

U.S. Donor Conceived Council: A Voice For Donor Conceived People https://www.dcc-usa.org/ | Instagram: @donorconceivedcouncil

VIA EMAIL

January 14, 2022

New York State Senate Health Committee c/o The Honorable Gustavo Rivera, Chairman 172 State Street, Capitol Building, 502C Albany, NY 12247 Email: grivera@nysenate.gov

RE: MEMORANDUM IN SUPPORT OF S7602 (DONOR CONCEIVED PERSONS PROTECTION ACT)

Dear Chairman Rivera and Health Committee Members:

Please accept this brief memorandum in support of Senate Bill 7602 ("Donor Conceived Persons Protection Act") on behalf of the U.S. Donor Conceived Council, Inc.—the only nonprofit in the U.S. that is founded and led by donor-conceived persons ("DCP") to advocate for the interests of DCP—and several allied nonprofits. DCP are persons who were conceived through artificial insemination and/or assisted reproductive technology involving the use of gametes by a third person (e.g., a sperm "donor"). We support S7602 because it is a much needed and common sense measure to address a major problem with the very loosely regulated donor-conception industry in the U.S.—sperm banks, fertility clinics, and gamete donation programs do not adequately verify donors' self-reported medical, educational, and/or criminal felony conviction histories with appropriate records. This lack of verification has resulted in serious injury and death to many DCP.

For example, attached please find a copy of a recent Wall Street Journal article that details the tragic story of the late Steven Gunner, a New York DCP who, despite the best efforts of his parents David and Laura Gunner (residents of New York), suffered from schizophrenia and died at the age of 27 from a drug overdose. Like Steven, Steven's biological father ("Donor 1558") suffered from schizophrenia and died of a drug overdose at a young age. According to the article and the Gunners, when providing his gametes to Fairfax Cryobank, Donor 1558 did not disclose his hospitalization for behavioral issues and never notified Fairfax of his schizophrenia diagnosis. Sadly, other DCPs have experienced similar tragedies, *see, e.g.*, James, S., *Sperm Donor's 24 Kids Never Told About Fatal Illness* ABC News (July 20, 2011). This article discussed how John's DCP offspring were at risk for inheritingMarfan's syndrome, a potentially fatal genetic heart defect, and autism spectrum disorder. At least three of John's family members were diagnosed with the heart defect, yet he failed to report the condition in his donor profile. Learning John's medical history saved the life of at least one of John's DCPP offspring. Tyler went in for a screening upon receiving the updated medical information and discovered the aortic aneurysm, which was "waiting to rupture."

Page 2 of 3 January 12, 2022 The Honorable Gustavo Rivera

The Donor Conceived Persons Protection Act will help prevent such tragedies, save DCP lives, and protect parents of DCPs by requiring gamete banks/clinics to verify donors' self-reported information using the donor's medical, educational, and criminal felony history records. The anticipated objections to the bill are meritless. The costs of these verification requirements pale in comparison to the immense medical costs (many borne by the public) and human suffering endured by DCPs, like Steven Gunner and his family. Additionally, the costs are a one-time expense for banks/clinics that sell enough sperm to create dozens to hundreds (if not more) offspring per donor.

The requirements of the bill are also entirely consistent with the industry trade group's own non legally binding guidelines which state that "donors with a personal history of a serious mental illness or those with a first-degree relative with a serious mental illness . . . should be excluded [from being donors]."¹ The requirements also make sense because most serious mental illnesses are substantially heritable and there is a much greater cumulative genetic risk of passing along the mental illness because banks/clinics create dozens or hundreds of offspring per donor. In fact, the heritability of schizophrenia and bipolar disorder are approximately 70%, and when one biological parent (the "donor") has one of these illnesses there is a substantially increased risk of their offspring developing the same or another serious mental illness.²

Finally, it is critical that the bill's protections apply to donor sperm shipped into or out of New York (as provided for in Sections 3(f) and 3(g)) because this is a common occurrence. This provision is constitutional because Congress has failed to address this issue, the requirements apply equally to all donor sperm (regardless of which state it is procured in) and do not prevent New York from participating in the national market for donor sperm. Most importantly, the requirements achieve a legitimate state goal of protecting the health and welfare of donor conceived persons and their parents from the risk and consequences of serious mental illness.³

Thank you very much for your attention to this important bill. We are happy to answer any questions you may have about the bill, donor conception, or other arguments raised in opposition to the bill. If you have any questions or concerns or would like to talk further about the bill, please contact Jillian Phillips with the U.S. Donor Conceived Council at dccouncilusa@gmail.com.

¹ American Society for Reproductive Medicine, Guidance Regarding Gamete and Embryo Donation, 115 FERTILITY AND STERILITY 1395, 1405 (June 2021).

² See Baselmans et al., *Risk in Relatives, Heritability, SNP-Based Heritability, and Genetic Correlations in Psychiatric Disorders: A Review*, BIOLOGICAL PSYCHIATRY (2020), *available at* <u>https://www.gwern.net/docs/genetics/heritable/2020-baselmans.pdf</u>.

³ See, e.g., Kassel v. Consolidated Freightways Corp., 450 U.S. 662 (1981) (upholding Iowa law that prohibited trucks from using Iowa highways if they did not meet certain requirements related to traffic safety).

Page 3 of 3 January 12, 2022 The Honorable Gustavo Rivera

Sincerely,

Jellim Phillips

Jillian Phillips, MPH Vice President of Government Affairs U.S. Donor Conceived Council, Inc.

Attachments Wall Street Journal Article, <u>https://www.wsj.com/articles/a-grieving-family-wonders-what-if-they-had-known</u> <u>-the-medical-history-of-sperm-donor-1558-11641119405</u>

> ABC News Article, <u>https://abcnews.go.com/Health/sperm-donors-24-children-told-fatal-illness-medic</u> <u>al/story?id=14115344</u>

cc: Senate Health Committee Members (via email) Assembly Health Committee Members (via email) Majority Leader Andrea Stewart-Cousins (via email) Assemblywoman Paulin (via email) Speaker Carl Heastie (via email)