Sebastiana Gianci, DrPH testimony in favor of HB0482 "Donor-conceived Person & Families of Donor-conceived Persons Protection Act"

February 24, 2023

Distinguished Committee Members,

My name is Sebastiana Gianci. I have been an active resident of Maryland since 2006. I work in local government in Maryland and hold a Doctorate of Public Health (DrPH) from a Maryland state university. I manage a group entitled "DC²: Donor -conceived people in/around the DMV (DC, MD & VA) social media group which introduce these Marylanders testimonies to you.

What does it mean for one's life to be a "living experiment"? Fundamentally, as a donor-conceived person you are bombarded by instances which stretch the boundaries of acceptability regarding human rights and beyond.

I grew up in an Italian-American family mainly living overseas. I am an only child with no siblings of any kind (a rare reality in the donor-conceived community). I found out I was donor-conceived twenty-two years ago, at age 23.

Curiously, though I was from a loving family, there were significant issues with my relationship with my social Dad's side of the family (The family of my Dad who raised me). I had the same cultural ethnicity on my mom's side and the differences were noticeable. For example, before knowing I was donor-conceived I visited my social grandmother's relatives in Sicily and I was told I should not have gone there with no explanation. Then I was left out of my traditional grandmother's inheritance. I was often puzzled, so I asked my mother what was going on. She told me the night before going for a surgery that I was donor-conceived and for me not to disclose to my Dad that I knew. Ironically, my entire family (cousins, aunts/uncles) knew I was donor-conceived before I did, multi-level trust and rejection challenges ensued.

I didn't know where my idiosyncrasies and mannerisms came from. I felt awkward and had a visceral feeling of being "other", but it was not clear why. Only later did I understand this was the other half of me that I inherited from my paternal bio family's genetics. I do not know many of my paternal bio family, however the few I do know reflect many of my own characteristics. When my DC status was disclosed to me, it was first a relief as finally much made sense. However, shortly thereafter came an identity crisis. I did not know who I was anymore, looking in the mirror was difficult. Not being able to access my bio family's identity left me asking myself, who am I? And a harder question, am I brave enough to find out?

My life as a social experiment began to reveal itself once I was able to unveil my truth. Through consumer DNA testing, I solved a seemingly impossible puzzle by triangulating distant relatives, using school yearbooks of medical students from the year I was conceived.

Then I found him (who I now call Biodad), I had been looking for him for at least 10 years. I found him six years ago. I was in a relationship with him for about three years in which we visited each other. I was not able to predict the effect that meeting him and experiencing emotional extremes would have on me, that was scary.

Sebastiana Gianci, DrPH testimony in favor of HB0482 "Donor-conceived Person & Families of Donor-conceived Persons Protection Act"

Through him, I discovered that I have Jewish heritage from my Biodad. I visited my bio greatgrandmother's shtetl as she escaped prior to the Holocaust. I could understand my past life of "nurture", but I didn't yet know how my "nature" experience would shape my life. Today, I derive inspiration from learning and practicing that same tradition, honoring ancestral memory.

For identity and family challenges, I turned to mental health practitioners to deal with isolation and donor-conceived dynamics. I quickly learned that clinicians were often totally confused by my experience and I often had to educate them about donor-conceived basics. This led me to write my doctoral dissertation study on the "Mental Health Professionals and their accredited training to serve Donor-Conceived Adults". After interviewing 130 clinicians, the study's sample overwhelmingly identified the need for clinicians to educate themselves via in-service and accredited academic training using donor-conceived-client-centered approaches. My doctoral dissertation can be found at https://www.proquest.com/openview/5f240c3fad4be2fca1ffcb434ed5fb59/1.pdf?pq-origsite=gscholar&cbl=18750&diss=y.

Importantly, my biodad and I discovered not only were we both in healthcare, but we were both lied to by my mother's fertility doctor. The fertility doctor kept both of us in the dark regarding such things as identity, number of offspring / siblings and vital medical information.

My own medical situation leaves me puzzled even today and navigating a minefield. My wish is for donors to be required to update their medical history every five years. An accurate medical history is not a one and done situation. Narelle Grech's story illustrates this well. Narelle was a groundbreaking Australian donor-conceived rights advocate. She spent 15 years trying to access information about her bio father and kin, along with knowledge of her medical history. She appealed to the Australian authorities that held her sealed records saying "I believe the truth will set me free...and I ask for access to my records for this reason". It was not until Narelle was diagnosed with stage four cancer and was in the last 6 weeks of her life, that she was finally permitted the information that enabled her to find and meet her bio father. Narelle died at just 30 years old, learning too late of a genetic predisposition to bowel cancer on her paternal side. There is now a law in Australia that overturns donor anonymity in her state: Narelle's Law.

Ultimately, governmental regulation and legislation are necessary to guarantee the fundamental rights to an identity, medical history and improve the health and well-being of donor-conceived individuals. The UN Convention on the Rights of the Child (UN CRC) guarantees these rights. In sum, I feel like I am part of a GMO program, like breeding apple varieties or creating modified corn. Genetically modified animal husbandry has better ethics and welfare management. Without legislation like HB0482: Donor-conceived Persons Protection Act passing, donor-conceived people in MD remain unrepresented commodities in a twisted societal experiment.

Thank you for your consideration of this matter. Many thanks also to the many advocates that made this same legislation Law in the State of Colorado.

I can be reached at <u>sgianci@gmail.com</u> or (301)520-9286 with any questions or to discuss further.