# Act 156 Task Force Uniform Law on Parentage (ULP) Birth Heritage Permitted Interaction Group (BH-PIG) Policy Concept Report (06/28/2024)

#### Supporting Current ULP Article 9 (revised by the ULC on January 25, 2024)

**Policy Concept:** The Birth Heritage Permitted Interaction Group (BH-PIG) was established to discuss the policy concept of allowing persons conceived through assistive reproductive technologies (ART) using donor gametes (including via traditional surrogacy) to access identifying birth heritage and non-identifying health and medical information about their gamete donor(s) who are their genetic but not legal parents.

Background: This concept arises from the longstanding practice of using gametes provided by anonymous donors (i.e. sperm, ova, embryo donors as well as traditional surrogates) in ART procedures to enable the creation of families for individuals and couples who otherwise would not be able to conceive naturally. This means that a donor conceived child may have: one legal parent, who is their genetic parent and one genetic but not legal parent; two legal parents, one genetic and one non-genetic parent; or two legal non-genetic parents. The legal parents are not provided with the donor's identity, and the donor conceived child upon becoming an adult also has no access to this information. Further, the donor's non-identifying health and medical information offered at the time of the donor conceived child's birth is not routinely reported and updated throughout the child's development. This practice of anonymity leaves donor conceived children with incomplete birth heritage, health, and medical information, which is otherwise accessible or available to persons raised within their genetic families.

These concerns about anonymity of gamete donors and traditional surrogates derive 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 20<sup>th</sup> century. Adoption was created to provide legal parents for children who could not be cared for by their genetic parents. However, little information about genetic parents was shared with the adoptive family nor was this information available to adoptees upon reaching

adulthood. This lack of birth heritage, health and medical information presented adoptive families with challenges in supporting their child's health care, medical conditions, and developmental stages. National and international advocacy groups comprising adult adoptees, adoptive parents, and genetic parents began to advocate for access to identifying birth heritage and non-identifying health and medical information in response to these adverse impacts on adoptive families.

Further, beginning in the 21st century, research in the field of genetics identified links between genes and myriad medical conditions, ethnicity, and personality traits. Genetic parent and genetic family heritage, health and medical information could be vital to both diagnosis and treatment of medical conditions presenting in the lives of adoptees and donor conceived children. The creation and marketing of direct-to-consumer DNA tests and online genetic matching databases have minimized anonymity offered through sealed adoption records due to matches between adoptees and genetic parents or related family members. Similarly, DNA tests and online matching databases have resulted in donor conceived children and their families questioning donor anonymity. These families have supported the establishment of online sibling matching databases and organizations advocating for the rights of donor conceived children to know their birth heritage. However, these informal methods of deriving birth heritage information are not always accurate nor complete, depending upon which genetic family members are matched.

Subsequent to the introduction of the ULP to the 2023 Hawaii legislature, the National Conference of Commissioners on Uniform State Laws (NCCUSL) provided an update to their 2017 Uniform Parentage Act, and "recommended it for enactment in all the states"(1). The updated Article 9, "premised on a Washington state provision WA Rev. Code section 26.26.750",(2) recognizes the importance of sharing information between donors, their donor conceived children, and the legal parents of donor conceived children.

- (1) Uniform Parentage Act dated January 25, 2024, Prefatory Notes and Comments
- (2) Article 9, page 94, Uniform Parentage Act dated January 25, 2024

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

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

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

Non-identifying information including race, ethnicity, health status and medical conditions of gamete donors and surrogates should be released to legal parents and/or the donor conceived children, upon request.

In 2016, Hawaii's adoption law was amended to allow adult adoptees, upon their request, access to their sealed adoption records that contain genetic parent information.

Donor conceived children, upon becoming adults at age 18, should be allowed access to identifying information about their donor(s) and/or surrogates, 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 key decision point for the Task Force is whether Hawaii should include the current NCCUSL approved Article 9 or the older, supplanted Article 9 of the Uniform Parentage Act of 2017.

Two members of the BH-PIG met once and three members met once to discuss this issue. Two members recommend inclusion of the current Article 9 in the Draft ULP to be presented by the Task Force for consideration by the Hawaii legislature, so that "it keeps state law up-to-date".(3)

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

(3) Uniform Parentage Act dated January 25, 2024, Prefatory Notes and Comments

**Attachments:** 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 - <u>The Children of Sperm Donors Want to Change the Rules of Conception</u>

American Psychological Association - 2018 - Genetic testing and family secrets

Harvard Health - 2019 - DNA testing forever changed donor conception

Psychology Today - 2022 - <u>DNA = Donors Not Anonymous</u>

Scientific American- 2019 - <u>Consumer DNA Tests Negate Sperm-Bank-Donor Anonymity</u>

#### National Organizations advocating for and supporting the sharing of donor information

<u>Adoption Knowledge</u> - US organization offering education and support for adoptee searches, including donor conceived community members <a href="https://www.adoptionknowledge.org">https://www.adoptionknowledge.org</a>

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

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

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

### **Uniform Parentage Act (2017)**

drafted by the

## NATIONAL CONFERENCE OF COMMISSIONERS ON UNIFORM STATE LAWS

and by it

## APPROVED AND RECOMMENDED FOR ENACTMENT IN ALL THE STATES



#### WITH PREFATORY NOTE AND COMMENTS

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This act was initially approved in <u>1973</u> and was amended in <u>2000</u>, <u>2002</u>, <u>2017</u>, <u>2019</u>, and 2023. In 2023, the ULC approved amendments to Article 9.

#### **ABOUT ULC**

The **Uniform Law Commission** (ULC), also known as National Conference of Commissioners on Uniform State Laws (NCCUSL), now in its 126th year, provides states with non-partisan, well-conceived and well-drafted legislation that brings clarity and stability to critical areas of state statutory law.

ULC members must be lawyers, qualified to practice law. They are practicing lawyers, judges, legislators and legislative staff and law professors, who have been appointed by state governments as well as the District of Columbia, Puerto Rico and the U.S. Virgin Islands to research, draft and promote enactment of uniform state laws in areas of state law where uniformity is desirable and practical.

- ULC strengthens the federal system by providing rules and procedures that are consistent from state to state but that also reflect the diverse experience of the states.
- ULC statutes are representative of state experience, because the organization is made up of representatives from each state, appointed by state government.
- ULC keeps state law up-to-date by addressing important and timely legal issues.
- ULC's efforts reduce the need for individuals and businesses to deal with different laws as they move and do business in different states.
- ULC's work facilitates economic development and provides a legal platform for foreign entities to deal with U.S. citizens and businesses.
- Uniform Law Commissioners donate thousands of hours of their time and legal and drafting expertise every year as a public service, and receive no salary or compensation for their work.
- ULC's deliberative and uniquely open drafting process draws on the expertise of commissioners, but also utilizes input from legal experts, and advisors and observers representing the views of other legal organizations or interests that will be subject to the proposed laws.
- ULC is a state-supported organization that represents true value for the states, providing services that most states could not otherwise afford or duplicate.

#### **UNIFORM PARENTAGE ACT (2017)**

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UPA (2002) did not address the applicable rules in the event of a breach of the agreement. New subsection (a) follows the approach taken by several of the recently enacted comprehensive surrogacy statutes, and provides that the parties are entitled to remedies available at law or in equity. *See, e.g.*, Me. Rev. Stat. tit. 19-a, § 1938(3); Nev. Rev. Stat. § 126.790(1), (2) (providing that, in the event of a breach, the intended parents or the gestational surrogate, as appropriate, are entitled to "any remedy available at law or equity."); N.H. Rev. Stat. § 168-B:18(I), (II) (providing that, in the event of a breach, the intended parents or the gestational surrogate, as appropriate, are entitled to "all remedies available at law or equity").

New subsection (b) expressly states that a court cannot order that a surrogate be impregnated, terminate or not terminate a pregnancy, or submit to medical procedures. Such an order may violate the constitutional rights of the surrogate. *See also* Me. Rev. Stat. tit 19-a, § 1938(5) (addressing impregnation and termination, but not submission to medical procedures); Nev. Rev. Stat. § 126.780 ("There must be no specific performance remedy available for breach of the gestational agreement by the gestational carrier that would require the gestational carrier to be impregnated.").

#### [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.

#### [ARTICLE] 10

#### **MISCELLANEOUS PROVISIONS**

**SECTION 1001. UNIFORMITY OF APPLICATION AND CONSTRUCTION.** In applying and construing this uniform act, consideration must be given to the need to promote uniformity of the law with respect to its subject matter among states that enact it.

SECTION 1002. RELATION TO ELECTRONIC SIGNATURES IN GLOBAL

AND NATIONAL COMMERCE ACT. This [act] modifies, limits, or supersedes the

Electronic Signatures in Global and National Commerce Act, 15 U.S.C. Section 7001 et seq., but