

Office of Legislative and Regulatory Modernization
Health Products and Food Branch
Health Canada
Address Locator: 3000A, 11 Holland Avenue, Suite 14,
Ottawa, Ontario
K1A 0K9

January 8, 2019

Re: Proposed Assisted Human Reproduction Act (AHRA) regulations

Dear Sir / Madam,

We, the Donor Conceived Alliance of Canada, are writing to express our serious concerns with the proposed Assisted Human Reproduction Act (AHRA) regulations (i.e. to update Section 8, Consent, and to implement Sections 10, 12, and 45-58)¹. We also want to express our disappointment with the consultation process regarding these proposed regulations.²

The Principles of the Assisted Human Reproduction Act are enshrined in Section 2, and these principles are supposed to underpin all of the regulations that follow. **Section 2(a) of the AHRA states that:**

(a) the health and well-being of children [sic] born through the application of assisted human reproductive technologies must be given priority in all decisions respecting their use

We are glad to see that this principle remains in the AHRA, **but we do not feel that this principle has been adequately reflected in the proposed regulations.**

The proposed Assisted Human Reproduction Act Regulations are focused on helping provide clarity to the fertility industry with regards to how fertility establishments should be run, which expenses incurred by donors or surrogates can be reimbursed, and how consent should be documented with respect to the use of sperm, ova and embryos. **The proposed regulations fall short of what is required for protecting the health and well-being of donor-conceived people.** The following sections detail the changes that we want to see to the regulations and to the practices of donor conception more broadly.

Continued next page

¹ As published in the Canada Gazette, Part I, Volume 152, Number 43:
<http://www.gazette.gc.ca/rp-pr/p1/2018/2018-10-27/html/index-eng.html>

² "Consultation on proposed assisted human reproduction regulations," from October 27 2018 to January 10 2019: www.canada.ca/en/health-canada/programs/consultation-assisted-human-reproduction-regulations.html

1. Ban donor anonymity

The proposed regulations aim to offer more protection for the anonymity of donors. While we understand that this is intended to close an existing loophole in the existing donor documentation process, **the focus of the Canadian government on protecting anonymity for donors is regressive and goes against the trend toward abolishing donor anonymity around the world.**³ It also ignores the reality that donor anonymity is effectively over due to the rising popularity of direct-to-consumer DNA testing.

Offering more protection for the anonymity of donors is troubling on several counts: (1) In a recent survey, **the majority of donor-conceived people were firmly opposed to anonymous sperm and egg donation.**⁴ There have been several academic studies that have echoed the same results.⁵ (2) We believe that it is wrong to purposely create people who are denied knowledge about their medical, cultural and genetic identity. (3) We also believe that it is wrong for a government, doctor, private business or organization to withhold personal information about a person from that person. (4) The right to know one's identity is also enshrined in the UN Convention on the Rights of the Child, to which Canada is a signatory.⁶ (5) Furthermore, the claim that the fertility industry can offer anonymity to sperm and ova donors is deceitful. With the explosion of consumer DNA testing it has become relatively easy for most donor-conceived people to identify their biological parent(s) (sperm / egg / embryo donors), even if the donors themselves never have their DNA tested. **We want to see Health Canada and the fertility industry formally recognize that “anonymous” gamete donation should no longer be offered or promised to prospective sperm and egg donors.**

2. Expand donor health screening

While we support the development of testing and screening requirements to ensure donor sperm and eggs are screened for certain infectious diseases and serious genetic diseases, we do not think the screening criteria go far enough.

There is a **need for even more screening criteria and disease screening** in order to protect the long-term health and well-being of donor conceived people. Additional criteria should include screening for mental health (e.g. history of schizophrenia) and additional potentially-heritable health risks (e.g. Alzheimer's, kidney disease, early onset cancers, diabetes).

³ Several jurisdictions have banned gamete donor anonymity and/or amended their legislation to take donor-conceived peoples rights into account including: Sweden (1985), Austria (1992), Switzerland (1998), Norway (2003), Holland (2004), New Zealand (2004), Netherlands (2004), United Kingdom (2005), Australia (2005), Finland (2006), Washington State - United States (2011), Croatia (2012), Germany (2015), Argentina (2014), and Ireland (2018).

⁴ See results of 2018 We Are Donor Conceived survey for more details:

<https://www.wearedonorconceived.com/guides/we-are-donor-conceived-2018-survey-results/>

⁵ For example, see: J.E. Scheib, M. Riordan, and S. Rubin, “Adolescents with open-identity sperm donors: reports from 12-17 year olds,” *Human Reproduction* 20, no. 1 (2005); Patricia P. Mahlstedt, Kathleen LaBounty, and William Thomas Kennedy, “The Views of Adult Offspring of Sperm Donation: Essential Feedback for the Development of Ethical Guidelines within the Practice of Assisted Reproductive Technology in the United States,” *Fertility and Sterility* 93, no. 7 (2010); J.E. Scheib, A. Ruby, and J. Benward. “Who Requests their Sperm Donor's Identity? The First Ten Years of Information Releases to Adults with Open-Identity Donors.” *Fertility and Sterility* 107, no. 2 (2017).

⁶ Article 8 (Preservation of identity): “Children have the right to an identity – an official record of who they are. Governments should respect children's right to a name, a nationality and family ties.”

In addition, **donors should be required to keep health records updated** in the event that they develop new medical conditions after donating, such as schizophrenia or early onset cancers. Many donors who provide gametes do so when they are young, before they are aware that they may be carriers of serious health conditions.

3. Require longer record keeping

We support the proposal that establishments will now be required to keep records regarding donor conception, but **the proposed regulations would have primary establishments keep donor sperm or egg records for a mere 10 years**. This is woefully inadequate for ensuring the protection of the health and well-being of donor-conceived people.

Under this proposed regulation the donor conceived person will have no way of knowing the medical history of the donor if the recipient parents have not retained the records, or if the donor-conceived person only finds out the truth about his or her conception after the age of 10 years old. **By contrast, Germany requires records to be kept for 110 years — we believe this should be the requirement in Canada as well**, especially given that gametes can be frozen for long periods of time.

Quebec's 2008 legal challenge to the AHRA quashed plans for a stand-alone national donor registry. Provincial donor registries should be mandated and this information should be searchable through a Canada-wide system. This would ensure that records are kept if establishments shut down, and that records would be easily accessed by donor-conceived people. There should be no minimum age limit on when donor-conceived people can access these records.

4. Update terminology about donor-conceived people

The proposed regulations consistently use the term “donor-conceived child(ren)” when referring to the people produced through Assisted Human Reproduction. While it is correct that AHR initially produces children, the use of this word infantilizes the rights and interests of donor-conceived adults. Considering the health and well-being of donor-conceived adults raises additional concerns, such as how to facilitate contact between siblings conceived by the same donor and protect donor-conceived adults from accidentally having romantic relationship with genetic half-siblings.

We want to see all instances of “donor-conceived child” and “children” to “donor-conceived person” or “people” throughout the Assisted Human Reproduction Act.

5. Set limit on the number of donor conceived people created per donor

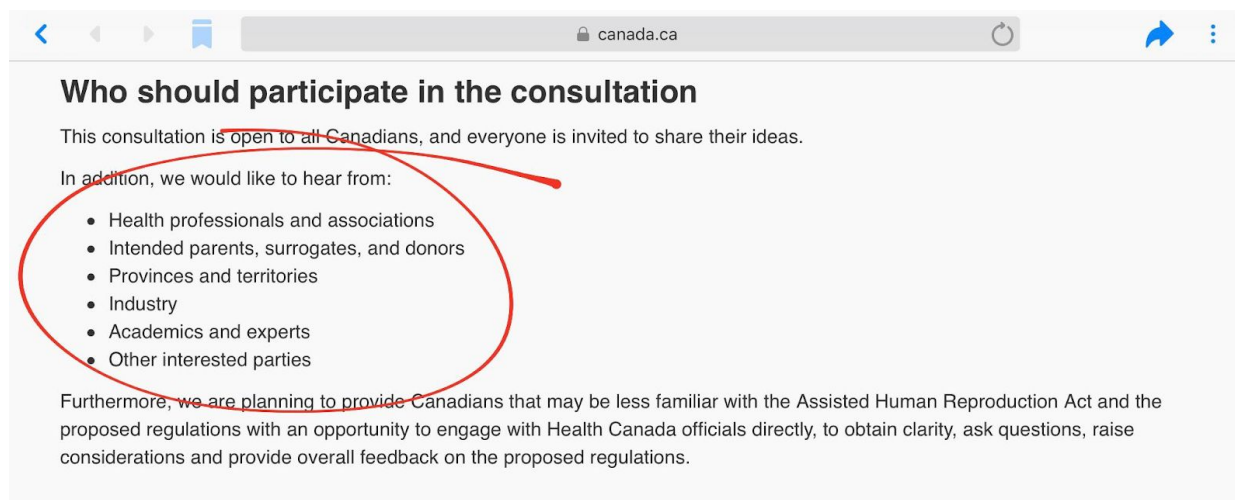
Finally, DCAC calls on Health Canada to include in the legislation a legal limit for the number of offspring that can be created from a single donor. Currently there are no limits (only recommendations) in Canada or the United States for the number of offspring per donor, so donor-conceived people can end up with dozens or even hundreds of siblings. Xytex sperm bank, for example, will supply up to 60 families worldwide with sperm from the same donor and multiple children can be conceived from the same donor within a family; rumours are circulating that Xytex is now increasing the family limit to 80. This is not only disconcerting — it also raises the risk of accidental incest.

6. Add information about donor conception to birth certificates

Donor-conceived people have the right to know that they were donor-conceived. A “donor-conceived” annotation should be added to long-form and short-form birth certificates to make it more likely that donor-conceived people will know the truth about their conception. While not specifically within the jurisdiction of Health Canada, reform is required in this area to avoid the negative health impacts on donor-conceived people from lack of parental disclosure and deception by the state.

Feedback on the Health Canada consultation process

Our second set of concerns pertains to Health Canada’s consultation process itself. As donor-conceived people, our health and well-being is the most directly impacted by third-party reproduction. The very core of who we are — our physical health, mental health, identity, and predisposition to disease — has been strongly affected by the decisions of policy makers such as yourselves. And yet, **donor-conceived people were not identified as a stakeholder group of interest for the development of these regulations** (screenshot below, taken October 26 2018):



The list of stakeholders was updated on December 7 2018, after members of our community spoke with Health Canada staff to express our profound disappointment at being excluded from the list of key stakeholders:

< > canada.ca

Who should participate in the consultation

This consultation is open to all Canadians, and everyone is invited to share their ideas.

In addition, we would like to hear from:

- Health professionals and associations
- Intended parents, surrogates, and donors
- Donor conceived individuals
- Provinces and territories
- Industry
- Academics and experts
- Other interested parties

Furthermore, we are planning to provide Canadians that may be less familiar with the Assisted Human Reproduction Act and the proposed regulations with an opportunity to engage with Health Canada officials directly, to obtain clarity, ask questions, raise considerations and provide overall feedback on the proposed regulations.

Likewise, donor-conceived people were not officially engaged by Health Canada in their 2017 “[Strengthening the Assisted Human Reproduction Act](#)” consultation process. According to the summary documentation, the stakeholder groups who were consulted in that process included:

- an association representing the views of medical professionals in the field of AHR in Canada
- representatives of the AHR industry
- academics
- surrogates
- advocacy groups
- intended parents; and
- fertility lawyers

Despite this, members of our community *did* participate in the process, but neither our participation nor our comments were captured or reflected in the [summary document](#) that was produced.

In closing, we support the development of regulations to bring the Assisted Human Reproduction Act into force, and we agree that the AHRA needs to be strengthened. However, the proposed regulations **do not go nearly far enough to protect the health and well-being of the very people that the Act is committed to protect.**

We appreciate the chance to provide these comments, and we welcome the opportunity to work with Health Canada in the future on matters affecting the health and well-being of donor-conceived people in Canada.

Sincerely, on behalf of the Donor Conceived Alliance of Canada,

Ash Splawinski, Toronto, Ontario
Kevin Martin, Cleveland, Ohio (Canadian)
Sarah Primeau, Windsor, Ontario
Thordur Thordarson, Markham, Ontario
Andréane Letendre, Ste-Françoise, Quebec
Rob Hunter, Toronto, Ontario
Erin Jackson, San Diego, California (Canadian)
Barry Stevens, Toronto, ON
Erin Melbourne, Kingston, ON

WHAT IF HALF OF YOUR IDENTITY WAS A SECRET?

What if your birth certificate hid an important truth: that you were #donorconceived? What if you had no way of finding your donor and no access to your medical history? For people created from anonymously donated sperm and eggs #thisisreality.

WHAT IF YOU MARRIED YOUR SISTER OR BROTHER?

What if this happened because your parents hid the fact that you were #donorconceived? What if your kids were born with a genetic disorder as a result? In Canada, where most sperm and egg donations are anonymous and most parents don't tell, #thisisreality.



WHAT IF YOUR MEDICAL HISTORY WAS UNKNOWN?

What if you were never able to know your medical history because you were #donorconceived? What if you missed vital health checks as a result? In Canada, where fertility clinics can destroy donor records, #thisisreality.

WHAT IF YOUR BABY WAS SWITCHED AT BIRTH?

If you discovered this shocking truth, would you search for your biological child? Now flip it. What if the person you thought was your biological parent was not? What if this was planned and you were deliberately kept in the dark? For **#donorconceived people**, **#thisisreality**.

WE ARE CANADIANS CREATED BY ANONYMOUS SPERM & EGG DONATION.

We call on the government, the fertility industry and parents to listen to our perspective. **It's time.**

1. ABOLISH ANONYMOUS DONATION.

Knowing who your biological parents are, including their genetic, cultural, and medical background, is a **fundamental human right**. Countries around the world recognize this and are banning anonymous donation. Furthermore, in an era of DNA testing **it is no longer feasible or honest to promise anonymity to donors.**

2. LEGALLY LIMIT PEOPLE MADE PER DONOR.

In Canada, **unlimited numbers of people** can be created per donor. Discovering that you have dozens (or hundreds) of siblings can feel dehumanizing and increases the risk of **accidental incest**. Many other countries set limits of **5-10 offspring per donor.**

3. GIVE US ACCESS TO OUR MEDICAL HISTORY.

Health information should be **kept for decades** (as in other countries), **not a mere 10 years**. Donors should provide **regular health updates** and donor conceived people should be able to access these records. **This lifesaving information should never be intentionally denied or destroyed.**



DONOR CONCEIVED
Alliance of Canada

donorconceivedalliance.ca