

## **Article 9 Comments:**

Susan Crockin, SART/ASRM observer

October 25, 2016

These comments are in response to the reported Concerns and Courtney's Responses, and are followed by a few tentative proposed edits to Article 9 on those issues.

New Article 9 aptly addresses a critical need to preserve donor information in light of rapidly expanding gamete donation practices, which is now occurring on a national and international scale, with distribution to multiple recipients and storage and redistribution by multiple entities.

My comments and suggested edits are intended to address these realities. Increasingly, eggs and sperm are collected from 1 physical site and by 1 entity (IVF clinics for eggs and embryos; non-medical sperm bank facilities for sperm), stored in a variety of facilities (from medical programs to stand-alone banks), offered to recipients on websites, and ultimately shipped to and amongst a number of recipients by various entities interstate and internationally.

For Article 9 to be effective, I believe it must recognize that donor identifying information and affidavits of disclosure or non-disclosure need to accompany any donor gametes, not simply retained by the initial entity. Requiring this affidavit and information accompany the gametes will help ensure donor conceived persons ("DCPs") will not be precluded from finding this information if they do not know where the gametes were originally collected. I believe it also avoids extra-territorial concerns by requiring any entity within the state to collect, store or transmit this information. While imperfect, it is a significantly improved initial step toward preserving and accessing donor information.

I therefore agree with the RESPONSE to alter the scheme to require the Affidavit accompany any transmittal of gametes or embryos. That will: 1) at a minimum ensure this information is accessible at the source of any particular set of gametes; 2) minimize patient vulnerability as to programs going out of business; and 3) be a safeguard if a recipient or DCP cannot identify or locate the original program or entity. I believe the potential complications and vulnerabilities are both outweighed by the benefits and can be minimized.

Regarding a donor's change of mind to identity disclosure: 1) I agree it can only be in the direction of more disclosure (i.e. no change to non-identifying); 2) while ideally it should go to the initial entity, lodging it with any entity is better than none and there will be occasions where the initial entity is not known or has closed; and 3) any entity reached by a DCP would be able to go back up the 'supply chain' and in most cases learn of the changed affidavit.

Finally, with respect to enforcement, it may be an imperfect system, but much better than ignoring the issue. I am involved in a long standing SART affiliated task force that hopes to in establish a centralized donor gamete registry or entity. At some future point, there may well be

such a centralized repository, and some programs could of course elect to add to any affidavit that a donor may elect to have any information placed into a future entity, but I think this is a good current step forward.

Highlighted below is some specific, tentatively proposed, language to address the above issues:

**Article 9:**

**SECTION 902. COLLECTION OF IDENTIFYING INFORMATION.** A gamete bank or fertility clinic licensed in [this state] shall collect from any donor the individual's identifying information and medical history. If the gametes are thereafter transferred to another gamete bank or fertility clinic licensed in [this state], the sending entity must forward any donor's identifying information and medical history, including a donor's signed Affidavit Regarding Disclosure set forth in Section 903, received from a donor to the receiving entity which must collect and retain the information about the donor, and the gamete bank or fertility clinic from which it received the gametes. A gamete bank or fertility clinic licensed in [this state] shall disclose the information as provided under Section 904.

**SECTION 903. AFFIDAVITS REGARDING DISCLOSURE.**

(a) A gamete bank or fertility clinic licensed in [this state] that collects or stores gametes shall provide to the donor written information regarding identity disclosure.

(b) A gamete bank or fertility clinic licensed in [this state] that collects or stores gametes shall require any donor to sign an affidavit regarding identity disclosure. The individual must be given the choice to sign either:

(1) an affidavit agreeing to disclose the donor's identity ("Affidavit for Identity Disclosure") to the resulting child upon request once the child is at least eighteen years of age; or

(2) an affidavit that the donor does not presently agree to disclose the donor's identity to the resulting child ("Affidavit for Identity Nondisclosure")

**SECTION 904. DISCLOSURE OF IDENTIFYING INFORMATION.**

(a) Upon request by a child conceived through assisted reproduction who is at least 18 years old, the gamete bank or fertility clinic licensed in [this state] that collected, stored, and/or released for use the gametes shall provide the resulting child with the identifying information of the donor who provided gametes, unless the donor signed and did not withdraw an Affidavit

of Nondisclosure as described in Section 903. If a donor has signed, and not withdrawn, such an affidavit, the gamete bank or fertility clinic licensed in [this state] that collected, stored, and/or released for use the gametes shall make good faith efforts to notify the donor, who may elect to withdraw the donor's affidavit.

(b) Regardless of whether the donor signed an Affidavit of Nondisclosure, upon request by a child conceived through assisted reproduction who is at least 18 years old, the gamete bank or fertility clinic licensed in [this state] that collected, stored, and/or released for use the

gametes shall provide to the 14 resulting child access to the nonidentifying medical history of the donor. 15

**SECTION 905. RECORD KEEPING.** A gamete bank or fertility clinic licensed in 16 [this state] that collects, stores, and/or releases ...gamete donors, and records of all gamete 18 screening and testing, in accordance with federal and applicable law of this state.