It's time for a national sperm donor registry

Vanessa Gruben and Alana Cattapan

A recent documentary has revealed that three sperm donors from the same family in Quebec are the biological progenitors of hundreds of children. Posting ads on Facebook, they travelled across the province to provide sperm to people looking to have a child.

There are reasons to be concerned about such prodigious procreation. Two of the donors have a hereditary condition affecting the liver, which could be passed on to any genetic children. And the situation raises concerns about consanguinity, given the significant numbers of genetic half-siblings and potential half cousins clustered within a relatively small geographic area.

When the documentary was brought to the attention of Quebec's director of public health, he noted that he was "shocked" and that no one in Canada "saw this coming."

But many people did.

Policymakers, scholars and donor-conceived people have been sounding the alarm for decades, calling for a registry to track sperm donors and their offspring and to limit the number of births per donor.

The history is a long one, but as early as 1993, the Royal Commission on New Reproductive Technologies called for a limit of no more than 10 live births per sperm donor and a national registry. In 2004, the federal Assisted Human Reproduction Act also foresaw the need for a donor registry to advise donor-conceived people of a potential health and safety risk as well as a mechanism for them to identify genetically related siblings.

But the parts of the act that would have allowed the federal government to establish a registry were overturned in 2010. The Supreme Court found it was outside of federal authority, leaving it up to the provinces to act. Yet the provinces have not stepped in, instead continuing to overlook the need for a donor registry - until now.

The concern over excessive sperm donation generated by these three men has moved the Government of Quebec to action; the province is looking into how to set limits on how many children are born from sperm donation. That's a good first step. But this work cannot fall to Quebec alone.

All provincial governments need to collaborate to build a national donor registry, and there is an important role for the federal government in convening provincial/territorial ministries of health and spearheading efforts to mitigate the risks facing donor-conceived people.

Many other countries have long-established registries that enable governments and agencies to track sperm and egg donations, or otherwise set limits on the number of times a donor's sperm (or eggs) may be used. For example, in the United Kingdom, the Human Fertilisation and Embryology Authority (HFEA) has a database that contains information on all donors and children conceived by donor since 1991. Additionally, the HFEA sets a limit of 10 families that can be created using the gametes of one donor.

Similar regulatory frameworks exist in Australia, Belgium, Denmark, France, the Netherlands, Norway and many others. Increasingly, experts are calling for
international limits as well, recognizing that sperm and sperm donors often travel across borders.

Regulations are not foolproof. Scandals can happen even where registries and limits exist.

Last year, news outlets reported that a Dutch man had more than five hundred genetic offspring in spite of a registry and donor limit, after misinforming intended parents and fertility clinics about the number of times he had previously donated.

Some cases are also difficult to track, especially when - as occurred in Quebec - the donations occur outside of fertility clinics.

Still, donor registries and donor limits are important tools that will signify that Canada takes the interests of donor-conceived people and their families seriously.

An effective donor registry will hold the information of both donors and donor-conceived people, allow for tracking of multiple donations, and allow donor-conceived people and their families to share information. An ombudsperson to address complaints and concerns regarding potential problems might also go a long way.

The fact that three men in Quebec have hundreds of genetically-related children between them comes as no surprise to those who have been paying attention to the governance of fertility in Canada and elsewhere. But we hope it offers the impetus for Quebec, and for the rest of Canada, to develop a co-ordinated and comprehensive approach to safeguard the interests of donor-conceived Canadians.

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