

28/04/2022

Committee Secretary
Legal Affairs and Safety Committee
Parliament House
George Street
Brisbane Qld 4000
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Dear Committee Members,

Please accept my submission for the Inquiry below.

Given I have a very unusual name that can be easily identified, I would appreciate that my name is withheld, and any identifying information also remain confidential. I do consent to my submission being published in full though.

Kind regards,

SUBMISSION-QUEENSLAND PARLIAMENT INQUIRY INTO MATTERS RELATING TO DONOR CONCEPTION INFORMATION

Background:

I am a sperm donor recipient who underwent several treatments through a large Queensland-based fertility clinic. I am now a grateful and fortunate (solo) parent to a wonderful, donor-conceived tween boy, as a result of a local donor's altruistic actions. I have read my submission with my son, and I have asked for his input, and consent to share our story.

It is only following my son's birth, as a member of a national community of donor recipients and their families, I have become more aware of the following issues that are a possibility, or have indeed occurred in Australia:

- donors lost to follow-up by the fertility clinic/s,
- inconsistent data provided to donor recipients about the donor/donor siblings,
- donors withdrawing consent to contact,
- inconsistent age threshold, between Australian states/territories, in when the identity of the donor is formally released to the donor-conceived individual,
- the same donor gametes being provided to multiple clinics within the same state and/or to clinics interstate, therefore exceeding the expected family limits within each state (and likely increasing the number of the same donor, donor conceived individuals, living within Australia),
- donors may donate through both a fertility clinic and/or by private arrangement,
- donor recipients may have travelled interstate for fertility treatment then returned to their home state, and/or moved interstate or overseas,
- donors may also move interstate or overseas,
- donors may become deceased before the age of donor identity release,

- that with donor information/communication being provided inconsistently by the fertility clinics, and with there being central and voluntary donor registries only available in some states/territories, there has been inequality across Australia in access to donor and donor sibling information and
- the lack of a national donor registry could potentially eventuate in intimate co-sanguine relationships between donor-conceived individuals.

I provided a submission to the Federal Senate Inquiry into Donor Conception Practices (in Australia), in 2011, communicating my concern about some of the issues outlined above. Unfortunately, in lieu of the establishment of the optimal, national donor registry, the Federal Senate elected to recommend that each state/territory set up their own donor registry. I am aware of the Victorian, New South Wales, West Australian, and South Australian models for managing donor conception information and more recent progressive movement within the sector in the Australian Capital Territory.

As the next best solution to setting up a national donor registry, I attempted twice in the last decade, to lobby the Queensland Government (Liberal/National & Labor terms), to follow-up on the Federal Senate's recommendation in establishing a Queensland state donor registry. Up until now, concerns about donor conception issues in Queensland have sadly fallen on deaf ears. Queensland is one of the last states/territories to display any advancement with donor conception information issues and to show sensitivity towards those with concerns.

Following the more recent, tireless, and committed efforts of several interested parties, including small contributions by myself, and the support of Queensland Members of Parliament in instigating positive reform, I am pleased and thankful that donor conception issues and practices in Queensland are now being considered seriously. I fully appreciate that the Legislative Assembly of Queensland's Legal Affairs and Safety Committee, is now undertaking this Inquiry.

Personal Experiences:

I am a member of a paid worldwide online donor registry, an informal online registry as part of a forum of solo parents of donor conceived children, several Facebook gamete donor sites/registries and I was a member of a couple of now defunct, free online donor registries.

When my son was still a baby, to my delight, I was contacted by another (same donor) recipient via a free (now discontinued) registry, who's child was born one month earlier than my own son. This puzzled me as the fertility clinic had told me that I was the first pregnant and gave me the impression that I had the first live birth to this donor. As it was predominantly up to donor recipients to voluntarily report a live birth to the fertility clinic, and that this data was not captured by the Queensland Births, Deaths & Marriages registry, I can understand how this situation could arise if the first live birth was not declared readily to the clinic or has been forgotten to be reported all. (In all fairness though, there is a possibility that we both conceived our children through the clinic at a similar time, with the other donor recipient's child being premature and mine post-term, changing the order of expected birth).

I also have a vague memory of the clinic contacting me months down the track, asking about the outcome of one of my pregnancies that ended up being non-viable, when they had already been notified, and the outcome should have been on record (there may have been poor communication between the Fertility Specialist and the fertility clinic as well). I was also provided with the wrong number of frozen embryos that I had left for IVF after the first embryo transfer (I worked out later that they re-froze one thawed embryo without my knowledge).

Consequently, Queensland fertility clinics could potentially be unaware of live births arising from gamete donations, or their records could be inaccurate or not up to date.

Before my child turned one, I was again grateful to be contacted by another mother, pregnant using the same donor. She had located me via the informal donor registry on the online solo

parenting forum. To my surprise, I discovered that she lived interstate and had sought fertility treatment in Queensland, outside her home state.

I am pleased to say that our three families have all met up and remain in contact. We as the same donor, donor recipient mothers, seem committed to facilitating contact between each other's families to help maintain relationships with their donor siblings, and into the future if they so desire. I personally felt that it was important that my child establish some connection with his donor siblings at an early age, within his formative years. In the event of the other donor recipients reaching out to me before or soon after their own child's birth, I am under the impression that this was especially important to them as well. It has concerned me also that since our more immediate family is sparse and elderly and our extended family live a considerable distance away, that when I do pass away, if my son had not made positive connections, of some sort, with his donor and his siblings, that he may feel devoid of people that he may relate to in some way as family/blood relatives.

Although there are five known families, arising from our same donor (who donated in Queensland), so far, I (or the other donor recipients to my knowledge), have had no contact from the other two remaining families. Our contact details have continued to be available over several online sites indicating our openness to contact by the donor, and other donor recipients and their donor conceived children. I understand that the donor and other families may not be interested in seeking us out at this stage or at all. Donor conception information is, however, significantly diluted by having several unofficial registries and not having one distinct, formal avenue for accessing donor information and making these connections in Queensland. The other families potentially may have had difficulties sourcing any useful information or be unaware how to locate my son and the other donor siblings they have in common. Difficulty with accessing information may also apply to donors. Donors may want accurate and more updated information about their donor offspring numbers, genders and years of birth, continued to be provided over the years (that the clinics may not readily supply), or they may be interested in early contact, but they are unsure how this can be facilitated.

Therefore, there was, and continues to be, no official process in Queensland that donors, donor recipients and donor offspring can share information or make voluntary contact between each other. As in our personal situation, where one donor family does live interstate, there also continues to not be any formal pathway for donor recipients and their donor conceived children to be connected, with some donor families living outside of Queensland. If a national registry is not possible, then some cross-referencing and sharing of data (with consent), between state & territory registries, would be most optimal.

The fertility clinic I went through in Queensland, does not allow any de-identified information about donor offspring to be forwarded to the donor before the donor conceived child is 18 years old. Requests to forward letters to the donor communicating gratitude or providing pictures or non-identifying information about their donor offspring, have been declined, to both myself and others (although other clinics nationally seem to have facilitated this). Letters will be accepted but kept on file at the clinic until the child is of age.

This clinic also does not provide a formal donor sibling linking service that its sister interstate clinics do provide (same group ownership). I also lobbied this Group, to provide the same service at our Queensland clinic. Although it was considered, it was not established. They have however, allowed donor recipients and their families to connect if both recipients indicate that they are interested in doing so. Unfortunately, they have not widely advertised this to their customers as a service so there are likely few connections. In addition, although I (and at least one friend) were told verbally by the clinic Counsellor that both my offspring and I would be given lifetime counselling (covered by the initial clinical registration fee), if I was to make a match with another donor recipient, both I and the other recipient would be charged for additional counselling to facilitate this arrangement. Although I understand there would be staff and administrative costs, sadly, I saw the clinic as seeing donor recipient/donor sibling matching as a money-making exercise, given they were not honouring their initial promise of including counselling in their original fee.

Both instances above highlight inequity that exists when fertility clinics possess all the donor information and have different policies in respect to the right to information/communication with/between the donor, donor recipients and donor offspring (and the potential of clinics further profiting from facilitating donor sibling matching). Creating an official Queensland central donor registry, with a complementary voluntary registry (similar to the Victorian, NSW, SA and WA registers), would help to address these inequalities.

Over the years since my son's birth, I have made regular contact with the fertility clinic to obtain information regarding the number of allocated families to the donor, the number of births and the years of birth and genders of my son's donor siblings. Since this time, I have learned that:

- the number of allocated families have varied. His sperm was initially 'snapped up' quickly in the clinic by the 'maximum' 10 families. I only determined that the donor's family allocation in the clinic had dropped off when I enquired about donating my own embryos a few years later,
- that potentially the donor's sperm could have been transported to sister clinics within the state (so donor siblings could be more widely spread throughout Queensland),
- the clinic had not promptly or voluntarily told me (or the other donor recipients known to us) that the donor had 'retired,' nor gave me a reason why he was retired and whether it was voluntary or instituted by the clinic for some reason,
- the donor had five out of the potential ten families with six donor offspring born using his sperm once he retired. I am still unclear though if there were any frozen embryos utilising the donor's sperm and whether these were included within the allocated five families or not, or whether there will be any future donor siblings conceived using frozen embryos or donated embryos,
- the clinic gave another donor recipient conflicting information about two donor sibling girls born within the same year (i.e., one Mum was given the impression that twin girls were born in one year whereas I was told that two girls were born to separate families that same year, and most recently I have been told that there is only one donor sibling girl in total),
- the clinic only follows up donors on a two-yearly basis. I am unsure what onus is put upon the donor to communicate the development of any significant, new medical conditions relevant to himself or his immediate family (and whether they would understand what is a significant medical issue that should be reported), or to provide updates on any other issues of a more urgent nature (i.e., they have a terminal illness) and
- the clinic has a form for donor follow-ups that provides the opportunity for the donor to complete more details about their medical conditions. There was some very relevant information, from one of their more recent follow ups, which was not given to me in the original donor profile, more than ten years prior. The clinic had at no stage volunteered that they were in possession of this additional medical information nor provided this information without me enquiring directly.

Given the degree of variability that can happen in the numbers of families allocated to a donor, the possibility of donor recipient families being created throughout Queensland (and elsewhere) and the potential for fertility clinics to keep inaccurate records and provide inconsistent information, or to not supply updated important donor information promptly, it is more sensible to have a State-run central donor registry, that is better resourced with more consistent and rigorous, consumer- focussed processes.

My son's official and commemorative birth certificates both have large blank areas under the 'Father' section. I personally found this an affront, based on archaic notions that can give the impression that the 'Father' is unknown, or their identity is being hidden. I would have been happy for the words 'sperm donor conceived' to be written in lieu of 'Father' and the heading modified to 'Father/Donor/Parent.' I am unsure whether this has yet to be rectified and whether a more contemporary layout and progressive language have been considered, demonstrating greater awareness that families are now created in many ways. I am aware that there is still an issue with

donor conceived siblings within the same family unit being included on their other sibling's Queensland birth certificates, which has been a source of distress for many families.

Therefore, the lack of inclusivity shown within these official government birth documents, (especially documents of great significance to individuals), may have negative implications upon an individual's self-identity and can be a cause of distress for many.

In the absence of my fertility clinic voluntarily offering up important information about the donor, the lack of a central, but particularly a voluntary register, and with no hope for reform expected from the Queensland Government, I sought out finding the donor independently, (with my son's consent and interest), for the following reasons:

- I was concerned that because the donor had been retired without explanation that he may be regretting his choice of donating his sperm and potentially may withdraw consent or be lost to contact,
- my son was exhibiting behaviours seen in certain medical conditions and had been diagnosed with another disorder often seen in conjunction with these medical conditions. A more holistic family history would have been helpful for his assessments by his healthcare providers. One donor sibling was diagnosed with one of the conditions of note that I was about to have investigated in my son also,
- the potential of the clinic not keeping updated contact details for the donor, the donor may move interstate or overseas and that the follow-ups were not completed as regularly as I had expected,
- an older donor being used and the potential of the donor passing away before my son turned 18 (even more relevant now with the COVID pandemic) and the donor's family therefore also likely to be lost to contact,
- the inequality of not having access to a voluntary register when the donor and his family may have been potentially consensual to early contact all along, if they had been given the opportunity,
- information to be able to track down the donor or his family may be lost off the web in the meantime (which has already occurred), if he was lost to contact or died,
- my son's general ambivalence about the donor (he has been openly discussed since early days). I was concerned that having limited information about the donor and having no photo of him had resulted in the donor being a concept /person foreign to my son. Consequently, I felt that my son had developed a 'disconnect' with the donor and that my son did not fully understand the importance of the donor's contribution to half of his genetic/biological makeup,
- my own interest in genetic traits and curiosity about those inherited from the donor. We were not provided with any child (or understandably adult) photos of the local donor at that time, although later on, it is my understanding that local donor profiles were sometimes provided with photos through the clinic. The clinic seems to have not requested child photos from their more long-term local donors when they have done their follow-ups, or none that were offered up anyway,
- my son has facial and physical traits that run strongly through my mother's line. Others comment on our similarities regularly, so having a photo of the donor and seeing which features he may have acquired from the donor may have helped my son identify with the donor more,
- my son was at an age that his peers were curious about his 'Dad' (who we refer to as his donor). Having additional information and more connection with the donor may have assisted with these (de-identified) discussions and help with completing school subject projects related to family composition,
- I have a keen interest in genealogy and had resumed researching our own ancestry, and more recent family history, with my son,
- the small possibility of a co-sanguine intimate relationship, (with an unknown donor sibling), once my son started developing an interest in intimacy/sex and

- the other donor recipients were interested in finding out additional information about the donor as well.

I was able to locate the donor via DNA testing, ancestry websites and considerable detective work to ensure that I had indeed located the correct person. Having additional donor information and pictures/video of the donor has been helpful, for my son and myself. Tracing the donor has also come with some regrets though, as to ensure that the correct person was identified, I came across information that I ordinarily need not have been privy too, to be able to substantiate facts and relationships.

Although I was not sure from the outset whether I (or my son, via myself) would have attempted to make early contact with the donor, (in the absence of a voluntary register to help facilitate this), we have since decided that we will not attempt to do so at this stage. In my search, I established that the donor (who had no children at the time of donation with his partner), had started his own family several years after he originally donated to the clinic (which I thought the clinic may have apprised us of). This could potentially be the reason he was retired as being a donor at our clinic around five years after my son was born. If I had been informed by the fertility clinic that the donor had since has his own child/ren, I may have not been as concerned about locating the donor independently. I would have had less doubts being raised about whether the donor would withdraw contact or be lost to contact. I would have understood the donor changing his mind about the total number of families having access to his donor sperm and maybe wanting additional privacy, to protect his own family/offspring.

The fact that the donor has since had his own child/ren, does however raise the question, whether any of my son's donor siblings, reported by the clinic, include, or do not include the donor's own child/ren. Should donor recipients and donor conceived individuals be notified of the donor's children's births, gender, and birth years if the births occur following the original sperm donation to the fertility clinic? There is an answered question in the clinic's original profile for the donor, from when he donated, about whether he had pre-existing children (i.e., zero children), but there appears to be ample room for detail to have been provided on the form about a donor's child/ren (de-identified, of course). I am not sure what the difference is with knowing non-identifying details of a donor's family's make-up at the time of donation and then knowing later on if the donor family's composition changes to include children or additional children i.e., is this an invasion of the donor privacy or something that donor conceived individuals should be informed about?

Had there been a Queensland voluntary donor registry, then I, with my son's consent, would have taken the more conventional step of requesting additional donor information and/ or have requested early contact with the donor (although I do appreciate that this may have also been declined or counselling proposed first).

Recommendations:

- 1) Notification of live births of children created through assistive reproductive technology with donor gametes and particularly through Queensland fertility clinics, should be managed by the Queensland government department of Registry of Births, Deaths, and Marriages and added to a state government-managed central donor registry. (I am unsure how one would capture births of children conceived through private sperm donation though),
- 2) The Registry of Births, Deaths, and Marriages, in managing donor conception information, should also review their processes and modify both the official and commemorative birth certificates to be more inclusive by using all relevant information and non-discriminatory language such as 'parent', 'donor/s' or 'egg/sperm/embryo donor conceived', 'surrogate' etc, if they have already not done so. An option to include donor conceived children on their sibling's birth certificates, (within the same family unit), should also be considered, Re-issuing of historical birth certificates with these new improvements, at no or minimal cost, should also occur if requested,

- 3) Allowing equity of and timely access to donor information by establishing both a consumer-focused, well-resourced central and voluntary Queensland donor registry, independent of fertility clinics. Consideration given to permitting open communication with other state/territory donor registries to allow cross-referencing of donor information and sharing of data, given consent of donors, donor recipients, donor siblings and donor conceived individuals,
- 4) Broad promotion of an established Queensland voluntary donor registry so all parties that have a personal stake are aware that there is a more conventional pathway to access donor information and make connections, given all interested parties consent. This may potentially also assist with ensuring a more balanced degree of privacy for donors and their families, (in the age of DNA technology and DNA 'detectives'), where donors can indicate preferences around providing further information and about early identity release and contact through the voluntary registry,
- 5) Free or minimal fee to provide equal opportunity access to donor information and counselling, with counselling offered independent of fertility clinics e.g., by organisations well-suited to understanding the needs of people who were adopted and/or donor conceived, like Jigsaw Queensland, and
- 6) Donors are followed up on a regular basis (yearly) and donor recipients and donor conceived individuals are provided with timely updates regarding number of families allocated to a donor and notified promptly if the donor is retired or withdraws consent. Also, appropriate notification if there are any medical or other significant updates and if the donor has had their own offspring after the donor recipient was provided with the original donor profile.

Thank you for the opportunity to contribute to the Inquiry.