

October 2015

Maximizing Autonomy and the Changing View of Donor Conception: The Creation of a National Donor Registry

Jean Benward

Andrea Mechanick Braverman

Bette Galen

Follow this and additional works at: <https://via.library.depaul.edu/jhcl>

Recommended Citation

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 (2009)

Available at: <https://via.library.depaul.edu/jhcl/vol12/iss1/9>

This Article is brought to you for free and open access by the College of Law at Digital Commons@DePaul. It has been accepted for inclusion in DePaul Journal of Health Care Law by an authorized editor of Digital Commons@DePaul. For more information, please contact digitalservices@depaul.edu.

MAXIMIZING AUTONOMY AND THE CHANGING VIEW OF DONOR CONCEPTION: THE CREATION OF A NATIONAL DONOR REGISTRY

Jean Benward, L.C.S.W.

Andrea Mechanick Braverman, Ph.D.

Bette Galen, L.C.S.W.

“It has long been an axiom of mine that the little things are infinitely the most important”

Sir Arthur Conan Doyle

INTRODUCTION AND OVERVIEW

We can only estimate the number of donor conceived children in the United States. The frequently cited number of 30,000 births a year from sperm donation comes from a US government sponsored study done in 1987, over 20 years ago.¹ Although most donor sperm now comes from commercial sperm banks that keep records on donors and sale of sperm, neither physicians, IVF programs, nor parents consistently report pregnancies or births to sperm banks nor do most sperm banks reliably follow up with recipients to track births. The use of a known donor for a private insemination adds to the difficulty of establishing an accurate number. Similarly, egg donor births are not reported in a way that an aggregate number is easy to calculate. The Centers for Disease Control (CDC) issues an annual report on donor egg pregnancies and births, but it does not include data on donor sperm births. The CDC's last published statistics (2005) showed 12% of all ART cycles (16,161) used donor eggs.² The same CDC statistics also show there were 5,877 donor egg pregnancies of which 53% were singleton pregnancies, 38% were twins, and almost 5% were triplets.³ The number of live births was 5,043 of which 59.2% were singletons, 38.9% were twins, and 1.9% were triplets or more.⁴ Thus the children

¹ UNITED STATES CONGRESS, OFFICE OF TECHNOLOGY ASSESSMENT, *Artificial Insemination: Practice in the United States: Summary of a 1987 Survey—Background Paper*, OTA-13P-BA-48 (Washington, DC: US Government Printing Office, August 1988), at 3.

² CENTERS FOR DISEASE CONTROL AND PREVENTION .US DEPARTMENT OF HEALTH AND HUMAN SERVICES. *2005 Assisted Reproductive Technology Success Rates, National Summary and Fertility Clinic Reports* (Atlanta, 2007), at 14.

³ *Id.* at 56.

⁴ *Id.*

conceived and born from donor eggs in just 2005, inferred from the CDC data, are estimated fairly accurately to be about 7,200 babies. Historically no records have been kept about gamete donors, let alone the children born. A majority of physicians who took part in a study conducted by the Office of Technology Assessment said they would never let a recipient review the donor's medical records, even if information about the man's identity had been removed.⁵ Nearly half of the physicians in the survey reported they did not even keep basic records that would permit them to match a donor to a recipient who had become pregnant.⁶ While sperm banks tended to keep better records, only 3 of the 15 sperm banks surveyed in 1987 allowed offspring from donor sperm to access the records, even with identifying information removed.⁷ Recipient parents were actively urged to not tell their children that the parents had used a donor. One mother whose child was born in 1986 stated, "clinics were ... encouraging [us] never to tell the child ... I wanted someone to guide me... how to go about it, but when I did ask, I was told to ...leave it at that".⁸ It was also assumed that the need for information on donors was unnecessary because parents were not going to disclose to their children.

A CHANGING PERSPECTIVE

The decades-long practice of absent and destroyed records in donor conception reflected the uncertainties, anxiety and secrecy that surrounded (and sometimes still surrounds) the practice of donor insemination (DI).⁹ Parents did not disclose the existence of a donor to their offspring and donors "disappeared" with little likelihood of being found.¹⁰ This secrecy and anonymity occurred within a medical framework in which providers had great authority and medical recommendations were generally accepted without question. The focus

⁵ *Supra* note 1, at 46.

⁶ *Id.*

⁷ *Id.* at 71, table 3-10.

⁸ Anonymous, 2008 Donor Sibling Registry archives, at www.donorsiblingregistry.com (membership required to view content).

⁹ K. Daniels, *Artificial Insemination Using Donor Semen and the Issue of Secrecy: the Views of Donors and Recipient Couples*, 27 SOCIAL SCIENCE & MEDICINE 377 (1988). See also S. Shapiro et al., *Changes in American A.I.D. Practice During the Past Decade*, 35(5) INTERNATIONAL JOURNAL OF FERTILITY 284 (1990).

¹⁰ Daniels, *supra* note 9. See also Shapiro et al., *supra* note 9. See also E.V. Haimes, *Do Clinicians Benefit from Gamete Donor Anonymity?* 8(9) HUMAN REPRODUCTION 1518 (1993).

of fertility treatment then, as is often the case now, was to help a couple have a baby, with little consideration of the long-term impact on the donor conceived. The interests and voices of donors and offspring were not recognized and they experienced little decision making or choice about the secrecy and anonymity.

Several cultural, societal, and professional changes have occurred since the early days of donor insemination. Donor conception has been widely covered by the media, leading to more public awareness. There is more openness in general in the culture; there are more alternative families, and greater acceptance of alternative families. Professionals no longer assume secrecy is the preferred choice. Sperm banks tended to keep more complete records on donors than did individual physicians, and when sperm banks became the primary providers of donor sperm, record keeping improved. Over the past 15-25 years, several aspects of donor conception practice have been questioned by professionals, lay advisory groups, and the participants in donor conception; this has resulted in a changed and changing practices. These transformations include recognition of the importance of retaining donor information for offspring and/or their parents, the shift internationally toward the creation of donor registries, and the elimination of donor anonymity.¹¹ At the same time, concepts of decision making in medicine have changed. Currently, a fundamental ethical principal in the practice of medicine is that authority and responsibility are shared between doctors and patients.¹² Patients choose voluntarily from options whose relative risks and benefits have been explored.

A recurring theme heard from participants in donor conception in the past two decades has been the desire for more complete information about donors and more choice in donor selection. Driven by consumer demand, sperm banks and egg donor programs began to

¹¹ Eric Blyth and Jennifer Speirs, *Meeting the Rights and Needs of Donor-Conceived People: the Contribution of a Voluntary Contact Register*, 24(4) NORDISK SOSIALT ARBEID 318 (2004). See also Jean Benward "Donor Registries in Reproductive Medicine". In *Advanced Counseling Issues: Third Party Reproduction*, American Society for Reproductive Medicine 31st Annual Post-Graduate Course, San Francisco (1998).

¹² Timothy E. Quill and Howard Brody, *Physician Recommendations and Patient Autonomy: Finding a Balance between Physician Power and Patient Choice*, 125(9) ANNALS OF INTERNAL MEDICINE 763 (1996).

provide extensive information about donors.¹³ Donors provide photos of themselves, and some donors even include audio and videotapes. Increasingly sperm banks and donor agencies provide potential parents with the choice of identifiable donors. Since the first sperm bank (TSBC) offered identifiable donors in 1983, the number has grown.¹⁴ About 30% of sperm banks have started identifiable donor programs, including several of the largest US sperm banks.¹⁵ The director of one of the banks, which began to offer Identity Consent donors last year, stated, “this is truly driven by what the public has asked us to provide.”¹⁶ Another states that, “In response to requests from patients, [The Sperm Bank] is now pleased to be offering the Identity Consent program.”¹⁷ A 2006 study found 10.7% of DI programs had open identity donors in 1996 and 32% had open identity donors in 2006.¹⁸ In addition, the longer the DI program offered identifiable donors, the greater the percentage of their donors were open identity.¹⁹

Despite increased openness and information sharing in donor conception, there continue to be significant limitations on the autonomy of participants in donor conception. One significant constraint is that parents cannot guarantee the future availability of donor information for either themselves or their children. Practice with regard to information collection in gamete donation, especially ovum donation, varies widely around the country.²⁰ We have no single standard for collecting information; there is no guarantee that information will be accessible if providers go out of business, and no guarantee donors can be located if necessary. Agencies and medical programs alike have closed their doors, leaving the fate of records in question. One large

¹³ J.E. Scheib et al., *Adolescents with Open Identity Sperm Donors: Reports from 12–17 Year Olds*, 20 HUMAN REPRODUCTION 239 (2005).

¹⁴ J.E. Scheib and R.A. Cushing, *Open-Identity Donor Insemination in the United States: Is it on the Rise?*, 88 FERTILITY AND STERILITY 231, 232 (2007).

¹⁵ *Id.*

¹⁵ *Id.*

¹⁶ Fairfax Cryobank, at www.fairfaxcryobank.com/IDConsentDonor.aspx.

¹⁶ Fairfax Cryobank, at www.fairfaxcryobank.com/IDConsentDonor.aspx.

¹⁷ Cryogenic Laboratories Inc., at

<http://www.cryolab.com/Default.aspx?section=selection&page=SpermBankingwithCryogenicLaboratoriesIDConsent>.

¹⁸ Scheib and Cushing, *supra* note 14, at 232.

¹⁹ *Id.*

²⁰ S.C. Klock and D.A.Greenfeld, *Parents' Knowledge about the Donors and their Attitudes toward Disclosure in Oocyte Donation*, 19 HUMAN REPRODUCTION 1570, 1575 (2004).

egg donor agency, for example, went bankrupt last year with 11 file cabinets worth of information in limbo.²¹

During infertility treatment most intended parents are too preoccupied to think much about their child's (or their own) interest in having information about the donor available later on. Most states require medical records to be preserved for about seven years. That coincides with the beginning of first grade for a child conceived by ovum donation, when many parents are just beginning to think about sharing information with their children. The practice of sperm donation is largely handled by commercial sperm banks, and although comparatively small in number, they are responsible for a larger number of donor offspring than egg donor programs.²² Sperm banks are not necessarily subject to state laws on the maintenance of medical records. The State of New York has the most stringent requirement for the preservation of sperm bank records: 25 years.²³ The FDA requires tissue bank records be kept for 10 years after the "tissue" is used.²⁴ Thus, when parents of donor offspring seek non-identifying information about the donor several years after their child's birth, they can encounter multiple obstacles: they don't remember the donor number or never had a donor number, or they find that the donor agency, medical provider, or sperm bank is no longer able to disclose donor information to them.

In 2004, the American Society for Reproductive Medicine's Ethics Committee issued a position paper about disclosure. The Ethics Committee noted that, with respect to disclosure: [c]linicians, mental health professionals, academics, and children themselves have in recent years called for openness in donor conception in order to protect the interests of offspring. Further, they recommended that disclosure is "ultimately the choice of recipient parents," but, "disclosure to

²¹ Teri Sforza, *Sometimes, It's Hush-Hush over Donor Eggs*, THE ORANGE COUNTY REGISTER, Oct. 7, 2007, available at <http://www.oregister.com/article/egg-donor-children-1879669-donors-egg> (last visited May 29, 2008).

²² Jeff Stryker, *Regulation or Free Markets?*, SCIENCE PRESS, November 7th, 2007, at <http://www.scienceprogress.org/2007/11/regulation-or-free-markets/>.

²³ Tissue Banks and Nontransplant Anatomic Banks - Required records, N.Y. COMP. CODES R. & REGS. TIT. 10, § 52-2.9(b) (2008), ... "In cases of reproductive tissue transfer/artificial insemination/implantation, records shall be kept for at least seven years after the release of tissue not resulting in live births and 25 years for tissue resulting in live births."

²⁴ DEPARTMENT OF HEALTH AND HUMAN SERVICES, FOOD AND DRUG ADMINISTRATION, 21 C.F.R. § 1271.270, ... "You must retain the records pertaining to a particular HCT/P [Human Cell Tissue Products] at least 10 years after the date of its administration..."

offspring of the use of donor gametes is encouraged.”²⁵ This recommendation marked a significant change in the culture and practice of gamete donation. Historically, children were not told about their donor conception and preservation of the information was thought unnecessary or even risky. With the ASRM’s recommendation to encourage disclosure to donor conceived persons, information about the donors has taken on new meaning as parents begin to consider donor information an integral part of the disclosure process. From a culture of anonymity and secrecy, we have moved substantially in the direction of information sharing.

The American Society for Reproductive Medicine (ASRM) guidelines recommends the permanent storage of records on donor conception.²⁶ Further, the 2006 guidelines for gamete donation include a strongly worded statement that “a mechanism must exist to maintain these records as a future medical resource for any offspring...”²⁷ While few have argued against the preservation of records, we have no evidence that many programs have set up a way to maintain the records indefinitely. The proliferation of egg donor agencies, internet sites, and IVF programs, who recruit egg donors, combined with the lack of legal requirements for the handling and retention of gamete donor records, increases the urgency to create a mechanism to preserve donor information. The current system of data preservation is deficient. We lack both adequate systems of tracking outcomes and maintaining information and, more importantly, we lack the belief in its importance. We should now take the next step and discuss a model for preserving information that is effective, and that will be available when the offspring reach adulthood. The creation of a donor registry is a way to preserve donor information and assure its availability even if providers are no longer available. Without a registry, donor conceived persons must be able to identify and find the program used by their parents, hope the program is still in existence; and must also hope the information is available. Sperm banks receive phone calls regularly from donor conceived persons who know they were conceived by sperm donation but do not know where, and have no information about their donor.²⁸

²⁵ ASRM Ethics Committee Report, *Informing Offspring of their Conception by Gamete Donation*, 81(3) FERTILITY AND STERILITY 527 (2004).

²⁶ ASRM Practice Committee, *2006 Guidelines for Gamete and Embryo Donation*, 86(5) FERTILITY AND STERILITY S38, S43 (2006).

²⁷ *Id.*

²⁸ Personal Communication with Charles Sims, California Cryobank, 2008.

Internationally, the importance of information preservation and the potential for information release have been recognized for several years, and this has led to the creation of legally mandated donor registries in several countries.²⁹ Internationally we find no single model for a donor registry. Some registries collect minimal information on donors,³⁰ others release anonymous information only, and others are required to release the donor's identity.³¹ There are a number of reasons why the creation of a donor registry is valuable, and a number of functions it can serve. But what all the international registries have in common is their ability to link donor and offspring, and at the moment we have no formal system that can accomplish this. The debate about the creation of a donor registry in the US has taken place for over ten years. The topic continues to be controversial. Arguments in the professional community have been based on medical, ethical, psychological and practical considerations. Examination of DI support groups, DI websites, papers presented at conferences, and articles written by donor offspring demonstrate that in the lay community of donor conceived persons and recipient parents, a voice is emerging to advocate the preservation and release of donor information.³² The most understandable and socially acceptable arguments are related to obtaining the donor's medical and genetic history for health reasons. The argument continues that without access to their genetic information, donor conceived persons are "disenfranchised."³³ Reports from adult offspring who have been unable to access information about their donor describe a sense of genetic discontinuity, sadness, and frustration at not having adequate

²⁹ Benward, *supra* note 11.

³⁰ Eric Blyth and J. Hunt, *Sharing Genetic Origins Information in Donor Assisted Conception: View from Licensed Centres on HFEA Donor Information Form*, 13(11) HUMAN REPRODUCTION 3274 (1998).

³¹ *Id.*

³² S. Franz and D. Allen, *Report to Health Canada on "The Offspring Speak – An International Conference of Donor Offspring,"* TORONTO: INFERTILITY NETWORK August 12, 2000. See also www.dcnetwork.org; www.daisynetwork.org; www.ukdonorlink.org.uk; www.groups.yahoo.com/group/InfertilityNetwork; <http://members.optushome.com.au/dcsg/index.html>.

³³ Joanna Rose, *From a 'Bundle of Joy' to a Person with Sorrow: Disenfranchised Grief for the Donor-Conceived Adult*, Queensland University of Technology Applied Ethics Seminar Series 2001, available at http://eprints.qut.edu.au/archive/00000737/01/rose_fromabundle.PDF.

information about the donor.³⁴ Questions about the donor continue for many years.

While providers and others have dismissed offspring interest as one of “mere curiosity”, the desire for information goes deeper than curiosity. A compelling and perhaps less understood 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.

What is identity and what motivates the search for identity? Identity construction is a major human developmental task. It reflects a universal longing to create a narrative, to tell a story about who we are and what our place is in the world. The “who am I” question has to do with similarity and difference. How am I like or unlike others? How am I similar or different in appearance, traits, and talents? One’s sense of self is influenced by one’s connections. Donor offspring face the task of defining both their connection to their families and to their donors, specifically, how am I similar and dissimilar to my family members? The issue of genetic relatedness is hard for donor conceived persons to ignore, as it is so often raised in our culture. Everyone grows up listening to “resemblance talk.”³⁵ Who do you look like? Where did you get that trait from? As one donor offspring reported: *When children are told they have father’s eyes, mothers laugh, grandma’s strength they build a strong internal impression of themselves; when you are raised in family with different genetic origins nobody tells you you have dad’s eyes; the face in the mirror does not belong to anyone.*³⁶

Genetic heritage is an important influence in temperament, appearance, abilities, and other traits. Biologically based experiences of the self are significant components of a person’s identity. Knowledge about one’s genealogy is knowledge about oneself. Thus, the inability to obtain donor information can have serious negative

³⁴ A.J. Turner and A. Coyle, *What Does it Mean to be a Donor Offspring? The Identity Experience of Adults Conceived by Donor Insemination and the Implications for Counseling and Therapy*, 15(9) HUMAN REPRODUCTION 2041 (2000). See also Blyth and Speirs, *supra* note 11.

³⁵ Gay Becker et al., *Resemblance Talk: A Challenge for Parents Whose Children Were Conceived with Donor Gametes in the US*, 61(6) SOCIAL SCIENCE & MEDICINE 1300 (2005).

³⁶ SUZANNE BENNET, LET THE OFFSPRING SPEAK: DISCUSSIONS ON DONOR CONCEPTION 138 (The Donor Conception Group of Australia, 1997).

consequences for the offspring' successful identity formation and their sense of psychological well being.³⁷

A recurring theme in the reports of donor offspring is the struggle to create an identity narrative, when the "other" remains forever an unknown. It is the unanswered questions about oneself, the search for seeing oneself in another that draws the offspring to the donor, not a desire for a parent.

As Barry Stevens, award winning filmmaker and donor conceived adult, put it: "Throughout our culture, the stories from Oedipus to *Star Wars*, the theme of finding one's father, for better or for worse, are there. To know our genealogy, not just as a hobby, but as a visceral and real thing, is significant to understanding who we are..."³⁸

Societies attach great importance to genetic ties and a person's genetic ties to their parents are especially valued. At the same time the offspring's genetic ties to the donor are minimized or rejected. Thus donor offspring grow up in a state of cognitive dissonance, a psychological state of discomfort from holding two apparently true yet contradictory thoughts or beliefs. Again, Barry Stevens sums it up: "My father was still my father. It didn't change that. But somehow it did change things. It left a big question mark."³⁹ Interestingly, the theory of cognitive dissonance also suggests the incompatibility of two beliefs or experiences can serve as a driving force that compels an individual to take action in order to make sense of the conflict. The voices of donor offspring echo the struggle to bring resolution to the dissonance: "In spite of her profound regret that she does not know the identity of her donor, she wanted to convey 'how much I feel my father's daughter because of all the things I see in myself that he gave

³⁷ Scheib et al., *supra* note 13. See also K. Vanfraussen et al., *Why Do Children Want to Know More About the Donor? The Experience of Youngsters Raised in Lesbian Families*, 24(1) JOURNAL OF PSYCHOSOMATIC OBSTETRICS AND GYNECOLOGY 31 (2003). See also Turner and Coyle, *supra* note 34.

³⁸ Barry Stevens, *Testimony at the Proceedings of the Standing Senate Committee on Human Rights, Issue 10 – Evidence*, October 2, 2006, available at http://www.parl.gc.ca/39/1/parlbus/commbus/senate/Com-e/huma-e/10ev-e.htm?Language=E&Parl=39&Ses=1&comm_id=77 (last accessed July 15, 2008).

³⁹ Susan McLelland (quoting Barry Stevens), *Controversy over Sperm Donor Anonymity*, MACLEAN'S MAGAZINE, May 22, 2002, available at <http://www.thecanadianencyclopedia.com/index.cfm?PgNm=TCE&Params=M1ART M0012412> (last accessed July 15, 2008).

me, through environment though not through genetics.”⁴⁰ As we discuss the creation of a national donor registry, the psychological welfare of donor conceived persons and their identity formation needs should be of paramount concern.

What issues will emerge for children as they are told about their donor origins? In the 2005 study of adolescents whose parents had chosen open-identity donors, Scheib et al. found the majority of youths were comfortable with their donor origins. Of the offspring who might contact the donor, 82.8% wanted to do so in order to learn more about the donor so they could learn more about themselves.⁴¹ Only 6.9% wanted a father/child relationship.⁴² Will extensive profiles on the donors mitigate their sense of loss about the lack of genetic connection, and will it mitigate their curiosity? How satisfying can a profile of a young adult be – when the profile is a snapshot in time? Pictures may not be as satisfying as a three dimensional moving portrait.

One portion of the donor conception community can be accessed on the internet site for the Donor Sibling Registry. In 2000, the Donor Sibling Registry (DSR) was founded, “to assist 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.”⁴³ This may include: “the donor, donor offspring, genetic siblings and parents of donor offspring.”⁴⁴ The DSR has addressed the desire expressed by donor offspring, to connect with other genetic relatives, especially half-siblings, as well as an interest to know about the gamete donor. The DSR has struck a chord in the donor conceived community and reflects the need to share experiences and emotional concerns. Because of the stigma still attached to donor conception, many have not found a comfortable place to talk about their experiences. As Turner describes: “When self disclosure becomes difficult, it can limit the choice of interpersonal coping strategies . . . [I]solation . . . cuts down the possibility of forming social support networks.”⁴⁵ The DSR reports there have been 4767 matches between genetic half siblings and/or gamete donors. Some donor offspring have

⁴⁰ M. Kirkman, *Genetic Connection and Relationships in Narratives of Donor Assisted Conception*, 2(1) AUSTRALIAN JOURNAL OF EMERGING TECHNOLOGIES AND SOCIETY 16 (2004)

⁴¹ Scheib, *supra* note 13, at 239.

⁴² *Id.*

⁴³ Donor Sibling Registry, at <http://www.donorsiblingregistry.com/about.php>.

⁴⁴ *Id.*

⁴⁵ Turner, *supra* note 34.

discovered large numbers of genetic siblings and some maintain contact with each other.⁴⁶

The DSR is currently the largest site on the internet for the donor conception community. However, at least three other US based internet registries are available for connecting donors, parents, and offspring.⁴⁷ Looking for their children's genetic siblings or donors, some parents have turned to organizations such as the Donor Semen Archive (DSA), launched in 2007, which stores donor DNA samples retrieved from vials and syringes used in insemination and from the children themselves.⁴⁸ The goal of their genetic archive is to "[match] biological offspring with semen donors, identify half siblings (male and female) through genetic testing; obtain... a genetic profile".⁴⁹ The drawback for the DSR and the other registry sites is that official records are not available through the website so participants are left to struggle with incomplete or perhaps inaccurate information. The DSR, as well as other internet sites, reveals that donor offspring do not speak with one voice. As one young donor offspring put it. "I am a DC [donor conceived] offspring and I am very happy that my donor is not known and cannot be known."⁵⁰ Nonetheless, what comes through from all the donor offspring is the need to talk and share with others. As another donor offspring said, "I was amazed . . . at the openness and strong feelings that were being shared via email, by so many donor offspring world-wide."⁵¹

In previous decades, a donor's interest in offspring was presumed to be problematic, the ideal donor was emotionally detached and providers believed donors would not donate unless guaranteed anonymity.⁵² However, studies on sperm donors for the past 20 years have shown donors have diverse views on anonymity and some donors are open to contact. Sauer et al. (1989) found 29% of donors did not

⁴⁶ Vasanti Jadva et al., *Searching for Donor Relationships: the Experiences of Donor Conception Offspring, Parents and Donors*, 88(3) FERTILITY AND STERILITY S250 (2007).

⁴⁷ Donor Offspring Registry, at donoroffspringregistry.com; its offshoot, Donor Offspring Matches, at donoroffspringmatches.com, and Donor Offspring Health, at donoroffspringhealth.com.

⁴⁸ The Donor Semen Archive has since changed its name to Cayman Biomedical Research Institute, at <http://www.cabrimed.org/donorgametearchive.jsp>.

⁴⁹ *Id.*

⁵⁰ Anonymous, 2008 Donor Sibling Registry archives, at www.donorsiblingregistry.com (membership required to view content).

⁵¹ Turner, *supra* note 34, at 2048.

⁵² S.C. Lui and S.M. Weaver, *Attitudes and Motives of Semen Donors and Non Donors*, 11(9) HUMAN REPRODUCTION 2061, 2065 (1996).

favor strict anonymity and 12% would accept offspring contact with donor.⁵³ Schover reported 29% of semen donor candidates would donate if records were open to potential offspring.⁵⁴ Mahlstedt and Probasco reported 37% of the sperm donors felt positively about the idea of openness between donors and recipients, 41% would not object if the offspring wanted to meet them, and 36% of the men would be donors without guarantee of anonymity.⁵⁵ Rowland reported 42% of donors would still donate if their names were available and that they would be interested to know if a child was born.⁵⁶

The changing culture of gamete donation has opened the door to a better understanding of the views of donors. Daniels et al., in their 2005 study, re-interviewed donors from an earlier study who had previously donated.⁵⁷ The donors, who had donated from 3 to 17 years previously, said that they do think about their donation and the possible offspring.⁵⁸ The donors, who would donate even if they had to release their identity, would do so because they felt that offspring had the right to know and that they believed that some offspring would want to know the donor.⁵⁹ Over time, an increased percentage of those donors had a positive view of sharing their identity.⁶⁰ Although donors hold diverse views about anonymity, in general the results indicate donors are not as concerned about information sharing and contact with offspring as has been assumed. Kirkman found that donors can feel some sense of responsibility for the offspring which can range from active involvement in their lives to basic concern they are doing well.⁶¹ Crawshaw et al., in their 2007 article, note that several donors saw

⁵³ M.V. Sauer et al., *Attitudinal Survey of Sperm Donors to an Artificial Insemination Clinic*, 34(5) JOURNAL OF REPRODUCTIVE MEDICINE 362 (1989).

⁵⁴ L.R. Schover et al., *The Personality and Motivation of Semen Donors: A Comparison with Oocyte Donors*, 7(4) HUMAN REPRODUCTION 575, 576 (1992).

⁵⁵ P.P. Mahlstedt and K.A. Probasco, *Sperm Donors: Their Attitudes Toward Providing Medical and Psychological Information for Recipient Couples and Donor Offspring*, 56 FERTILITY AND STERILITY 747 (1991).

⁵⁶ R. Rowland, *The Social and Psychological Consequences of Secrecy in Artificial Insemination by Donor Programmes*, 21(4) SOCIAL SCIENCE & MEDICINE 391, 396 (1985).

⁵⁷ Daniels et al., *Short Communication: Previous Semen Donors and their Views Regarding the Sharing of Information with Offspring*, 20(6) HUMAN REPRODUCTION 1670 (2005).

⁵⁸ *Id.*

⁵⁹ *Id.* at 1673.

⁶⁰ *Id.* at 1674.

⁶¹ Kirkman, *supra* note 40, at 14.

knowledge about the outcome as personally satisfying.⁶² The semen donors they interviewed continue to process thoughts and feelings about the donation as their personal and social experiences changed.⁶³ The donors expressed strong support to have some control over information release and access to advice and support from professionals.⁶⁴ Others indicated an interest in meeting “a child conceived from my semen.”⁶⁵

Donors have also joined the previously mentioned DSR group. Donors’ anecdotal accounts about their thoughts range from passing interest, wondering about the number of offspring, and wondering about the looks, personality and happiness of the offspring. A formerly anonymous donor, expressing his willingness to be contacted by offspring, states that “It was at the point of parenthood for myself . . . that the whole meaning of what it was to be a parent made sense”.⁶⁶

As with donor conceived persons, not all donors share the same view. In an Australian study, Broderick and Walker report that donors and recipients alike used the analogy of blood donation to relate to gamete donation; that donors and recipients would likely not participate if the law required release of identifying information on donors, and that some donors and recipients endorsed a registry which would include non-identifying information but not identifying information.⁶⁷ Certainly many donors are happy to remain anonymous, but others have supplied updated medical information, and have engaged or interacted with offspring and recipient families. Sperm banks report some formerly anonymous donors, when they receive a request from offspring, agree to have some sort of contact or to provide additional non-identifying information.⁶⁸

VOLUNTARY REGISTERS

In several countries the law mandates that the donors’ identifying information be made available to adult offspring. The offspring who

⁶² M.A. Crawshaw et al., *Past Semen Donors’ Views about the use of a Voluntary Contact Register*, 14(4) REPRODUCTIVE BIOMEDICINE ONLINE 411 (2007).

⁶³ *Id.* at 412.

⁶⁴ *Id.*

⁶⁵ *Id.* at 413.

⁶⁶ Anonymous, 2008 Donor Sibling Registry archives, at www.donorsiblingregistry.com (membership required to view content).

⁶⁷ P. Broderick and I. Walker, *Donor Gametes and Embryos: Who Wants to Know What About Whom, and Why?*, 20 POLITICS AND THE LIFE SCIENCES 29 (2001).

⁶⁸ *Supra* note 28.

were born prior to the legislation are not guaranteed donor identifying information. Responding to this disparity, governments such as the UK, Australia and the Netherlands, have come together to create voluntary contact registers.⁶⁹ These registries allow an offspring to learn the identity of the donor who had originally donated anonymously, if the donor consents. The infertility treatment authority in Victoria State, Australia, which has created voluntary registries, has received unsolicited inquiries from donors who had donated in the 1970's and 1980's who want to provide information for the offspring or to have contact with them.⁷⁰ Beyond government created registries, providers who originally did not maintain records, such as the Royal Hospital for Women in Australia, now create their own voluntary registries.⁷¹ The concept of a voluntary release of a donors' identifying information to offspring is a model that could work in the US. Currently, outside of the internet and a few sperm banks, there is no opportunity for mutual consent contact between donors and offspring.

CONSIDERATIONS FOR THE STAKEHOLDERS

Any discussion of a registry must consider what the various stakeholders would want and expect from the information sharing and what information would be shared. There may be inherent conflict among the stakeholders. Releasing identifying information about donors or facilitating offspring contact with donors, even when done voluntarily by the donor, is fraught with complexities. Each party will construct their own meaning about the information sharing and will approach the release of information or potential contact with different feelings and expectations. Recipients may be of different ethnic, racial, religious or sexual orientation than the donors. Consider the possible discomfort for the donor who is age 18 when selected and the recipient single mother who was age 42 at the time of conception.

Although the donor conceived adults may be able to make contact with the donors, experience is still unfolding as to how these contacts will develop. Conversations with donors make clear the

⁶⁹ Blyth and Speirs, *supra* note 11, at 318.

⁷⁰ <http://www.voluntaryregister.health.wa.gov.au/home/> The Infertility Treatment Authority is the statutory body established by the Victorian Parliament to administer the regulation of infertility treatment within the State of Victoria, Australia. It has been established under the provisions of the Infertility Treatment Act 1995.

⁷¹ Donor Conception Support Group of Australia, *at* <http://www.clan.org.au/dcsg/offspring/intro.html>; California Cryobank Sibling Registry, *at* <http://cryobank.com/Services/Sibling-Registry/>.

complexity of the issue. One donor reported that although he felt a responsibility to make himself available to the offspring, he did not see himself as a parent or in an emotionally involved role.⁷² One donor, who has at least 26 genetic offspring, wonders what the future will bring in terms of time commitments, contact, role definition, and how to incorporate the needs of the genetic offspring into his life. Keeping track of children on a spreadsheet was probably the farthest thing from the donor's mind when he was donating.⁷³

However, as in all human relationships, that potential conflict can be negotiated with preparation, thought, and counsel. Release of donors' identity does not compel the donor to have contact, nor does it mean that the offspring will like the donor or want to stay in touch. The issue, however, is who makes the decision: doctors, mental health professionals, the law or the participants themselves? If practitioners subscribe to the concept of individual choice and an ethic of autonomy, then decision making control about contact should be in the hands of donors and offspring, the parties most directly affected. When given adequate information, most adults are able to make decisions in their own best interests. As gamete donation has emerged out of secrecy and as members of the donor conceived community attempt to make contact, it becomes even more important to ensure that donors give informed consent about the extent to which information may be shared. Preparation must be made for how their feelings might change over time, and the possibilities of donor conceived persons searching for them must be considered. Providers should expect to prepare donor conceived persons, donors, and recipients about future issues.

Registries must also consider the possibility the donor's children may have an interest in contact with the offspring born through their parent's gamete donation. No study to date has looked at the attitudes of the donor's children. Others may also have interest in the registry, including the donor's parents or siblings who would also be genetic relatives to any donor conceived person. The registry must be clear about which stakeholders in the process will have access to the information and what type of information will be available.

Although other countries have banned the practice of anonymous donation and guaranteed donor offspring identifying information, given the diverse cultures and stakeholders in the United

⁷² Kirkman, *supra* note 40, at 15.

⁷³ Silvia Galipeau, *Father of 26 Living Children*, LA PRESSE, June 17, 2007, available at <http://www.donorsiblingregistry.com/pereenglish.pdf>.

States, we will not find “one” voice that represents the entire donor conception community. Optimally, a registry will be flexible enough to respect the wishes of those who have been historically overlooked: donors and offspring who desire to make contact.

CONCLUSION

From numerous sources, we see there are a range of opinions among the donor conceived and donors about anonymity. However, we know many donors will provide a great deal of information about themselves with the knowledge the information will be shared with recipients and offspring. There are also a lesser number of donors who will consent to their identity shared with offspring and are perhaps willing to meet. Although we don't know the proportion of donor offspring who desire identifying information, there clearly are offspring who seek to know more about their donor and would seek contact if possible. A registry that considers the release of identifying donor information must recognize the variety of contact experiences donors and offspring might have, whether positive or disappointed. Providers in donor conception must also face the fact that if they do not assist offspring or are unable to provide donor information (anonymous or non anonymous) in an organized way, participants in donor conception will turn to other means to find information or genetic relatives. Just as there is no one correct form of family, there is no one correct form of sharing donor information. But if we are to support autonomy for participants in donor conception then we should provide true choices, including allowing donors to consent to release of identity information to offspring. Contact between donor and offspring may not be for everyone and should not be forced upon them; however, it is a choice that should be available to those who desire it.