# Scheib, J.E. & Benward, J. (2018). Information transfer: From gamete providers and parents to DNA database members?

Commentary on McGovern & Schlaff (2018). Fertility & Sterility Dialog.

Sperm donor anonymity: a concept rendered obsolete by modern technology.

Inklings

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### Abstract:

The use of donor sperm began as a medical practice with a level of secrecy bordering on shame. In the United States, donor sperm insemination was first performed by Dr. William Pancoast in 1884 at Thomas Jefferson Medical College in Philadelphia. The patient was never told, and it is unclear whether the husband was completely informed as to exactly what was occurring. This was done to prevent "irreparable harm" to the resultant child and the marriage. The case was not published until 1909, 25 years later.

#### Read the full text here.



#### Fertility and Sterility

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#### Information transfer: From gamete providers and parents to DNA database members?

McGovern and Schlaff capture the growing transformation in how we think about donor anonymity in gamete donation, both in the US and internationally. Based on this change, they encourage us to consider whether we need to move to a system that makes available donor identities to donor-conceived adults. How serious need we take these issues?

The reevaluation of donor anonymity has been taking place outside the US for some time. McGovern & Schlaff cite the UK's 2005 move to an all-open-identity donor conception system. But this move has been going on much longer. Sweden moved to all open-identity donation in 1985, followed by several other countries, both legislatively and informally (Blyth & Frith 2015). The Victorian state of Australia now has the best developed, government-implemented and supported system – VARTA – for open-identity donation (VARTA.org.au). Donor identities have been released to donor-conceived adults and their families through this system for several years now.

In 2016, Harper et al. reviewed how direct-to-consumer DNA testing means we can no longer guarantee donor anonymity. Because of the explosion of people using DNA-based tools in medicine, ancestry searches and curiosity-driven past times, growing numbers of families will have their donor and donor offspring genetic connections revealed in accidental and potentially traumatic ways. Johannes Evers, physician, researcher and ESHRE former chair, responded by publishing in Human Reproduction "Due to genetic testing donor anonymity does no longer exist" (June 2016). Similarly, Elaine Gordon packed the hall at a 2016 ASRM symposium on the need to re-think how we approach donor identifiability in her talk "The myth of anonymity: Are we misleading our patients?"

In the US, we continue to question the benefits and feasibility of open-identity donation (Nelson et al. 2015). In Europe, influential bioethicist, Guido Pennings (2017), questioned whether child outcomes evidence could justify recommending that parents share their family's donor origins with their children. Responses, including from those that generated the evidence (Golombok 2017), mental health professionals, policymakers, advocates, people with donor origins (Crawshaw et al. 2017) and others (Pasch et al. 2017) called for the need to re-focus the question away from sufficiency of evidence, to how to support parents, so they need never face the trauma of unintended disclosure for their families

The time has come in the US to acknowledge that the current system of donor anonymity is no longer feasible. Further, we believe that many donor egg-IVF programs and donor agencies have buried their heads in the sand with regard to responding to the growing requests from donor-conceived adults for information about their donors. Some sperm donation programs have taken a more varied approach with increasing options for openness. Although considerable financial investment is required, we now have 35 years of evidence from one American program that open-identity sperm donation can work (Scheib et al., 2017). We also have guidance on how to support these programs (e.g., Crawshaw et al. 2015; van den Akker et al. 2016; Visser et al. 2016).

There is now a substantial risk to all donor conception participants of being identified unexpectedly. If we, as practitioners, cannot prepare for donor identification and provide information in a manner to support all parties – parents, people conceived through donor conception, donors and the donor's own families – those parties will go ahead without us. Control of information about one's genetic links is being transferred passively from gamete providers and parents to DNA database members, some of whom may be unprepared for what they find.

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## **Jason Kovac** about 1 year ago

Interesting commentary and concept. The idea that sperm donor anonymity may be a concept that is rapidly disappearing is something that needs to be considered.

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### **Debbie Kennett** 7 months ago

Just to add to Joanna Scheib's excellent comments, your readers might also be interested in the 2017 case report by Marilyn Crawshaw "Direct-to-consumer DNA testing: the fallout for individuals and their families unexpectedly learning of their donor conception origins".

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