

Review: *The End of Donor Anonymity?*

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This spring, Human Reproduction (HR) released two articles within weeks of each other, perhaps to subtly alert us to a possible change in family-building through gamete donation. If you missed it, HR Editor-in-Chief, Hans Evers made it clear at the European Society's website: "Due to genetic testing donor anonymity...no longer exists," (www.eshre.eu/Publications/Journals/Human-Reproduction/Past-highlights.aspx). The first article, by Visser and colleagues (2016) in the Netherlands, focused on open-identity sperm donation and counseling. The second, by Harper et al. (2016) in the UK, was also about identifiability, predicting in the title: "The end of donor anonymity: How genetic testing is likely to drive anonymous gamete donation out of business." This made Visser et al.'s counseling article all the more timely.

Harper et al.'s "end of anonymity" focused on gamete donors becoming easily identifiable, but, as importantly, it also considered parents losing control over information about their family's origins. While ASRM (2013) recommends counseling prospective parents about the risk of offspring unintentionally discovering having a donor, Harper et al.'s article is important because it emphasizes how the situation has changed and

is riskier than in the past, when, for example, school children extrapolated family relations from eye color or blood type. The risks they outline below imply that non-disclosure to children may no longer be feasible.

The change identified by Harper et al. comes from so many people now centralizing their genetic and (often) contact information, in one of several large worldwide DNA databases. More than two million people have tested and stored their DNA at Ancestry.com's database, AncestryDNA (dna.ancestry.com/#dnaFaqWrap), making it the largest direct-to-consumer (DTC) genetic database in the world. The database has existed since 2012, yet half the testing has happened in the last 18 months alone. This explosion in genetic testing is possible because it is available directly to any consumer with access to the web, a mailing address, their saliva, and \$100-\$200. This and other DTC genetic databases can assist individuals in obtaining ancestry and health information (e.g., disease markers) and in discovering genetic relatives. The continued growth in database membership also means that the likelihood of finding relatives is increasing.

For example, if you test your DNA at the DTC database, 23andme.com, you receive not only the names of ancestors, but also a map of others (often with their name) who tested at the database and a link to email them through the website. One of us (JES) discovered and contacted a former employer who was also a third cousin. More than four million third cousin and closer matches have occurred at AncestryDNA alone (corporate.ancestry.com/press/company-facts/). The

point is, without much effort or (especially) thought, people interested in their origins, whether they know they have a donor or not, can submit their DNA, choose their degree of identifiability (now required by some databases), and then, eight weeks later, learn of and connect with relatives. If a donor and/or their sibling, parent, or child does this, they become potentially identifiable to a recipient parent and/or offspring who does the same. Or vice versa. A donor-conceived person with an interest in their health, for example, can discover that their mother is not their genetic relative, and become identifiable to their donor's sister, who also, for example, submitted her DNA for health interests.

Donor programs now have to consider the implications of the existence of these external, uncontrollable sources of genetic information available to recipients, donors, and their respective families. The reality is that offspring, now more than ever, may discover their donor origins, completely independently of parents and/or donor programs. In the US, fertility clinics are in a privileged position when they have a mental health professional who meets with recipients, and who can help inform and prepare them for the risks of identifiability. In contrast, donor insemination programs have a serious challenge because counseling of prospective parents is not a typical part of the process.

What about donors? As Harper, Borry and others (2014; ASRM 2014) have cautioned, programs can no longer guarantee anonymity to donors, and should include this in their legal documentation. In addition, the larger challenge is in adequately preparing donors, especially in programs that have primarily anonymous sperm or egg donors. Whereas anonymous donation can be appealing, the benefits to donation that is "no-guarantee" anonymous or open-identity (i.e., identifiable to adult offspring) are that they require donors to think longer-term, including considering that they may meet offspring. This may, in turn, inadvertently improve the quality of information they provide. Their motivation will have to go beyond the short-term financial gain, and include a better understanding of what it actually means to help others create families. In addition, where open-identity programs may already be preparing donors for the possibility of contact with adult offspring, implications counseling could also include the possibility that DNA database information may identify donors prematurely, to underage offspring who can have different expectations and needs than adults.

These new risks bolster the relevance of Visser et al.'s (2016) findings on whether donors found counseling helpful or not. In interviews with 25 current and past open-identity Dutch sperm donors, 18 felt they would benefit greatly from counseling when adult offspring contact them, including how to manage expectations and boundaries with both offspring and families. Twelve of the 15 who had participated in counseling while in the program reported greatly appreciating the opportunity. Similarly, eight out of 10 who did not, regretted not receiving counseling, especially in how to talk to family and others about

being a donor. In addition, these views became more evident once they learned that actual children had been born through their donations. This reveals how, even with counseling, and even among donors who know they will be identified, it is difficult for counselors to convey and donors to fully comprehend the long-term implications of gamete donation.

Whether or not the end of donor anonymity is near, it is interesting that the debate on banning anonymous programs may be resolved, not because of offspring rights and/or health and psychological identity development consequences, but because of something completely different. The stakes have changed with the growing popularity of DTC genetic products; there is now a substantial risk to all participants in gamete donation of unexpectedly being identified. Control of donor information is passively, unintentionally and, until now, quietly being transferred from gamete providers and parents to DNA database members.

References

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The Mental Health Professional Group (MHPG) is a multidisciplinary group that formed in 1985 with the full support of the American Society for Reproductive Medicine (ASRM). Its mission is to promote scientific understanding of the psychological, social, and emotional perspectives of infertility patients.