

Act 156
Uniform Law on Parentage (ULP)
Birth Heritage Permitted Interaction Group (BH-PIG)
Policy Concept Report

Policy Concept: The Birth Heritage Permitted Interaction Group (BH-PIG) was established to discuss the policy concept of allowing children born from surrogates and assistive reproductive technologies (ART) to access identifying and non-identifying health and medical information of their surrogates and/or gamete donor(s) who are their genetic but not legal parents.

Background: This concept derives from more than 50 years of research about the adverse effects of sealed adoption records on adoptees and adoptive families created under the closed adoption system of the 20th century. Adoption was created to provide legal parents for children who could not be cared for by their genetic parents. Information about genetic parents was not shared with the adoptive family. Subsequent research in the field of genetics identified links between genes and myriad medical conditions, ethnicity, and personality traits. Further, direct-to-consumer DNA tests and online genetic matching databases eliminated anonymity offered through sealed records due to matches between adult adoptees and genetic parents or related family members. However, this informal method of deriving birth heritage information is not always accurate nor complete, depending upon which genetic family members are matched. In 2016, Hawaii's adoption law was amended to allow adult adoptees access to their sealed adoption records, upon their request.

Like adoption, surrogacy and ART allows creation of a family comprising genetic and non-genetic parents. This means that a child of a surrogate or ART may have one genetic parent and one non-genetic parent as their legal parents, or two non-genetic legal parents. Most surrogacy arrangements and ART clinics offer anonymity to surrogates and gamete donors. Donor recipients and/or legal parents are not provided with their donor's identity. This practice of anonymity leaves donor children with incomplete health, medical and birth heritage information like the experience of adoptees without genetic parent information.

Subsequent to the 2023 introduction in the Hawaii legislature of the ULP, the National Conference of Commissioners on Uniform State Laws provided an update to their 2017 draft. The update, Article 9, recognizes the importance of sharing information between donors, their genetic children, and the legal parents of donor children. Article 9 is attached to this report.

Points of Discussion: BH-PIG offers the following comments on the policy concept.

Most gamete or fertility clinics do not share identifying information of donors with donor recipients nor the donor children.

Non-identifying information including race, ethnicity, health status and medical conditions of surrogates and gamete donors should be released to legal parents and genetic children of surrogates and gamete donors.

Gamete or fertility clinics should request updates to health status and medical conditions from gamete donors at regular intervals until the donor child achieves age 18 and/or upon request from donor child's legal parents.

Same gender couples may face additional barriers to creating families through surrogacy and ART, if donors cannot be anonymous.

Creating families through surrogacy and ART presents similar issues for donor children that are experienced by adopted children who are not provided birth heritage information about their genetic parents.

Adults born from surrogates and donors should be allowed access to identifying information at age 18, upon their request, and aligns with current Hawaii adoption law allowing adult adoptees access to sealed adoption records containing birth heritage information.

Recommendations for Discussion by Task Force:

The BH-PIG recommends inclusion of Article 9 into the Task Force draft ULP to be presented for consideration by the Hawaii legislature.

The BH-PIG did not reach agreement about including genetic parent information on the birth center record and original birth certificate for donor children of surrogates and ART.

Attachments:

Resources related to donor anonymity and organizations advocating for and supporting the sharing of donor information.

Article 9, Uniform Parentage Act (2017) approved by the National Conference of Commissioners on Uniform State Laws, January 25, 2024

Birth Heritage PIG - Resources

Donor Anonymity and DNA

The Atlantic - 2021

<https://www.theatlantic.com/science/archive/2021/10/do-we-have-right-know-our-biological-parents/620405/>

American Psychological Association - 2018

<https://www.apa.org/monitor/2018/06/cover-genetic-testing.html>

Harvard Health - 2019

<https://www.health.harvard.edu/blog/dna-testing-forever-changed-donor-conception-2019072317394>

Psychology Today - 2022

<https://www.psychologytoday.com/us/blog/donor-family-matters/202211/dna-donors-not-anonymous>

Scientific American- 2019

<https://www.scientificamerican.com/article/consumer-dna-tests-negate-sperm-bank-donor-anonymity/>

National Organizations advocating for and supporting the sharing of donor information

Adoption Knowledge - US organization offering education and support for adoptee searches, including donor conceived community members

<https://www.adoptionknowledge.org>

Donor Sibling Registry - US organization founded in 2000 to educate, connect, and support donor families <https://donorsiblingregistry.com>

Right to Know - US organization advocating for right to know genetic information (national and international members) <https://righttoknow.us>

Untangling Our Roots - US organization sponsoring conference to connect adoptees, children of ART, and unknown fathers over issues re: genetic heritage and access to genetic information <https://untanglingourroots.org>

[ARTICLE] 9

INFORMATION ABOUT DONOR

Comment

Article 9 is a new addition to the UPA. The content of this article was not included in UPA (2002). The content of new Article 9 is premised on a Washington State provision. Wash. Rev. Code § 26.26.750. A revision to Article 9 was approved in December 2023.

SECTION 901. DEFINITIONS. In this [article]:

(1) “Identifying information” means:

(A) the full name of a donor;

(B) the date of birth of the donor; and

(C) the permanent and, if different, current address, telephone number, and

electronic mail address of the donor at the time of the donation.

(2) “Medical history” means information regarding any:

(A) present illness of a donor;

(B) past illness of the donor; and

(C) social, genetic, and family history pertaining to the health of the donor.

SECTION 902. APPLICABILITY. This [article] applies only to gametes collected on or after [the effective date of this [act]].

SECTION 903. COLLECTION OF INFORMATION.

(a) A gamete bank or fertility clinic licensed in this state shall collect from a donor the donor's identifying information and medical history at the time of the donation.

(b) A gamete bank or fertility clinic licensed in this state which receives gametes of a donor collected by another gamete bank or fertility clinic shall collect the name, address, telephone number, and electronic mail address of the gamete bank or fertility clinic from which it received the gametes.

(c) A gamete bank or fertility clinic licensed in this state shall disclose the information collected under subsections (a) and (b) as provided under Section 905.

SECTION 904. (RESERVED).

SECTION 905. DISCLOSURE OF IDENTIFYING INFORMATION AND MEDICAL HISTORY.

(a) On request of a child conceived by assisted reproduction who attains 18 years of age, a gamete bank or fertility clinic licensed in this state which collected the gametes used in the assisted reproduction shall provide the child with identifying information of the donor who provided the gametes.

(b) Regardless whether a child has made a request under Section 905(a), on request of a child conceived by assisted reproduction who attains 18 years of age, or, if the child is a minor, of a parent or guardian of the child, a gamete bank or fertility clinic licensed in this state which collected the gametes used in the assisted reproduction shall provide the child or, if the child is a minor, the parent or guardian of the child, access to nonidentifying medical history of the donor.

(c) On request of a child conceived by assisted reproduction who attains 18 years of age, or, if the child is a minor, of a parent or guardian of the child, a gamete bank or fertility clinic licensed in this state which received the gametes used in the assisted reproduction from another gamete bank or fertility clinic shall disclose to the child or, if the child is a minor, the parent or guardian of the child, the name, address, telephone number, and electronic mail address of the gamete bank or fertility clinic from which it received the gametes.

SECTION 906. RECORDKEEPING.

(a) A gamete bank or fertility clinic licensed in this state which collects gametes for use in assisted reproduction shall maintain identifying information and medical history about each gamete donor. The gamete bank or fertility clinic shall maintain records of gamete screening and testing and comply with reporting requirements, in accordance with federal law and applicable law of this state other than this [act].

(b) A gamete bank or fertility clinic licensed in this state that receives gametes from another gamete bank or fertility clinic shall maintain the name, address, telephone number, and electronic mail address of the gamete bank or fertility clinic from which it received the gametes.