

2010

How the Internet is Reshaping Assisted Reproduction: From Donor Offspring Registries to Direct-to-Consumer Genetic Testing

Andrea Braverman

Follow this and additional works at: <https://scholarship.law.umn.edu/mjlst>

Recommended Citation

Andrea Braverman, *How the Internet is Reshaping Assisted Reproduction: From Donor Offspring Registries to Direct-to-Consumer Genetic Testing*, 11 MINN. J.L. SCI. & TECH. 477 (2010).

Available at: <https://scholarship.law.umn.edu/mjlst/vol11/iss2/3>

The Minnesota Journal of Law, Science & Technology is published by the University of Minnesota
Libraries Publishing.

Braverman AM. How the Internet is Reshaping Assisted Reproduction: From Donor Offspring Registries to Direct-to-Consumer Genetic Testing. *Minnesota Journal of Law, Science & Technology*. 2010;11(2):477-96.

Articles

How the Internet is Reshaping Assisted Reproduction: From Donor Offspring Registries to Direct-to-Consumer Genetic Testing

Andrea Mechanick Braverman, Ph.D.*

I. INTRODUCTION

In the traditional medical model, assisted reproductive technologies (ART) featured the doctor acting in the role of the sole decision-maker, choosing what was best for the patient. The patients were passive participants in the building of their families through gamete donation; indeed, it was frequently the doctor or nurse who selected the sperm donor for an infertile couple. As the structure of the family has changed over the past few decades and options for family building have grown, the role of the intended parents has evolved from passive customers to informed consumers. The growth of the Internet has allowed previously unheard of access to information sharing—whether through posting on boards, real time selection of gamete donors, direct-to-consumer genetic testing, or voluntary gamete registries. Intended parents now have access to options beyond what their physicians offer simply by logging onto the Internet and conducting a search. This paper discusses how these changes have evolved and will affect future policy, and the implications of these changes for the practitioner, intended parents, and the donor conceived persons.

© 2010 Andrea Mechanick Braverman.

* Dr. Andrea Mechanick Braverman is the Director of Complementary and Alternative Medicine of Reproductive Medicine Associates of New Jersey.

II. HISTORICAL PERSPECTIVE

Gamete donation has arguably been practiced outside the medical office for millennia, but the first documented use of sperm donation occurred in the late nineteenth century in Philadelphia.¹ A merchant and his wealthy Quaker wife (who was ten years younger than he) sought out medical assistance after being unable to have a child.² Upon examination, the wife was not found to have any fertility issues and attention was turned to her husband.³ His examination led to the discovery that he was azoospermic (the absence of sperm).⁴ An anonymous donor was selected from among the medical students—the most attractive student was chosen—to inseminate the wife, and the insemination was performed while she was under anesthesia.⁵ The husband was told about the use of the donor later and was reported to have been pleased that his wife was pregnant, but he asked that the wife not be told about the use of a donor.⁶ The wife delivered a healthy boy.⁷

This story was reported later by one of the medical students involved; it is not known if he was also the donor.⁸ The reporting student sought out the son when the son was twenty-five years old and later published the report.⁹ In early twentieth-century Philadelphia, the anonymity of the recipient couple was jeopardized, as information was published about the case in the medical community.¹⁰ In that report, there was enough information to identify both of the recipients and/or the donor: the age of the son and the wife's status as a Quakerin high society, for example, could have easily compromised anonymity.¹¹ Similarities exist today regarding whether the

1. ROBERT SNOWDEN & G. D. MITCHELL, *THE ARTIFICIAL FAMILY: A CONSIDERATION OF ARTIFICIAL INSEMINATION BY DONOR* 13 (1981).

2. *Id.*

3. *Id.*

4. *Id.*

5. *Id.*

6. *Id.*

7. *Id.*

8. *See id.*

9. *See* A. D. Hard, *Artificial Impregnation*, 27 *MED. WORLD* 163, 163 (1909).

10. *See id.*

11. *Id.* at 163–64.

identities of donors in ovum donation are truly protected, as full biographical information is available on the Internet accompanied by pictures of the donor and, not infrequently, other family members, children, or friends.¹²

In contrast to sperm donation, ovum donation can only take place in the medical office.¹³ Ovum donation historically involved both anonymous donors as well as known donors such as friends or family.¹⁴ The first use of ovum donation occurred in 1983.¹⁵ By 1998, 10% of all ART cycles involved donor ovum (7,756 cycles),¹⁶ and by 2005 the percentage of all ART cycles that involved ovum donation had risen to 12% (16,161 cycles) and resulted in 5,043 live births, “of which 59.2% were singletons, 38.9% were twins, and 1.9% were triplets or more.”¹⁷

Currently, there are no good estimates of the number of children born through sperm donation. The old statistic of 30,000 babies per year originated in a government sponsored survey from the Office of Technology Assessment, but advances in male factor fertility treatment alone have generated significant challenges to the accuracy of that number.¹⁸

Traditionally, the law has considered genetics to be of significant value in the assignation of parenthood.¹⁹ This valuation reflects a societal view that genetics is central to kinship. Determination of fatherhood was predicated upon the presumption that any child born within a marriage was

12. See Jean Benward, Andrea Mechanick Braverman & Bette Galen, *Maximizing Autonomy and the Changing View of Donor Conception: The Creation of a National Donor Registry*, 12 DEPAUL J. HEALTH CARE L. 225, 227–28 (2009).

13. See University of California San Francisco Medical Center, For Recipients: Ovum Donation Process, http://www.ucsfhealth.org/adult/edu/ovum_donation_process_for_recipients/index.html (last visited Mar. 6, 2010).

14. Benward et al., *supra* note 12, at 227–28.

15. Clare Murray et al., *Egg Donation Parents and Their Children: Follow-up at Age 12 Years*, 85 FERTILITY & STERILITY 610, 610 (2006).

16. Ctrs. for Disease Control & Prevention, *Use of Assisted Reproductive Technology—United States, 1996 and 1998*, MORBIDITY & MORTALITY WKLY. REP., Feb. 8, 2002, <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5105a2.htm>.

17. Benward et al., *supra* note 12, at 225.

18. See *id.*

19. Anne Reichman Schiff, *Frustrated Intentions and Binding Biology: Seeking AID in the Law*, 44 DUKE L.J. 524, 529 (1994).

considered the legitimate child of the marriage.²⁰ For donor insemination, which has been an established procedure for over a century, the law is less clear due to a patchwork of state laws: “Present law concerning AID [artificial insemination by donor] tends to be piecemeal, failing to provide a coherent response to the complexities and challenges presented by this not-so-‘new’ reproductive practice.”²¹ As Schiff later points out, the intent to conceive historically has played a limited role in coital procreation.²² As genetics and gestation were further separated with the introduction of donor ovum, donor embryos, and gestational surrogacy, intentionality has become a critical consideration.²³

This trend continues into current legal analysis.²⁴ Pre-birth orders have been issued for genetic intended parents to be placed on the birth certificate and precedent has been set for intended parents using a gamete donor also to be placed on the birth certificate.²⁵ Crockin and Jones summarize the current zeitgeist regarding the gestational carrier:

In contrast to traditional surrogacy, in most states gestational surrogacy or gestational carrier arrangements have been interpreted more liberally. A woman carrying a pregnancy that does not involve her genetic material has been less likely to be legally deemed to be the mother and instead is usually allowed to contract or agree to having the genetic mother and father (or in a smaller number of states, the intended mother and genetic father where an egg donor was used) recognized as the legal parents of the child. Increasingly, state courts have recognized the value of parentage orders (allowed before birth in some states), at least for genetic, intended parents and often even for intended parents using donor gamete(s). Cases involving both donor sperm and donor egg have raised more legal questions than situations where only one of the two is used. A few statutory developments have been reported. Illinois has enacted limited legislation that authorizes the intended genetic parents . . . of a child carried by a gestational carrier to be recognized and entered onto the child’s birth certificate without a court proceeding. Outcomes

20. *Id.* at 530.

21. *Id.* at 534.

22. *Id.* at 550–51 (stating that in the course of human history, conception has had more to do with chance than with the couple’s intentions).

23. *See id.*

24. *See* SUSAN L. CROCKIN & HOWARD W. JONES, JR., LEGAL CONCEPTIONS: THE EVOLVING LAW AND POLICY OF ASSISTED REPRODUCTIVE TECHNOLOGIES 213 (2010) (“Other state courts have placed more emphasis on the intentions [rather than the biological connections] of the parties”).

25. *Id.* at 213–14.

are still very much state- and fact-specific and can be dramatically affected by both choice and conflict of law issues.²⁶

Legal actions involving gestational carriers and gamete donation are now compelling courts to consider intentionality when presented with cases in which genetics is separate from gestation and, upon occasion, when intended parents have no genetic or gestational contribution to the unborn child.²⁷ In contrast, other countries will only consider gestational contribution as the determinant of parenthood.²⁸ For example, in an English court, the gestational carrier and her partner are considered the legal parents; the gestational carrier and her husband must wait a minimum of six weeks after the birth of the child to reach their decision about whether to relinquish parentage.²⁹

As most intended parents begin to consider gamete donation or gestational surrogacy, the first step either prior to, or immediately following, the doctor's visit is to "Google" instantly available articles and websites for more information. Information about changing laws are now only a click of the keyboard away, and intended parents have access to current court cases as well as laws. Newspapers continue to cover the controversies arising from the new technologies and query what determines parentage when donor gametes or a gestational carrier are involved.³⁰ If intended parents choose to discuss their parenting options with family members or friends, those confidants are informed by access to articles and opinions on the Internet, whereas a scant decade ago those same confidants may never have known of these collaborative reproductive options. Consequently, information via the Internet has thrown open the door of the doctor's office; it is no longer solely the doctor-patient relationship which informs the decision-making process.

III. DISCLOSURE OF GAMETE DONATION TO DONOR

26. *Id.*

27. *Id.* at 213–15.

28. Louisa Ghevaert, *What Happens When Surrogacy Goes Wrong: The Recent Indiana Surrogacy Case in Wider Context*, BIONEWS, Feb. 9, 2010, http://www.bionews.org.uk/page_54415.asp.

29. *Id.* ("English surrogacy law . . . overrides natural paternity and maternity and instead requires intended parents to apply to court for an order recognising them as their surrogate-born child's legal parents.")

30. See Stephanie Saul, *Building a Baby, with Few Ground Rules*, N.Y. TIMES, Dec. 13, 2009, at A1.

CONCEIVED PERSONS

Historically, parents were discouraged from disclosing donor conception to their children; these parents were told to “go home and forget all about it.” Much of the medical conceptualization focused on achieving a pregnancy and did not consider the emotional issues that might arise from having non-genetic offspring.³¹ Since gamete donation was originally used for married heterosexual couples, much of the reflection was directed to the male partner concerning how he would attach to a non-genetic child. When ovum donation became a family building choice, the dynamic was subtly shifted because the procedure gave the recipient mother a reproductive role whereas, in sperm donation, the recipient father had no such role. Recent studies have shown that recipient mothers and fathers attach to their non-genetic offspring and that family dynamics are positive.³²

Recipient parents were given little information on their donors.³³ Both sperm and ovum donors supplied a medical history and physical characteristics along with a limited psychosocial history.³⁴ Currently, sperm banks have largely similar information on the donors, but there exists a wide range of information available to recipients regarding their ovum donors, due in large measure to the greater number of medical practices performed on ovum donors and donor recruiters extant.

However, the information given, no matter how extensive, is still just a snapshot in time. Recipients began to anticipate that their children might one day grow up and show curiosity about other aspects of the donor or how the donor had changed over the years.³⁵ In addition, single mothers by choice and lesbian couples had already begun to request more information on the donors as those recipient mothers anticipated their children’s curiosity and made clear that they would disclose such information to their children.³⁶

31. See Benward et al., *supra* note 12, at 226–27.

32. Murray et al., *supra* note 15, at 614–16.

33. Benward et al., *supra* note 12, at 226–29.

34. *Id.*

35. See T. Freeman et al., *Gamete Donation: Parents’ Experiences of Searching for Their Child’s Donor Siblings and Donor*, 24 HUM. REPROD. 505, 513–14 (2009).

36. See Joanna E. Scheib & Rachel A. Cushing, *Open-Identity Donor*

What also became apparent is that no one was clearly addressing the identities of the burgeoning number of stakeholders in gamete donation. The stakeholders are numerous—donor conceived persons, donors, recipient parents, extended family, medical professionals, mental health professionals, legal professionals, sperm banks, ovum donor recruiters, and society—and many of those stakeholders' needs conflict. For example, if a donor conceived person wanted to seek more information on the donor, but the donor had not consented to be contacted, whose needs take priority? By keeping the practice of gamete donation anonymous, conflicting stakeholders' needs and interests would be unmet if the person conceived never knew whether or how to raise her own concerns.

IV. A HISTORIC SHIFT

A historic shift in the medical view of disclosure of the use of donor gametes to donor conceived persons occurred in 2004 when the ASRM Ethics Committee endorsed disclosure by parents to their children.³⁷ The Committee summarized, “[w]hile ultimately the choice of recipient parents, disclosure to offspring of the use of donor gametes is encouraged.”³⁸ As noted earlier, traditional medical advice was to “forget” that the donor was involved in the conception and to not disclose to the child.

In the United Kingdom, the issues about stakeholder concerns have been addressed in a way very much different from that of the United States. The Human Fertilisation and Embryology Act of 2008 permits donor conceived persons to access identifying information about their donors when they reach age sixteen.³⁹ The Act also allows gamete donors to access information about resulting children.⁴⁰ Current debate challenges whether the policy goes far enough because it does

Insemination in the United States: Is It on the Rise?, 88 FERTILITY & STERILITY 231, 232 (2007).

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

38. *Id.*

39. Human Fertilisation and Embryology Act, 2008, c. 22, § 31ZA(1)–(4) (Eng.), *available at* http://www.opsi.gov.uk/acts/acts2008/ukpga_20080022_en_1.

40. *Id.* at § 31ZD.

not ensure that donor conceived persons are told of their donor conception.⁴¹ This emerging voice argues strongly that the donor conceived person's rights and needs supersede those of all others.

Multiple websites give voice to the feelings and concerns of donor-conceived persons.⁴² The overwhelming sentiment is that information and connection with the donor are critical. The men and women who post on these sites decry the practice of anonymous sperm, egg, and embryo donation and argue vigorously against the various justifications for anonymous gamete donation, for example, that genetics is trumped by the person who loves you and raises you, or that these children feel more loved because they are planned.⁴³ As blogger Lindsay posts on "Confessions of a Cryokid":

So many times I hear people tell me that their child is so loved and so wanted, more wanted than children conceived during normal sexual intercourse since the parents had to go through so much for that child to be alive. My response is that first of all, as a couple (or a single woman) is going through treatments in order to get pregnant, they believe that this child is so loved and wanted only because THEY want a child so badly. They also cannot love that child as an individual as he or she has not even been conceived yet! This change in pretense from personal wants and needs for a child into a child that is so wanted and thus loved has occurred without little resistance . . . My second argument of the love is all you need theory (as opposed to being raised by two genetically connected parents), is that how can genetics be a double standard?? What I mean is that we are told that genetics should not matter and that it is the parents who raise us who matter, and that nature really has little role in our identity aside from trivialities, and it's all about nurturing and who changed our diapers. Yet at the same time these are same parents who HAD to have a child that was at least biologically related to one of them and that's why they had to resort to donor conception instead

41. Lucy Frith, *Telling Is More Important Than Ever: Rights and Donor Conception*, BIONEWS, Jan. 19, 2010, http://www.bionews.org.uk/page_53094.asp.

42. *E.g.*, Confessions of a Cryokid, <http://cryokidconfessions.blogspot.com> (last visited Mar. 8, 2010); Donor Conception Network, Offspring Reflections, <http://www.dnetwork.org> (click "Articles & Personal Stories" from the right-hand index, then click "All Personal Stories," then click "Offspring Reflections" and select the desired donor conceived child article) (last visited Mar. 8, 2010); Donor Conception Network Forums, <http://www.donor-conception-network.org/forum/index.php> (must be a member to view forums) (last visited Mar. 8, 2010).

43. *See, e.g.*, Lindsay M. Greenawalt, *All You Need Is...Love??, CONFESSIONS OF A CRYOKID*, (Mar. 15, 2008, 5:40 PM), http://cryokidconfessions.blogspot.com/2008/03/all-you-need-islove_15.html.

of adoption. So you want a biologically related child because it's important to you, but we are not allowed to feel grief that one or both of our biological parents are not raising us?!⁴⁴

As recipient parents' behaviors began to shift towards choosing to disclose to their children their donor origins, information on the donors began to expand. Parents became much more aware that the medical history of their donor would be different from their own and that this information may have to be shared with the child.⁴⁵ Other recipient parents began to explore their feelings concerning the moral and ethical rights of their children to know the children's own genetic origins.⁴⁶ Clearly, many donors conceived persons and others feel it is the child's inherent right to know her own genetic origins.⁴⁷

With disclosure came the recipient parents' need to get more information to tell the child her own story. Sperm banks moved to providing in-depth psychosocial histories along with medical information.⁴⁸ Currently, sperm banks will also provide audio interviews, childhood pictures, adult pictures, silhouettes, and staff impressions of the donor.⁴⁹ Requests from the recipients also reflected the change toward more open arrangements and the desire for the opportunity for future contact.⁵⁰ In 1996, 10.7% of sperm banks sampled in one study had open identity donors; by 2006, the percentage had tripled to 32%.⁵¹

Another agent of change was the growing public face of infertility and family building. Newspapers and magazines began to publish articles about sperm donation and noted that there were usually multiple offspring for a given donor.⁵² Deep concerns were also raised about the potential for a large number of persons to be conceived utilizing a single donor.⁵³

44. *Id.*

45. *See* Freeman et al., *supra* note 35, at 509.

46. *See id.* at 513–14.

47. *Id.* at 514.

48. *Accord* Benward et al., *supra* note 12, at 227–28 (noting the shift among sperm banks and egg donor programs toward providing more complete information about donors).

49. *See id.* at 227–28.

50. *See id.* (stating that there is increased consumer demand for more donor information).

51. *See* Scheib & Cushing, *supra* note 36, at 232.

52. *See, e.g.*, Emily Bazelon, *The Children of Donor X*, O MAG., Apr. 2008, at 250, 251.

53. *See, e.g.*, Joanna E. Scheib & Alice Ruby, Letter to the Editor, *Beyond Consanguinity Risk: Developing Donor Birth Limits That Consider*

Heretofore, donor conception was not openly discussed, but media attention, including an Oprah show, has begun to highlight genetics, nurture, and the issues related to families conceived through donor gametes.⁵⁴

Despite the anonymous nature of their conceptions, donor conceived persons became aware that they had genetically related half-siblings, and the Internet provided the tool to make contact. In 2000, The Donor Sibling Registry was established, and it has purported to have made, as of the date of writing, 7157 connections between donor conceived persons, half-siblings, and/or donors.⁵⁵ In addition, several other registries have appeared, including at one of the large U.S. sperm banks.⁵⁶ Websites, such as those for single mothers by choice, allow members to informally make the connection that they had used the same donor.⁵⁷

The medical model was originally built on the assumption that patients would never know that the same donor was used; however, the Internet directly challenged that assumption by putting the tools of information exchange directly in the hands of the recipients who could then choose whether or not to seek connections. As the Internet has grown, the fluidity of information exchange has also challenged the medical model of anonymity and discrete information. Today donors' backgrounds or other sensitive information are very likely to be a part of the readily accessible information on the Internet by participating in Facebook, MySpace, and Twitter. Donor profiles that detail education, activities, and family member characteristics, among other factors, continually challenge the idea of a fortress of anonymity. Additionally, many sperm banks and ovum donor recruiters have childhood and other

Psychosocial Risk Factors, 91 FERTILITY & STERILITY e12, e12 (2009).

54. *The Oprah Show: The Ultimate Reunion: When Dad Is a Sperm Donor* (Syndicated television broadcast Feb. 8, 2008), (summary available at http://www.oprah.com/showinfo/The-Ultimate-Reunion-When-Dad-Is-a-Sperm-Donor_2).

55. The Donor Sibling Registry, <http://www.donorsiblingregistry.com> (last visited Mar. 31, 2010).

56. California Cryobank's Sibling Registry, <http://www.cryobank.com/Services/Sibling-Registry/> (last visited Mar. 10, 2010).

57. Choice Moms, <http://www.choicemoms.org> (last visited Mar. 3, 2010); Single Mothers by Choice, <http://www.singlemothersbychoice.com> (last visited Mar. 3, 2010).

pictures posted,⁵⁸ further shattering the pretense that anonymity is preserved.

V. RESEARCH ON DONOR CONCEIVED PERSONS

Recent studies survey donor conceived persons about their thoughts, feelings and other issues.⁵⁹ The major drawback of the recent research is that it has been limited to internet based surveys, and it is questionable whether such surveys are truly a representative voice of donor conceived persons. Nonetheless, the studies described valid experiences and opinions of one part of the donor conceived community. Regardless of how representative the research is, the data clearly present a legitimate group of donor conceived persons and their views and issues. In 2009, one internet survey study found that almost half of the surveyed donor conceived persons learned of their conception after age 18 and had no information on their donor.⁶⁰ This group had searched for identifying information on their donor and half-siblings; the participants endorsed the belief that identifying donor information should be provided.⁶¹

In another 2009 internet study of the parents of donor conceived persons, in which 791 parents participated, the parents noted that their principal motivations for searching for donor siblings were curiosity and enhancing the child's sense of identity.⁶² Of those that had contact with donor siblings or the donor, the experiences were positive.⁶³ In an earlier study with sperm donor conceived adolescents whose parents used an open identity donor, 82.8% wanted to learn more about the donor so they could learn more about themselves,⁶⁴ echoing the 2009

58. Xytex Cryo International Sperm Bank, Patient Section: Answers to Sperm Donor Bank Questions, <http://xytex.com/sperm-donor-bank-patient/sperm-donor-bank-patient-faq.cfm#13> (last visited Apr. 3, 2010) (“[M]any donors provide both childhood and adult photos . . .”).

59. See, e.g., Freeman et al., *supra* note 35; Patricia Mahlstedt et al., *The Views of Adult Offspring of Sperm Donation: Essential Feedback for the Development of Ethical Guidelines within the Practice of Assisted Reproductive Technology in the United States*, FERTILITY & STERILITY (forthcoming); Joanna E. Scheib et al., *Adolescents with Open-Identity Sperm Donors: Reports from 12–17 Year Olds*, 20 HUM. REPROD., 239 (2005) [hereinafter Scheib et al., *Adolescents*].

60. Mahlstedt et al., *supra* note 59 (corrected proof at 4, available to subscribers at <http://www.fertstert.org/inpress>).

61. *Id.* at 4, 6.

62. Freeman et al., *supra* note 35, at 505, 507–09.

63. *Id.* at 511–12.

64. Scheib et al., *Adolescents*, *supra* note 59, at 239, 247.

study reporting that it is the desire to explore identity rather than seeking another parental relationship that motivated the participants.⁶⁵ Parents reported overall positive experiences in contacting or meeting donor siblings and the donor.⁶⁶ Much of the information seeking may be for psychosocial rather than medical reasons, and recent commentary suggests that this information may play an important role in identity formation for many donor conceived persons.⁶⁷

Resoundingly, studies have shown donor conceived children to be well-adjusted, developmentally appropriate, and attached to both their genetic and non-genetic parents.⁶⁸ In a follow-up of twelve-year-old children conceived through ovum donation, sperm donation, and in vitro fertilization (IVF), researchers found that there was no difference in the quality of parenting between families that conceived through egg donation and those that conceived through IVF.⁶⁹ Differences existed when comparing mothers of donor insemination children to mothers via egg donation.⁷⁰ Mothers of donor insemination children tended to be more emotionally involved with their children and more responsive to their children's needs than their egg donation counterparts.⁷¹ The study concluded, however, that conceived through ovum donation children were well adjusted with regard to their social and emotional development.⁷²

In a similar study, authors concluded that twelve-year-old children conceived through sperm donation were also well adjusted with regard to their social and emotional

65. Freeman et al., *supra* note 35, at 507–09, 513–14.

66. *Id.* at 511–12.

67. See Benward et al., *supra* note 12, at 232–33 (“A compelling . . . reason for providing full medical, genetic, and social information to donor conceived persons centers on the challenges to identity development that donor conception can pose.”).

68. Susan Golombok et al., *Families with Children Conceived by Donor Insemination: A Follow-Up at Age Twelve*, 73 CHILD DEV. 952, 962–66 (2002); Murray et al., *supra* note 15, at 616–17; Scheib et al., *Adolescents*, *supra* note 59, at 248.

69. Murray et al., *supra* note 15, at 616 (“This suggests that the absence of a genetic link with the mother is not essential for the development of positive family relationships.”).

70. *Id.*

71. *Id.*

72. *Id.* at 617–18.

development.⁷³ Adolescents, ages twelve through seventeen, conceived through donor sperm, also reported that they were comfortable with their donor origins in a different study.⁷⁴ Finally, an Australian study involving adolescents who were conceived via sperm donation explored, through in-depth interviews, their views on how to communicate donor conception within the family.⁷⁵ The recurrent theme was that honesty and parental attitudes will have the most profound influence on the donor conceived person's response.

Although these studies are important because they have documented that children and parents are doing well after delivery, issues related to how each stakeholder feels and what issues emerge have not been addressed. Clearly, cognitive and emotional development are each a process, and research has not addressed these different stages. These limitations, along with the very real issue of finding a representative sample, create the road map for researchers to consider when designing future studies.

VI. TOWARDS A DEVELOPMENTAL MODEL OF GAMETE RECIPIENT'S STAGES OF FEELINGS WITH DONOR GAMETES

It is reasonable to assume that recipient parents' feelings will not necessarily remain the same from the time of the initial consultation in the physician's office to the time when the parents' children have become adults. The loss of genetic connection is precisely that—a loss. As with any loss, the individual and the couple must grieve. Although focused on building a family, each intended parent must sort through his or her individual reaction to the loss of the planned-for and fantasized-about child. For example, most intended parents imagine a child similar to themselves or their families, e.g., "She'll have the best of both of us." When a donor is introduced, intended parents will react to their feelings at different stages and process the issues through the lens of those reactions.

Elisabeth Kubler-Ross introduced the concept of stages with death and dying and the idea of applying stage theory to

73. Golombok et al., *supra* note 68, at 964.

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

75. Maggie Kirkman et al., *Families Working It out: Adolescents' Views on Communicating About Donor-Assisted Conception*, 22 HUM. REPROD. 2318, 2320–23 (2007).

coping with many life events.⁷⁶ The five stages of the grief response cycle are denial,⁷⁷ anger,⁷⁸ bargaining,⁷⁹ depression,⁸⁰ and acceptance.⁸¹ Kubler-Ross never suggested a linear movement through these stages, but rather proposed that these stages existed and that individuals moved through them at various speeds, at times moving forward and backward within the stages.⁸²

Using the stages of the grief response cycle as a backdrop against which the emotions of gamete donation can be projected gives a better understanding of the process for the individual. As intended parents make the decision to involve a donor to create their family, they experience many feelings at the same time as they attempt to process information and make decisions. Prior to conception, intended parents have the task of grieving and processing their feelings about having a non-genetically related child. If an intended parent is deeply in the denial stage, information will not be processed at all.⁸³ Similarly, if an intended parent is managing the depression stage of the grief cycle, issues related to choosing whether to disclose the involvement of a gamete donor in her child's conception may not be considered; the most prominent feelings at that stage are likely those of sadness, and the conceptualization of a positive or happy future may be difficult or impossible.⁸⁴ Many of the grieving stages also give insight into the fact that emotional issues may take a backseat to the concrete tasks of selecting a donor and navigating inseminations or in-vitro fertilization.

Consequently, stage theory illustrates that the desire for information about the donor may change as the intended

76. See ELISABETH KUBLER-ROSS, ON DEATH AND DYING 34–121 (1969) (outlining the different stages of dying).

77. *Id.* at 34.

78. *Id.* at 44.

79. *Id.* at 72.

80. *Id.* at 75.

81. *Id.* at 99.

82. See *id.* at 122–23.

83. See *id.* at 35 (“Denial functions as a buffer after unexpected shocking news, allows the [person] to collect himself and, with time, mobilize other, less radical defenses.”).

84. See *id.* at 77 (describing the immense sense of loss and sadness that occur during the depression stage when “encouragements and reassurances are not as meaningful”).

parents' feelings and parenting demands evolve over time. If an intended parent is still in any stage other than acceptance, the decision about if and how to tell their donor conceived child cannot be addressed except through the prism of anger, denial, bargaining, or depression. As acceptance emerges, and particularly as a parent is deeply immersed in the daily activities of parenting while also growing in the emotional role of a parent, thoughts about the donor's information will similarly grow and change. Dealing with an inquisitive pre-adolescent, for example, may propel a parent to seek out more information on the donor. Or a parent of a young adult child may find that she is not as ambivalent about contact with the donor as her parental role with the child becomes more firmly established. Needless to say, intended parents prior to conception rarely imagine what it will be like to parent an older child, whether adolescent or adult. Their focus is on having the much desired baby and not on the demands of a pre-adolescent or young adult son or daughter.

As intended parents grow into their role as a parent, so does their need for information to properly parent their children. Information that may not have been sought at an early stage in the process may be very much desired as the child grows. Medical records that were of interest when selecting a donor may now have a different meaning and importance. However, medical records may be discarded after the required legal limit to retain them has expired. In some states, donor medical records must be maintained for seven years.⁸⁵ In seven years, the child would just be beginning first grade, a time when many parents are preparing to tackle the task of disclosing donor origins to their children. The only available venue for information, if donor records have been discarded, may be through the Internet. The ASRM Ethics Committee report stated that "[p]rograms and agencies should maintain accurate records related to tissue donation and are encouraged to set up systems to maintain the donor's psychosocial information and to enable information sharing in the future with any offspring if such information sharing is acceptable to the donor and offspring."⁸⁶ It is doubtful whether

85. See, e.g., GA COMP. R. & REGS. 290-9-8.16 (2010). The limit in New York, however, is twenty-five years after the donor tissue has been released, if the tissue has resulted in a live birth. N.Y. COMP. CODES R. & REGS. tit.10, § 52-2.9(b) (2009).

86. Ethics Comm. of the Am. Soc'y for Reprod. Med., *Interests*,

most programs or recruiters have made provisions for systems to maintain information well into the future. Record retention is affected by programs and recruiters that go out of business, the retirement of partners, or a change in ownership.

VII. INFORMATION AND EXPECTATIONS

Information is not neutral. Information given to the recipient parents, as well as to any donor conceived person, reflects bias. The simple act of giving information to the recipients or donor conceived person suggests that the information is of some importance; otherwise there would be no need to provide it. For example, one donor site in its personal profile on a prospective egg donor, gives a range of information from “favorite book” to “whether the donor likes to take walks in the rain.”⁸⁷ In an extreme example, the question “[d]o you like to kiss with your eyes open or closed” is information that the intended parents can view, but may also be seen by the donor conceived person at some point.⁸⁸ Asking the question implies that this information may be important, either as a genetic trait or simply as an insight into the donor’s personality. Yet does this information give either? And what meaning might the donor conceived person make of this information?

Recently, The Society for Assisted Reproductive Technology (SART) of the American Society for Reproductive Medicine created a donor application through the collaboration of physicians, nurses, and counselors.⁸⁹ The Uniform Donor Application is a comprehensive, twenty-six page application, intended for donor egg and sperm programs.⁹⁰ It includes a twelve-page glossary of inherited diseases, definitions, and additional genetic counseling resources.⁹¹ Although this will make information more consistent across programs and recruiters, and reflects a multi-disciplinary approach, the

Obligations, and Rights of the Donor in Gamete Donation, 91 FERTILITY & STERILITY 22, 22 (2009) [hereinafter *Rights of the Donor*].

87. Observed during the author’s personal clinical experience.

88. Observed during the author’s personal clinical experience.

89. Soc’y for Assisted Reprod. Tech., American Soc’y for Reprod. Med., Uniform Donor Application (2009) (available to members at <http://www.sart.org/index.html>).

90. *Id.*

91. *Id.*

document still reflects the medical bias that professionals have, including the information that donor conceived persons need or in which they have voiced interest. This document, however, marks a significant step forward in acknowledging that information about donors should be gathered and disseminated to the intended parents and donor conceived persons.

The current medical bias is to provide only relevant family medical history and physical characteristics.⁹² Additional information is provided at the discretion (and bias) of the egg recruiter, physician, or sperm bank.⁹³ Information such as favorite movie, earliest memory, or other likes and dislikes is queried based on the supposition that this information reflects directly on the personal character of the donor. The increasing amount of available information about the donor may also open the door to unexpected reactions by the donor conceived person or even by her parents. Learning that the donor had high academic achievement or specific hobbies or interests may lead to an expectation that the donor conceived child would share these abilities or interests.

Easily accessed information on the Internet has usurped the previously limited information provided about the donor. Competition among banks, recruiters, and programs alike has pushed the envelope on the information provided, allowing intended parents to make a more informed decision about their donor. But the information collected is based on various biases and not on what the donor conceived person has expressed her desire to know. When is the information provided too much? Or when is it not enough? And how do intended parents begin to express to their children that the donor's information is a constantly moving target? Personality, interests, and capabilities continually shape and reshape over time.

VIII. DIRECT-TO-CONSUMER-TESTING

Direct-to-consumer testing is another emerging area (along with the Internet) that continues the trend of intended parents making choices independent of their medical provider. Simply put, direct-to-consumer testing shifts the control from the clinician into the hands of the consumer. Available choices

92. See *Rights of the Donor*, *supra* note 86, at 23 (emphasizing the importance of obtaining an accurate donor medical and history and status).

93. See Benward et al., *supra* note 12, at 227–28.

exist, such as the scanning of an individual's genome,⁹⁴ the assessment of risk for heritable diseases,⁹⁵ or even for establishing paternity.⁹⁶ Prior to the Internet, information dissemination about the availability of these tests existed almost exclusively through the medical provider. Direct-to-consumer testing introduced the option for an intended parent to make independent choices, as long as they were willing to pay the costs of such services. The concept of "recreational genomics" was born.⁹⁷

This trend toward decision-making independent of the medical provider appears to be growing rather than disappearing. Physicians and nurses may approve or disapprove of their patients' decisions, such as the choice to select an open identity donor, a donor with very different physical characteristics, or a donor with a complicated medical history; but the medical care provider ultimately may not turn out to be an integral part of the information-seeking and decision-making process. After the initial consultation, the intended parent may spend time on the Internet consulting different websites that may hold a great deal of medical and non-medical information about their donor. Once the pregnancy is established, the intended parent will likely access other websites for information and advice.

When intended parents conceive their child with a donated gamete, the medical care provider may also be the last person to whom those parents would turn for information. In some cases, the medical provider is not involved in the process at all, as is the case in home inseminations with donor sperm. In addition, much of the information-seeking choices will occur long after the intended parent leaves the medical provider. The availability on the Internet of information and support may offer more immediate aid than the medical care provider who has contributed a narrow slice of medical information at the start of the journey towards parenthood. The website of the Donor Conception Network in the United Kingdom is an

94. Jane Kaye, *The Regulation of Direct-to-Consumer Genetic Tests*, 17 HUM. MOLECULAR GENETICS R180, R181 (2008).

95. *Id.* at R180.

96. See National Society of Genetic Counselors, Direct to Consumer Genetic Testing Position Statement (2007), <http://www.nsgc.org/about/position.cfm#DTC>.

97. Kaye, *supra* note 94, at R180.

excellent example of information available to intended parents.⁹⁸ Information and articles on raising children conceived by donor gametes is available, along with books written for children explaining their donor origins.⁹⁹

IX. CONCLUSION

In general, the Internet has provided an opportunity for donor conceived persons and intended parents to have more direct control over many aspects of communication and information regarding their involvement in the donor gamete process. The Internet provides a vehicle, independent of the medical provider, to explore the donor conceived person's genetic heritage and, consequently, their identity. Traditional concepts of the purview of the medical provider—with the doctor as the sole voice advising the patient in choosing the procedure for conception or choosing a donor based on medical health or family medical history—are shifting as intended parents consider those choices against a backdrop of parenting decisions regarding disclosure. An emphasis on individual autonomy is emerging, aided by the ready access to and availability of information on the Internet.

The expression “you can't put the genie back into the bottle” certainly applies to the shifting dynamics of family building with donor gametes. Empowering the individuals involved in the family building process—donor, parent, and donor conceived person—is an inevitable progression that mirrors the changes in how each individual is viewed. No longer is the donor an inert player who simply gives a gamete to create a child. Donors are now seen as playing an ongoing role in the donor conceived person's life. Independent feelings, issues, and needs have driven these participants to connect outside the realm and control of the doctor's office.

The challenge of the future is the need to reconcile the old model of the physician who is the exclusive source of the information given to donor gamete participants with the promise and the perils of unlimited Internet access unencumbered by information verification and oversight. When physicians embrace the fact that the Internet now holds a

98. Donor Conception Network, <http://www.donor-conception-network.org> (last visited Mar. 3, 2010).

99. See Donor Conception Network Booklists, http://www.donor-conception-network.org/dcn_booklists.htm (last visited Apr. 3, 2010).

multitude of choices for their patients that serve to supplement, but not replace, the experience and knowledge the medical provider can give, this will offer the best of all worlds for the intended parent and, ultimately, for the donor conceived person. A system in which all the provided information proves to be accurate and readily available will furnish the best pathway to meeting the needs of all the stakeholders.