

Egg donors need long-term follow-up: Recommendations from a retrospective study of oocyte donors in the US

By Jennifer Schneider, MD, PhD, Arizona Community Physicians, and Wendy Kramer, BA, Director, Donor Sibling Registry. | Yesterday

 More than 100,000 young women in the US have been recruited to become egg donors (1) with the offer of large sums of money, typically \$8-15,000 per egg retrieval cycle, but at times up to \$100,000. The US is also a destination for European women seeking to sell their eggs. Additionally, many couples seeking egg donors are from Europe, where paying for such services is illegal and waits can stretch for years (2).

In the US egg donation is a virtually unregulated industry. After egg retrieval, donors are discharged from the IVF clinic but are rarely contacted afterwards. Consequently, there has been a dearth of studies of both short and long-term adverse consequences of ovarian stimulation and egg donation. In addition, only a few published studies have considered the emotional and psychological effects of egg donation on donors.

We conducted a retrospective study of egg donors, up to 22 years after egg donation; 155 of them completed a survey on the website of Donor Sibling Registry (DSR), a US- based worldwide registry that helps donor-conceived individuals search for and contact their donor and/or their half siblings, as well as supplies support, news, and education for parents and former donors. The survey asked about medical complications and subsequent health problems, contact with IVF clinic, willingness to have contact with recipient families, donors' satisfaction with the donation process, and current feelings. Our results highlight the inattention by US IVF centres to the health and needs of egg donors and their genetic offspring.

Regarding early medical complications, we found a high prevalence of ovarian hyperstimulation syndrome (OHSS), now recognized as a common adverse effect - 14 per cent required hospitalization and/or paracentesis, a procedure to remove fluid that has accumulated in the abdominal cavity. One-quarter reported infertility and/or menstrual problems. As for late medical complications, several women developed various cancers, but in the absence of large long-term studies, it is uncertain whether the hormonal regimen they received to hyperstimulate their ovaries increased their cancer risk. Earlier studies of infertile women undergoing IVF suggest this is possible (1).

In the US, most egg donations are anonymous. In many IVF centres, this not only means that donors and recipients do not know each other's identities, but that the IVF centre does not follow up the donors. In our study, 96 per cent of the donors were never contacted by the IVF center for medical updates, so there is no opportunity for reproductive specialists to learn about potential long-term adverse effects on the donors.

Moreover, there is no effort to learn about medical developments in the donors that it might benefit their genetic offspring to know. In our study, one-third described medical changes they thought would be of interest to donor children (including a diagnosis of breast cancer in a donor and cystic fibrosis in a donor's child); half had attempted to report these changes to the clinic, with variable results, such as being told their chart was missing or destroyed, the clinic that had gone out of business or had relocated and couldn't be found, or that the clinic declined to notify the recipients on the basis of

20 January 2009

Published by
ProgressEducationalTrust

[About BioNews](#) | [Contact Us](#)

SEARCH

for
in 

 [BioNews by email](#)

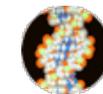
Receive a weekly news round-up via email, and keep up-to-date with what's new on our website

[→ Sign up](#) | [→ Privacy policy](#)

KEY TOPICS

You can view different items across the site according to a number of key topics which come up frequently in the news

Human genome research



[→ View News](#)
[→ View Update](#)
[→ View Commentaries](#)
[→ View all items](#)

Embryo screening



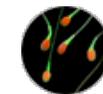
[→ View News](#)
[→ View Update](#)
[→ View Commentaries](#)
[→ View all items](#)

Sex selection



[→ View News](#)
[→ View Update](#)
[→ View Commentaries](#)
[→ View all items](#)

Egg & sperm donation



[→ View News](#)
[→ View Update](#)
[→ View Commentaries](#)
[→ View all items](#)

OTHER TOPICS

Human cloning

[→ View all items](#)

Stem cell research

[→ View all items](#)

Access to IVF

[→ View all items](#)

Genetic testing

[→ View all items](#)

Genetic privacy

[→ View all items](#)

anonymity. Donors who did not attempt to report these changes did not recognize the value of this information to recipients, or else confused anonymity with confidentiality, believing that 'anonymity' meant they were not to contact the clinic and/or that the clinic could not contact the recipients.

In recruiting potential egg donors, IVF clinics in the US tend to understate the medical risks. Even when known risks are fully discussed, the prospective donor is informed that long-term risks are unknown; young women may not clearly understand the difference between 'there are no risks' and 'there are no known risks'. The results of our survey make it clear that communication between egg donor and IVF clinic is often not encouraged.

IVF clinics need to give anonymous egg donors clearer guidelines about asking for outcome information or giving the clinic medical updates to benefit their biologic children. Additional long-term studies are needed to ascertain egg donors' risks of infertility or cancer. In order to make this possible, a national egg donor registry is highly desirable so that researchers can regularly contact donors. Given the reluctance of the US IVF industry to maintain such a registry, it may require passage of a law mandating a national egg-donor registry. Several groups in the US are working toward this goal.

We also found that pre-donation counseling often neglects the potential emotional impact on donors, which may change with time, and the emotional impact on the donors' children as well as the donor-conceived offspring. We learned that as egg donors get older, many want to know the outcome of the pregnancy. Those who initially prize anonymity may want to have more information and contact with their biological children. Donors need to be offered adequate opportunities to think about the long-term impact that donating might have on them, their family, the recipient family, and the genetic offspring.

We recommend that IVF clinics:

1. Maintain donor records indefinitely.
2. Develop protocols to contact the donors regularly to update medical information on the donor's health and information of interest to recipients.
3. Educate the egg donors about the importance of contacting the IVF clinic, even years later, to provide such information
4. Contact recipient families with relevant information provided by the egg donor.
5. Notify donors if any IVF-conceived children are born with genetic abnormalities or potentially inherited diseases as the woman may already have or someday want to have children of her own.
6. Make egg donors as well as recipients, and eventually egg donor children aware of resources for updating and sharing medical information. Until there is a mandatory record keeping system, the Donor Sibling Registry is successfully allowing thousands of families formed via donor conception to establish mutual consent contact and share important genetic, ancestral and medical information.

Currently the primary focus of fertility clinics is to serve the needs of infertile women by maximizing the likelihood of a successful pregnancy. The results of this study reinforce the need to broaden the concerns of IVF clinics include the short- and long-term health and safety of the egg donors and also to recognize the needs of donor-conceived children.

References:

- (1) Schneider, JP 2008. Fatal colon cancer in a young egg donor: A physician mother's call for follow-up and research on the long-term risks of ovarian stimulation. *Fertility and Sterility* 90:2016. Online: .e1-2016.e5.

Gene therapy

[→ View all items](#)

IVF research

[→ View all items](#)

Gene patenting

[→ View all items](#)

(2) 'Ova time: Women line up to Donate Eggs', Wall Street Journal, 9 December 2008,
Online at: <http://online.wsj.com/article/SB122878524586490129.html>

[← Commentaries list](#) | [↑ Top of page](#)



BioNews, c/o Progress Educational Trust, 140 Gray's Inn Road, London WC1X 8AX, UK
T: +44 (0)20 7278 7870 F: +44 (0)20 7278 7862 E: BioNews@progress.org.uk

[Terms and conditions](#) | [Privacy Policy](#) © Copyright 2005 Progress Educational Trust