Advocacy Snapshot: Courtney Tucker and the U.S. Donor-Conceived Alliance

Advocacy Snapshot is an ongoing feature that highlights the views and efforts of individuals working to raise awareness, amplify voices, and stand for rights. Here, Courtney Tucker, founder of the U.S. Donor-Conceived Alliance (USDCA) weighs in. There have been individuals and small groups around the world working for donor conceived people’s rights for many years, but there’s an issue with visibility. Even now, having been in the community for more than a year, I struggle to fully grasp what has happened and what is happening. My hope with the U.S. Donor-Conceived Alliance is to provide a platform where information and resources can be gathered and voices may be elevated. I saw what the Donor Conceived Alliance of Canada and organizations in other countries were building and was shocked to learn that the same hadn’t been done in the U.S. My background is in non-profit marketing and management, so while my strengths may not align with filing lawsuits or contacting representatives, I would love for our organization to support those who do choose to take those types of actions.

In the U.S. specifically, I think one of our biggest hurdles is that many of the changes we hope to make need to happen at the state level. Even if you succeed at banning anonymity in one state, there’s nothing stopping anyone from driving over to the next (or even mail ordering!) for anonymous gametes. This has to be a coordinated effort. Adoptee advocates seem to be gaining traction in that regard, with many states making changes toward the opening of original birth certificate (OBC) records. Earlier this year, the USDCA polled 85 donor conceived people about where our priorities should lie. The vast majority would like to see an end to anonymity, caps on the
number of offspring allowed per donor, better counseling for donors and commissioning parents, and stronger regulated record-keeping, including up-to-date family medical histories. There was slightly less emphasis placed on a central registry, such as Victoria, Australia’s Victorian Assisted Reproductive Treatment Authority (VARTA), and ending payment for gamete donations (an issue Canada is currently battling). The USDCA is still in the very early stages, but you can fill out this form to register as an ally and join our mailing list. If you are not in the U.S., we have a list of other organizations around the world here. On a local level, I highly recommend finding an adoptee support group to join. Of course, ask first to make sure groups are comfortable with a donor conceived person joining. I’ve made some very good friends in my group who right away said, “of course, you are half-adopted.” While our online communities are essential, it can also be very empowering to make “real life” connections. I think this depends on the individual. Working to create change can be cathartic, but I think it can also serve as a distraction – a means to avoid the real healing. And that’s okay. This process is an ebb and flow, and if distraction through action is what’s getting you through the days, go for it. We just need to stay mindful that when the flow pulls us away from advocacy, that’s okay too. Look out for each other, check in on occasion. Burnout is very common in both the non-profit world I come from and the advocacy world I’ve just dipped my toe into. I recently started reading “In it For the Long Haul: Overcoming Burnout and Passion Fatigue as Social Justice Change Agents” by Dr. Kathy Obear. The first couple chapters really resonate with what I’ve personally experienced and witnessed in others. Go into advocacy because you feel passionate about advocacy – if healing happens along the way, that’s just a bonus. Courtney Tucker is a 30-something donor-conceived individual living in Arkansas with her cat and a large collection of cameras and vintage clothing. She works as the marketing coordinator of a major local non-profit and in her spare time leads the U.S. Donor-Conceived Alliance. She
found her “donor” father and four half-siblings in 2018 and is always happy to show off photos of her new nieces and nephews!

Profile: Nick Isel Takes Aim Against the Fertility Industry Goliath

Nick Isel doesn’t take no for an answer. When at 15 years old he learned that the distant man with the hair-trigger temper who raised him wasn’t his father, he confronted his mother, demanding details. He learned that he’d been conceived with sperm from the infamous Repository for Germinal Choice, popularly known as the Genius Sperm Bank, a eugenics experiment carried out by an eccentric millionaire, Robert Graham, who believed the quality of American genetic material had gone to hell. The repository was responsible for the births of 229 children from 1982 until it closed in 1999. At least 30 of those children are Isel’s half-siblings.

Isel was determined to find out the identity of his biological father, but his mother couldn’t recall the details about the donor she’d chosen so many years earlier and didn’t know what had become of the paperwork. It seemed like a closed door, but Isel refused to be stopped. He tore through boxes and boxes of records, bent on finding something that would provide a clue to his origins. He persisted until he obtained a document that contained the donor’s code name – Coral 36 – and little else.

Having that piece of paper gave him some measure of peace and even optimism, but there was little he could do with it. There was no longer a repository he could contact and no records he could access. When he became aware that journalist David Plotz
was writing an article about the notorious sperm bank for Slate, he tracked him down and asked for his help. Plotz — who eventually wrote “The Genius Factory: The Curious History of the Nobel Prize Sperm Bank,” based in part on conversations with Isel — came through and provided Isel with the donor’s name. Just a teenager, Isel piled his family — his wife and baby son — into a car and drove from Illinois to Florida to meet his elusive father.

Isel brings this same tenacity and refusal to accept anything less than “yes” to his mission to persuade the government to protect the rights of donor-conceived people and force the mighty fertility industry — valued last year at $5.87 billion — to be accountable and bend to the needs of the individuals born from the genetic materials in which it trades.

Isel’s advocacy was spurred by the knowledge that like him, his 30 half-siblings from the sperm bank — thanks to the longstanding sway of donor anonymity — had no access to medical records that might allow them to assess their health risks. Nor did they have a way to obtain basic information about their genetic identities. Casting around for a way to make a difference, he lit on the idea of filing a US Food and Drug Administration (FDA) Citizen Petition to influence policy about donor anonymity and record retention, something that had never been done before. Isel researched online for about an hour and discovered that the FDA “already has an entire division dedicated to the regulation of biological and related products including blood, vaccines, allergenics, tissues, and cellular and gene therapies.” He then invested a full week’s time into reviewing the general process of submitting a Citizen Petition and developing his three-page document.

He took a pragmatic approach, not aiming to address all the ills of donor conception, but instead to target several of the most significant issues, setting a precedent and foundation for future action and creating a record state policymakers could draw on when proposing legislation.
Isel’s triple-pronged approach was designed primarily to ensure that donor conceived people are able to obtain their medical histories. It called for an end to donor anonymity, an extension of the record-keeping period from 10 to 50 years to allow individuals adequate time to obtain this critical information, and record redundancy – the retention of records in duplicate locations.

Like virtually all advocates, Isel believes an end to anonymity – which is being hastened by the advent of inexpensive DNA testing – is critical. “The environment of toxic secrecy created by the practice of donor anonymity places an unnecessary shame and stigma on all parties involved. Informed consent is not adequately provided to the donors or recipients when the unfulfillable promise of anonymity is made prior to donation,” Isel says. “Donor conceived people are divested of half of their biological identity and family medical history by design prior to conception and they are treated more unfairly by the practice than any of the other parties involved, despite the fact that by nature they are the only ones unable to provide any shape or form of consent,” he adds.

A 50-year record retention policy is essential, Isel says, “because many genetic diseases do not present until later on in life, and their transmission is not monitored.” Record redundancy, he adds, is crucial in case of the inadvertent destruction of records. “In the event of a catastrophic natural disaster, human error, or corruption of data by computer malfunction, records would still be preserved,” he says. “There also exists the potential for a breakdown in the lines of communication between the fertility establishment and donors, recipients, and donor conceived individuals – for example, if they go out of business or the donor conceived people don’t know which fertility establishment holds their records.” This, he adds, can be addressed by appointing a regulatory agency to maintain a duplicate copy of all records.
Once Isel began this fight, he knew he’d see it through no matter what it took. If the FDA denied his petition, he’d explore any legal recourse available.

The FDA accepted his petition in September 2016 and opened a comment period during which the public added positive responses and arguments for proposed changes to public health policy. In March 2017, the FDA announced that it needed more time to review the petition, and in September 2018 the petition “was denied on the erroneous grounds that the FDA doesn’t believe genetic diseases act as communicable diseases and, therefore, it has no reason to regulate the spread and transmission of genetic disease,” Isel says.

Not surprisingly, Isel adamantly disagreed. Undeterred, he hired a licensed federal district attorney to draft a petition for reconsideration, which, he explains, “addresses the issue in great detail, explaining why and how the FDA misinterpreted the language of its own code of federal regulations.” In the petition for reconsideration, Isel’s attorney stated, “The failure of the existing regulations to contemplate the difficulties of progeny such as Isel is precisely why new regulations must be promulgated, particularly when the old regulations divest this new group of their Constitutional Rights to receive and maintain their own personal, health, and genetic information.” She notes that donor conceived individuals weren’t capable of opting in or out of the destruction of their genetic information.

The FDA accepted the petition for reconsideration as “timely and cogent” and opened a new six-month comment period. When that ended on March 18, 2019, the public was no longer able to provide feedback. Once again refusing to be stopped, Isel requested and was granted a reopening of the comment period until the agency reaches a decision. Donor conceived people and allies can support his efforts by taking advantage of the extended comment period and weighing in with their own experiences. These comments are key to persuading the FDA to
acknowledge the deleterious effect genetic illnesses may have on donor conceived individuals and the importance of access to records. Individuals who’ve inherited genetic health risks can take this opportunity to educate the agency about the personal cost of lack of access to medical histories. Others, including allies, can voice their concerns as well. Comments can be made anonymously. Access the petition and comment here. (If you have questions about the petition or need help navigating the document, send Isel a message at nick.isel@gmail.com or call him at 630-923-2745.)

In addition to supporting the petition, Isel says, advocates should speak with their state representatives about sponsoring bills in their respective states, as he did in his state of Illinois. Isel lobbied his state representative, Keith Wheeler, who filed Illinois House Bill 2140 in February. If passed, it would require sperm banks in Illinois to retain records, including the name and contact information of every donor, for 50 years following the donation of sperm. It further calls for a sperm donor to “agree in writing that he has no expectation of anonymity with regard to his donation and that his biological child may be provided with his contact information upon request of the child or the child’s parent or guardian if the child is under the age of 18.” The bill is currently in committee.

Although he advocates for state legislation since the FDA has been slow to act, Isel insists that donor anonymity should be banned on the federal level in the interest of public health and wellness. In addition, he says, a federal prohibition would align the FDA’s Code of Federal Regulations “with the FDA’s stated mission and congressional mandate to regulate the fertility industry.” If it were to happen at the state level, he adds, “it would need to be done in every state to prevent ‘reproductive tourism.’ Isel has called his efforts to petition the FDA “a game of inches,” acknowledging that there are many additional aspects of donor conception that must be regulated.
He notes that there exist no screening procedures as there are with adoption. Furthermore, “There are no limits on the number of offspring sired per donor and no federal civil or criminal penalties established for fertility fraud,” he observes. “There are many more steps that can be taken to make the practice of donor conception more ethical and reduce the systematic injustices inherent in the status quo. Preservation of family medical history is the low-hanging fruit.” He identifies the following additional needs:

**Limiting the number of times a donor’s sperm can be used.** “Using the same sperm or egg to produce an excessive number of offspring increases the eventual chances of consanguineous unions, lowers the genetic diversity of our species, and, by extension, survivability during a global pandemic or other catastrophe.”

**Requiring stricter comprehensive medical and genetic testing of donors.** “There are more than 7,000 different types of rare disease, and only about 200 to 300 of those are commonly tested for at the more thorough fertility establishments.”

**Mandating reporting of births resulting from donor sperm.** “This is the only way to ensure that proposed limits on the number of offspring per donor are adhered to.”

**Developing a national registry that keeps track of donors.** This is necessary “to prevent reproductive tourism. Base universal guidelines and best practices must be established and agreed upon by all countries.”

**Tracking donors’ health and updating parents about changes.** “This information has the potential to be life-saving.”

**Educating sperm banks and clinics about those impacts and the needs of donor-conceived people.** More information about these issues is needed so recipients and donors can be better informed prior to their participation. “The job of the fertility establishment should not be over after a recipient
achieves pregnancy; rather its responsibility for the person it helped create should extend throughout that person’s lifespan." In addition to commenting on the petition, speaking out in other ways can be equally effective. According to Isel, the personal is political. “In a community as underrepresented as this one, simply sharing your own personal story is a form of advocacy because it increases the visibility of the donor conceived community and pushes other people to ask questions they’ve never considered before,” he says. This type of advocacy, he adds, elicits empathy from people who weren’t previously aware of the experiences and concerns of donor conceived people. It doesn’t take a megaphone and a soap box to make a difference. “Many members of the community are performing advocacy work without even realizing it when they casually tell their friends about their backgrounds.”