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"Knowing Where You Come From": The Rights of Donor-Conceived Individuals and the Meaning of Genetic Relatedness

Vardit Ravitsky*

I. INTRODUCTION

The use of donor sperm or donor eggs allows prospective parents to overcome the obstacle of infertility and bring into the world a child that is genetically related to one of them, while still being able to experience pregnancy and childbirth. The first generation of donor-conceived offspring is now becoming young adults who are beginning to share their unique perspectives. Many are telling a story of psychological distress. They describe a strong need to know "where they came from;" to know their genetic origins as an essential part of constructing their identities.

Most fertility experts did not anticipate this outcome. They focused on their patients, helping them create the families they desired while perceiving the donor as a mere means in the process.¹ The interests of donor-conceived offspring in accessing information about donors have initially been a neglected element in the thriving practice of gamete donations. This trend was maintained because most donors wish to remain anonymous and have no intention of establishing a relationship with offspring, and most parents choose to keep the circumstances of conception secret.

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1. 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, 807 (2001).

In recent years, however, the interests of donor-conceived offspring are coming to the forefront. They have become the center of a lively academic debate² as well as a driver for support networks,³ educational campaigns,⁴ and legislative changes.⁵ While most countries still maintain the norm of protecting donor anonymity, a trend towards disclosure of donor identity is gathering momentum as a growing number of countries are adopting laws and regulations banning anonymity.⁶ In the United States, disclosure of donor identity is not regulated either by state or by federal law. Professional guidelines do exist but the compliance of sperm banks, egg and sperm donation programs, and fertility clinics with such guidelines is voluntary. Furthermore, no central registry exists to record and keep information that would allow future possible linkage of donors and offspring.

The debate surrounding disclosure of donor identity is typically framed as a tension between the rights⁷ of donors and parents on one hand,⁸ and those of donor-conceived offspring on

2. See Glenn McGee et al., *Gamete Donation and Anonymity: Disclosure to Children Conceived with Donor Gametes Should Not Be Optional*, 16 HUM. REPROD. 2033, 2033–35 (2001); Pasquale Patrizio et al., *Disclosure to Children Conceived with Donor Gametes Should Be Optional*, 16 HUM. REPROD. 2036, 2036–38 (2001).

3. Such as the Donor Conception Network, dedicated to “supporting and guiding would-be and current parents in the issues they face about how to be open with children about donor conception, thereby avoiding damaging secrets.” Donor Conception Network, <http://www.donor-conception-network.org/> (last visited Feb. 26, 2010). See also the Donor Sibling Registry (DSR), which focuses on “assisting individuals conceived as a result of sperm, egg or embryo donation who are seeking to make mutually desired contact with others with whom they share genetic ties.” Donor Sibling Registry, <http://www.donorsiblingregistry.com/> (last visited Feb. 26, 2010).

4. See, e.g., VARTA: Victorian Assisted Reproductive Treatment Authority, Time to Tell, <http://www.powerfront.com/ita/www/257/1003057/displayarticle/time-to-tell-1003788.html> (last visited Feb. 26, 2010) (explaining VARTA’s campaign to educate and help parents talk to their children about “how they became a family”).

5. Eric Blyth & Lucy Frith, *Donor-Conceived People’s Access to Genetic and Biographical History: An Analysis of Provisions in Different Jurisdictions Permitting Disclosure of Donor Identity*, 23 INT’L J.L., POL’Y & FAMILY 174 *passim* (2009).

6. *Id.* at 175.

7. In this paper, the term “right” refers both to a moral right and to a legal right. The assumption is that once a moral right is acknowledged, it can in some cases justify the creation of a full-fledged legal right.

8. It has been argued that in some cases, particularly in the case of

the other.⁹ Donors, it is argued, have a right to maintain anonymity in order to avoid potential future liabilities¹⁰ and parents have a right to keep the circumstances of conception private.¹¹ On the other hand, it is argued, offspring have a right to know their genetic origins.¹²

The arguments made within this debate attempt to explain why certain rights should trump others. Consequently, these arguments serve as justifications for different policy options for the oversight of the practice of gamete donation.¹³ According to this framing, policies adopted by different jurisdictions and professional bodies can be presented as different answers to the question "whose rights should prevail?" In Sweden and the United Kingdom, for example, the rights of offspring prevail and donor anonymity is banned,¹⁴ whereas in Canada¹⁵ and

single mothers and lesbian couples, the tension is actually between the rights of the parent(s) and the offspring on one hand, and those of the donor on the other. Heterosexual couples are often interested in hiding the circumstances of conception in order to keep the fact of infertility private and in order to protect the relationship of the child with his genetically unrelated father. Single women, however, are sometimes interested in the disclosure of donor identity, because questions regarding the identity of the donor arise naturally and the donor does not "compete" with a rearing father. See Cheryl Miller, *Donated Generation*, 21 NEW ATLANTIS 27, 27–44 (2008), available at <http://www.thenewatlantis.com/publications/donated-generation>.

9. Lucy Frith, *Gamete Donation and Anonymity: The Ethical and Legal Debate*, 16 HUM. REPROD. 818, 820–22 (2001).

10. Roger Collier, News, *Disclosing the Identity of Sperm Donors*, CANADIAN MED. ASS'N J. (forthcoming 2010), available at <http://www.cmaj.ca/cgi/rapidpdf/cmaj.109-3144v1?maxtoshow=&hits=10&RESULTFORMAT=1&author1=collier%2C+r&title=disclosing+the+identity+of+sperm+donors&andorexacttitle=and&andorexacttitleabs=and&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&sortspec=date&resourcetype=HWCIT,HWELTR>.

11. Patrizio et al., *supra* note 2, at 2036–38.

12. Lucy Frith, *Beneath the Rhetoric: The Role of Rights in the Practice of Non-Anonymous Gamete Donation*, 15 BIOETHICS 473, 477 (2001).

13. The term "policy" is used here in a broad sense to include legislation and regulation in specific jurisdictions, guidelines endorsed by professional societies and organizations, and standards of practice adopted voluntarily by various bodies engaged in gamete donations such as sperm banks, egg and sperm donation programs, and fertility clinics.

14. Blyth & Frith, *supra* note 5, at 176.

15. See Ken Daniels et al., *Sperm Donation: Implications of Canada's Assisted Human Reproduction Act 2004 for Recipients, Donors, Health Professionals, and Institutions*, J. OBSTETRICS & GYNAECOLOGY CANADA, July 2006, at 609 (citing that since 1996, Health Canada has disseminated regulatory documentation that designs a system utilizing anonymous sperm donation, but that the Assisted Human Reproduction Act 2004 allows

Israel,¹⁶ the rights of donors and parents prevail and donor anonymity is legally permissible, and is still the norm.

In this paper I argue that such framing is rudimentary and that we need a more nuanced understanding of what is at stake. Different claims are being made under the umbrella concept of “the right to know one’s genetic origins” in a manner that confounds the debate. To achieve greater conceptual clarity, some necessary distinctions must be made.

The “right to know one’s genetic origins” encompasses at least four aspects that can be discerned in different claims made within the debate. Each of these aspects relies on a distinctive understanding of the meaning of “genetic relatedness.” Moreover, each aspect can be addressed by a different policy. This paper describes each of the four aspects and delineates the different meanings and policies associated with it.

The *medical aspect* points towards the right to know one’s full medical history and to know medically relevant genetic information about the donor. The *identity aspect* points towards the right to personal information about the donor as a person (narrative information) that would assist offspring in overcoming identity issues. The *relational aspect* points towards the right to know the full identity of the donor in order to contact him or her and attempt to establish a relationship. Finally, the *parental disclosure* aspect relates to the right to know the *truth* about the circumstances of one’s conception as trumping parents’ right to privacy.

Each of these aspects is based on a different understanding of the meaning of *genetic relatedness*. The medical aspect expresses a *narrow* understanding of genetic relatedness as meaningful solely in a *biological* sense. The identity aspect expresses a *broader* understanding of genetic relatedness as having an effect on *personal identity*. The relational aspect expresses an *extensive* understanding of genetic relatedness as justifying an appeal for a *personal relationship*. Finally, the *parental disclosure* aspect expresses the most *far-reaching*

disclosure of the donor’s identity if the donor gives consent).

16. See The Tel Aviv Sourasky Medical Center, The Sperm Bank, http://www.tasmc.org.il/e/lis/fertilityresearch/sperm_bank/ (last visited Apr. 23, 2010) (“In Israel, sperm donations are completely anonymous. . . . Unlike other countries, it is illegal to disclose the donor’s identity when offspring reach adulthood.”).

understanding of genetic relatedness, seeing it as creating a *connection* powerful enough to justify state intrusion into the family.

In addition, each of these aspects can be addressed by a different policy solution, from disclosure of medical history and genetic information, through disclosure of de-identified personal information, all the way to disclosure of donor identity and to legal enforcement of truth-telling within the family.

This paper therefore argues that these policy options are based on distinctive notions of the role that genetic relatedness should play in the construction of families and in social life. As we expand the scope of the meaning of genetic relatedness, we expand the scope of the right and provide justification for policies that allow it to trump the rights of other parties (donors, parents, and the fertility industry) and to trump other considerations (such as pragmatic¹⁷ or economic¹⁸ ones). Finally, the paper proposes an argument in favor of adopting at least three policies that can address the rights of donor-conceived individuals without violating the rights of donors.

II. THE "RIGHT TO KNOW ONE'S GENETIC ORIGINS": A FUNDAMENTAL DISTINCTION

What underlies the notion of a "right to know one's genetic origins"? Is it evidence that lack of such knowledge harms donor-conceived individuals? Or is it the idea that knowing is a fundamental human right that requires no empirical support (such as the right to life or liberty)?

Both approaches, the "human rights approach" and the "consequentialist approach," can be traced in the donor-conceived individual rights debate.¹⁹ The human rights approach assumes that the right to know one's genetic origins is a basic human right, regardless of the availability of empirical data to support claims about lack of knowledge being

17. For example, the shortage of sperm donors.

18. For example, the cost of collecting and maintaining regularly updated records with full medical history.

19. Frith, *supra* note 9, at 821 ("Two of the most common reasons given for why knowledge of one's genetic origins is thought to be a right are; it is deemed essential to human well-being and that people have the right to the truth about their origins. . . . It has been argued that being denied knowledge of one's biological origins can be harmful to donor offspring.").

harmful. In the words of Mary Warnock: "I cannot argue that children who are told of their origins . . . are necessarily happier, or better off in any way that can be estimated. But I do believe that if they are not told, they are being wrongly treated."²⁰

The consequentialist approach argues that knowledge of one's genetic origins is essential for one's psychological well-being, for the development of personal identity, and for the establishment of healthy family relationships. Depriving individuals of such knowledge, it is argued, results in the creation of complex identity issues and psychological distress.²¹ Thus, the right to know one's genetic origins is based on the profound interest that people have in avoiding psychological harm and in leading full and healthy lives.

The arguments made in this paper do not rely solely on the consequentialist approach justifying the right. Indeed, they find support in small studies and in the powerful testimonies of donor-conceived individuals, but they rely also on the notion of a human right to know one's genetic origins regardless of evidence of significant harm to a statistically significant portion of the donor-conceived population. What precisely this right means will be discussed in the remainder of this paper.

Research studies on small populations²² and online networks in which individuals share their stories and concerns are beginning to provide anecdotal data regarding the existence of harms to donor-conceived individuals.²³ However, the collection of data on the psycho-social issues facing donor-conceived individuals is particularly challenging because most do not know the circumstances of their conception.²⁴ Large-scale research data is thus not available. Furthermore, typical recruitment of research participants through support networks may lead to a significant selection bias, as individuals who are members of such networks may be the ones looking for support because they are suffering from identity issues and other

20. Mary Warnock, *The Good of the Child*, 1 *BIOETHICS* 141, 151 (1987).

21. See discussion *infra* Part III.B.

22. See, e.g., McWhinnie, *supra* note 1; A.J. Turner & A. Coyle, *What Does It Mean to Be a Donor Offspring? The Identity Experiences of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy*, 15 *HUM. REPROD.* 2041 (2000).

23. See Donor Conception Network, *supra* note 3.

24. See McWhinnie, *supra* note 1, 810–11.

psychological difficulties.

Moreover, because the first generation of donor-conceived individuals is still relatively young, there is no data from completed longitudinal studies (the gold standard in social science research) that would ideally follow donor-conceived individuals throughout life and collect data on the impact of their unique viewpoint on various life stages and transitions. Hence, it is still too early to answer questions such as how being donor-conceived impacts one’s relationships with his own children.

III. WHAT IS IT THAT DONOR-CONCEIVED INDIVIDUALS HAVE A RIGHT TO?

Researchers, policy makers, and professionals (such as social workers and psychologists) have made a variety of claims regarding what it is that donor-conceived individuals actually want to know or are entitled to know. More importantly, donor-conceived individuals themselves are making such claims.²⁵ Unsurprisingly, not all express the same attitudes, needs or interests. The lively debate surrounding this issue allows for a richer and more nuanced analysis and draws attention to the different aspects of the “right to know one’s genetic origins.”

A. KNOWING YOUR GENETIC ORIGINS: THE MEDICAL ASPECT

The first aspect of “the right to know one’s genetic origins” is the right to have access to one’s medical family history and genetic heritage in order to be aware of health risks, be able to take preventive measures, and have better ability to diagnose conditions as they emerge. In 2009, a single mother of donor-conceived twins took legal action to force the New England Cryogenic Center to reveal the identity and medical records of her donor after her daughters were diagnosed with a growth disorder and other “health crises” that—according to her—they inherited from the donor.²⁶ She explained that doctors struggled to correctly diagnose their condition, which would have been easier to diagnose if she had access to the donor’s medical family history.²⁷

25. See, e.g., *infra* notes 36, 38, 49, 50, 53, 64.

26. Laurel J. Sweet, *Doe Spells Out Daddy Issues; Says Clinic Assured Contact with Donor*, BOSTON HERALD, Oct. 5, 2009, at 4.

27. *Jane Doe’s Full Statement*, BOSTON HERALD, Oct. 5, 2009, available at <http://bostonherald.com/news/regional/view.bg?articleid=1202234>.

Considering the hereditary nature of many conditions, access to family history and genetic information is also important for reproductive decisions that donor-conceived individuals are and will be making when they have children of their own. Without information about inheritable conditions and increased genetic risks, their decision-making capacity is significantly compromised.

1. Policy Solutions and the Meaning of Genetic Relatedness

Allowing donor-conceived individuals access to medical and genetic information does not require disclosure of donor identity. Sperm banks, egg and sperm donation programs, and fertility clinics can collect and keep on record extensive medical family histories and donors' genetic test results, and share relevant information with families. The American Society for Reproductive Medicine (ASRM) publishes guidelines that provide criteria for evaluating donors' medical history and a list of recommended laboratory tests.²⁸ Since it is not feasible to screen sperm and egg donors for every known genetic condition, the ASRM recommends testing all donors for cystic fibrosis carrier status, and performing other genetic testing "as indicated by the donor's ethnic background in accordance with current recommendations after obtaining a proper family history."²⁹

However, will records containing all this medical information be available to offspring many years into the future? The FDA requires that records pertaining to each donor (including screening procedures and test results) be maintained for at least ten years,³⁰ which in this context is a very short period of time. On the other hand, the ASRM recommends maintaining "a permanent record of each donor's initial selection process and subsequent follow-up evaluations" and, to the extent possible, recording "the clinical outcome of each insemination/donation cycle"³¹ It also acknowledges that

28. Practice Comm. of the Amer. Soc'y for Reprod. Med. & Practice Comm. of the Soc'y for Assisted Reprod. Tech., *2008 Guidelines for Gamete and Embryo Donation*:

A Practice Committee Report, 90 FERTILITY & STERILITY S30 *passim* (2008) [hereinafter ASRM].

29. *Id.* at S32.

30. 21 C.F.R § 1271.55 (2009).

31. ASRM, *supra* note 28, at S36.

"a mechanism must exist to maintain such records as a future medical resource for any offspring produced."³² In reality, the record-keeping practices of sperm banks, programs and clinics vary greatly.

Another concern is related to the need for medical follow up with donors. At the time of donation donors are typically young³³ and may not exhibit symptoms of certain conditions. It is reasonable to expect that some medical issues will emerge years, possibly decades, after the donation has been made. A policy that appropriately addresses the right to know full medical history thus requires that sperm banks, programs, and clinics remain in touch with donors in the long run and update their evolving medical records on a regular basis. This would allow them to re-contact recipient families if and when new relevant information becomes available. Having a DNA sample from donors on file would also be of use, in case further genetic testing has to be performed.

Furthermore, donors may never exhibit symptoms because they may be only carriers of a mutation that causes a genetic disease that might manifest in the offspring. If conceived offspring are diagnosed with conditions that may be traced back to the donor, it can become crucial to test the donor's DNA. When testing confirms the presence of a mutation, further use of sperm or eggs from that donor should be stopped in order to prevent the birth of consequent children who would inherit the disease. Donors should also be alerted to the fact that they should refrain from donating again elsewhere. In 2006, for example, a sperm donor passed an extremely rare and dangerous genetic condition—severe congenital neutropenia—to five children born to four couples.³⁴ The sperm bank could not contact the donor and warn him not to make additional donations because contact with him was lost.³⁵

Drawing the policy line at the level of medical history and genetic information disclosure emphasizes the bio-medical

32. *Id.* at S36, S40.

33. The ASRM recommends an age limit of forty for sperm donors because "increased male age is associated with progressive increase in the prevalence of aneuploid sperm," and an age range of 21–34 for egg donors. *Id.* at S32, S37.

34. Laurence A. Boxer et al., *Strong Evidence for Autosomal Dominant Inheritance of Severe Congenital Neutropenia Associated with ELA2 Mutations*, 148 J. PEDIATRICS 633, *passim* (2006).

35. Denise Grady, *Sperm Donor Seen as Source of Disease in 5 Children*, N.Y. TIMES, May 19, 2006, at A16.

meaning of inheritability. It acknowledges only this aspect of the right as providing strong enough justification for disclosure and reveals a social attitude that does not value other aspects of the right. In the words of a “Phoebe,” a donor-conceived woman:

I got the impression that ‘society’ didn’t feel I have a right to anything more than a medical history. People don’t acknowledge a need/right to know traits, history, or even realize that their sense of identity might be tied up with their family history, or family stories, or remembrances about a person.³⁶

Even if other aspects of the right are conceptually acknowledged, they are not seen as significant enough to justify appropriate policies. Rather, they are perceived as easily trumped by the rights of other parties or by other considerations. Indeed, this aspect of “the right to know one’s genetic origins” is the most easy to defend. Being denied access to medical history and genetic information can cause severe, but preventable, harm, and the interest of donor-conceived individuals in avoiding such harm is strong and clear.

Failure to acknowledge this aspect cannot be justified by reference to the donor’s right to privacy because, as mentioned, information can be shared without full identification. Sperm banks, programs and clinics can serve as intermediaries and follow up with donors and recipient-families when medical issues emerge. Certainly, keeping medical records and updating them by following up with donors can be costly, but considering the harms this practice can prevent, such investment is ethically required.

B. KNOWING YOUR GENETIC ORIGINS: THE IDENTITY ASPECT

The second aspect of “the right to know one’s genetic origins” is the right to have access to information about the donor as a person, information that individuals see as relevant and important to their sense of self. The development of personal identity requires understanding “where you came from” in a sense much broader than knowing the medical implications of the donor’s genetic makeup. It means knowing what the donor is like in ways that would help offspring understand why they are the way they are. Katrina, a donor-conceived woman, expresses this sentiment:³⁷

36. Turner & Coyle, *supra* note 22, at 2047.

37. The question of whether certain traits or predispositions are

I'm 18, and for most of my life, I haven't known half my origins. I didn't know where my nose or jaw came from, or my interest in foreign cultures. I obviously got my teeth and my penchant for corny jokes from my mother, along with my feminist perspective. But a whole other part of me was a mystery. That part came from my father . . . I had never met him, never heard any stories about him, never seen a picture of him.³⁸

From this perspective, knowing who you are requires knowing how you came to be. The understanding of oneself—from physical characteristics all the way to personality traits, talents and interests—is associated with an understanding of where these characteristics and traits came from. In this sense, knowing one's "genetic origins" is an important component of deepening one's understanding of oneself.³⁹

Furthermore, the biological aspect of our connection to our past provides a sense of continuity. As we develop a sense of personal identity we constantly refer to "where we come from" as a way of grounding ourselves, establishing a sense of belonging, of our place in the world. Lack of knowledge about the donor as a person could thus create a gap or a void in the formation of personal identity, undermine a sense of continuity and grounding, and lead to troubling and disruptive feelings of incompleteness.⁴⁰

The need to understand "where you came from" thus creates a need to have access to information that relates to the donor's narrative identity, not just biological or genetic identity.⁴¹ Donor-conceived individuals speak of their need to hear stories, to know biographical facts, and to see pictures of the donor. In the words of a donor-conceived individual: "All I wanted was some information, not necessarily to meet him, and

inheritable or the outcome of environmental exposure (the famous "nature-nurture debate") is complex and would necessitate a discussion that goes beyond the scope of this paper. Katrina's sentiment may reflect a position that assigns to genetics more than have ever been scientifically studied, but it is brought here to exemplify how some individuals frame their need to know.

38. Katrina Clark, *Who's Your Daddy?; Mine Was an Anonymous Sperm Donor. That Made Me Mad. So I Decided to Find Him.*, WASH. POST, Dec.17, 2006, at B1.

39. See McWhinnie, *supra* note 1, at 812–13; Miller, *supra* note 8, at 27–28.

40. See Geraldine Hewitt, *Missing Links: Identity Issues of Donor Conceived People*, 9 J. FERTILITY COUNSELLING 14 *passim* (2002); Turner & Coyle, *supra* note 22, at 2042.

41. Shane Green, *Openness in Gamete Donation: It's Not About Genetics* (unpublished manuscript, on file with author).

never for him to feel any obligation towards me.”⁴² These needs can be met without full disclosure of donor identity, as outlined below.

1. Policy Solutions and the Meaning of Genetic Relatedness

Extensive personal information can be collected about donors and shared without disclosing their identity. Today, most sperm banks and programs offer basic information about physical traits such as height, eye color, hair color and texture, skin tone, body build, and ancestry/ethnicity.⁴³ Some offer additional information about education level, area of study, and religion. Others go much further and offer baby pictures, essays written by the donor, audio interviews, handwriting analysis, personality questionnaires, and in the near future, even short films featuring the donor (neck-down to protect identity) participating in favorite activities.⁴⁴

The impetus for providing such a wide range of information about donors may be a financial one. Many couples and single mothers wish to know more about the donor in order to make an informed decision when choosing one, and they are willing to pay for it. However, since sperm banks, programs or clinics are collecting this information and making it available to parents, they can also make it available to offspring in the future.

If parents are interested in this type of information—and are willing to pay extra for it—it is because they feel it matters to them when they choose a donor. They are interested in more than a clean bill of health and a certain physical appearance because they take an “identity approach” towards genetic relatedness.⁴⁵ Their conception of inheritability is broader and includes elements such as temperament, personality, intelligence, talents, and behavioral predispositions. The California Cryobank, for example, offers a *Keirse*

42. Anonymous, *How It Feels to Be a Child of Donor Insemination*, 324 BRIT. MED. J. 797, 797 (2002).

43. See California Cryobank, Donor Profiles, Sample Long Profile 1, available at http://www.cryobank.com/_resources/pdf/SampleInformation/ProfileSample.pdf.

44. Miller, *supra* note 8, at 35, 38.

45. Guido Pennings, *The Right to Choose Your Donor: A Step Towards Commercialization or a Step Towards Empowering the Patient?*, 15 HUM. REPROD. 508, 508–09 (2000).

Temperament Sorter (a widely used self-assessed personality questionnaire) for many donors, explaining to potential parents that it "may provide an interesting insight into your own child's temperament some day."⁴⁶

Allowing donor-conceived individuals access to this type of non-identifying personal information about the donor can, in some cases, satisfy the need to know facts that may help close identity gaps and provide some degree of relief from the sense of discontinuity and detachment that can stem from donor conception. Collecting, recording and sharing such information is thus an effective way to minimize potential future harm to offspring without compromising the donor's desire to remain anonymous. While these policies are currently adopted voluntarily by some sperm banks and programs in the United States, it is possible to demand their execution by legal oversight if an "identity approach" towards genetic relatedness becomes socially accepted. The issues involved in implementing such a system of oversight go beyond the scope of this paper.

C. KNOWING YOUR GENETIC ORIGINS: THE RELATIONAL ASPECT

The third aspect of "the right to know one's genetic origins" is the right to know the identity of the donor in order to make contact and initiate a potential relationship. The concept of "kinship" has traditionally referred to the overlap of a biological and a social relationship. "The conventional understanding of kinship is based on the idea of an inherited relationship, one in which a biological and genetic connection permits offspring to inscribe that relationship in their social identity."⁴⁷ In the case of donor conception the two are detached and a parent-child relationship is constructed in the absence of the genetic connection.⁴⁸ This detachment can leave a psychological void

46. California Cryobank, Sample Donor Information, <http://www.cryobank.com/Donor-Search/Sample-Donor-Information/> (last visited Feb. 26, 2010).

47. Jennifer Harrington et al., *Nonreproductive Technologies: Remediating Kin Structure with Donor Gametes*, 33 SCI. TECH. & HUM. VALUES 393, 394 (2008).

48. In the case of egg donation, however, the biological connection created by pregnancy, childbirth and possibly breast feeding is present and may be experienced—by mother and offspring—as compensating to some degree for the loss of the genetic connection. Judith Kottick, Mercer County Woman, *Adoption or Egg Donation?*, <http://www.countywomannewspapers.com/wordpress/?p=1284> (last visited Apr. 24, 2010) ("The advantages of egg and sperm donation include a biological

that offspring long to fill.

Some donor-conceived individuals express a desire to meet with their donor and to establish a relationship. Such desires are framed in two slightly different ways. The first is based on the idea that personal interaction is the best way to get to know the donor in order to better know or understand oneself. In this sense, the relationship is desired as an effective way to fill in the identity blanks. However, rather than settling for information that is provided indirectly through dry facts, writings, recordings or movies (as described in the previous section), the need is to glean the information directly by personal interaction. In the words of “Rose,” a donor-conceived woman:

I'd like to 'see' the personality traits I've inherited—it'd be fun to recognize them in my donor father. I'd like to know what the donor does for a living, what conflicts he's had, how he's resolved them, what issues he struggles with. My fantasy is that we could learn from each other about how to deal with life.⁴⁹

The second framing is based on the idea that the donor is, in some sense, a component in the fabric of the family that has been missing and can now be re-introduced. The donor in this case is perceived as a “genetic *parent*,” in a way that is analogous to the biological parent of an adoptee. Meeting the donor is perceived as a step towards establishing a long-term relationship that would connect donor-conceived individuals with a missing part of their family narrative and potentially open the door for new enriching experiences. In the words of Karen, a donor-conceived woman:

My imagination left me with so many more questions and revelations. I might have more grandparents, aunts, uncles, and cousins. I might even have siblings! I was excited. I couldn't wait to find these people and introduce myself. We shared a biological connection. We were family! I was sure they'd want to meet me.⁵⁰

Some donor-conceived individuals describe fantasies about who the donor might be and about meeting him or her someday. Researchers have argued that such fantasies are a

connection through pregnancy, the ability to control prenatal environment and breast feed, and the knowledge of half of your child's genes For some people pregnancy is a healing experience and offers the change to feel 'normal'”)

49. Turner & Coyle, *supra* note 22, at 2046.

50. Karen, A Donor-Conceived Woman and Mother, *When the Children Grow Up*, in 1 VOICES OF DONOR CONCEPTION: BEHIND CLOSED DOORS: MOVING BEYOND SECRECY AND SHAME 51, 53 (Mikki Morrissette ed., 2006).

coping strategy that is employed in the absence of a real relationship with the donor to block the "threat to their identity by providing temporary escape through wishful thinking or speculation."⁵¹ Be that as it may, the desire to meet one's donor can run deep and create strong motivation to search for that person and attempt to make contact with him or her.

An obvious concern is that donors may reject the request to meet or the suggestion of a long-term relationship, thus causing disappointment and heartache. In the words of "Rachel," a donor-conceived woman: "He ignored me—wouldn't respond or take my phone call . . . he behaved as I thought he would—disrespectfully and without conscience or compassion for me."⁵² Such rejection can even lead to emotional devastation, if it comes following years of fantasies about the long awaited "reunion."

1. Policy Solutions and the Meaning of Genetic Relatedness

Addressing the relational aspect of the "right to know one's genetic origins" requires a policy of full-identity disclosure and a mechanism that would allow offspring to contact donors at a certain age and explore the possibility of establishing the desired relationship. Of the three aspects, this one requires the most demanding policy solution and is currently the most controversial in the United States. In the words of the ASRM's Ethics Committee:

[S]upport has grown in recent years for disclosing the fact of donation to children and allowing access to non-identifying information to offspring who request it. There is less agreement about the relative merits of releasing identifying information about donors, but it is widely agreed that such release is acceptable if all parties agree.⁵³

The appropriate policy solution therefore requires that donors agree in advance to their identity being disclosed to offspring and to the fact that offspring might attempt to contact them years later. Many have argued that this requirement would lead to a severe shortage of donors (since most donors do not agree to identity disclosure)⁵⁴ and that such a shortage would end up hurting couples and women in need of a

51. Turner & Coyle, *supra* note 22, at 2046.

52. *Id.* at 2047.

53. Ethics Comm. of the Amer. Soc'y for Reprod. Med., *Informing Offspring of Their Conception by Gamete Donation*, 81 FERTILITY & STERILITY 527, 527 (2004).

54. Collier, *supra* note 10.

donation.⁵⁵ Some evidence does exist to support these claims from countries that have banned anonymity by law.⁵⁶ Others, however, argue that after an initial drop, numbers would increase again as donor recruitment strategies would adapt, for example from strategies focused on monetary compensation to a focus on altruism.⁵⁷

In the United States, disclosure of identity is not regulated by law and donor anonymity is still the norm. However, the practices of sperm banks, programs and clinics vary. A growing number of sperm banks hold a “double track” policy: alongside traditional anonymous donation they offer “open donation” or “identity release” programs which allow disclosure of donor identity to offspring when they reach adulthood.⁵⁸ In these programs donors agree in advance that identifying information be shared with offspring years later.⁵⁹ A review has shown that the ratio of open identity to anonymous sperm donors in a program increases the longer the program offers an open identity option.⁶⁰ An initial study of families who chose an open identity sperm donor concluded that almost all parents had no regret and almost all told their child early on about his or her conception and reported a neutral to moderately positive impact.⁶¹

In most jurisdictions around the world donor anonymity is still protected, either by explicit legislation or by virtue of being permissible and accepted practice. Over the past twenty-five years, however, eleven jurisdictions have passed legislation

55. Peter Wardle, *The Real Impact of the Removal of Donor Anonymity*, BIONEWS, Feb. 8, 2008, http://www.bionews.org.uk/page_37975.asp.

56. *Id.* Wardle quotes a recent survey of Donor Insemination services performed by the British Fertility Society, following the 2005 implementation of the new U.K. law banning anonymous donations. The survey found that 94% of clinics were finding it harder to buy in donor sperm; 89% charged more for treatment because of the increased cost of the sperm they are able to purchase; 74% had increased their waiting lists; and 86% were able to offer less choice of donor.

57. Joanna E. Scheib & Rachel A. Cushing, *Open-Identity Donor Insemination in the United States: Is It on the Rise?*, 88 FERTILITY & STERILITY 231, 232 (2007).

58. Miller, *supra* note 8, at 30–31.

59. *Id.*

60. Scheib & Cushing, *supra* note 57, at 232 fig. 1.

61. J.E. Scheib et al., *Choosing Identity-Release Sperm Donors: The Parents' Perspective 13-18 Years Later*, 18 HUM. REPROD. 1115, 1121 (2003).

formally prohibiting anonymous donation,⁶² based on an acknowledgement of the strong interest that donor-conceived individuals have in knowing their genetic origins as trumping the donors' right to anonymity.⁶³

Such an acknowledgement is based on a view that assigns the broadest meaning to genetic relatedness: a view of genetic relatedness as a connection and therefore as justifying an appeal for a personal relationship. It makes an implicit assumption that genetics are responsible for much more than inheritability; that it is an aspect of what connects human beings to each other and cannot be ignored or relinquished. In the words of a potential donor-egg recipient:

To me genes have always been about connections. It is not so much that I want a child that looks or acts like me. . . . It is that genes provide an actual, physical link between persons. . . . I like knowing that my ancestors are PART of me. I always pictured myself like in one of those paper doll chains, linked on both sides to countless other people. . . . [T]he idea makes me feel connected to humanity. . . . It makes me feel grounded.⁶⁴

D. KNOWING YOUR GENETIC ORIGINS: THE PARENTAL DISCLOSURE ASPECT: WHAT IF PARENTS DO NOT TELL?

The "right to know one's genetic origins" is multifaceted, but none of its aspects can be claimed by donor offspring if they are unaware of the circumstances of their conception. However, a policy that forces parents to tell has not been implemented anywhere. As Lucy Frith points out: "none of the countries, which have adopted a policy of non-anonymous donation, have formalised a system for ensuring that children know how they were conceived; the decision . . . is left to the parents."⁶⁵ Therefore, "a child's legal right to identifying information is

62. See Blyth & Frith, *supra* note 5, at 177 tbl. 1 (citing the eleven jurisdiction's legislation prohibiting anonymity). New Zealand, three Australian states (Victoria, Western Australia and The New South Wales) and seven European countries (Sweden, Austria, Switzerland, The Netherlands, Norway, the UK, and Finland) banned anonymity by legislation. Only in Austria, Sweden, and Victoria have donor-conceived individuals reached the age at which they can request the identity of their donor. There is no information yet about their experiences in attempting to access information.

63. Blyth & Frith, *supra* note 5, at 175.

64. katedaphne, *All About Genes*, IT'S EITHER SADNESS OR EUPHORIA (Oct. 5, 2008), <http://sadnessoreuphoria.wordpress.com/2008/10/05/all-about-genes/> (last visited Apr. 24, 2010).

65. Frith, *supra* note 12, at 477.

contingent upon its parent's fulfillment of a moral, rather than a legal, duty."⁶⁶ If parents choose not to tell, no open-identity policy can achieve the goal of providing offspring with information, because without knowing the truth they cannot explore how they feel about their conception and what needs are raised by this knowledge.

Studies show that an overwhelming majority of parents choose not to tell their children that donor sperm or eggs were involved in their conception.⁶⁷ Reasons include the wish to protect the child from knowledge that is perceived as disruptive, to protect both parent and child from negative reactions by society, to protect the relationship of the child with the genetically-unrelated parent, and to hide the fact of infertility.⁶⁸ However, there is growing support in recent years for the position that telling children the truth about their conception is in their best interest.⁶⁹ Small studies also show that disclosure at an early age is psychologically preferable, since disclosure later in life—as well as accidental disclosure by a third party—causes mistrust, anger, and confusion.⁷⁰ Moreover, as the role of genetic testing in medical practice becomes more prevalent, inadvertent disclosure becomes more probable than in the past.⁷¹

66. *Id.* at 478.

67. See A. Brewaeys et al., *Anonymous or Identity-Registered Sperm Donors? A Study of Dutch Recipients' Choices*, 20 HUM. REPROD. 820, 823 (2004) (finding that only 17% of parents choosing an anonymous donor intended to disclose to the child the circumstances of his or her conception); Claes Gottlieb et al., *Disclosure of Donor Insemination to the Child: The Impact of Swedish Legislation on Couples' Attitudes*, 15 HUM. REPROD. 2052, 2054 (2000) (contrasting a finding that 52% of parents of donor-conceived children had told or planned to tell the child about the child's origins with earlier studies showing much lower rates of disclosure); Susan Klock et al., *A Prospective Study of Donor Insemination Recipients: Secrecy, Privacy and Disclosure*, 62 FERTILITY & STERILITY 477, 481 (1994) (finding that only 27% of couples surveyed planned to tell the child of his or her donor origin).

68. Maggie Kirkman, *Parents' Contributions to the Narrative Identity of Offspring of Donor-Assisted Conception*, 57 SOC. SCI. & MED. 2229, 2234–35 (2003); Robert D. Nachtigall et al., *The Disclosure Decision: Concerns and Issues of Parents of Children Conceived Through Donor Insemination*, 178 AM. J. OBSTETRICS & GYNECOLOGY 1165, 1166–67 (1998).

69. Ethics Comm. of the Am. Soc'y for Reprod. Med., *supra* note 53, at 527.

70. See Hewitt, *supra* note 40 *passim*; Turner & Coyle, *supra* note 22, at 2044–45.

71. McGee et al., *supra* note 2, at 3.

1. Policy Solutions and the Meaning of Genetic Relatedness

In light of the accumulating evidence and the subsequent gradual change in social attitudes, two approaches are discussed by researchers and policy makers to address the issue of parental disclosure. The first is to enhance our educational efforts and endorse a culture of openness and acceptance, encouraging parents to be honest with their children and providing them with counselling and tools for doing so.⁷²

The second approach supports the creation of a legal mechanism ensuring that the child is told. This could be accomplished by adding to birth certificates the words "by donation" by the father's and/or the mother's names, or by issuing a "donor conception certificate" that would be attached to the child's birth certificate.⁷³ A policy that forces parents to tell would be based on the most far-reaching understanding of genetic relatedness, seeing it as a powerful connection that is embedded in the nature of being human. Assigning such significance to genetic relatedness means that it is weighty and extensive enough to justify state intrusion into the family. It is an acknowledgement that society should not partake in scenarios in which individuals are forced to relinquish the genetic tie by virtue of ignorance. Some have even argued that a policy which allows parents not to tell means that the state colludes with parents in deceiving their children.⁷⁴

This second approach is still considered by most to be extremely controversial as it infringes upon the parents' right to privacy and intrudes into the intricate fabric of family dynamics. Such an approach conflicts with the traditional liberal approach of protecting the privacy of the family sphere from state intrusion. One can argue that the protection of children within the family should trump considerations related to the protection of parents' privacy, as in the case of child abuse or neglect. However, in light of the lack of evidence from

72. Ethics Comm. of the Am. Soc'y for Reprod. Med., *supra* note 53, at 530.

73. Eric Blyth et al., *The Role of Birth Certificates in Relation to Access to Biographical and Genetic History in Donor Conception*, 17 INT'L J. CHILD. RTS. 207, 208 (2009).

74. David Gollancz, *Time To Stop Lying*, GUARDIAN (London), Aug. 2, 2007, available at <http://www.guardian.co.uk/g2/story/0,,2139678,00.html>.

large-scale studies regarding the impact of non-disclosure on offspring, this argument is—at least currently—difficult to defend. Therefore, most researchers currently endorse the implementation of educational campaigns and improved counselling for parents, rather than straightforward enforcement of disclosure, with the hope that social change is underway and that further evidence will assist in pushing forward new legislation and regulation, in due time.

IV. CONCLUSION

The “right to know one’s genetic origins” is complex and multifaceted. This paper presented four aspects of this right, the understanding of genetic relatedness that underlies each, and the policy solutions required to address them. Two of these policies allow addressing the needs of donor-conceived individuals without violating the rights of donors: supplying complete and updated medical history and medically relevant genetic information, and supplying non-identifying personal “narrative” information about the donor, to assist offspring in dealing with identity issues. I therefore argue that these policies should be implemented.

A third policy, of providing parents with education and counselling to encourage them to tell children the truth about the circumstances of their conception, allows pushing forward the agenda of donor-conceived individuals without violating the rights of parents to privacy and therefore should also be implemented, as is currently done in many countries.

Some believe that the current trend towards openness in gamete donation mirrors the process that the practice of adoption went through over the past years.⁷⁵ Will donor-conceived individuals’ right to know the truth and to have full access to all information about donors be eventually acknowledged by society and by law makers? Only time will tell.

75. ADAM PERTMAN, ADOPTION NATION: HOW THE ADOPTION REVOLUTION IS TRANSFORMING AMERICA 222–25 (2000).