

Inquiry into access by donor conceived people to information about donors

My name is Narelle Grech. I am 28 years old, donor conceived and on May 2nd this year I was diagnosed with stage 4 bowel cancer. My life has been turned upside down since my diagnosis.

I have never been ill in my life, there is no history of cancer on my maternal side of the family and there were no real warning signs that this illness would strike at such a young age. It is believed that a person who is diagnosed with stage 4 (medically deemed to be "incurable") bowel cancer has likely inherited it through their genes. When I was first told about this diagnosis by my surgeons following emergency surgery (to remove the large tumour which had caused my large bowel to rupture) he said it was most likely related to a genetic factor. At this point I cried, not only for the fact that I was now terminally ill, but also as I most likely inherited this disease from my paternal family and my anonymous sperm donor T5.

Never having a complete medical history was never a concern to me, until this year. And now I see why it is vital that not only donor conceived people have access to their genetic information, but they are also given full access to their medical histories and where possible this is updated every 5 years or so.

Had I known that cancer is in my family I could have been scanned and tested for this years ago. The choice to be tested would have been mine and this is the most frustrating thing in all of this. The system that has helped to create me has also left me powerless to know basic information regarding my identity and more importantly my own health. If I had this knowledge upon finding out at 15 years of age I would be able to make the decision to be tested for this type of cancer. The cancer may also not have grown by this point, or at least not be metastasised (having spread extensively to my liver and lungs) deeming me incurable. Maybe it could have been caught early, giving me the opportunity to beat it, but as it stands the prognosis is grim. My oncologist told me that on average people who present as I do can expect to live for approximately 5 years at most. I am not ready to die and have started chemotherapy, but this is to "increase my life expectancy" and it is a terrible experience to have to go through. I can not work or enjoy the life that I once knew. I feel like my youth has been taken away from me and I am furious to think that this could have been prevented. I can not explain what it's like to have to face such questions about mortality at the age of 28.

I am also concerned that my 8 half siblings, who were conceived by the same donor, may be walking about and carrying this possible disease without knowing it. Not only may they have no idea that they

are donor conceived they may also be terminally ill. They may have passed this illness onto any children they have. This diagnosis does not only effect me, it possibly effects so many other people and they should be made aware if this is the case.

In seeking to access my records and information about my biological father (sperm donor T5) I am not wishing to impede on his privacy or cause him any undue effects. What I want is something that most people take for granted, the choice to know their ancestry, their identity and their complete medical history. I never realised how great an impediment answering "unknown" to the question of paternal medical history on my medical forms would be. Now I am facing dying before I know who my father is, who my paternal family is, who I am. I am beyond angry. I am beyond frustrated and I am tired of waiting for the legislation to change so that ALL donor conceived people are treated with the dignity and respect that every other Victorian is awarded - that they are provided with **THEIR TRUTH.**

This is a practice that states the best interests of children should be of paramount consideration. I no longer trust or believe that the law is fair, for I have been disregarded and feel like a second rate citizen. I am unable to search for my father, it is still unknown whether Births Deaths and Marriages are willing or able to allow my mother's treating doctor to undergo another search (one attempt was made when I initially found out about my DC status) and I am not provided with any support services regarding this. I have been told to accept this and manage on my own. It's not good enough. As a qualified social worker I feel that the lack of empathy and support services to myself and others who have been left in limbo is unacceptable. People are awarded more support when they are seeking work in this country!

The Adoption Act (1984) is a blueprint for how a similar legislation allowing all DC people could be enacted. If such legislation was passed over 20 years ago, why can't it be done now? Surely you would think that revealing the truth of circumstances to people who were adopted would be far greater a concern - the reasons they were adopted would have been varied and heartbreaking I'm sure - whereas with donor conception it is understood that men were donating for altruistic purposes or for money. I can accept this and do not believe that revealing such information to DC people will cause the world to implode.

I urge the State Government to implement legislation awarding all DC people the same rights as every other Victorian - the right to know themselves and their kin.

I have written a submission to the previous inquiry, which you can refer to for more information about my story prior to my diagnosis. I

am available and happy to be contacted for further information or to speak in person if necessary.