Position Statement of Carol E. Lockwood Birth Heritage PIG

Summary:

- The deliberations of the Birth Heritage Permitted Interaction Group (the "BH-PIG") have focused mainly on the issue of whether, and to what extent, individuals conceived through the use of Assisted Reproductive Technology ("ART") using donor gametes (sperm/ova) should be entitled to non-identifying and identifying information regarding their donors.
- The members of the BH-PIG are largely in agreement that donor-conceived children (and, during their minority, said children's legal parents) should be granted access to non-identifying information regarding the race, ethnicity and medical history of their donors.
- The members of the BH-PIG have diverging viewpoints as to whether Hawaii's amended Uniform Parentage Act ("UPA") should mandate the disclosure of donor-identifying information to anonymous donor-conceived children when they reach the age of eighteen, which mandate would effectively prohibit the collection and use of anonymous donor gametes by gamete banks and fertility clinics licensed in the State of Hawaii (excluding gametes imported from outside the State). Two members of the BH-PIG believe Hawaii's amended UPA should include the mandate; one member of the BH-PIG believes that Hawaii's amended UPA should not include the mandate; and the remaining two members of the BH-PIG have not stated their position on this issue. As further detailed below, each position is reflected in a version of the UPA drafted by the National Conference of Commissioners on Uniform State Laws (the "Uniform Law Commission"), with disclosure of donor identifying information mandated in the original UPA (2017) and disclosure of donor identifying information mandated in the revised UPA (2017). The members of the BH-PIG are seeking the assistance of the other members of the Act 156 Task Force in deciding which approach to recommend to the Hawaii State Legislature.

Background:

Availability of Non-Identifying Donor Medical History:

- The United States 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, among other things, (1) risk factors for and clinical evidence of relevant communicable disease agents (including HIV, Hepatitis B, Hepatitis C, Creutzfeldt-Jakob disease), and (2) risk factors for and clinical evidence of infection due to communicable diseases of the genitourinary tract (including chlamydia and gonorrhea). 21 C.F.R. § 1271 (2024), Subpart C;
- Gamete cryobanks perform a variety of additional donor screening, which can include detailed family and medical histories, chromosome analysis, genetic screening, psychological evaluations, criminal background checks, and supplemental disease screening. Gamete cryobanks purport to be extremely selective in donor qualification (e.g., California Cryobank claims its "stringent donor qualification process allows less than 1% of all applicants to make it into [its] program" and the Seattle Sperm Bank claims that "only about 5% of all donor applicants are able to pass [its] screening requirements").
- Gamete cryobanks provide Intended Parents with detailed non-identifying information regarding anonymous donors during the donor selection process (including, among other things, ethnic origin; ancestry; religion; height; weight; eye color; hair color; hair texture; complexion; blood type; CMV Total Antibody status; donor and family medical history; genetic, chromosome, and disease screening

results; and sometimes donor personality analysis (e.g., Keirsey Temperament Assessment), voice recordings, donor personal essay, donor childhood and/or adult photos, and donor staff impressions.

- The non-identifying information provided to Intended Parents by gamete cryobanks in connection with the donor selection process far exceeds the health information required to be collected and preserved in connection with Hawaii adoptions (and almost certainly exceeds the information typically exchanged between sexual partners prior to natural conception). Moreover, the donor screening required under applicable law, plus the additional donor screening performed by gamete cryobanks, provide assurances of a baseline level of health not present in typical adoptions.
- While a variety of gamete cryobanks now offer "Known Donor" or "Donor ID" options (typically with premium pricing) guaranteeing the release of donor-identifying information once the donor-conceived individual turns eighteen, they share one key limitation: none affirmatively requires donors to engage or communicate with the donor-conceived individual on any kind of meaningful basis (although some programs require a single, oral or written communication of indeterminate length or substance). Thus, disclosure of donor-identifying information does not necessarily equate to enhanced access to donor medical, family, or personal histories.
- It is also worth noting that, with the advent of commercially-available genetic testing through companies like Ancestry.com and 23andMe, anonymous donor-conceived individuals are no longer dependent upon mandatory disclosure laws, gamete bank/fertility clinic policies, or the whims of gamete donors to access birth heritage and family history information (and that, to whatever extent Intended Parents are contractually bound not to seek to identify their child's donor, those agreements are almost certainly not legally binding on adult donor-conceived children).

Uniform Parentage Act:

- <u>Current Hawaii Law</u>: Hawaii's current Uniform Parentage Act (HRS Chapter 584) does not address the topic of gamete donors or the disclosure/non-disclosure of donor information.
- Original UPA 2017: The original version of UPA (2017) introduced Article 9, requiring (among other • things) that a gamete bank/fertility clinic licensed in [the subject] state (i) collect (a) donors' identifying information and medical history at the time of the donation, and (b) the name, address, telephone number, and email address of any gamete bank or fertility clinic from which it receives gametes; (ii) obtain a sworn declaration from gamete donors (a) agreeing to disclosure of donor's identity once the donor-conceived individual reaches 18, or (b) stating that donor does not agree to disclosure of donor's identity to the donor-conceived individual; (iii) permit donors to withdraw a prior non-disclosure declaration at any time and substitute a disclosure declaration; (iv) on request of a donor-conceived individual who attains 18 years of age, provide donor-identifying information unless donor signed and did not withdraw a non-disclosure declaration; (v) if donor signed and did not withdraw a non-disclosure declaration, make a good faith effort to notify donor of the donorconceived individual's request and offer donor the opportunity to withdraw the non-disclosure declaration; and (vi) provide, on request of the donor-conceived individual (or a minor child's legal parents) (a) the non-identifying medical history of donor, and (b) gamete bank/fertility clinic information.

In Short: The original UPA 2017 (adopted in CA, CT, RI, and WA) requires the collection and release of the non-identifying medical history of the donor but *does not* require the release of the donor's identifying information (i.e., it *does not* effectively prohibit the collection and use of anonymous donor gametes by banks and clinics licensed in the State (excluding gametes imported from outside the State)).

• <u>Revised UPA 2017 (Approved 12/2023)</u>: The revised version of UPA (2017) approved by the Uniform Law Commission in December 2023 updated Article 9 to require that a gamete bank/fertility clinic "licensed in this state" (i) collect (a) donors' identifying information and medical history at the time of the donation, and (b) the name, address, telephone number, and email address of any gamete bank or fertility clinic from which it receives gametes; (ii) on request of a donor-conceived individual who attains 18 years of age, provide donor-identifying information; and (iii) on request of the donor-conceived individual (or said minor individual's legal parents), provide (a) the non-identifying medical history of donor, and (b) gamete bank/fertility clinic information.

In Short: The revised UPA 2017 (approved Dec. 2024) *requires* the release of both the nonidentifying medical history of the donor *and also* donor's identifying information (i.e., it *does* effectively prohibit the collection and use of anonymous donor gametes by banks and clinics licensed in the State (excluding gametes imported from outside the State)). This version of the UPA has not yet been adopted in any state (although CO has adopted a separate law mandating disclosure of donoridentifying information).

Discussion:

- <u>Arguments In Favor of Mandatory Disclosure of Donor Identifying Information</u>: The BH-PIG members favoring mandatory disclosure of donor identifying information argue that access to medical history and birth heritage information is critical to the physical and mental wellbeing of donor-born children. These BH-PIG members believe that mandated disclosure of donor-identifying information would properly align the amended UPA with current Hawaii adoption law, which grants adoptees access to sealed adoption records containing birth heritage information once they attain the age of eighteen. [The position of these BH-PIG members is set forth in more detail in their separate report to the Task Force.]
- <u>Arguments Against Mandatory Disclosure of Donor Identifying Information</u>: Mandatory disclosure of donor-identifying information and the effective prohibition against the collection and use of anonymous donor gametes by banks and clinics licensed in the State (excluding gametes imported from outside the State) raise significant equitable, legal, and practical concerns, including the following:
 - Equitable Concerns; Unequal Treatment: It is not uncommon for children to be born in the State 0 of Hawaii with unknown genetic fathers. Anonymous sexual encounters, one night stands, alcohol or drug abuse, multiple sexual partners, sexual violence, and other circumstances regularly result in the birth of children with no access to their paternal medical history and birth heritage information. Moreover, a variety of other factors, including divorce, family schisms, illiteracy, poor recordkeeping, loss or destruction of records, immigration and language differences, parental abandonment, or the death of one or both parents can deprive individuals of access to parental medical histories and birth heritage information. However, no legislative effort is currently underway to prevent or even curtail the natural conception or births of children with unknown genetic fathers, nor to mandate the documentation and preservation of family medical histories and birth heritage information by Hawaii families. Thus, a prohibition on the use of anonymous donors would, in effect, impose a precondition solely on the infertile, LGBTQ+, and single individuals conceiving children through the use of ART – a population already forced to surmount immense obstacles on the road to parenthood (including, among other things, years of infertility, miscarriages, stillbirths, invasive and sometimes painful medical procedures, the side effects of fertility medications, social stigma, and enormous - and typically uninsured - expenses). A law that prohibits this limited class of individuals - but no one else in the State of Hawaii - from conceiving a child unless they can preserve and later disclose said child's medical history and family heritage violates the basic principle of equitable treatment under the law.

- Intrusion on Parents' Reproductive Freedom; Government Overreach: A prohibition against the 0 use of anonymous donor gametes would constitute an unprecedented governmental intrusion into the reproductive freedom of Hawaii's parents. Hawaii does not currently restrict or regulate gamete selection for use in ART procedures (such as in vitro fertilization, intrauterine insemination, and embryo transfers). There is no legal test for "permissible" or "impermissible" gamete use based on the genetic or chromosomal characteristics of the gametes: parents may legally use gametes at risk for passing on inherited conditions such as cystic fibrosis, sickle cell anemia, diabetes, or coronary artery disease – and even gametes known to contain chromosomal abnormalities like Down Syndrome or Trisomy 13. Similarly, Hawaii law provides no basis for restricting gamete use based on subjective judgments regarding the potential future quality of life of the resulting child: parents with potentially hereditary disabilities like dwarfism, deafness, or dyslexia are nonetheless free to use their own gametes in ART procedures (as are, of course, parents conceiving children through so-called "natural" (i.e., non-ART) procreation). Against this backdrop, a selective prohibition against the use of anonymous donor gametes due to the unavailability of donor-identifying information (which is often otherwise obtainable, as described below) would constitute clear government overreach. Moreover, it would be the first step down a slippery slope towards social engineering and even eugenics: if the government can intervene to prevent the conception and birth of a child due to "quality of life" concerns based solely on the potential lack of donor-identifying information, what prevents it from doing so for other potential "quality of life" issues like physical or mental disabilities, risks of heritable diseases, parents with disabilities, family instability, or extreme poverty? The Task Force should carefully consider whether it wants to start down this path which, taken to the logical extreme, could arguably justify governmental attempts to regulate or restrict even natural procreation.
- "Protection" through Elimination: The primary argument in favor of mandating disclosure of 0 donor-identifying information is that it is necessary to "protect" anonymous donor-conceived children from the harm resulting from their inability to access medical and birth heritage information. There is, however, a glaring logical fallacy in this argument because the disclosure mandate – and the resulting prohibition against the use of anonymous donor gametes – would not "protect" anonymous donor-conceived children but rather prevent their very existence. For the Task Force to take the position that the disclosure mandate "protects" anonymous donorconceived children, it would have to conclude that such children are better off not existing at all. The available evidence, however, does not support this proposition.¹ Anonymous donorconceived children are, by definition, planned and wanted by their families. They are typically the product of years (sometimes decades) of infertility struggles and tens (sometimes hundreds) of thousands of dollars invested in infertility treatments. Intended parents through ART are typically older, more mature, and more financially stable than parents of "naturally" conceived children. Moreover, available studies indicate that, even when offered the option of obtaining their donor's identity, a significant percentage of anonymous donor-conceived children elect not to do so.² In fact, the most significant harm to donor-conceived individuals appears to result from family secrecy: late discovery of an individual's donor-conceived leads to feelings of betraval and implies shame.³

¹ See Comparing the Psychological Outcomes of Donor and Non-Donor Conceived People: A Systematic Review, Talbot, Hodson, Rose and Bewley, BJOG: An International Journal of Obstetric and Gynecology, May 2024.

² Public testimony at the Task Force's June 14, 2024 meeting suggested approximately 40% of anonymous donor-conceived individuals seek to identify their donors. 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 (<u>Who requests their sperm donor's identity? The first ten years of information releases to adults with open-identity donors (ucdavis.edu)</u>). <u>See also Adult Offspring of Lesbian Parents Reflect on Having Been Donor Conceived: Feelings About Their Sperm Donor and Donor Siblings</u>, American Psychological Association Society for Couple & Family Psychology: Research and Practice, 2024 (2024-nllfs-adult-offspring-feelings-sperm-donor.pdf).

³ <u>See</u> footnote 1, above.

- <u>ART Is Not Adoption</u>: Analogizing the proposed mandatory disclosure of donor-identifying information to the adoption record disclosure requirements of HRS § 578-15(1)-(5) ignores significant differences in the context of ART vs. adoption, including the following:
 - An adoptee has an original set of birth parents who, under normal circumstances, would be
 raising the adoptee but who make the decision at some point *post-conception* or even *post- birth* to instead place the child for adoption (typically with strangers). The adoptee exists
 prior to, and totally independently of, the adoptive placement;
 - An anonymous donor-conceived child is the result of extensive *pre-conception* planning and effort by its Intended Parent(s), is conceived solely through the efforts of the Intended Parents using ART procedures and gametes provided by the Intended Parent(s) (typically, one Intended Parent's gametes combined with the anonymous donor gametes selected, purchased, and owned by Intended Parents). The anonymous donor-conceived child would not exist *but for* the efforts of its Intended Parents;
 - An adoptee is gestated and delivered by and then separated from his/her/their birth mother;
 - An anonymous donor-conceived child can be and often is gestated and delivered by his/her/their intended legal mother, who may also be the child's natural and genetic mother (if her gametes were used in the ART procedures) or the child's natural but not genetic mother (if she gestated and delivered a child conceived with donor gametes);
 - Even where an anonymous donor-conceived child is gestated and delivered by a gestational surrogate, she/he/they can still be the genetic child of the intended legal mother (if her gametes were used to create the embryo);
 - An adoptee is relinquished by his/her/their birth mother (and birth father, when identifiable and participating) and placed for adoption with the adoptive family (typically strangers);
 - An anonymous donor-conceived child is the intended legal child of its Intended Parents from before conception through the child's birth: there is no adoptive "placement" nor any "relinquishment" throughout the gestation and birth process (even when a gestational surrogate has been involved, neither she nor the Intended Parents consider her a "parent" of the child she is gestating);
 - Unlike adoptees, a child born through ART is typically the genetic child of at least one (and sometimes both) of its Intended Parents;
- <u>Unintended Effects/Practical Considerations</u>: In addition to the foregoing, the mandatory disclosure of donor-identifying information and the effective prohibition against the collection and use of anonymous donor gametes by banks and clinics licensed in the State (excluding gametes imported from outside the State) risks the following unintended effects which will impose further burdens on the infertile, LGBTQ+, and single individuals conceiving children through the use of ART:
 - Potential reduction in the pool of available gamete donors, resulting in shortages, waitlists, diminished selection, and reduced diversity;⁴
 - Potential reduction in quality of donor gametes (for example if the lack of anonymity discourages altruistic donors or donors more inclined to consider the potential long-term ramifications of disclosure but does not discourage financially-motivated or more impulsive donors);

⁴ Bernstein, Gaia, Unintended Consequences: Prohibitions on Gamete Donor Anonymity and the Fragile Practice of Surrogacy (December 18, 2012). Indiana Health Law Review (Symposium) (2013), Forthcoming, Seton Hall Public Law Research Paper No. 2190992, Available at SSRN: <u>https://ssrn.com/abstract=2190992</u>; Cohen, I. Glenn, Sperm and Egg Donor Anonymity: Legal and Ethical Issues (April 28, 2015). Oxford

SSRN: <u>https://ssrn.com/abstract=2190992;</u> 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: <u>https://ssrn.com/abstract=2600262</u>.

Potential cost-prohibitive increases in gamete prices (for example, California Cryobank currently prices anonymous donor vials at \$1,195/each; whereas known-donor vials are \$2,195 each – a difference that could add \$8,000 to \$10,000 to the overall cost of donor insemination and price the procedure out of reach of some infertile, LGBTQ+, and single individuals.

Recommendation:

• For all of the reasons set forth above, I urge the members of the Act 156 Task Force to consider recommending the adoption of the original version of the UPA 2017, which requires the collection and release of the non-identifying medical history of the donor but *does not* mandate the release of the donor's identifying information.