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Reproductive Genetic Screening: More Questions Than Answers

Posted by [Lawrence Moore](#) on December 16, 2009



The Genomics Law Report has published a couple of [guest commentaries](#) recently dealing with genetic screening—a topic our own [Adam Doerr](#) also addressed in [two posts](#) this summer dealing with “wrongful life” claims brought against sperm banks by children with genetic diseases inherited from their donor fathers. Such claims are premised on the failure of the sperm bank to conduct genetic screening that could have detected the defective genes—thereby avoiding the conception of the child on whose behalf the wrongful life claim is brought.

In this post, I look at a recent gamete screening controversy—the revelation that a man fathered at least two dozen children, all but two through the donation of his sperm to a bank, despite having a potentially serious genetic defect—and examine numerous issues the story raises. Many relate to whose interests are valued the highest. Should the wellbeing of the children born of the process—the only people involved who have no say in the matter—come first, or does respect for the autonomy of the parents control? I do not attempt to answer the questions posed, but seek to encourage discussion with respect to the need for clearer policies and guidance in a number of these areas.

Another “Bad Sperm” Case.

Keith Syerson of the Chicago-Kent [Institute for Science, Law and Technology](#) recently addressed the topic of genetic screening of gamete donors in recent post, [The Story of a Sperm with a Bad Heart](#). Syerson reviewed a [study](#) in the [Journal of the American Medical Association](#) (JAMA) by Maron, *et al.* dealing with an

anonymous donor who turned out to be a carrier of a mutation associated with the development of hypertrophic cardiomyopathy (HCM). HCM is a congenital heart defect that results in thickening of the heart muscle, which can lead to numerous problems, up to and including [sudden cardiac death](#) resulting from the exertion of athletic activity. As [Danielle Conrad's piece](#) on [GINA](#) notes, basketball stars Hank Gathers of Loyola Marymount and Reggie Lewis of the Boston Celtics both collapsed and died on the basketball court, and were discovered to have suffered from HCM.

The Maron *et al.* study revealed that the donor had fathered 22 children through donations, and had two more children with his wife. One of the children had already died of HCM-related heart failure, at the age of two. Sixteen of the children born via donation received genetic tests; eight tested positive for a mutation associated with HCM. One of the donor's children with his wife also tested positive. Two of the affected children had "massive LV hypertrophy" and the donor had "extensive myocardial fibrosis" of which he was previously unaware.

The authors of the study noted that "some sperm banks test for cystic fibrosis, thalassemia anemia, sickle cell trait, Tay-Sachs, and other genetic diseases that have increased frequency in Ashkenazi Jews; all of these conditions are much less common than HCM in the general population." While they acknowledged that genotyping for HCM-related mutations would be unlikely "due to its current expense and limited clinical sensitivity," they recommended echocardiography of potential donors to screen for HCM and, potentially, other diseases that can cause sudden death. The authors also noted that the case "underscores the need for guidelines to notify gamete donors, recipients, and other affected parties once genetic disease arises."

Syerson cited a commentary JAMA published along with the Maron *et al.* study, in which Judith Daar and Robert Bryzski [described the current environment in which sperm banks operate](#)—with no federal regulation requiring genetic screening, and with the majority of banks not complying with the voluntary "established screening protocols" of the [American Society for Reproductive Medicine](#). ([Those protocols](#) (pdf) do call for genetic screening of donors, including for cystic fibrosis and autosomal or X-linked dominant disorders, among others). The regulations that do apply to donations are designed to protect the mother from communicable diseases, not to promote the health of the child.

The Maron *et al.* study and its recommendations raises numerous ethical questions, many of which will need to be addressed as reproductive genetic screening, including but not limited to the screening of donated gametes, becomes capable of providing more information on a wider range of conditions at a decreased cost, thereby likely becoming more widespread than at present. I identify a number of these questions below. Many relate to whose interests are valued the highest. For example, should not the wellbeing of the children born of the process—the only people involved who have no say in the matter—come first? I do not intend to provide answers to the questions posed. I note, though, that the interests of the children often seem to come last.

Does the Propriety of Genetic Screening Depend Upon the Stage of Life at which It Is Performed?

There seems to be general agreement among those writing on the subject that, as Syerson puts it, "taking added precautions to prevent women from unknowingly receiving sperm carrying genetic mutations that are associated with deadly diseases is a good thing." Both he and Daar and Bryzski, in their JAMA commentary, express concern that the cost of such testing may affect the ability of the poor to use sperm donors, but neither suggests there is any intrinsic harm in performing such tests. As Adam Doerr reported in "[Strict Liability for Sperm?](#)", a federal court recently held that a sperm bank could be liable for negligence "in failing to properly screen the sperm" under New York law—so that there can be a legal duty to conduct pre-conception screening. But why is there such a duty? Shouldn't donor children and their mothers take their chances like the rest of us? Is the fact that we *can* perform such testing reason enough to decide that we *ought*?

As Hank Greely's [recent ELSI commentary](#) observed, though, with the forthcoming postconception but prenatal genetic testing that will be both cheap and safe, society needs to decide whether to "encourage, discourage, or view as neutral" such tests. Is the same not true for pre-conception screening?

As Danielle Conrad observes, under GINA, once someone is born, it is [illegal to screen them for health insurance and employment](#) purposes—which means that basketball players suspected of having HCM will not be subject to genetic tests by their employers, and that even pilots whose passengers' lives may be at risk from their collapse are exempt from screening for HCM. Of course, GINA applies only to existing people, and donor screening is promoted in order to prevent people with genetic diseases from being conceived. Perhaps the reasoning behind the duty to screen gametes is that no one is hurt by such screening (except perhaps through the stigma attached those who live with the disorders for which screening is performed). Is it simply uncontroversial that mandatory genetic screening before conception is always to be promoted, that mandatory genetic screening after birth for reasons other than medical care is always to be proscribed, and that the only gray area is in between the two, depending on one's view of the morality of abortion and the destruction of embryos?

Implications of the Duty to Conduct Pre-Conception Genetic Screening

If pre-conception screening is such a clear good, and if sperm banks have a duty to screen for certain genetic disorders simply because such screening is possible, then does it not follow that obstetricians have a duty to provide screening for fertile couples? In Iran, for example, a mandatory premarital screening program originally designed to prevent communicable diseases has been [modified to include certain non-communicable genetic disorders, including blood disorder thalassemia](#). Iran's experience with mandatory premarital screening for genetic disorders also resulted in it changing its laws to permit prenatal genetic screening, the costs of which are borne by (governmental) health insurers—accompanied by a [fatwa](#) (pdf) under Islamic law permitting abortion in thalassemia cases. Iran's program is [generally regarded as having been successful](#) (pdf) in reducing the rate of thalassemia and integrating genetic screening into an existing healthcare system.

Similar premarital and prenatal genetic testing options are offered elsewhere around the world, typically through traditional providers of reproductive assistance, including in vitro fertilization (IVF) clinics, although some companies now [offer genetic screening directly to prospective parents via the internet](#). In addition, some countries, including the United States, presently permit genetic screening—typically through a combination of embryo selection and screening that utilizes pre-implantation genetic diagnosis (PGD) and IVF—for non-medical conditions including [sex selection](#) (which is illegal in many other countries, including the United Kingdom, India and China) and even the possibility of selecting for simple genetic conditions such as [eye and hair color](#). However, the practice of utilizing genetic screening to influence non-medical traits or conditions is [highly controversial](#), even in the United States where attitudes toward genetic screening for non-medical traits are generally more permissive. Given advancements in reproductive technologies and scientific understanding, it is conceivable that, eventually, it will be possible to screen for alleles that affect more complex traits such as [obesity](#) (pdf) or even elements of [cognition](#). If there is a duty to engage in genetic screening to ward off disease, is there a duty to offer the opportunity to optimize a patient's children?

And if we take steps to ensure that potential donors with genetic defects do not father children through the donation process, why stop there? Why not take steps to protect children born to such potential fathers through more traditional methods, including implementing mandatory premarital screening (such as employed in Iran and other countries), imposing other conditions or even restrictions on prospective parents with identified genetic conditions, or granting children born with certain conditions the right to sue their parents for the effects of defects that could have been avoided if they had had themselves screened prior to having children?

Is part of the answer that, as practiced in the United States, sperm donation itself can promote genetic defects?

Returning to the case of the HCM donor with which we started this discussion, recall that he had 24 children. Another New York donor estimates that he has provided sperm for [hundreds](#) of children. There is no legal limit on the number of children a single donor may father in any one city—donors may sire children in numbers not seen since the days of [Genghis Khan](#). If the donor has a genetic defect for which screening is too expensive or not yet possible, he may pass that trait on to a far larger number of descendants than would otherwise be the case. And even if he has no genetic defects, the practice of donor anonymity, combined with the absence of limits on the number of donor children creates a risk that half-siblings will unknowingly meet and conceive children together. England, for that reason, provides that only 10 families may receive gametes from any one donor. In the U.S., though, there is still no legal limit—which can be seen as another example of the law’s focus on the interests of the mother (who would not be directly affected by unintentional consanguinity) rather than the child (who might be).

Screening can also be used by parents who are deaf or are dwarfs, or have other heritable traits, to ensure that their children are like them. This has [already happened](#) informally, engendering [considerable controversy](#), and may be happening [at fertility clinics](#) as well. Do children deliberately conceived deaf without their consent have a claim against the clinics that assisted in their birth, or against their own parents? Children whose deafness is caused by negligent medical treatment have a claim against those who cause their deafness, as does a child born with hereditary deafness following a physician’s failure to detect and advise her parents of the genetic risk.¹ Is it not inconsistent for states that permit [wrongful life claims](#) to deny such claims to children born without hearing due to the intentional actions of others, including their parents?

Donor Anonymity

Returning to the Maron *et al.* study, it is odd that Syerson as well as Daar and Bryzski read that study as calling for a national searchable database to pass along information about any genetic disorders that may arise. The study contained no such recommendation, but simply noted that the case “underscores the need for guidelines to notify gamete donors, recipients, and other affected parties once genetic disease arises.” However, a database is certainly one way to accomplish that notification and both [voluntary](#) and [mandatory](#) databases have been suggested by others. Syerson expresses concern that in a database “[w]ithout adequate privacy protections, recipients of a donor’s sperm may be able to contact the donor despite his desire to stay anonymous.” But as the GLR has noted before, when dealing with genomic data, even robust efforts to ensure [anonymity may be illusory](#). Since a donor’s son has a copy of his Y chromosome, the child may have the relevant genomic data necessary to identify the donor father—as one donor’s 15-year old son [demonstrated](#) by sending a cheek swab to [Family Tree DNA](#), finding two matches for his Y chromosome with the same last name, and then using the name and the limited information his mother had from the sperm bank to locate his father.

Even if donor anonymity is feasible, is it ethical? Proponents of anonymity are concerned about the effect ending donor anonymity may have on the supply of gametes. Daar, for example, has elsewhere [written](#) that “a non-anonymous donor policy in the U.S. would reduce the availability of donor sperm for unmarried women.” In other circumstances, there is a strong presumption that the father should remain responsible for his children. The policy against leaving a mother to support her child alone is so strong under U.S. law, in fact, that even young male victims of statutory rape must pay child support. Courts have “uniformly concluded that the fact that a child results from the criminal sexual act of an adult female with a minor male does not absolve the minor from the responsibility to pay child support.”² Similarly, a husband is presumed by law to be the father of his wife’s children, and the courts in most states will require a man to continue to provide support for those children even when [subsequent genetic testing](#) reveals that his wife had cheated on him and the children are not his. Should children of donors be denied the financial support of a father that is compelled on behalf of other children?

Daar is of the view that “[o]n balance, children of single ... parents fare as well as children raised in marital ... homes.” Her argument implies that, just as there is a duty to screen for genetic problems, it is appropriate to consider the environment in which the donor child is to be raised. However, even an [article](#) by authors sympathetic to single parenthood notes that “[m]uch of the literature on single-parent families has focused on the negative consequences for children.” For example, “[even in Sweden](#) with its generous welfare state, a major 2003 study found that children raised in single-parent homes were at significantly higher risk for addictions and serious psychiatric problems.” Does the weight to be given the effect of anonymity on the supply of donors depend on the effect single-parent homes have on children?

And even if there is a sufficient number of donors, does an extreme case such as “Octomom” [Nadya Suleman](#), the indigent single mother with 14 donor-conceived children, suggest that limiting access to certain reproductive technologies based on the ability to support the children might in fact be desirable? Not at all, according to [several academic commentators](#). At least [one author](#) has taken the contrary position that “[t]he state has a compelling interest to act in the best interest of the offspring that result from infertility treatment” —including an interest in “the ability of the potential parents to provide for the children.” What about limitations based on the age of the recipient mother? A 66-year old woman who [lied about her age](#) to a California fertility doctor gave birth to two boys—and died when they were two. The [American Society for Reproductive Medicine](#) voluntary protocols include no upper age limit, but do suggest medical evaluation of potential recipients over 45. More generally, Daar argues that “imposing reproductive regimes that deny procreative rights to certain members of a society is dangerously reminiscent of our eugenics past.” Ironically, as we saw above, Daar favors screening gamete donors for genetic defects, which could be considered the actual practice of eugenics. (Of course, such screening would not prevent the rejected donor from fathering children on his own.)

Anonymity itself comes with a cost. One need only spend a little time on the [website](#) created by a donor child searching for her father and half-siblings to understand the pain some of these children feel at being deprived of the knowledge of their biological father’s identity. As the daughter of an anonymous donor put it on [another such website](#), “[m]y mother’s need to have a genetic link to her child was valued, while my need to know, love and understand the father with whom I have a genetic link was not.” More than 25,000 such children, their parents, and donors, have registered at the [Donor Sibling Registry](#), trying to connect donor children with half-siblings and fathers—up from fewer than 10,000 two years ago.

Article Seven of the 1989 [United Nations Convention on the Rights of the Child](#) (pdf) explicitly protects a child’s “right to know ... his or her parents.” Several signatory countries, including Holland, Norway, and Sweden have outlawed anonymous sperm donation out of concern for the effect on the children. In 2002, a British court found that a child does have the “right to obtain information about a biological parent [a sperm donor] who will inevitably have contributed to the identity of his child.”³ In 2005, the UK abolished anonymity for donors, and gave donor children the right to access their “biological pasts” at the age of 18.

Things are different in America. The United States is one of only two countries (along with Somalia) that has [not ratified](#) the Convention on the Rights of the Child, and no state bans anonymous donation. A California court has held that a donor child with a genetic disorder has the right to her father’s medical information, any promise of anonymity made by the sperm bank notwithstanding. However, cases involving adoption suggest U.S. courts will not follow the British precedent and provide children with a right to learn the father’s identity. U.S. donor children appear to be left to self-help—including resources such as FamilyTreeDNA.com—if they wish to discover their biological fathers.

The Future of Genetic Screening

Everyone seems to agree that at least some genetic testing of donated gametes is desirable, yet few clinics do

it, and no state requires it. As [one commentator observes](#), “hardly anyone in the public or the legislatures is paying attention. The designing of children is occurring subtly, as a result of individual choices through an open market.” While many countries, from Iran to England, have enacted laws affecting genetic screening, for the benefit of the children to be born to those involved, the reproductive legal landscape in the U.S. is sometimes termed [Wild West](#). The lack of regulation is itself a policy choice, and may be the one on which the country settles—but any such decision should be the result of conscious deliberation, considering the interests of children as well as that of their parents.

¹[Turpin v. Sortini](#), 643 P.2d 954 (Cal. 1982).

²[L.M.E. v. A.R.S.](#), 261 Mich. App. 273, 288-289 (2004).

³[Rose v. Secretary of State for Health](#), 2002 WL 1446174

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[...] This article by an intellectual property lawyer reviews many of the issues surrounding genetic screening and anonymous sperm donors. If you think these are simple issues, you haven’t thought about them enough. Here is one of my favorite passages: Anonymity itself comes with a cost. One need only spend a little time on the website created by a donor child searching for her father and half-siblings to

understand the pain some of these children feel at be deprived of the knowledge of their biological father's identity. As the daughter of an anonymous donor put it on another such website, "[m]y mother's need to have a genetic link to her child was valued, while my need to know, love and understand the father with whom I have a genetic link was not." More than 25,000 such children, their parents, and donors, have registered at the Donor Sibling Registry, trying to connect donor children with half-siblings and fathers—up from fewer than 10,000 two years ago. [...]

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