

Act 156 Task Force
Uniform Law on Parentage (ULP)
Birth Heritage Permitted Interaction Group (BH-PIG)
Policy Concept Summary (FINAL - 07/19/2024)

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 also 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 right to access this information (although the donor-conceived person typically may request contact at age 18, it is entirely within the donor's discretion whether to disclose their identity). 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.

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 20th century. Adoption was created to provide legal parents for children who could not be cared for by their genetic parents or related family members. However, little information about genetic parents or related family members 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.

For the donor conceived child's legal parents, concerns about non-identifying health and medical information can be addressed to some extent by federal regulations and cryobank procedures. The U.S. Food and Drug Administration (FDA) requires the screening of donors of human cells, tissues, and cellular and tissue-based products (including sperm and ova) for risk factors for and clinical evidence of relevant communicable disease agents such as HIV, Hepatitis B and C, Creutzfeldt Jakob disease, and genitourinary tract diseases such as chlamydia and gonorrhea. Further, gamete cryobanks perform a variety of additional donor screenings that can include detailed genetic family medical histories, chromosome analysis, genetic screening, psychological evaluations, criminal history background checks and diagnostic screenings for specific diseases. Gamete cryobanks also provide intended parents with non-identifying information about anonymous donors during the donor selection process, including ethnicity, religion, physical characteristics, blood type, donor personality analysis, family photos and essays.

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 related family heritage, health and medical information could be vital to both diagnosis and treatment of medical conditions presenting in the lives of 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 as such tests and databases are voluntary and access to identifying information is authorized by the test taker. Some families of donor conceived children 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. *Please see attached Appendix A [Direct to Consumer DNA Tests and Donor Anonymity](#)*

Since the elimination of donor anonymity beginning in the United Kingdom, including Great Britain, Australia, and New Zealand, amongst other countries, there has been much research about the impacts on donor conceived families and potential donors. In the U.S., the American Society for Reproductive Medicine (ASRM) recommends that donor evaluations assess a donor's understanding of the "risk of losing anonymity" due to social media, direct to consumer DNA online registries, and facial recognition online applications. Further, in an ASRM Ethics Committee opinion issued in 2019, the committee noted that "planned disclosure of a gamete donor's identity, if all agree, allows

accurate information to be given, and it has the potential of satisfying the developmental needs of a child who enters young adulthood”.

Points of Agreement:

For some families created through ART and surrogacy, using anonymous donors results in incomplete health, medical and birth heritage information for donor conceived children and their families.

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, but not limited to ethnicity, race, health status and medical conditions of gamete donors and surrogates should be released by gamete banks and fertility clinics via agreements with legal parents and/or upon request of the donor conceived person.

Direct-to-consumer DNA tests have mitigated the promise of anonymity given to donors at the time of their donation, and donors should be advised of potential contact from donor conceived families and/or the donor conceived person.

Donor conceived persons do not have the opportunity to give consent to the anonymity imposed upon them by their donors and legal parents and are seeking the same information from their donors that is available and accessible to persons raised within their genetic families.

Most research about eliminating donor anonymity is focused on the needs of the donor conceived persons seeking information and results differ based upon the type of family structure the donor conceived person experienced.

In 2016, Hawaii’s adoption law was amended to allow adult adoptees, upon their request, to access their sealed adoption records that contain genetic parent identities, to allow adult adoptees to obtain health, medical and birth heritage information about their birthparents.

Current Hawai’i law does not address donor identification and/or disclosure of identifying nor non-identifying information to the donor conceived person nor their legal parents.

Points of Disagreement:

Eliminating donor anonymity may reduce the numbers of potential donors and/or increase the costs for certain classes of persons seeking to create families via ART and/or surrogacy.

Genetic parents' legal names should be included on the birth center record and/or original birth certificate for donor conceived children and filed with the Department of Health prior to issuance of an amended birth certificate from the Department of Health.

Donor conceived persons, upon becoming adults at age 18, should be provided identifying information about their donor(s) and/or surrogates, upon their request.

Recommendations for Discussion by Task Force:

Subsequent to the introduction of the ULP to the 2023 Hawaii legislature, the National Conference of Commissioners on Uniform State Laws (NCCUSL) approved the 2024 update to their 2017 Uniform Parentage Act, and "recommended it for enactment in all the states". The updated Article 9 recognizes the importance of sharing information between donors, their donor conceived children, and the legal parents of donor conceived children. Key points of each are summarized below.

2024 - Donor Information - (1) Requires collection and retention of non-identifying medical history of donor and donor's family, to be released, upon request of the donor conceived person at age 18 years, or to the parent or guardian of the donor conceived child. (2) Identifying information, to include full name of donor, date of birth of donor, and permanent or current address telephone number and email of the donor at the time of the donation, is collected and retained. Upon the request of a donor conceived person at age 18 years, above information shall be released. Please see attached Appendix B titled **Research Submitted in Support of Donor Identity Disclosure**

2017 - Donor Information - (1) Requires collection and retention of non-identifying medical history of donor and donor's family, to be released, upon request of the donor conceived person at age 18 years, or to the parent or guardian of the donor conceived child. (2) Identifying information is collected but may only be released to the donor conceived person at age 18, if the donor signs a sworn declaration agreeing to disclosure, or if a prior non-disclosure declaration is subsequently revoked by the donor. Please see attached Appendix C titled **Research Submitted in Opposition to Donor Identity Disclosure**

The Birth Heritage PIG members' positions are as follows:

2 members support inclusion of the current 2024 Article 9 in the Draft ULP to be presented by the Task Force for consideration by the Hawai'i legislature.

1 member supports inclusion of the original 2017 Article 9 in the Draft ULP to be presented by the Task Force for consideration by the Hawai'i legislature.

2 members have abstained from stating a position within the BH PIG.

The key decision point for the Task Force is whether Hawai'i should include the current Uniform Law Commission (ULC) approved 2024 Article 9 or the original 2017 Article 9 of the Uniform Parentage Act.

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

Appendix A Direct to Consumer DNA Tests and Donor Anonymity

Appendix B Research Submitted in Support of Donor Identity Disclosure

Appendix C Research Submitted in Opposition to Donor Identity Disclosure

Appendix A

Direct to Consumer DNA Tests and Donor Anonymity

- The Atlantic - 2021 - [The Children of Sperm Donors Want to Change the Rules of Conception](#)
- American Psychological Association - 2018 - [Genetic testing and family secrets](#)
- Harvard Health - 2019 - [DNA testing forever changed donor conception](#)
- Psychology Today - 2022 - [DNA = Donors Not Anonymous](#)
- Scientific American- 2019 - [Consumer DNA Tests Negate Sperm-Bank-Donor Anonymity](#)

National Organizations 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>
- [Colage](#) - US organization (originally Children of Lesbians and Gays Everywhere) dedicated to empowering and supporting children of LGBTQ+ families. <https://www.usdcc.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 related to genetic heritage and access to genetic information. <https://untanglingourroots.org>
- [US Donor Conceived Council](#) - US organization that strives to increase awareness of the needs, interests, and challenges of donor conceived people and advance change that promotes and protects their health, welfare, and human rights. <https://www.usdcc.org>

Appendix B
Research in Support of Donor Identity Disclosure

- Updated terminology for gamete and embryo donors: Directed (identified) to replace “known” and nonidentified to replace “Anonymous”: A committee opinion. (2022). *Fertility and Sterility*, 118(1), 75-78.
<https://doi.org/10.1016/j.fertnstert.2022.02.032>
- Cahn, Naomi R. and Suter, Sonia M., Developing a Reproductive Justice Approach to Regulating Formal and Informal Sperm Donation (December 14, 2023). Almeling, Rene, Lisa Campo-Engelstein, and Brian T. Nguyen, co-editors. *Sperm|Health|Politics*, New York University Press, Forthcoming, Virginia Public Law and Legal Theory Research Paper No. 2023-78, Available at SSRN: <https://ssrn.com/abstract=4665036>
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- Interests, obligations, and rights in gamete and embryo donation: An ethics committee opinion. (2019). *Fertility and Sterility*, 111(4), 664-670.
<https://doi.org/10.1016/j.fertnstert.2019.01.018>
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- Cahn, Naomi R. The New “Art” of Family: Connecting Assisted Reproductive Technologies & Identity Rights, 2018 *University of Illinois Law Review*, 1443-1471 (2018).
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<https://doi.org/10.1093/humrep/dey088>

- Adams DH, et al., Does the removal of anonymity reduce sperm donors in Australia? J Law Med. 2016 Mar;23(3):628-36. PMID: 27323639.
- Gartrell, N. K., Bos, H., Goldberg, N. G., Deck, A., & van Rijn-van Gelderen, L. (2015). Satisfaction with known, open-identity, or unknown sperm donors: reports from lesbian mothers of 17-year-old adolescents. Fertility and sterility, 103(1), 242-248. <https://doi.org/10.1016/j.fertnstert.2014.09.019>
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- Jadva, V., Freeman, T., Kramer, W., & Golombok, S. (2010). Experiences of offspring searching for and contacting their donor siblings and donor. Reproductive biomedicine online, 20(4), 523-532. <https://doi.org/10.1016/j.rbmo.2010.01.001>
- Mahlstedt, P. P., LaBounty, K., & Kennedy, W. T. (2010). 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(7), 2236-2246. <https://doi.org/10.1016/j.fertnstert.2008.12.119>

Appendix C
Research in Opposition to Donor Identity Disclosure

- [Comparing the Psychological Outcomes of Donor and Non-Donor Conceived People: A Systematic Review](#), Talbot, Hodson, Rose and Bewley. BJOG: An International Journal of Obstetrics and Gynecology, May 2024
- A 2017 study by the Department of Psychology at the University of California, Davis found that approximately 33% of open-donor offspring sought their donor's identity during the first 10 years of eligibility ([Who requests their sperm donor's identity? The first ten years of information releases to adults with open-identity donors](#) (ucdavis.edu))
- Adult Offspring of Lesbian Parents Reflect on Having Been Donor Conceived: Feelings About Their Sperm Donors and Donor Siblings, American Psychological Association Society for Couple and Family Psychology: Research and Practice, 2024 ([2024-nllfs-adult-offspring-feelings-sperm-donor.pdf](#))
- Bernstein, Gaia, Unintended Consequences: Prohibitions on Gamete Donor Anonymity and the Fragile Practice of Surrogacy (December 18, 2012) Indiana Health Law Review (Symposium) (2013) Seton Hall Public Law Research Paper No. 2190992, Available at SSRN: <https://ssrn.com/abstract=2190992>
- Cohen, I. Glenn, Sperm and Egg Donor Anonymity: Legal and Ethical Issues (April 28, 2015). Oxford Handbook of Reproductive Ethics (Leslie Francis ed, Oxford University Press, 2015, Forthcoming, Available at SSRN: <https://ssrn.com/abstract=2600262>

[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.