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THE FUTURE IS NOW: A VOLUNTARY GAMETE DONOR REGISTRY IS FEASIBLE

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On March 28, 2008, the Health Law Institute at DePaul University College of Law co-sponsored a one-day symposium entitled, "Tracking Change: The Feasibility of a Voluntary Gamete Donor Registry in the United States." The symposium was a gathering of professionals from a range of disciplines working in the field of assisted reproductive technology (ART). Attorneys, reproductive endocrinologists, medical directors of sperm banks, mental health professionals, and information technology experts convened to discuss where a need for a gamete donor registry exists, what issues a registry must take into account from the perspective of the myriad stakeholders impacted and what the risks and benefits of such an undertaking might be.

Summarizing this first of its kind national meeting in one short essay is a difficult task. What makes this task even more daunting is to summarize the genesis of this meeting – the many months of discussion that culminated in this one day event that brought together groups of individuals that at times have been at odds regarding this particular topic. The issue of collection, storage, and dissemination of genetic, medical, mental health, and social information about gamete donors and their offspring has been rife with controversy.¹ In recent years, however, as the use of donor gametes has increased,² children of gamete donation have come of age,³ and genetic medicine is no longer just the wave of the future,⁴ the topic has been more in the fore nationally and internationally.

¹ See, e.g., *Johnson v. Superior Court*, 80 Cal. App. 4th 1050; 95 Cal. Rptr. 2d 864 (2000) (Parents of a child affected with a genetic condition sought to depose an anonymous sperm donor); Denise Grady, "As the Use of Donor Sperm Increases, Secrecy Can Be a Health Hazard," *The New York Times*, June 6, 2006 at 5.

² CDC, "2005 Assisted Reproductive Technology (ART) Report," 2007 (The number of cycles using donated eggs was 16,661 in 2005, this is up significantly from over a decade ago when just over 5,000 cycles were reported using donor egg, CDC, "1996 Assisted Reproductive Technology Success Rates," (1998)).

³ See, e.g., Scott Harris, "Families on the Cusp of an Uncharted Realm; Relationships* As They Approach 18, the Children of Women who Patronized a Pioneering Sperm Bank Face the Choice of Learning Donor Fathers' Identities," *Los Angeles Times*, May 3, 2002 at Part 5, Page 1.

⁴ See, e.g., Human Genome Project Information, "Medicine and the New Genetics," at http://www.ornl.gov/sci/techresources/Human_Genome/medicine/medicine.shtml last visited on June 2, 2008.

In October 2006 the authors of this essay reminisced about an educational panel we had both participated in four years earlier regarding disclosure of gamete donor information. We marveled at how timely such a topic had become in four short years. Our reminiscing soon turned to brainstorming as we contemplated how to revitalize this discussion among the many disciplines working in ART. In just a few hours we had developed a list of sixty or more professionals from a full range of disciplines whom we believed would contribute greatly to a discussion of what information about gamete donors, their offspring and the recipients should be collected, stored, and maintained and under what circumstances. Our next task was to decide what to do with this list.

Despite the vast expertise we had identified, we needed a structure or a framework to bring this group together for a productive discussion of the issues. Our central question being: Is a gamete donor registry even feasible? We soon concluded that the question was too big for us to answer and thus a roundtable discussion would be a productive way to measure the interest in a donor registry, identify the potential pitfalls; concerns and benefits. With no funding nor any formal organizational support we reached out to the sixty individuals we identified and invited them to attend a half day discussion which would proceed the 2007 Annual Meeting of the American Society for Reproductive Medicine. To our great amazement, over half of the invitees attended and nearly all the invitees expressed great interest in the discussion.

The meeting, as anticipated, generated far more questions than answers, however, one thing became very clear – interest was piqued. All involved believed that examining the feasibility of a gamete donor registry was vital, however, no one was quite willing to take a next step. As the meeting concluded, attendees turned to these authors posing the question “What’s next?” And, thus the idea for the “Tracking Change” symposium was born.

Recently, concerns about secrecy in the use of donor gametes have led to regulatory responses in a number of European nations and Australia.⁵ The United States, greatly concerned with potential infringement on reproductive rights and privacy, however, continues to

⁵ See, e.g., Janssens, et. al., "A New Dutch Law Regulating Provision of Identifying Information of Donors to Offspring: Background, Content and Impact," 21 Human Reproduction 852-856 (2006), Human Fertilisation and Embryology Authority, Statutory Instrument 2004 No. 1511, "The Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004

take a somewhat *laissez faire* approach with piecemeal solutions being implemented by individual sperm banks⁶ or consumer groups such as the Donor Sibling Registry⁷ and the Single Mother's by Choice Sibling Registry⁸ and for-profit entities such as "Genetisafe"⁹ which seek, for a fee, to keep gamete recipients up to date on significant health conditions of the donor. These lay registries have emerged without public discourse, public accountability, multidisciplinary expertise, uniformity or oversight or any other enforcement mechanism. Additionally, legislative proposals have begun to emerge in the United States¹⁰, and thus the time had come for those professionals most directly impacted by the collection, storage and dissemination of such information to take the lead in the discussion and develop a solution that is feasible; acceptable to donors, recipients and offspring alike; and is cost effective and not unduly burdensome. Such a solution necessitates consideration of the implications for all stakeholders such as privacy and confidentiality including compliance with the Health Insurance Portability and Accountability Act (HIPAA), reproductive freedom, and children's rights.

Creation of a centralized, voluntary gamete donor registry is one mechanism that could facilitate collection and maintenance of pertinent medical, health and genetic information; may help avoid identity issues or familial disconnect experienced by some children born as a result of gamete donation; would be useful in avoiding inadvertent consanguinity and enable offspring to make more informed reproductive decisions; would enable ART programs to share information with one another about donors; would ensure that donors do not participate in multiple programs and more times than is medically recommended; and could facilitate outcomes/epidemiological research which is currently lacking despite, the thousands of birth annually in the U.S. utilizing donated gametes.

The Tracking Change symposia examined the feasibility of taking a multi-disciplinary approach to developing a registry, including practical, theoretical and ethical benefits and barriers with a particular

⁶ See, e.g. California Cryobank at http://www.cryobank.com/sibling_registry2/faqs1.cfm

⁷ The Donor Sibling Registry at <http://www.donorsiblingregistry.com/> last visited June 2, 2008.

⁸ Single Mother's by Choice Sibling Registry at <http://www.singlemothersbychoice.com/sibling.html> last visited June 2, 2008.

⁹ "Genetisafe," at <http://www.genetisafe.com/> last visited June 2, 2008.

¹⁰ Virginia HB412 "Gamete donors; anonymous donations thereof prohibited in medical procedures," Introduced January 2006.

focus on the legal and policy considerations necessary to its implementation, acceptance, and effectiveness. These considerations were discussed from the perspectives of the range of stakeholders: physicians; fertility centers/sperm banks; recipients of donor gametes; donors; mental health professionals who work with recipients, donors and offspring of donor gametes; and society. One issue became abundantly clear throughout the day . . . to develop an effective registry requires a balancing of interests of the child, donor, intended parents, health care professionals, and society in addition to a risk/benefit analysis in an effort to protect, promote and enhance this important reproductive option and ensure the physical and emotional safety and privacy of all participants including the resultant offspring.

What follows is a detailed outline of the most salient issues that should be considered in the development and implementation of any gamete donor registry in the United States.

Overarching Issues

- A. Need for a registry
 - No
 - Yes: Voluntary or Mandatory
- B. Appropriate information to be collected regarding:
 - Donor
 - Offspring
 - Intended parents
- C. Length of time information remains available
- D. Function of the registry
 - Provide information
 - 1. Offspring
 - 2. Medical professionals
 - 3. Parents
 - 4. Donors
 - 5. Researchers

Medical Considerations

- FDA concerns
- Safety
 - Recipient
 - Donor
 - Offspring
- Practicality
- Cost

- Logistics

Mental Health/Psychosocial Issues

- Offspring
- Donors
- Donors' offspring
- Recipients

Ethical Issues

- A. Expectations – (Autonomy/Justice)
 - Donors
 - Recipients
 - Medical professionals
- B. Obligations of and Obligations to – (Beneficence/Justice)
 - Offspring
 - Donors
 - Donors' offspring
 - Medical Professionals
 - Recipients

Legal Considerations

- A. Privacy/Confidentiality
 - Access
 - Information Available
 - Information Disclosure
- B. Other Constitutional Law Issues
 - a. Procreative Liberty
 - b. Right to care, control and upbringing of child
- C. Type of Liability of impacted party(ies) Responsible party(ies)
 - a. RE/Fertility Center
 - b. Donor Agency
 - c. Sperm Bank
 - d. Other

Logistics Considerations

- A. Information System
 - Privacy protections
 - Design
 - Hosting party(ies)
- B. Cost
- C. Uniformity
- D. Administration
 - Data collection
 - Maintenance

➤ Disclosure

This one day symposium touched on most if not all of these issues, and as the day came to a close, it became clear that most speakers were in agreement that the first question of this outline should be answered in the affirmative -- a voluntary registry is very important. The reasons such a registry is significant are manifold, including medical considerations for donors, donor's children, offspring, and offspring's children; psychological considerations; ethical concerns and, even political motivation in the sense that self regulation may be more effective and efficient than reactive legislation. Creation of a registry would enable the industry, long shrouded in secrecy to become more transparent and more accountable which may ultimately lead to eradication of the stigma so long associated with gamete donation.

Another reason for the importance of a registry is akin to many other kinds of registries that exist in the public health sphere such as tumor registries or other disease specific registries. A registry could promote progress, quality assurance, and protection of patient/participant safety, through surveillance and empirical research, two areas currently lacking in ART.

Participants made it clear, though, that if any registry were to exist the flow of information maintained would need to multi-directional. Thus, a registry would encompass more than just information flow to offspring. Information might flow between medical centers, from offspring to donors, etc. From an ethical perspective, this is one means of fairly distributing the benefits and the burdens and attempting to balance the autonomy of all stakeholders.

Another factor raised for consideration was the flexibility and fluidity of the structure and implementation of a registry. As the technology changes, so too do the issues that must be considered and the information that is available. For example, the ability to freeze and bank eggs as we currently do sperm, looms on the horizon,¹¹ how or should this impact any existing registry? How does the function of a registry change if the time comes and we all carry genetic identification cards? These are only some of the future considerations that must be taken into account in developing a registry that will be functional over time.

¹¹ See, e.g., Chang, Ching Chien, "Two Successful Pregnancies Obtained Following Oocyte Vitrification and Embryo Re-Vitrification," 16 *Reproductive BioMedicine Online* 346-349 (January 2008).

What became most obvious during the course of the day, however, is that this is a tremendously complex issue, but its complexity is no reason to avoid or ignore it. The mere free flow of information and discussion throughout the symposium suggested that a voluntary registry is more likely to expand rather than limit the options of all whose lives may be impacted by gamete donation. Even more significant was the recognition that development of a registry is not synonymous with eliminating anonymity in gamete donation. The collection, storage and dissemination of information does not necessitate revelation of identities unless all participants involved agree to such openness. The decision of when, what, how and to whom to disclose information of such a personal nature is highly personal and to some may be tantamount to a secret, but that does not and should not equate with negativity so often attributed to the word "secret." Ethicist Sissela Bok captures the essence of this when she writes: "While all deception requires secrecy, all secrecy is not meant to deceive."¹²

¹² Sissela Bok, *Secrets: On the Ethics of Concealment and Revelation*, Pantheon 1982.

