Aspects pertaining to the practice of donor conception within Tasmania at present, in the past and in the future will be discussed particularly in relation to the child’s ability to access information on their donor (biological father/mother). When analysing the practice and its outcomes the most important factor to consider is the child. National Health and Medical Research Council's Ethical Guidelines on the use of Assisted Reproductive Technology in Clinical Practice and Research, refers to the welfare of the child as being paramount. Specifically it states:

"In these guidelines, AHEC has recognised that the welfare of people who may be born as a result of the use of ART is paramount."\(^1\)

In addressing this aspect the voices of those most affected must be heard and that is the voices of the donor conceived offspring themselves. They are the ones left to live with the consequences of other people’s actions and decisions every day. Decisions that were made on their behalf and ones which they were not a party to nor had any control over. These decisions have the potential to adversely affect their psychological and physical well-being. Current and previous models implemented which have in many instances caused pain and trauma to offspring have resulted from the paternalism of the medical big business fertility

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industry, catering to the desires of adults while at times neglecting the needs and welfare of the children they are creating. The consequences of these practices are not only restricted to the current generation of offspring but have the potential to be felt in and passed on to future generations that will be born to donor conceived people. As such there is a duty of care to a far greater proportion of the population than just the figures of donor conceived people would lead one to believe.

Damian Adams is an adult donor offspring who was conceived during the early stages of the clinical practice in South Australia. He is a published medical research scientist with numerous articles in peer reviewed journals including articles on donor conception, and has presented at conferences on the subject of the ethical practice of donor conception. He is currently undertaking PhD studies at Flinders University investigating the welfare and outcomes for donor conceived people. He has also been an invited speaker at conferences and symposiums on donor conception, has been regularly sought after for media interviews and has provided evidence for federal and state inquiries on donor conception in Australia. Additionally he has also provided evidence for court proceedings in Canada on this subject. As a father himself, he has a unique insight into the ramifications that have and are currently being made on behalf of the Donated Generation.

This submission will address the term of reference:

"That the Standing Committee on Community Development inquire into and report upon issues and options, including non-legislative options, relating to facilitating and/or promoting access to identifying or non-identifying information for donors and their donor-conceived siblings, prior to the introduction in Tasmania in 2004 of the National Health and Medical Research Council 'Ethical guidelines on the use of assisted reproductive technology in clinical practice and research' and any matters incidental thereto."
Legislative and Regulatory Frameworks

Donor conception legislation falls under the area of health law and is therefore governed by the States. The States of Victoria, South Australia, Western Australia, and New South Wales have their own legislation dealing with the practice of donor conception. Tasmania has no such legislation and therefore must rely on the implementation of the National Health and Medical Research Council's "Ethical guidelines on the use of assisted reproductive technology in clinical practice and research" (NHMRC Guidelines). These guidelines are mandatorily followed by all clinics in Australia through the accreditation process of the Reproductive Technology Accreditation Committee (RTAC) under the auspices of the Fertility Society of Australia (FSA). As such the NHMRC Guidelines provide the only national consistency regarding the regulation of donor practice in Australia. Given that legislation overrides guidelines, it is therefore not surprising that there is variation in the practice of donor conception within Australia, especially between those States that have implemented legislation.

In 2011 as a result of an inquiry into donor conception the Senate Legal and Constitutional Affairs References Committee recommended that nationally consistent legislation relating to donor conception be developed as a matter of priority. The NHMRC guidelines do not represent national consistency from a legislative perspective and subsequently the recommendation of the Senate Committee has not been fulfilled to date.

As a result of the findings of the Victorian Law Reform Committee's Inquiry into Access by Donor-Conceived People to Information about Donors, Victoria has passed amendments to legislation in parliament that would for the first time treat the welfare of all donor-conceived children as paramount regardless of the date that they were conceived. Their needs and welfare have finally been placed ahead of the others in the triad (recipient parents and donors). It would therefore be not only logical but also assist in moving towards

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nationally consistent legislation by introducing legislation that mirrors the Amended Act passed by the Victorian parliament.

**Access to identifying and non-identifying information.**

The need to access identifying and non-identifying information as a function of the donor conceived person’s welfare has been a component of a peer reviewed academic journal article I have written. This information is vitally important for the donor conceived which will be outlined below with excerpts from this manuscript.

*Separation from kinship and the desire to know the genetic family*

"All donor conceived offspring, irrespective of their knowledge of their conception, are separated from their next of kin on their donor’s side. For some who are aware of their conception, this loss has the potential to be traumatic............. the majority of offspring believe that they should know the identity of their donors, and also the identity of any halfsiblings. The parity between the desire to know their progenitors and half-siblings exhibits the value that offspring put into all biological connections. Discussion regarding offspring’s right to genealogy has typically focussed on the donor and only rarely has included consideration of the entire genetic family, which has been shown to be equally important to DC offspring. The search and desire for biological family is not borne out

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through poor sociological parent relationships, thereby also highlighting the importance of genetic kinship to offspring."

It is therefore important and pertinent to consider the ability of donor conceived people to be able to access information on their siblings in addition to that of the donor (biological father/mother).

**Loss of identity**

Without access to identifying information on the donor, the donor conceived person's identity may be adversely affected. They in effect have a loss of kinship.

"Loss of kinship can equate to a loss of heritage and is also associated with identity loss. Adolescence is a critical time for a person in terms of identity formation; it is the transition to adulthood and is often highlighted with confusion. The absence of one or both biological links clouds this process by removing the mirror in which we see ourselves, our looks, our personality and behaviour that are evident in our progenitors and our kin. When approximately 41 percent of our behaviour is inherited, this is a substantial mirror missing from these offspring’s lives. The right to an identity is as much about not being deceived as it is about knowing the truth of one’s origins."

A lack of knowledge of our progenitors, our next of kin can lead to genealogical bewilderment, resulting in a person whose own identity and place in the world remains unclear to them. It is clear that for the general population that this sense of identity derived from kinship and desire to know our ancestry is extremely important. We only have to see the television shows such as "Who Do You Think You Are" and the recent "DNA Nation", in conjunction with the fact that genealogy is one of the most popular hobbies in the world to

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realise the importance of family, including our biological forebears. Yet it is something deprived of donor conceived people. In numerous conversations I have had with other donor conceived people, they have expressed great distress at how the rest of society celebrates the importance of genealogy, but that because they are actively deprived of information, they feel like second class citizens.

The statement regarding that identity is as much about not being deceived relates to the observed data that the majority of donor conceived people are not informed of their origins. If they are deprived of knowledge that they are donor conceived they may have difficulty assimilating this information later on, as numerous donor conceived people report finding out in adulthood. This late discovery has been shown to be harmful causing them great distress and potentially leading to mistrust and anger toward their parents.\textsuperscript{16, 17} It has been reported that less damage may occur by telling the child of their conception at an early age,\textsuperscript{18, 19} and is encouraged to occur before the identity construct window of adolescence occurs.\textsuperscript{20}

Due to a critical age of identity construction occurring in adolescence, the current paradigm of only allowing donor conceived people access to information once they reach the age of 18 is questionable. Rather it may be better to allow it to occur at a younger age if the donor conceived person wishes the information and that they receive adequate counselling.

\textit{Incomplete medical histories}

Under the current paradigm, donor conceived people, particularly those conceived prior to 2004, have difficulty in obtaining a complete familial medical history on the donor. Coupled with the fact that there are no provisions to ensure that donors report problems that may


\textsuperscript{17} Turner AJ, Coyle A. What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy. Hum Reprod. 2000, 15(9):2041-51.


appear as they get older and ones which may be crucial for the offspring to know. The ability for a donor conceived person to answer medical questions accurately becomes impossible. In an article I wrote for the Medical Journal of Australia, I argued that the donor’s medical records are also the medical records of the donor conceived person.\(^{21}\) Not only does access to such medical information, which could be de-identified, provide the donor conceived person with the knowledge to make lifestyle changes to improve health trajectories as well as the information required to inform medical practitioners fully to aid in their health treatment, it assists in reducing the financial and resource health care burden on the state of Tasmania.

Furthermore, such release of medical information is catered for under the Commonwealth Privacy Act.\(^{22}\) In terms of privacy, Professor Allan states that privacy in Australia has never been absolute and that access to identifying as well as non-identifying information such as medical histories is supported by various legislation and guidelines, and that therefore it is possible to provide this access under the law.\(^ {23}\)

**Consanguineous relationships**

“Australia precludes consanguineous relationships on moral and biological grounds and prohibits them by the Australian Marriage Act.\(^ {24}\) The current ability of donor offspring to know who their siblings and half-siblings are is severely hampered. Not only must they have been informed of their conception status, they must also have access to the identity of their donor’s biological children—born both ‘naturally’ and via other donations. While current practice restricts the number of recipient families for one donor, for those conceived before restrictions were imposed there is concern about the possibility of a consanguine event, as records show that the number of donations for some donors exceeded several hundred.\(^ {25}\)

\(^{22}\) Commonwealth of Australia. *Privacy Act*. 1988 s.95AA.
Thus, there is the very real potential for a donor offspring to have numerous siblings. A compounding factor for these children is that they are often born within a relatively short timeframe when compared to normal sibship construction, and birth generally occurs within geographical boundaries. Coupled with a sizable proportion of a person’s behaviour and other attributes being inherited, there is a possibility that these offspring could meet through vocational interests. There has since been very little achieved, apart from a reduction in the number of families assisted, to prevent consanguinity from occurring, even though this was recognised as a concern more than 30 years ago.26

Exacerbating the problem is the possibility of genetic sexual attraction,27,28 whereby kin who have been separated since birth or conception become attracted to each other due to shared similarities, which normally is quashed due to the Westermarck effect,29 of cohabitation in early childhood. Removing cohabitation, as can occur in donor offspring, potentially also removes the kin recognition model of the persons involved and their aversion to consanguinity; this aversion is nonconscious and predicated by individuals’ cohabitation and not their beliefs.30 The onus is then forced on the offspring themselves to ask all potential partners of their conception status and to possibly test them genetically to ensure that they are not related, provided that they know of their mode of conception themselves. The emotional and financial burdens of ensuring non-consanguinity is already being carried by donor offspring but is not being addressed by states or clinics that hold records that could prevent such an event from occurring. Recently, the concern has been highlighted by federal and Victorian inquiries.3,4

Subsequently, by allowing donor conceived people access to identifying information on siblings, whether conceived through other donations or through the donor’s own natural family, they can avoid a consanguineous relationship. Not only does this then prevent them from breaking the law, but would prevent irreparable emotional trauma by finding out at a later date that they were related. In the latter case of knowing identifying information on

28 Greenberg M. Post adoption reunion—are we entering uncharted territory? Adoption and Fostering 1993, 17(4): 5-17.
the donor’s natural children this would be achieved through the release of identifying information of the donor themselves as the clinic or registry would not necessarily have information pertaining to his natural children.

**Access to information in other areas**

Adoption in Australia has already gone through a transition similar to what is being observed in donor conception. Originally, adoptions were conducted with sealed records in which the adoptee could not access identifying information on their birth parents. Sociological research over the decades has shown that this secrecy was harmful to adoptees. We as a society also recognised that it is vitally important to a person to know about their origins. Furthermore the rights of children and their need to know about their parents is enshrined in the United Nations “Convention on the Rights of the Child”, to which Australia is a signatory. It was deemed that the welfare of the adoptee was of paramount importance, which is the same level of importance that is stipulated to apply to donor conceived people, and that therefore adoptees would have access to identifying information on their birth parents. This would occur regardless of when the adoptee was born and regardless of whether the parent had originally wanted to remain anonymous.

As there have been similarities drawn between adoption and donor conception in regards to various aspects, and as all children in Australia should be afforded the same rights regardless of how they came into being, then it would not only be logical but also equitable that donor conceived people have access to identifying information on their biological father/mother (the gamete donor). To not do so would be discriminatory based on how a person was conceived. To only provide access to those conceived after a certain date as currently occurs is discrimination based on a person’s age.

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Conclusion

Tasmania should introduce legislation which mirrors that currently in effect in Victoria. The Victorian legislation not only addresses the issue of access to information in a manner which respects the welfare of the child paramountcy principle, but also ensures that Victoria meets its obligation under the UN Convention on the Rights of the Child. If Tasmania introduced similar legislation it would therefore also treat donor conceived people on an equal standing as those who are adopted who have also had to deal with kinship separation and associated problems. By providing this access to all donor conceived people regardless of when they were born would remove discriminatory treatment. Furthermore, mirror legislation would move Tasmania toward national harmonisation of donor conception legislation as was recommended by the Senate.