

Conceived and Deceived: *The Medical Interests of Donor-Conceived Individuals*

BY VARDIT RAVITSKY

Many donor-conceived individuals want to know their genetic origins. This has become a growing issue of public debate and bioethical concern. Some concentrate on their interest in donors' medical and genetic information, which can be relevant to medical decision-making. Others emphasize broader interests in donors' personal information, which could help donor-conceived individuals construct their identities and thus promote their psychological well-being. While both interests have already been acknowledged as deserving legal protection in several jurisdictions worldwide,¹ legislators in the United States have only just taken a first step in this direction.²

Effective July 22, 2011, a new law in the state of Washington requires any donor of sperm or eggs to provide a medical history and identifying information to fertility clinics. It also allows donor-conceived individuals to request this information from clinics once they reach the age of eighteen.³ This is a significant legislative milestone and a promising development in a country that has consistently shied away from regulating the infertility

industry in any way. Although donors may still veto disclosure of their identifying information, offspring will now have guaranteed access to nonidentifying medical history.⁴ This represents a tremendous improvement over the current reality in all other U.S. states, where fertility clinics can destroy donor medical records before the child turns eighteen.

In Canada, although the Assisted Human Reproduction Act mandated the registration of information related to donors and donor offspring as early as 2004, this measure has never been implemented, and consequently Canadian clinics can also destroy donor records. This has been the experience of Olivia Pratten, a journalist conceived through anonymous sperm donation who has been unsuccessfully attempting for years to access medical and identifying information about her donor. Pratten decided to take her case to court in an attempt to change the legal reality for future generations of donor-conceived individuals.⁵ Relying on principles of equal treatment, she argued that donor-conceived individuals are being systematically discriminated against when compared to adoptees, who have legal rights to information about their genetic origins.

"Before forming an opinion about this," she says, "I always ask people to put themselves in my shoes: if you found out tomorrow that your dad wasn't your biological father, could you honestly say that you would be satisfied never knowing who he was? And furthermore, would you tolerate being told you had no right to find out?"⁶

In May 2011, the Supreme Court of British Columbia rendered a decision in her favor,⁷ giving the province fifteen months to draft new legislation that will not violate Section 15.1 of Canada's Charter of Rights and Freedoms.⁸ The Court also granted a permanent injunction to prohibit the destruction and disposal of the records of gamete donors.

The government of British Columbia appealed the decision shortly thereafter, arguing that the trial judge erred in law. However, if this landmark decision is upheld, it will be an important legislative milestone for Canada.⁹ The future of this case is of great interest in particular since in December 2010, Canada's Supreme Court—following a constitutional challenge by the

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provincial government of Quebec—returned to the provinces the authority to regulate most aspects of assisted human reproduction.¹⁰ In the coming years, all Canadian provinces will have to make legislative decisions on this topic, and a legal precedent banning donor anonymity in one province may lead the way for others to follow suit.

A similar case heard by the High Court in the United Kingdom in 2002 was partially responsible for consequent legislation banning anonymous gamete donation.¹¹ It could be only a matter of time before a similar case is brought before a U.S. court.

Knowing One's Genetic Origins

What do we as a society owe donor-conceived individuals in terms of obtaining access to information about their genetic origins?

There are different ways of approaching this question.¹² Some argue that there is a fundamental human right to know one's genetic origins, while others argue merely for addressing the interests of donor-conceived individuals if and when there is satisfactory empirical evidence that current practices are harming them. Even those who acknowledge a fundamental human right to know—and therefore advocate banning donor anonymity—are divided regarding its implications. Should parents be merely encouraged to tell their donor-conceived children the truth about the circumstances of their conception, or should the state force them to do so by marking birth certificates to indicate “donor birth”?¹³ This essay addresses just one of this set of issues: the regulatory changes required to address the *medical* interests of donor-conceived individuals, regardless of whether a human right to know one's genetic origins is acknowledged.

Tens of thousands of babies are born from donated gametes each year worldwide. Although exact numbers are not available, an estimated one million donor-conceived individuals live in the United States alone. In recent years, as donor-conceived individuals have begun coming of age, their voices and interests have come to the fore. They have become the center of a lively academic debate,¹⁴ as well as a driver for support networks,¹⁵ educational campaigns,¹⁶ and legislative changes.¹⁷

Ample public attention has also been given to this issue, with hundreds of media reports in recent years. A number of documentaries have explored the psychological ramifications of the journeys of individuals searching for their donors and donor siblings (those conceived by the same donor but raised in a different family).¹⁸ The topic has captured the attention of the entertainment industry as well, with the Academy Award-nominated *The Kids Are All Right* bringing the interests of donor-conceived individuals to wide audiences. Another interesting phenomenon is the use of the Web to search for donors and donor siblings. For example, the Donor Siblings Registry, a voluntary private organization founded in 2000, has over 30,000 members and to date has helped to connect over 8,400 half-siblings and/or donors and

offspring.¹⁹ Donor-conceived individuals have also used online genealogy DNA-testing services to track their donors.²⁰

Most fertility experts had not anticipated these outcomes. They focused on their patients, helping them to create the families they desired. They perceived donors as mere means in the process, promising anonymity (a promise that cannot always be kept, as demonstrated by the success of Internet searches). In the context of infertility, pregnancy is the Holy Grail. It can be all too easy to lose sight of the fact that the child resulting from that pregnancy might struggle for the rest of her life with the absence of information about half of her genetic origins. This absence, imposed by social arrangements that fail to acknowledge the consequences of gamete donation, can become a psychological and medical black hole for offspring.

The interests and concerns of donor-conceived individuals that are gradually emerging from a growing body of literature are complex and multifaceted. Many voice concerns about their inability to access donors' medical information or to have a full picture of their family medical history. As the new Washington law demonstrates, such information can be anonymized and does not require full disclosure of donor identity, making it possible to respect *both* the medical interests of offspring and donors' interests in anonymity.

Others voice identity concerns, highlighting their psychological need for information that would assist them in constructing their own sense of identity. They claim that the understanding of oneself—from physical characteristics to personality traits, talents, and interests—is associated with an understanding of where these characteristics and traits came from. Such information can be nonidentifying, indicating, for example, a donor's physical appearance, cultural or religious background, education, profession, and hobbies. Many sperm banks and egg donation agencies currently provide such information to their clients, some of it at additional cost. This information can also include the full identity of the donor, which offspring may desire in order to contact him or her and attempt to establish a relationship.

While some sperm banks in the United States run open-identity programs that allow full identification of the donor,²¹ most sperm and egg donations in North America are still anonymous. It is worth noting that even nonidentifying personal information about donors can and often does lead to identification when given some “detective work,” especially when it utilizes the power of social networks and other Web-based tools. Arguably, providing this type of personal information does assist offspring in their searches and therefore exposes donors to the possibility of being identified later on.

This distinction between medical concerns on one hand and identity concerns on the other is important for two main reasons. First, the burden of proof is perceived as different. Medical claims are generally easier to justify given the obvious importance of knowing one's genetics and family history for medical purposes. Some still consider concerns about the psychological and social harms of not knowing one's genetic origins to be controversial, primarily because we still lack

robust empirical evidence showing that donor anonymity actually harms offspring, or even that a statistically significant number of donor-conceived individuals wish to access personal information about their donors or know their identity.

Collecting such data is challenging for a number of reasons. Many donor-conceived individuals are not told the truth about the circumstances of their conception by their parents,²² a fact that creates an insurmountable limitation to the study sample in any research on their life experiences. Confidentiality issues also make recruiting donor offspring exceptionally challenging, so sample sizes of studies are typically small. Typical recruitment strategies, which use support networks, may lead to a significant selection bias, since people probably join the networks precisely because they have concerns about their genetic origins or suffer from specific harms. Finally, because of all these challenges, no longitudinal studies (the gold standard in social science research) have been completed that would ideally follow individuals throughout life and record the impact of their unique status on various life stages and transitions. Thus, “donor-conceived people are challenged to prove ‘scientifically’ the harm done to them.”²³

The second reason the distinction between medical and identity concerns is important is that an “all-or-nothing” approach to policy-making in this area is harming donor-conceived individuals. Campaigns to secure all aspects of the “right to know one’s genetic origins” by completely banning anonymous gamete donations have been successful in some jurisdictions, but it may be much more difficult to achieve such success in societies with different cultural norms or regulatory approaches. Acknowledging and highlighting medical interests therefore allows legislators and regulators to take a gradual approach and make immediate progress in protecting at least medical interests. Moreover, focusing on medical interests permits regulators to implement mechanisms that do not require full disclosure of donor identity, circumventing issues related to donors’ right to anonymity or to shortage of donated gametes. Such mechanisms are proposed below.

From this perspective, the recent achievement in Washington is a case in point. The new law acknowledges the interest of donor-conceived individuals in identifying information about donors, but in allowing donors to veto such access, it does not treat this interest as a legal right. It does, however, acknowledge a legal right to access nonidentifying, medically relevant information, making Washington the first U.S. state

to do so—a huge leap forward compared to the rest of the country.

Medical Concerns and Their Policy Implications

The medical concerns of donor-conceived individuals are obvious. When it comes to your genetic origins, what you do not know can indeed hurt you. In 2009, the National Institutes of Health released a State of the Science Panel Statement on “Family History and Improving Health.”²⁴ The panel “recognized that family history has an important role in the practice of medicine and may . . . influence clinical interventions.” Knowledge of one’s genetic heritage is indeed necessary for proper awareness of health risks, for taking preventive measures, for having better ability to diagnose conditions as they emerge, and for making informed reproductive decisions. Donor-conceived individuals who are denied access to this information about their family history are clearly harmed. Many of them also make false assumptions about half of their genetic heritage because their parents never tell them the truth about the circumstances of their conception, so they assume that their social parent is also their genetic parent.

In the United States, the American Society for Reproductive Medicine publishes guidelines providing criteria for evaluating donors’ medical history, as well as a list of laboratory tests that it recommends donors undergo before donation.²⁵ Since it is not feasible to screen sperm and egg donors for every known genetic condition, the ASRM recommends testing all donors for cystic fibrosis carrier status and performing other genetic testing “as indicated by the donor’s ethnic background in accordance with current recommendations after obtaining a proper family history.” It also recommends maintaining “a permanent record of each donor’s initial selection process and subsequent follow-up evaluations” and acknowledges that “a mechanism must exist to maintain such records as a future medical resource for any offspring produced.” However, the Food and Drug Administration requires that these records be maintained for only ten years, which is hardly enough time in this context. Since compliance with the ASRM professional guidelines is voluntary, in reality the practices of sperm banks, egg donation agencies, and infertility clinics vary greatly.

A first necessary step would be for the FDA to adopt the ASRM recommendations and require that records be kept indefinitely. Furthermore, all states should follow in the

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footsteps of Washington and ensure by law that fertility clinics collect full medical information and make it accessible to donor offspring upon request. A future comprehensive regulatory step would be to form central state registries that would record all data related to gamete donations for an indefinite period, as is currently done in some jurisdictions. Since past initiatives have failed to make progress in this direction, some think this is unlikely to happen in the United States, which has consistently refrained from regulating the infertility industry. However, considering the potential harms to donor-conceived individuals, the push to create such registries should persist.

Canada, in its Assisted Human Reproduction Act of 2004, has already mandated by law establishing a Personal Health Information Registry that would record information relating to donors and donor-conceived offspring. This registry was never established, however, and it was one of several provisions declared unconstitutional by the Canadian Federal Supreme Court in 2010 following the constitutional challenge to the act by the provincial government of Quebec.²⁶ As a result, the authority to establish registries in Canada currently lies with the provincial governments, and their future remains to be determined.

Another medical concern is related to the need for medical follow-up with donors. Donors are typically young,²⁷ and they may not exhibit symptoms of conditions that emerge later in life. Or they may never exhibit symptoms at all—they may only be carriers of a genetic mutation. It is thus crucial to follow up with donors and update their evolving medical records in order to recontact recipient families if and when new relevant information becomes available. In a recent case, an egg donor was diagnosed with colon cancer at the age of only twenty-nine.²⁸ Informing recipient families would have allowed them to have their children screened through colonoscopy at an early age, but this was impossible because the records had been destroyed by the egg donation broker.

Medical follow-up with donors can be done by having fertility clinics, sperm banks, or egg donation agencies contact them periodically. It can also be done by creating online portals where donors can confidentially update their contact information and medical history. This would require obtaining informed consent for follow-up procedures at the time of donation. It would also require counselling donors to make them aware that their commitment extends into future years and educating them to see the donation not as a one-time act,

but rather as an ongoing responsibility for the well-being of potential offspring and recipient families. Unfortunately, the majority of clinics, banks, and agencies in North America fail to do any of this.

Furthermore, when offspring are diagnosed with a condition that may be traced back to the donor, it is critical to test the donor for confirmation and subsequently stop the use of sperm or eggs from that donor to prevent the birth of children who might inherit the disease. In 2006, a sperm donor passed a rare and dangerous genetic condition—severe congenital neutropenia—to five children born to four couples.²⁹ The sperm bank could not contact the donor and warn him not to make additional donations because contact with him had been lost.³⁰

Yet another concern is related to the ability of families who have used the same donor to alert each other when medical conditions emerge in a child conceived using that donor. A Web-based interactive tool, such as the Donor Sibling Registry, can be extremely effective in allowing such an exchange. This does not necessitate disclosure of full donor identity and can be done on the basis of coded information, such as donor number. In another recent case, a sperm donor did not notify the three sperm banks through which he helped conceive twenty-four offspring that he had been diagnosed with a genetic heart defect. The mother of one of these children looked for information about the donor, discovered his identity, and subsequently learned about his medical condition. Following these discoveries, her son's asymptomatic aortic aneurysm—which could have ruptured at any moment—was also diagnosed, and surgery was performed that probably saved his life.³¹ She then alerted five of his donor siblings through the Donor Sibling Registry,³² probably saving more lives. It is therefore crucial that all banks, agencies, and clinics involved in gamete donation indeed provide coded donor numbers to donor-conceived families and to the donors themselves, allowing them to voluntarily update each other about any new medical information that becomes available. This would also allow families to contact each other if there is ever a need to identify a compatible bone marrow or organ donor.

Finally, the number of children created from one donor should be limited in order to prevent rare genetic conditions from being inherited by a large number of offspring. Such limits would also decrease the chances of accidental incest and the potential negative psychological implications

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of having dozens of genetically related donor siblings. The case of one donor producing over 150 offspring has recently received public attention.³³ While some jurisdictions, such as the United Kingdom, have already set such limits, this matter is not regulated in North America. In Canada, limits are even more problematic because payment for sperm donation has been banned, and as a result, the pool of donors is very limited.³⁴ This means that there is even more incentive to overuse the sperm of each individual donor. Limiting the number of uses of gametes from one donor is yet another example of a regulatory measure that can be taken to mitigate medical risks without revealing the identity of donors.

Donor-conceived individuals' interests in accessing medically relevant information about donors should be legally recognized everywhere. Moreover, there are many regulatory mechanisms that can address these interests without necessitating full disclosure of donor identity, circumventing the debate about the rights of donors to anonymity and the concern that a ban on anonymity might lead to a shortage of donated gametes. These mechanisms should be implemented without delay. As a society that allows and promotes gamete donation, this is the minimal protection we owe a generation that currently has no access to potentially lifesaving information.

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The Ghosts of Institutionalization at Pennhurst's Haunted Asylum

BY EMILY SMITH BEITIKS

In the woods of Spring City, Pennsylvania, lies Pennhurst, a school for people with developmental and physical disabilities from 1908 to 1987. During its years of operation, a total of over 10,500 people lived at Pennhurst, many passing their entire lives within its bounding walls. But like many institutions, Pennhurst eventually became a place of abuse and neglect. Two Supreme Court cases on behalf of Pennhurst residents, as well as a 1968 television news exposé by journalist Bill Baldini called "Suffer the Little Children," helped bring these issues to light.¹ Investigations in the late 1960s found that over 3,500 residents were living in Pennhurst with only 600 workers to assist them, and that many staff were mistreating and sometimes physically harming the residents. There were cases in which residents were raped, sometimes while others watched and did not attempt to stop it. Residents who acted out were cruelly punished—one man was beaten repeatedly with a toilet bowl brush, leaving welts all

over his body. Others were neglected, some left naked in beds or caged in cribs all day long.

Nearly twenty years after these stories of abuse were made public, Pennhurst was finally shut down, and the residents were relocated into group homes. The property sat abandoned for years, with much of the equipment—wheelchairs, hospital beds, and medical devices—left behind. Two years ago, a group well educated about Pennhurst's past formed the Pennhurst Memorial and Preservation Alliance, a nonprofit dedicated to making Pennhurst into a national museum. Standing in the way of PM&PA's vision was a businessman named Richard Chakejian, who purchased Pennhurst from the state for \$2 million.² He developed a composting operation on the grounds, but struggled to turn it into a money-making venture until his teenager suggested that he capitalize on Pennhurst's frightful allure and convert it to a haunted house.³ At the turn of the century, people with disabilities were often regarded as a threat to the social order. It was this fear that motivated Pennhurst's original construction and this same fear, fused with ignorance, insensitivity, and commercialism, that led to Pennhurst's September 2010 rebirth as Chakejian's "Pennhurst Asylum."

Pennhurst is not the first haunted house to be set at a deinstitutionalized asylum or state school.⁴ But given the significant role that Pennhurst played in the deinstitutionalization movement—from the public attention captured by the news exposé to the two Supreme Court rulings—this attraction is of particular importance. PM&PA made a public plea to Chakejian and Randy Bates, a local haunted house creator hired to design the attraction, to show respect for the history of Pennhurst. PM&PA suggested that if a haunted house were hosted on the site, then it should be themed with vampires and Frankenstein monsters rather than mental patients and people with disabilities. Chakejian assured PM&PA and reporters that the request would be heeded,⁵ but the attraction opened with the asylum theme, melded with a fictional legend of an Austrian scientist named "Dr. Chakajian" (an alternative spelling of Chakejian), whose experiments on prisoners went awry.

The result is a bizarre hybrid of history and legend, and of criminality and commercialism, that simultaneously evokes and erases Pennhurst's troubled past. The legend of "Dr. Chakajian" and his deranged, lab-rat prisoners is ostensibly meant to distance the Asylum from Pennhurst's history. Bates told a reporter from the *Philadelphia Inquirer*, "We created a backstory specifically to counteract any type of correlation between the former residents and what we're doing here."⁶ Nonetheless, the attraction largely plays off, and often directly references, Pennhurst's actual history. On the Pennhurst Asylum Web site, Bates writes, "Not only does this place have an incredible ambience, a built in cult following, and a treasure trove of unique props, it has a history; a history of mental patients chained to the walls in dark tunnels, children left for years in cribs, sexual abuse by the staff and even murder. . . . I am blown away by this scene. I can picture the thousands

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