclear whether a more concise definition of the legal rights of the donor would correlate into increased willingness to disclose non-identifying information. Id.

95 Chung, supra note 30, at 295. “Sperm banks in the United States have a lot to lose should donor anonymity become threatened.” Bauman, supra note 22, at 216-17. Bauman balances the industry’s concerns that disclosure will lead to fewer donors with a child’s access to information about their donor. Id. Bauman justifies her position for disclosure by demanding an “avenue to uncover information that may determine a course of treatment” and ultimately impact the health of a child who is diagnosed with a genetically-linked disease. Id. But see Shelf, supra note 40, at 1066. The author dismisses the notion that the loss of anonymity would doom the fertility industry. Id. Shelf sees this view of the donor-offspring relationship as being limited to a bubble concept, whereas an increase in social experience with these relationships and more families discussing their children’s origins with them “the possibility of a known donor must be projected into a changed society.” Id.

96 See Ethical and Legal Debate, supra note 62, at 823 (noting drop, then rise, of donor applicants in Sweden, Victoria, and Australia). Sweden and New Zealand’s donor rates stabilized within a year of inception of the new legislation. Id. Donor numbers have dipped but have since recovered in Sweden, New Zealand, and Australia. Id. Hetty Crist from London’s Department of Health attributes an active recruiting campaign to the sustained level of donor numbers since the disclosure law took effect. Linn, supra note 90 (citing stabilization of donor numbers in Sweden and New Zealand). “The dire predictions that allowing persons created by [assisted reproduction] the right to their identity will sound a death knell to the industry is reminiscent of the rhetoric of those here in the U.S. who would refuse adoptees the same right because it would hinder relinquishments.” Kevin Carey & Ron Morgan, The Right to Know: Two Views on Identity Rights & Assisted Reproductive Technology, G21 THE WORLD’S MAGAZINE, available at http://g21.net/do95.htm. (last visited November 29, 2006). Drop in donor numbers have not been researched thoroughly and studies indicate these claims have been exaggerated. See Chestney, supra note 49, at 386-7. The drop in donor fear is outdated, and dips in numbers in Sweden were only temporary. See Swanson, supra note 9, at 173. In the 1991 survey of donors from two clinics, 90% stated they were willing to fill out extensive surveys with medical and
Many fertility doctors are also adverse to openness for a variety of reasons spanning from shielding donors from claims of inheritance rights to protecting all parties from emotional distress. This author feels that the medical profession should have an interest in openness. Updated and accurate information would be of great health importance not only when the donor or child is found to have a disorder, but also for purposes of future research on the successes and transgressions of artificial insemination in general. Granted, efforts must be made to address concerns over the size of the donor pool and the emotions of the involved parties, but attention must also be focused on more practical problems including how the roll back of anonymity barriers may result in a donor pool that is generally older than before, possibly resulting in a decrease in the quality of gametes.

Naturally, it is complicated to visualize how a “right to information about one’s personal histories; 96% said they would consent to granting access to non-identifying information; 60% would consent to disclosure of identifying information once the donor child reached 18; 72% left a personal message for potential children when given the option; 29% stated anonymity as a condition of donation; 36% said they would donate without an absolute guarantee of anonymity. Swanson, supra note 9, at 171-72 citing Patricia Mahlstedt & Kris Probasco, Sperm Donors: Their Attitudes Toward Providing Medical and Psychological Information for Recipient Couples and Donor Offspring, 56 FERTILITY & STERILITY 747, 752 (1991). The proposition that more openness correlates to a drop in donors is “by no means a proven outcome.” Id. The total number of sperm donors in the Netherlands has decreased from 900 to 300, sperm banks have decreased by half, and the waiting time for treatment has surpassed two years in a ten year span. Patrizio, supra note 8, at 2037.

97 See Swanson, supra note 9, at 171. The Curie Cohen Study found that 82.6% of doctors opposed legislation requiring the maintenance of donor records. Id. Reasons given included protection of the donor offspring, parents, and donors from emotional distress, concerns over inheritance rights, and issues of legitimacy and paternity. Id.

98 Id. at 182.

99 See Henderson, supra note 9, at 2. The typical age of donors in the UK has increased from that of a student to 35 years of age. Id. Donors are now typically a “35 year old who has started a family and wants to make an altruistic donation compared to the medical student seeking beer money.” Id. An older donor pool could result in problems with the quality of sperm that is being transferred. See Ian Sample, The Biological Clock Also Ticks For Fathers: Warning on Risk of Down’s Syndrome Fertility Doctors Worry Over Older Sperm Donors, GUARDIAN, November 3, 2005, available at https://www.guardian.co.uk/print/0,5324455-110592,00.html. (last visited November 29, 2006). (discussing recent study that found older men have greater chance of fathering babies with Down Syndrome). Sperm and eggs become defective as they got older, but traditionally there has been a difficulty isolating exactly what effect this has had on the child. Id. A survey from 1994-2003 found that of 1,100 potential donors, 88% of applicants were under the age of thirty six, more than half were single students, 85% were unmarried, and more than three-fourths had no children. Id. The fear is that the percentage of younger donors will drop if anonymity is no longer guaranteed. Id.
One practical hurdle is that the donor offspring’s access to donor information would be contingent on the parent’s disclosure of the procedure. Countries that have abolished anonymity have not created a formal process or mechanism to guarantee the offspring would ever discover he or she came from donated gametes. This Catch-22 has been discussed, and policymakers will be hard pressed to balance the complex ethical and logistical elements it takes to implement a system that guarantees the donor offspring the option to determine if he or she was born from artificial insemination. One solution is to create a separate gamete donor certificate that the donor offspring could access once they reach the age of eighteen. Emily Jackson, Donor Anonymity and Right, Jan. 27, 2004, available at http://www.ivf.net/content/page-o259.html. The author feels that “the legislative process is too slow and enforcement too rare to provide the needed swift, effective solution” to sperm bank liability. Hodgson, supra note 6, at 360-61. Instead, the author suggests applying warranty law to economically compel banks and physicians to improve complications in the insemination process.

Parents are less likely to disclose that the child is the product of a gamete donation compared to those willing to reveal that their child was adopted. See Susan Lewis Cooper & Ellen Sarasohn Glazer, Choosing Assisted Reproduction: Social Emotional and Ethical Considerations [Book Excerpt], Perspectives Press Website, available at http://www.preconception.com/resources/articles/social2.htm. (last visited September 14, 2006). Most couples still keep the procedure a secret from the child. Ethical and Legal Debate, supra note 62, at 822 (citing study finding 73% of parents in US would not reveal procedure to child). If donor offspring are granted the right to know their genetic origins, it should not be contingent on the honesty of the parents. Johnston, supra note 20, at 52. In the current system, disclosure depends on a combination of the birth parents, the donor, and the system, thus rendering the child powerless. Id. See Pennings, supra note 7, at 10-11, 15. As long as the child is living under the assumption that his parents are also his genetic parents, the child will not ask for this information. Id. at 10.

No country that has adopted non-anonymous donation has implemented a formal system of telling the child. See Ethical and Legal Debate, supra note 62, at 822. Swedish law relies on the openness of the parents and thus far disclosure has been low. Id. See also supra note 100 (discussing difficulty of forcing parents to tell children, the traditional protection of freedom to raise child according to certain values, and the balancing of child’s right to know and the parent’s freedom of choice). Genetic testing in adoption will render those with a poor genetic history “unadoptable.” Id. But this is not the case in artificial insemination: although people will still be attracted to a donor with superior features, a living child is not at stake. Id. Therefore “collection and maintenance of genetic material and medical history has no potential deleterious effect upon offspring.” Id.

Beneath the Rhetoric, supra note 50, at 480-82. This would be similar to an adoption certificate that can be accessed at age 18. Id. Another option is to put a special notation on the birth certificate that indicates “by donation.” Id. Most policy decisions in this area do not focus on
If the donor offspring has access to such a certificate, it would allow the individual at least the choice of whether or not to seek more information regarding his or her genetic history. More questions will continue to develop as science and the law progress.

Mechanisms to ensure the child has access to existence of AI procedure. Id. See also Ethical and Legal Debate, supra note 62, at 822. The author discusses how the British House of Commons defeated a measure in 1990 proposing that the birth certificates of donor offspring must bear the demarcation “by donation.” Id. The proposal was seen as causing the child unnecessary embarrassment. Id. See also Pennings, supra note 7, at 13. In England, the government does not seek out artificially inseminated offspring. Id. Rather, any eighteen year old can check whether or not he or she was created through such a procedure, but donor identity is not revealed. Id. See also Pennings, supra note 7, at 15. “Mentioning on the birth certificate that donor material was used implies that the matter of telling is no longer for the parents to decide.” Id. See also Shields, supra note 50, at 39 (discussing how in identity-release system, offspring has choice to access genetic details of donor).

Many commentators have raised the question of reciprocal obligations between the donor and offspring that may be raised with the implementation of such a system. Id. A request to know the status of the offspring could come from the donor himself for a number of scenarios. Id. For example, the donor may want to seek out the offspring for a tissue, bone marrow, or organ transplant. Id. The authors also point out the benefit to infertility clinics in having the ability to cease using a donor’s sperm or eggs once a genetic disorder is found. Foster, supra note 60, at 57. The U.S. National Bioethics Advisory Committee guidelines suggest alerting relevant parties of the presence of a health risk only when the findings are scientifically sound, significant implications for the individual exist, and a course of action to treat any concerns is readily available. See McHale, supra note 79, at 90-1 (inquiring into what happens when health risk is discovered while information is in genetic database). See Patrizio, supra note 8, at 2037. “One could also ask whether disclosure could be used the other way around, i.e. whether donors could later be an unwelcome intervener in family relationships through their attempts to identify their half-sibling, even if the offspring are not interested in knowing their biological origins.” Id. See Swanson, supra note 9, at 175-76, 182. The donor should be notified if the donor child finds out he has a genetic disorder and vice versa. See also Sarah Cotton, et al., Creating Life? Examining the Legal, Ethical and Medical Issues of Assisted Reproductive Technologies, 9 J. GENDER RACE & JUST. 55 (Fall 2005) (discussing extensive Model Assisted Reproductive Technology Act). The Model Act contains provisions for clinical reporting requirements, donor screening, and testing donor registries, and disclosure and access to donor information. Id. at 62, 65, 78-80. In Israel, The Public-Professional Committee to Investigate In-Vitro Fertilization reported that a central registry with information about the donor, recipients, and offspring should not be established, citing difficulty in preventing unauthorized access to such sensitive information and the danger of errors. See Landau, supra note 15, at 3271. Some experts have even warned of “fertility tourism” and “back-street babies” fears, in which people would seek fertility treatment abroad or even resort to home inseminations. Back Street Babies’ Fear. STAR, Jan. 3, 2005, available at 2005 WLNR 74312 (noting expert fears concerning openness). Some within the industry predict that individuals will try to find donors themselves if they are unable to get treatment at clinics. Id.

The obvious implication would be that donors would not be effectively screened. Id.
Conclusion

For the Cook family, the settlement they reached with the sperm clinic is little solace for a family that has fallen victim to a largely unregulated and unaccountable industry. Children born from artificial insemination should be granted the legal right to non-identifying, genetic and medical information of their donor. The strides that will continue to be made in genetic science demand a system where an individual should not have to wait for an illness to set in to have access to a proper genetic history. It is time for the state and federal governments to address the rights of the growing population of donor offspring, and implement concrete provisions to guarantee the documentation, preservation, and disclosure of non-identifying donor information. The legal right to access this information would finally provide the significant population of donor offspring the ability to utilize the genetic information of their entire family tree.