Dear Hawai'i UPA Task Force Members,

I appreciate the opportunity to submit testimony to the Hawai'i UPA task force. My name is Jasmariah Ioana Swenson and I am a donor conceived person with an anonymous sperm donor who is half Native Hawaiian. I am writing this letter in support of the task force recommending the inclusion of the updated 2024 article 9 in the Uniform Parentage Act in Hawaii. Updated 2024 article 9 will give donor conceived people a better chance of receiving updated medical information through being able to contact the donor or other genetic relatives. It will help avoid life-threatening situations like mine described below.

When I was 24 years old I was diagnosed with an autoimmune condition. Nobody from my mom's family had a history of anything like this. Out of my 5 donor conceived half siblings, 3 of them have an autoimmune condition. We had a feeling that this was something inherited from our shared donor. I reached out to the cryobank to stress the importance of updated medical information for my doctors to better help me. When they reached out to him, he declined and requested to not be contacted again. If he was an identity release donor (like required by updated 2024 article 9) I believe he would've been more likely to respond to the request for updated medical information. He would have been more likely to consider the needs of the people born from his donation and possible future contact prior to making the decision to donate.

Beginning in 2018, I spent the next 5 years on a medical rollercoaster. I was referred to many different specialists, receiving abnormal labs, surgeries, and I failed to get a clear explanation. Finally, in August 2023, I met with a cardiologist that diagnosed me with an aortic root aneurysm. He and my primary care provider were surprised because at 29 years old I had the health problem of a 65 year old. They ordered genetic testing to see why this was happening to me. The first week of October while I was watching my son's soccer practice I received the call that I tested positive for a gene mutation (ACTA2). Due to this, my aorta and blood vessels are weaker & cause me to be susceptible to aneurysms. On that same call, I was told I needed to have the open heart surgery yesterday because this gives me a higher risk for rupture or dissection. I don't think I would've been on this medical rollercoaster if I had an identity release donor who would be more receptive to sharing medical information or the ability to identify other genetic family members who may possess family medical history.

I updated the Cryobank and it was later confirmed that the donor passed this gene mutation to me. You have a 50% chance of passing this to your children but, all 3 of my children are positive. My oldest son watched me go through all of this and now carries the fear that this will be his fate one day. Luckily, we know this early on because they have begun monitoring and testing to take necessary precautions. Knowing about this gene mutation is vital because of how life threatening it can be.

Months after my open heart surgery, I received notification that my donor passed away in 2021 due to heart complications–he was only 51 years old. His father had a heart attack & aortic aneurysm in the late 1990's at age 60. His mother lives with an aortic aneurysm that is currently being monitored. His paternal aunt died from an aortic aneurysm. His paternal uncle died during an open heart surgery following a heart attack. If I knew this information growing up, or at least had an identity release donor, so much could have been avoided & I would've had a better opportunity to manage my health.

This whole situation has always felt unfair to me. The donor conceived person doesn't have a fighting chance to fully understand how to support and care for their own health. We also lose access to our heritage and family history. Having the ability to access our donor's identity at age 18 would allow us to learn about our family history and connect with our roots. My donor is half Native Hawaiian and his mother was full Native Hawaiian. I wish I had the opportunity to connect with my Hawaiian side of the family to learn more. To be able to obtain any information, I had to work with a professional "search angel" to locate my half brother (the donor's son). I have been able to have some contact with him which he was open to after I found him.

No donor conceived person should have to fight for their life the way I have. We need access to half of *our* DNA, *our* heritage, *our* biological parent's identity–anything less is unjust and disheartening.

Thank you for your time and consideration of such an important issue for donor conceived people like myself.