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Potential National Voluntary Gamete Donor Registry Discussed at Recent Health Law Symposium

Pamela Foohey

Despite exponential growth in the past decades, most aspects of the assisted reproductive technology (ART) industry remain largely unregulated; recently, pressure has been mounting for coordinated study and regulation of this developing industry. On March 28, 2008, lawyers, health care professionals, representatives from sperm banks, consumers of ART services, and other stakeholders in ART industry gathered at DePaul University College of Law for its Health Law Institute’s symposium titled “Tracking Change: The Feasibility of a Voluntary Gamete Donor Registry in the United States.” The implementation of a registry would mark the first effort in the United States to centralize, maintain, and disseminate information about gamete donors by collecting and storing genetic and identifying information about egg and sperm donors. Establishing a registry requires balancing the interests of donor-conceived individuals, their parents, gamete donors, health care professionals, and society as a whole, as well as ensuring the privacy and safety of all involved. Further, the consideration of a voluntary registry invites debate about the desirability of a mandatory registry and increased systematic consideration and regulation of ART generally.

Background

Currently, it is impossible to know the exact number of donor-conceived individuals in the United States because no federal, state, or private agency tracks donor-conceived births. The ART industry in the United States is regulated primarily by voluntary guidelines issued by organizations such as the American Society for Reproductive Medicine (ASRM); as these guidelines are advisory only, the extent to which they are followed is unclear. There are few federal or state regulations, and those that do exist are not comprehensive. Thus, the result is a decentralized, private industry that has yielded a norm of anonymous gamete donation, an absence of information about the intricacies of the market for gametes and the effects of ART, confusion about the legal consequences of gamete donation, inconsistent record keeping of births, and a dearth of resources for donor-conceived individuals in search of their biological progenitors. Nowhere is this result more evident than in the realm of gamete donation: there are 26 sperm banks (five of which supply 75-80% of sperm distributed) and several hundred egg donor programs in the United States, most operating according to their own standards. An accurate estimate of the number of egg donor programs is impossible as no registration, licensing, or other requirements exist to track such entities.

In contrast to the United States’ model, many other countries heavily regulate ART, including mandating the non-anonymity of donors. Historically, the United States’ norm of donor anonymity and overall lack of regulation of ART reflected infertility’s stigma, a national emphasis on personal autonomy and privacy, and a heated political debate over abortion. Nevertheless, in recent years, the desirability of anonymous gamete donation has come into question, especially with regard to the interests of donor-conceived individuals (and their parents) in learning about their genetic origins. Donors themselves also have advocated for open-identity donation, indicating an interest in knowing the outcome of their donation and a willingness to have contact with offspring. This change in the perspective of ART participants has resulted in the following: (1) prompted the ASRM to promulgate guidelines advocating the collection and distribution of donors’ genetic information upon request to donor-conceived individuals and their parents; (2) led to the creation of Web sites dedicated to linking donor-conceived children with their genetic...
half-siblings and donor “parents” if all parties are in agreement;\(^14\) (3) encouraged sperm banks to establish open-identity donor programs that operate alongside anonymous donation programs;\(^15\) and (4) fostered an increase in the ratio of open-identity to anonymous donors.\(^16\)

Overall, there has been a trend toward open-identity donation, a term that describes gamete donors who agree to release their identifying information to their offspring when those offspring reach adulthood.\(^17\) As noted at the symposium, there also has been a recognition that all participants in the gamete donation process may have an interest in the collection, of information that a registry would facilitate and provide a forum for the key stakeholders to discuss the benefits, drawbacks, and design of a voluntary registry.

The symposium’s participants primarily examined how a registry might be designed to ensure that donor-conceived individuals’ (or their parents’) desire to access their biological progenitors might be advanced while protecting the interests of donors and parents. Even enabling this multi-directional exchange of information between donor-conceived individuals and their biological progenitors has the potential to generate benefits for many more stakeholders. Assuming

An improved understanding of ART may provide empirical grounds for the establishment of national standards for gamete donors and individuals undergoing ART procedures, limits on the number of children created by one individual’s gametes, limits on how many times or how frequently one individual may donate gametes, and regulation of the solicitation and compensation of gamete donors. Further, a registry may increase society’s confidence in and acceptance of gamete donation, while simultaneously recognizing its uniqueness as a means to facilitate procreation.

Benefits, Drawbacks, and Feasibility of a Registry
One of the main impetuses to creating a national voluntary gamete registry is donor-conceived individuals’ (or their parents’) desire to access information about their genetic origins. However, a registry would not merely be a place for donor-conceived individuals to go in search of their genetic origins, but it would also be a central database of information for health care professionals, researchers, consumers of ART services, donors, and half-siblings. “Tracking Change” focused on the multi-directional flow

Moreover, the societal benefits that may accrue from such a registry are immense. For example, tracking gamete donation could address a concern about inadvertent consanguinity.\(^20\) Beyond identifying genetically related individuals by following who is donating gametes where and when and the outcome of ART cycles using those gametes, health care professionals and researchers could draw upon information contained in a registry to generate data to better study the effects of ART on consumers of ART services, donors, and offspring. An improved understanding of ART may provide empirical grounds for the establishment of national standards for gamete donors and individuals undergoing ART procedures, limits on the number of children created by one individual’s gametes, limits on how many times or how frequently one individual may donate gametes, and regulation of the solicitation and compensation of gamete donors. Further, a registry may increase society’s confidence in and acceptance of gamete donation, while simultaneously recognizing its uniqueness as a means to facilitate procreation.

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a right to prevent disclosure of their identifying information, and disclosure may violate the recipient parents' privacy. Conflictingly, donor-conceived individuals may have a right to know information about themselves under certain circumstances. Though a gamete registry could be designed to address donors' privacy concerns by allowing the disclosure of donors' identifying information only upon their approval or precluding contact without their consent, donors' significant concerns about their parental status remain. A majority of states do have laws relieving sperm donors of parental rights so long as the intended parent(s) have consented, but only a few states have enacted similar legislation addressing egg and embryo donation. Further, even if donors are willing to submit their information to a registry, the lack of well-established and tested regulations may dissuade participation.

Disincentives from uncertain legal regimes is but one of a number of barriers to implementation of a registry. The tension between intended parents' privacy and the ability of donor-conceived individuals to access their genetic origins raises the question of how children might learn that they are donor-conceived in the first place, which was largely beyond the symposium's scope. Additionally, though a registry may provide health care professionals with greater information about how ART affects their patients, thereby allowing them to better inform and follow-up with patients, health care professionals note that a registry may intrude upon the practice of medicine. For example, it may increase the already high cost of ART, pricing more people out of these services; it may decrease the availability of gametes by reducing donations; and it may encourage international reproductive travel.

Logistical implementation issues also must be resolved. Open questions include who will be responsible for gathering information and ensuring its protection, how data will be verified, and what should be done with outdated records. Though no concrete proposal for a voluntary registry was discussed at the symposium, the three largest sperm banks in the United States have advocated for the creation of a voluntary registry run by a non-profit entity governed by a board of directors elected by its members, who will fund the non-profit and be comprised of sperm banks and egg donation programs. Yet, funding sources are influential, which leads others to question the appropriateness of vesting regulation in the industry being regulated.

Overall, symposium participants agreed that even if the implementation issues associated with a purely voluntary registry prevent the full realization of the potential societal and personal benefits discussed, the creation of a voluntary national gamete registry is a step in the right direction when compared with the status quo of sparsely regulated and sporadic record keeping.

What Should Voluntary Mean, and Is a Mandatory Registry Desirable?
Questions about implementation led some participants to assert that a mandatory registry is necessary, although the symposium's participants only briefly discussed the relative merits of a mandatory versus a voluntary registry. Some time was spent considering the related question of what "voluntary" should mean. The medical or psychological benefits that donor-conceived individuals might experience could be undermined if parties opt-out at any one of several moments in a purely voluntary scheme. Some sperm banks and egg donor programs may decline to participate in the registry, and donors within a participating program may themselves decline to provide information or may choose to provide only partial information. For example, a donor-conceived individual would only be able to access her genetic information or connect with her biological relative(s) if her parents chose a fully participating donor from a participating program. Further, the larger societal benefits noted above have little chance of being realized without a guarantee that a threshold level of information will be collected and maintained.

A mandatory registry would ensure that donor-conceived individuals are able to access information about their biological origins while protecting the privacy of donors by including safeguards concerning when and how donors may be contacted. Moreover, a mandatory registry may prompt federal and state legislators to enact statutes to resolve legal issues surrounding ART. Finally, a mandatory registry would guarantee that health care professionals and researchers have robust information to consult when studying ART techniques. However, given the United States' strong emphasis on personal autonomy and privacy, even if a mandatory registry is desirable, it may not be politically realistic.

Potential Impact on the Assisted Reproductive Technology Industry
As the first real national response to any consumer aspect of the ART industry, the mere proposal of a national registry has the potential to impact the ART industry far beyond providing for the needs of the donor-conceived individuals who initially motivated its suggestion, thus highlighting other aspects of the ART industry that invite systematic consideration and regulation. Although a discussion of these other aspects was almost entirely beyond the scope of "Tracking Change," it is interesting to hypothesize about some possible impacts of a registry on the ART industry that were only referenced in passing or not raised at the symposium.

In discussing the ART industry, commentators have focused on the consumers of ART services, ART's corollaries with and effects on adoption, and class inequalities in access to ART as aspects of the industry that could benefit from increased regulation. Additionally, the need for counseling of all participants in the ART process was specifically mentioned at the symposium. But perhaps the most important consequence of increased discussion of ART is the potential to improve recognition of how most aspects of ART, especially egg donation, affect women. Egg donation is complicated, painful, and
potentially life-threatening. With several hundred egg donor programs in the United States, it is virtually impossible to ensure that every woman who donates eggs is fully informed about the dangers of the procedure and that egg donation programs are taking the necessary safety precautions. Moreover, women themselves have become commercialized and sexualized apart from the eggs they donate, vastly more so than sperm donors. Not only do select college students' eggs fetch upwards of $100,000, an existing Web site offers the opportunity to bid on the eggs of the female models whose pornographic pictures members pay a monthly fee to view. Such high monetary values placed on certain women's eggs engenders questions about the frequency with which some women donate eggs, which may bring both physical and mental health risks of its own.

Further, little research has been conducted regarding the effects of multiple cycles of ART, multifetal pregnancies, and multifetal pregnancy reduction on a woman's body and psyche. While a registry may provide a forum for data collection that will aid research into the effects of ART techniques, it has a much greater potential to highlight egg donation practices as purchasers of eggs consider obtaining eggs from a donor that participates in the registry, especially now that eggs can be frozen and the egg market increasing resembles the impersonal sperm market. Though there is a possibility that the conditions of egg procurement could become more obscured and worrisome, this transition to an impersonal market more likely will cause egg donor programs that participate in the national registry to be the primary places egg purchasers obtain open-identity donated eggs, a result that will encourage more uniform scrutiny and verification of the how those eggs were obtained.

Any sustained direct focus on how ART affects its many stakeholders has the potential to be extremely valuable. “Tracking Change” centered on the benefits of a national voluntary gamete registry to donor-conceived individ-uals in search of their biological origins and to other stakeholders who may access the information in the registry. Entwined in the discussion of how best to implement a registry to achieve those benefits is a broader debate about the regulation of the ART industry. The creation of a voluntary registry has the potential to advance the interests of donor-conceived individuals, their parents, gamete donors, and health care professionals, and in doing so, to highlight other aspects of the ART industry that are in need of systematic consideration at a time of rapid technological innovation.

References
3. Id.
4. Id.
8. As noted by Dr. Charles Sims, co-founder of California Cyrobank. Arguments and observations are attributed to symposium participants in endnotes.
9. See Elster, supra note 2.
10. Id.
11. Id.
13. See supra note 5.
16. Id.
17. Id.
18. As discussed by Wendy Kramer, co-founder of the Donor Sibling Registry, Bette Galen, LCSW, Andrea Braverman, Ph.D., both of Reproductive Associates of New Jersey, and Jean Benward, LCSW, co-president of the Spermbank of California.
19. As discussed by Dr. Richard Scott, Director of Reproductive Medicine Associates of New Jersey.
20. Id.
21. Dr. David Adamson, President of the American Society of Reproductive Medicine, Dr. Scott, and Dr. Mark Hughes, founder of the Genesis Genetics Institute.
22. Professor Naomi Cahn and Susan Crockin, principal of the Crockin Law & Policy Group, discussed legal issues in donor registries and ART.
23. As discussed by Dr. David Adamson.
24. Dr. Charles Sims, Sean Tipton of the American Society of Reproductive Medicine, and Earl Furline, founder of Cardinal Technologies, addressed feasibility and implementation issues.
25. As discussed by Dr. Charles Sims.
26. As noted by Ms. Wendy Kramer.
27. Professor Naomi Cahn, Ms. Susan Crockin, and Ms. Wendy Kramer noted the desirability of a mandatory national registry.
32. See Alvare, supra note 7, at 12-14.
33. See Spar, supra note 1, at 44-46.


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