Queensland Legal Affairs and Safety Committee
Parliament House George Street
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Donor Conceived Australia

Submission to the Queensland Parliament’s Legal Affairs and Safety Committee Inquiry into Matters Relating to Donor Conception Information

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1 Introduction

Donor Conceived Australia (DCA) thanks the Queensland Legal Affairs and Safety Committee for the opportunity to make a submission to the Inquiry into Matters Relating to Donor Conception Inquiry. We are hopeful that the Inquiry will bring about positive changes to the lives of donor-conceived people, donors and recipient parents.

1.1 History and purpose of Donor Conceived Australia

For over two decades, individuals and small groups throughout Australia have been working to bring about reform on matters relating to donor conception. In November 2021, a group of donor-conceived people came together with the goal of unifying these individuals and groups. Donor Conceived Australia aims to be the peak body for donor-conceived people in Australia. We are a national, not-for-profit charitable organisation led by donor-conceived people offering support, education and advocacy on behalf of people conceived via Assisted Reproductive Treatments (ART) - including sperm, egg and embryo donation throughout Australia. With over 500 members across every state of Australia, and many in Queensland, we represent donor-conceived individuals at all ages and stages of discovery of their origins.

Donor Conceived Australia advocates for consistent legislation in the area of donor conception, whether that be through state-based or federal laws. Donor Conceived Australia is guided by the United Nations Convention on the Rights of the Child (the CRC) and the Geneva Principles on Donor Conception and Surrogacy which were provided to the UN Committee on the Rights of the Child by donor-conceived people on the 30th anniversary of the CRC, (Allen et al, 2019). Donor Conceived Australia advocates for a regulatory framework in which the rights of the child created are of paramount importance in all policy and practice relating to ART. This includes the right to identifying information about their origins, including donor and sibling linking services, regardless of when or where they were conceived.

1.2 Position on donor conception and ART

It is Donor Conceived Australia's position that:

1. The rights of the child created via donor conception are paramount in all policy, legislation, and decision-making related to donor conception practices
2. All children have the right to grow up knowing and having the opportunity of forming a relationship with their biological parents, siblings, and extended family members

3. Donor-conceived individuals should have the option of contacting their biological donor parent when they choose to do so, and be supported to do so.
4. Each state and territory have a centralised register and that there is a mechanism by which data from these registers can be linked, in the absence of a national register
5. Sibling information sharing and contact be facilitated
6. Consideration be given to the moral and ethical issues surrounding appropriate family limits for each donor
7. Any legislation or access to information via a register be retrospective.
8. Counselling be available for free for those affected by donor conception, particularly donor-conceived people, and that this be provided by a qualified and experienced professional.
9. Donor-conceived status be shared by the government with appropriate support, including the amendment of birth certificates
10. The importation and use of international gametes for use in Australia be made illegal.

1.3 Background comments on inquiry

Donor Conceived Australia considers the current inquiry a positive step towards the reform of donor conception practices in Queensland. We strongly advocate for the regulation of donor conception practices and assisted reproductive technology as a whole as the current NHMRC Guidelines are insufficient to protect the rights of donor-conceived individuals.

We are optimistic that the Committee will hold the best interests and wellbeing of donor-conceived individuals as paramount in decision-making and consider the establishment of a register that will enable donor-conceived individuals to have their rights recognised and upheld.

Historically, the people most affected by the ART process have not been consulted about it: donor-conceived people. We did not consent to part of this process and continue to be ignored by clinics and governments as the ongoing effects of past and present practices take a toll on our lives. We are therefore grateful for this opportunity to provide a submission to this inquiry and hope that the Queensland Government will continue to consult with the outcome of any ART process with us.

2 Response to inquiry prompts

2.1 Rights of donor-conceived persons, including to know their genetic origins

Access to identifying information about their genetic origins is a basic right for donor-conceived individuals. This right should be made inalienable regardless of when or where the individual was conceived or born.

Inter-jurisdictional comparison

Currently, the rights of donor-conceived people in Australia depend greatly upon where and when they were conceived or born. This means that the rights of members of Donor Conceived Australia to know information about their biological parents and siblings varies greatly and often within the same donor-conceived family (where the same donor has been used - and gametes sent across state borders), siblings have completely different rights to know the same information about their genetic origins.

The 2011 Senate Committee Inquiry (The Legal and Constitutional Affairs References Committee, 2011), recommended that a national register be formed to address these issues, a recommendation with which we very much support. In the absence of a national register, we advocate for each state and territory to have a centralised register and that there is a mechanism by which data from these registers can be linked, and staff that are resourced to provide this linking.

Aotearoa (New Zealand) also presents a useful comparison - especially when legislative reform is being considered. The rights and experiences of donor-conceived New Zealanders conceived prior to the 1990s were generally similar to those in Australia, whereby sperm was donated on the basis that a donor's identity would be kept anonymous, although non-identifying information was sometimes available to recipients and donor-conceived people.

Prior to 1987, when the *Status of Children Amendment Act 1987 (Parliament of New Zealand, 1987)* clarified the legal relationship that existed between donors and donor-conceived individuals, anonymity was promoted as desirable because it ensured the donor could not later find themselves burdened with legal parental responsibilities in relation to the child. From 1992, conception via egg donations also started to occur in New Zealand.

Although the 1987 legislative reform brought about some improvements by reducing parental preference for anonymity, it was the *Human Assisted Reproductive Technology Act 2004* (HART Act) (Parliament of New Zealand, 2004), that brought the most significant improvement in rights for donor-conceived people conceived using gametes or embryos donated *after* the HART Act's introduction. These included requirements for clinics and the Registrar-General to collect and keep information about donors, and 'donor offspring', and provisions (with conditions) for the access of this information by both donors and offspring. The HART Act also introduced a voluntary register for donors and donor-conceived people conceived before the Act's introduction, and established greater controls and governance over donor conception (including additional oversight and conditions for the import or export of gametes or embryos).

Although there are significant limitations with the Act, including with the effectiveness of the voluntary register and the implementation of the Act generally (particularly as donor-conceived people to which the Act applies are reaching the age in which they can access information), the learnings from the New Zealand experience indicate that despite the Act's limitations it has led to significant improvements in the rights of donor-conceived people conceived from 2005 onwards.

Human Rights and United Nations

In an article examining whether a human rights framework supports the release of identifying information of donors, Dr Sonia Allan concluded that, "from a human rights perspective, there is support for such release within the *Convention on the Rights of the Child*, the *International Covenant on Civil and Political Rights*, and the *European Convention on Human Rights*.", (Allan, 2013, p. 669).

Under the United Nations *Convention on the Rights of the Child* (1989), to which Australia is a signatory, the following articles are relevant to donor-conceived individuals:

> *Article 2* - relates to discrimination, explicitly identifying discrimination based upon birth status as being in breach of the Convention.
>
> *Article 3* - states that in all actions concerning children, the best interest of the child shall be a primary consideration.
>
> *Article 7* - states that from birth, children have the right to know and be cared for by their parents.
>
> *Article 8* - states that children have a right to an identity, including nationality, name and family relations.
>
> *Article 13* - states that children shall have the right to freedom of expression, including the right to seek, receive and impart information and ideas of all

> kinds. (United Nations Human Rights Office of the High Commissioner, 1989)

Donor Conceived Australia is guided by the *United Nations Convention on the Rights of the Child* (the CRC) and the Geneva Principles on Donor Conception and Surrogacy (Allan et al., 2019, see Appendix I) provided to the UN Committee on the Rights of the Child by donor-conceived people on the 30th anniversary of the CRC. A number of our members represented Australia at this important event. Principle 3 states that:

> *"All donor-conceived and surrogacy born people have an inalienable right to identifying information about all of their biological parents, regardless of when or where they were conceived or born"* (Allan et al., 2019, p. 2 - see Appendix I).

The release of information is important for donor-conceived individuals for a number of reasons, including but not limited to the following:

Identity
Evidence suggests that early disclosure of donor-conceived status is paramount. Information is best divulged at an early age as, "young children cognitively process the information in a factual, non-emotional way" (Rumball and Adair, as cited in Godman et. al, 2006), naturally incorporating this information into their identity. This results in donor-conceived people feeling more comfortable about their origins as they reach adolescence (Scheib, as cited in Godman et. al, 2006).
A recent paper by Macmillan et al, (2021), found of 69 donor-conceived Australian adults 88% attempted to obtain information about donors. When asked about their motivations the most commonly reported were 1 medical information, 2 for identity purposes, 3 for curiosity.

Medical Information
Without access to their family medical history, donor-conceived individuals are unable to identify whether they are at a higher risk than the general population to develop particular inheritable conditions and are consequently unable to take preventative measures.

At the time of donation, most donors were in early adulthood, prior to the onset of many diseases. They may also not be aware of their own family medical history at this early stage of adulthood. Were a donor or their biological children (whether donor-conceived or not) to be diagnosed with an inheritable disease, there is currently no mechanism by which donors or donor-conceived individuals can report this to other biological family members.

Whether it is information provided by donors at the time of donation or information that needs to be communicated afterwards, this lack of information sharing is, in the worst-case scenario, life-threatening.

Donor Conceived Australia has members who have been diagnosed too late with genetic diseases that do not run in the half family history they are aware of. If they had known earlier about any medical history and could have had screening tests for such illnesses they may not be as unwell as they are now.

Some of our members don't find this is a problem until they have children of their own, who inherit genetic diseases that are not in the known family history. Again, should this family history be known earlier, more could have been done to help these children from birth, to be aware they may have a predisposition towards certain diseases, rather than wait years for a diagnosis.

Finally, some donor-conceived adults go on to develop life-threatening genetic diseases and wish to communicate this to their siblings/donor. This is vital information for other genetic relatives to have, but currently, there is no way for the donor-conceived person to find all of their siblings and contact them to let them know they may have a predisposition to a certain disease. This needs to change.

Risk of Consanguineous Relationships

It stands to reason that being deprived of donor information can lead to inadvertent consanguineous relationships (i.e. a sexual relationship between second cousins or closer) between two unknowingly related donor-conceived individuals. As there are relatively few fertility clinics in Queensland offering donor gametes as a means of conceiving (particularly historically), and the time periods for which donors contribute gametes, it is not unreasonable to argue that most donor-conceived people and their siblings are likely to be born within similar geographical areas and within limited time-spans. This increases the risk of donor-conceived siblings coming unknowingly into contact with one another and possibly forming relationships, including sexual relationships.

The risk of forming inadvertent incestuous relationships is further increased by Genetic Sexual Attraction (GSA), which can be defined as a sexual attraction between biologically related adults who have been separated during infancy and become sexually attracted to one another later in life due to similar attributes. GSA is a phenomenon that has been identified within both the donor-conceived and adoption community.

Discovering that one has accidentally formed a sexual relationship with one's sibling and having possibly even conceived a child together would undoubtedly have significant social and emotional repercussions. Consanguineous relationships not only present social-emotional implications but have been linked to an increased risk of recessive genetic disorders. At each locus (position) of a chromosome, an allele is inherited from each parent. Therefore, if just *one* parent carries a mutant autosomal recessive gene, the offspring will not express the disorder as they have a remaining healthy allele. Offspring of consanguineous relationships have an elevated risk of inheriting autosomal recessive genetic disorders, due to a higher probability of expressing two mutated alleles (Joseph et al., 2014). An example of a severe autosomal recessive condition is cystic fibrosis, which is carried by 1 out of 20 people on average (Kumar et al., 2017). Other examples of autosomal recessive disorders include thalassaemias, haemochromatosis, and Tay-Sachs disease, all of which are capable of causing significant morbidity or mortality (NSW Health, 2020).

While limits placed upon the number of families able to conceive using gametes from a donor does assist in limiting the number of children born and therefore reducing the risk of consanguine relationships, we argue that the only method capable of truly removing this risk is the removal of anonymity through both the establishment of a register and through the recording of donor information on birth certificates. A register alone would not provide this protection as it would not ensure parental disclosure of donor-conceived status to individuals.

The opening up of closed adoption records provides a clear precedent for the removal of anonymity in the donor-conception sphere and a significant body of research relating to the impacts of anonymity on the social, emotional, and physical wellbeing of individuals.

Donor Conceived Australia recommends that the committee recognise and maintain the right of donor-conceived individuals to identifying information about their genetic parent/s, regardless of when or where they were born. Additionally, Donor Conceived Australia recommends that donor-conceived status be made clear to individuals through both the establishment of a register and the recording of donor information upon birth certificates.

2.2 Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors

Donor Conceived Australia strongly supports the rights of donor-conceived people to have access to identifying information about their genetic origins, including the compulsory retrospective release of identifying donor information. Many donor-conceived people conceived in Queensland have reported needing their mother/parents' consent to access medical records which represents a significant problem for several reasons: many donor-conceived people learn of their donor-conceived status from alternative actors such as extended family members, family friends or via direct-to-consumer DNA testing. For these individuals, seeking permission from their parents may not be comfortable/appropriate. In other cases, family members may be estranged or deceased.

It is important to draw a distinction between access to identifying information and contact with donors and donor siblings. In Victoria, the first state to retrospectively legislate, contact vetoes were introduced as a measure to 'balance' distinct stakeholder perspectives. Many donor-conceived people find this approach paternalistic and inflammatory. There is no evidence of instances of donor-conceived people pursuing unwanted contact, with or without contact vetoes in place. More recently, the proposed changes to the ART Act in South Australia are underpinned by the principle that donor conception be normalised, donor conception story be validated and openness about the practice be encouraged, (South Australian Parliamentary Counsel, 2021). As such, contact vetoes have been avoided. Given these five years of experience from Victoria, and principles outlined in South Australia, Queensland has the opportunity to build on this knowledge, centering the rights of donor-conceived people in line with international human rights principles. Those not wanting contact are able to express their wishes, just as any person has a right to do in other spheres of life.

In regard to privacy and anonymity of donors, some of whom retrospectively signed up as anonymous donors, there is no need to continue to offer them anonymity as the easy to access direct-to-consumer DNA testing market has done away with any level of anonymity. Even if they have not tested themselves, most DCP are able to work at finding their donor with the help of "Search Angels" - professional genealogists - who often volunteer their time to help families connect. Donor Conceived Australia is of the view that this information would be much better to be provided by a government organisation that can provide support and counselling at the same time, rather than a multinational corporation or a volunteer genealogist.

Donor Conceived Australia recommends that donor-conceived individuals be given access to identifying information about their genetic parent/s and siblings regardless of when or where they were conceived and be free to negotiate contact with their genetic family.

2.3 Access to historical clinical records and implications of retrospectivity

It is the position of Donor Conceived Australia that donor-conceived people should have access to historical clinical records, regardless of when they were born or any guarantees of anonymity provided to donors at the time of their donation(s). Additionally, Donor Conceived Australia argues that this access should not be determined by donor consent.

The current legislation relating to people conceived after 2004, Australian Government, 2017), alongside the current framework, creates different classes of donor-conceived people. Retrospective legislation will remove discrimination and afford donor-conceived people equality before the law irrespective of their parents' timing of treatment and treatment success.

We recognise that some donors who assumed infinite anonymity may feel uncomfortable about the prospect of their information being made available to offspring. However it is important to note, as discussed in detail within the Victorian 2012 inquiry, that not all Victorians were: under the assumption they were anonymous, supportive of ongoing anonymity, or unsupportive of such legislation, (Victorian Law Reform Committee, 2012). There are many donors who have actively sought to have their identifying information available to their biological children with no means of doing so or who have, at the very least, wondered about the people that they helped to create. It is highly probable that Queensland donors share a similar attitude. Donors have a right to express their current wishes, rather than it being assumed that they prefer to remain anonymous. Some donors have reported in other state inquiries that they signed (some forcibly) a consent form or 'contract' prohibiting the release of any identifying information from any party to any other. For some it was a non-negotiable condition of donation. Clinics engaging in this practice were misleading. Furthermore, such restrictions on information release could only apply to consenting adults, namely the donor and recipient parents. Donor-conceived people could not consent to such an arrangement, least of all because they were not born, but that a 'contract' cannot 'signed' on one's behalf.

Another common argument relating to the retrospective release of information is that in some instances, the records no longer exist or are highly limited and that therefore, it is not possible to share information. However, a lack of information caused by inadequate record-keeping and the loss or intentional destruction of patient files, should not prevent the release of information to donor-conceived people where it does exist. A register also affords donor-conceived people the opportunity to confirm the non-existence of information, or to obtain at least some information. In Victoria, after the establishment of a Central Register some of our members who had been on the voluntary register were able to report that they could now contextualise their lack of matching after learning their records were unavailable (whereabouts and condition unknown), others who were informed by clinics that their records were unavailable, became available. Whether this related to the accountability assigned to clinics with the enactment of legislation is unclear.

Donor Conceived Australia recommends that identifying information relating to donors and donor siblings be released to donor-conceived people retrospectively.

2.4 Access to support and counselling for donor-conceived persons and donors

Opt-in counselling for donor-conceived persons, donors, and their families is an essential aspect of managing information relating to donor conception. Currently, there are no Queensland-based counselling services providing specialised support in the donor conception sphere, with post-adoption services providing the closest thing to informed practice.

Two of the recommendations of The Senate Committee in their Report on Donor Conception Practice in Australia (2011) regarding counselling that Donor Conceived Australia strongly supports and considers important to implement are:

> *"donors and donor recipients should be able to elect to receive counselling on the donor conception process and its consequences from a counsellor independent of the fertility clinic in which they are undertaking treatment;* and
>
> *"donor conceived individuals should have access to counselling as they mature and, in particular, when making contact for the first time with their donor or half-siblings. Such counselling should be voluntary, except where the donor conceived person is aged under 18 and is making contact for the first time with their donor or half-siblings, in which case counselling should be mandatory."* (The Legal and Constitutional Affairs References Committee, 2011)

Donor Conceived Australia also wishes for counselling to be provided by professionals not involved in or affiliated with the fertility industry. This is because it is important that a client accessing counselling for issues related to third party reproductive treatment should feel confident that the counsellor is independent, objective and focussed on the interests of that client. This is difficult to achieve if the counsellor is employed by or is associated with fertility clinics. Even though many donors and donor-conceived people might be happy to seek counselling from their fertility clinic, it is important that the option is still available to them to elect to see a counsellor who is entirely independent to avoid any potential real or perceived conflicts of interest or biases.

Another recommendation by The Senate Committee worth consideration is

" The committee recommends that state and territory governments, in consultation with the Fertility Society of Australia, should develop guidelines or requirements to ensure that counsellors providing counselling to donors, donor recipients or donor conceived individuals have an appropriate understanding of the issues involved with donor conception." (The Legal and Constitutional Affairs References Committee, 2011)

It is important that Counsellors are trained to provide support in the areas that the client is seeking assistance with. Donor Conceived Australia strongly believes that counselling for couples undergoing fertility treatment and counselling for people born of donor conception or surrogacy are different areas of expertise, and a fertility counsellor is not necessarily best placed to provide counselling to people born of third-party reproductive treatment.

Counselling provided by fertility clinics focuses on the infertility journey of the parents and does not prepare parents for the reality of rearing a donor-conceived child with their needs throughout their lifetime.

Many of our members have been forced to deal with well-meaning counsellors from fertility clinics just to gain access to their records of their biological family. Members report that often these counsellors have no understanding of the unique needs and trauma involved with late discovery donor-conceived people and they walk away feeling unsupported, unacknowledged and disappointed with their experience.

Currently there are very few counsellors experienced in counselling adult donor-conceived people in Australia. Donor Conceived Australia strongly advocates for training for counsellors, psychologists and other mental health professionals in the complexities associated with third party reproductive treatment. In the post-adoption sector, following the Victorian Apology for Past Adoption Practices, The Victorian Adoption Network for Information and Self Help, (VANISH) was funded by the State Government to build the capacity of Victorian professionals to respond to the needs of people affected. This involved developing a two-day programme which was delivered in various locations around Victoria. It also involved establishing a counsellor register that users could use to find a counsellor in their area who had undertaken the training. This type of training program is very much needed in the area of donor conception and surrogacy as members of society, including professionals, are often prone to misconceptions about ART practices and their outcomes and consequences. Donor Conceived Australia would hope to be involved in similar training Australia-wide for donor-conception counselling training for mental health professionals.

One more important issue that arises in discussions regarding legislation for ART is that of who can represent the persons born or to be born of donor conception? This question is pertinent when it comes to counselling for couples or individuals hoping to create a family. Currently, we feel that the fertility journey side of things is well represented, but recipient parents are not well counselled on HOW to bring up a donor-conceived child and the unique challenges they may come across throughout their lifetime.

Additionally, to the knowledge of Donor Conceived Australia, any pre-donation and pre-treatment counselling provided to donors and recipient parents is provided by the clinic providing treatment. This presents a clear conflict of interest given the financial incentive for clinics to recruit donors and provide donor conception services. Where donor linking is supported by clinics, support for donor-conceived individuals and donors is limited to a mandatory "counselling" session prior to the clinic facilitating first contact. For many people, this can feel like a significant invasion of privacy and intrusion into one of the most significant moments of their life; meeting their biological parent or child.

Donor Conceived Australia advocates for appropriate optional support services, including counselling and linking services, to be provided on a voluntary basis to donor-conceived individuals, donors, and any other relevant family members who feel that they would benefit from this support. This support needs to be independent of fertility clinics or actors representing the fertility industry. Additionally, donors and donor-conceived individuals require the provision of any support independent of each other. Such support services require this independence and separation to ensure that they practise in an ethical manner, avoid conflicts of interest, and facilitate a trusting and respectful therapeutic relationship with their clients.

Donor Conceived Australia recommends that support and counselling for donor-conceived people, donors and other relevant family members be provided independent of the fertility industry, including donor linking services. This support must be offered in a manner that prevents any conflicts of interest.

2.5 Whether a register should be established

Donor Conceived Australia strongly supports and advocates for the establishment of registers in each Australian state and territory in the absence of a uniform national register.

The current NHMRC guidelines, (Australian Government: National Health and Medical Research Council, 2017), do not work in practice to protect the rights of donor-conceived people since they are not enforceable as they are only guidelines. The ART industry is for-profit and largely unregulated. Additionally, the interests of clinics may be at odds with the interests of the people that they are creating. Given this lack of oversight and/or accountability, clear legislation is crucial to protecting the best interests of donor-conceived people. Further, fertility clinics change hands over time and may close. Historically, members of Donor Conceived Australia report this has resulted in the loss of records. In these situations, there needs to be an independent body able to manage and retain records in perpetuity.

While Queensland has been slow to act upon the recommendations of the Australian Senate Legal and Constitutional Affairs Reform Committee inquiry into donor conception practices in Australia made in 2011 (The Legal and Constitutional Affairs References Committee, 2011), being "late to the party" provides an opportunity for Queensland to learn from and improve on the work of other states.

Any register should not only include the information of Queensland donors but the information of any donors whose gametes are used to conceive a child in Queensland. This is necessary due to the use of international donors and the buying and trading of gametes across other states and territories. It should be noted that Donor Conceived Australia is strongly against the use of international donors and donor trading.
This register should also enable those who have used private donor conception arrangements to register the birth of their child or, for these donor-conceived people to register their own births. While Donor Conceived Australia does not condone the use of unregulated donor conception practices, there needs to be a mechanism for recording births and information and tracking these donors given the growing use of social media by recipient parents seeking donors and the growing number of donors providing gametes to multiple families outside of the fertility industry. This would also assist with maintaining the NHMRC's family limit recommendations, (Australian Government: National Health and Medical Research Council, 2017).

To access the register, we advocate for free access for donor-conceived people to ensure that the register is accessible to all. No donor-conceived people have chosen to be born in this way and so should not have to pay to access information about their genetic identity, which is a basic human right.

Donor Conceived Australia recommends that a register be established with records held by a government agency and that the register be retrospective, and link to other state and national registers.

2.6 Benefits, risks and implications of donor conception practices arising from any recommendations

Archiving records in a centralised, digital register is imperative for donor-conceived people, and future generations, who are seeking to access information decades after their authorship. The importance of this was highlighted in the Victorian Inquiry with the revelation of handwritten records deteriorating (Prince Henry's Hospital), and media reporting, and an internal investigation confirming record destruction (The Royal Northshore Hospital). Both stories underscore the vulnerability of records. (Victorian Law Reform Committee, 2012).

A major argument espoused by the fertility industry is that the release of identifying information about donors will reduce the supply of gametes to the fertility industry and consequently, recipient parents. However, as it has been established above, it is in the best interests of the child or person being conceived to be able to know their genetic heritage and that this information is best divulged at an early age. Donor Conceived Australia advocates for the recruitment of informed donors who have been provided with the necessary information to understand the social and emotional needs of their donor-conceived offspring and who are open to meeting those needs. A reduction in donors is not an adequate reason to negate the rights of donor-conceived individuals. To do so would be to place the interests of donors, recipient parents, and fertility clinics above those of the people they are creating. This is the status quo and it is no longer acceptable in the 21st century.

It is important to note that there has been no impact on donor numbers with the legislation to release identifying information in Victoria. Furthermore, following the National Health and Medical Research Council's guidelines implemented in 2005 removed a sperm donor's ability to remain anonymous in every Australian State except Victoria, which had removed anonymity completely by 1998, Adams, D., et al, (2016), assessed the impact of these changes on sperm donor numbers in Australia, between 2000 and 2012. They found there was actually an increase in total sperm donor numbers over the study period, surmising that the removal of a donor's ability to remain anonymous has not been detrimental to the availability of sperm donors in Australia.

We call for a paradigm shift from the rights of the recipient parents and donors to the rights of the child created. We call for open and transparent practices that put the child created at the centre of all decisions, and we call for an increased sense of identity for that child with access to their full medical and genetic records from birth as is a basic human right. Overall, the best interests of the person conceived via donor conception need to be paramount and this remains true regardless of the time or place of their conception or the practices occurring at that time.

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3 Appendix I

International Principles for Donor Conception and Surrogacy

Purpose:
The International Principles for Donor Conception and Surrogacy (the Principles) have been drafted to provide minimum standards for laws and practice in Nation States where surrogacy and/or donor conception are already permitted or tolerated. The Principles require strict regulation of such practices to uphold the human rights and best interests of people born as a result, in accordance with the principles universally agreed to by Member States as per the United Nations Convention on the Rights of the Child (UNCRC), the most successful human rights treaty in history.

Background:

Donor conception is the commonly used term for the practice of intending parents using third party gametes (such as third party sperm, egg or embryos) to create their own child(ren).

Donor conception also applies to people who are born via surrogacy arrangements, where one or more gametes do not come from the intending parents. These surrogacy-born people are also donor-conceived. The birth mother in surrogacy may or may not be related to the child she carries and births, but she is always also important to the person born as a result.

The Principles are based on the recognition that regardless of the type of assisted reproduction used, all donor-conceived people and people born of surrogacy have a fundamental human right to their full and true identity, a right to preserve relations with their families, and a right not to be bought or sold as enshrined in the UNCRC and other international instruments.

The Principles originally arose out of a presentation by the drafters at the Conference on the 30th anniversary of the UNCRC, at the Palais des Nations, Geneva, November 19, 2019. They are informed by the lived experience of the drafters as donor-conceived. They respond to practices past and present that have impacted and/or continue to impact their lives. Many feel that they are the products of an international industry in human eggs, sperm, embryos and wombs which profits from human life – their lives. Yet as of this writing there is no jurisdiction in the world that fully protects the human rights of donor-conceived or surrogacy-born people despite all UN Member States having signed, and all but one having ratified, the UNCRC.

The Principles are also informed by extensive engagement by the drafters in advocacy on behalf of their community at local, national and international levels, and examination of laws and policy that directly impact them and their genetic, social and gestational families. In addition, the drafters draw upon their professional legal, communications, policy, social services, scientific and other qualifications and experience to inform their work.

In drafting the Principles, it is recognised that many countries maintain prohibitions on assisted reproduction including surrogacy and/or donor conception, as contrary to their values and the human rights of men, women and children. The Principles are not intended to be used to condone, widen or to encourage such practices. Rather, they are intended to set minimum standards that should be adhered to by nations that already permit such practices, and to require strict regulation where such practices occur. They are relevant to all donor-conceived people, including those born of surrogacy – past, present, and future.

Former and current initiatives to formulate policy and/or principles on donor conception and surrogacy by government agencies and not-for-profits are unacceptable. They have failed to adequately consult with donor-conceived and surrogacy-born people. They often choose to ignore the voices of donor-conceived and surrogacy-born people who do not support certain practices in favour of the interests of the fertility industry and intending parents. All policy-making, both national and international, henceforth must include meaningful consultation with a broad representation of donor-conceived and surrogacy-born persons in recognition that the people created by reproductive technology are overwhelmingly those most affected by it. These voices need to be heard, listened to, and acted upon.

We call upon all governments, agencies, and lawmakers to hear directly from this constituency, to recognise the rights of donor-conceived and surrogacy-born people and to enact laws that uphold and implement the following principles.

The Principles:

Best Interests and Human Rights of the Child Paramount

1. The best interests and human rights of the child who will be or has been born as a result of donor conception and/or a surrogacy arrangement must be the paramount consideration in all relevant laws, policies and practices and in any judicial and administrative decisions relating to donor conception and surrogacy.

Pre-Conception Screening and Post-Birth Review

2. Pre-conception assessments and screening of donors, intended parents and potential surrogate mothers and post-birth review of the best interests and human rights of the child born as a result must occur in every case of surrogacy and donor conception.

The Right to Identity and to Preserve Relations

3. All donor-conceived and surrogacy-born people have an inalienable right to identifying information about all of their biological parents, regardless of when or where they were conceived or born.

4. All donor-conceived and surrogacy-born people have an inalienable right to identifying information about all of their biological siblings, be they half or full siblings, regardless of when or where they were conceived or born.

5. All surrogacy-born people have an inalienable right to identifying information about their surrogate mother, regardless of when or where they were conceived or born.

6. All donor-conceived and surrogacy-born people have the right to preserve relations with biological, social and gestational families, regardless of when or where they were conceived or born. Such relations should be able to be maintained if mutually agreeable.

7. Anonymous donation of gametes and embryos, and anonymous surrogacy must be prohibited.

Record Keeping, Birth Records, and Access to Information

8. Comprehensive and complete records of the identity and familial medical history of all parties involved in the conception and birth of donor-conceived and surrogacy-born people must be kept. Such records must be held by each Nation State in which the conception and birth is commissioned and/or occurs, in perpetuity and for future generations. Verification of the identity of donors, surrogate mothers, and intending parents must occur.

9. All children's births should be notified to and registered with the appropriate competent authority in the Nation State of birth. Truth in registration, noting the child is donor-conceived and/or surrogacy-born, must occur. Birth records must be maintained in perpetuity and for future generations that recognise biological, social, and birth parents.

10. All donor-conceived and surrogacy-born people have the right to be notified of their status and to access records pertaining to their identity, familial medical history, and birth registration.

11. Parents should be encouraged and supported to tell their children of their donor-conceived or surrogacy-born status as early as possible, and preferably from birth. This should be coupled with efforts to reduce stigma related to infertility.

Prohibitions on commercialisation of eggs, sperm, embryos, children and surrogacy

12. All forms of commercialisation of eggs, sperm, embryos, children, and surrogacy must be prohibited. This includes, but is not limited to any kind of consideration (payment or other consideration) for a) the recruitment of potential donors and/or surrogate mothers; b) gametes or embryos; c) 'services', time, effort, 'pain and suffering' related to the conception, pregnancy and/or birth of a child, or termination of pregnancy.

13. The sale and trafficking in persons and/or of gametes in the context of assisted reproduction and surrogacy must be prohibited.

14. The participation of paid intermediaries or agents in arranging surrogacy and/or recruiting or procuring women or donors of gametes for the purposes of surrogacy or gamete donation for profit, should be prohibited on the basis that their participation increases the risks of the sale and/or trafficking of women and children.

Prohibitions on transnational surrogacy and donor conception

15. It is not in the best interests of the child to be conceived or born in circumstances in which the 'intending parents' have circumvented or breached laws within their own country by engaging in cross-border assisted reproduction, including but not limited to donor-conception and/or surrogacy. States that prohibit such practices should include extraterritorial prohibitions in their laws. States that allow such practices should limit access to their own citizens. Extraterritorial prohibitions should be enforced.

16. It is not in the best interests of the child to be intentionally separated from their genetic families by geographical, linguistic or cultural barriers. As such, inter-country transfer of gametes should also be prohibited.

Family limits

17. To avoid the risk of consanguineous relationships, and the psychological impact of an unlimited number of potential siblings, the number of families that may be created using one donor's gametes should be limited to five.

Requirement for Counselling and Legal Advice

18. Independent counselling and legal advice must be a requirement prior to entering into donor conception and surrogacy arrangements. All parties to donor conception and/or surrogacy must be able to give their informed consent after receiving information about the processes involved, material risks, legal and financial implications and their rights and responsibilities. All information must be delivered in a language the person receiving the counselling and advice can understand. All decisions must be made autonomously and free from duress, coercion, and/or exploitation.

19. The provision of counselling and legal advice must always uphold and convey the best interests and human rights of the child(ren) born to be the paramount consideration.

Transfer of Legal Parentage (Surrogacy)

20. Upon the birth of a child conceived as a result of a surrogacy arrangement, the child should share the birth mother's nationality to avoid the situation that a surrogacy-born child is 'stateless', and records to this effect must be kept.

21. Transfer of legal parentage in cases of surrogacy from a surrogate mother to 'intending parent(s)' should never be automatic nor based solely on intention. Intending parent(s) do not have a right to exclusive legal parentage or parental responsibility of a child born through surrogacy, regardless of any expenses they may have incurred through the process. The surrogate mother must never be compelled to relinquish the child(ren) she has given birth to.

22. Where a surrogate mother has carried the full genetic child of another couple and does not wish to relinquish the child, legal parentage of the child should be determined by a Court dependent on the best interests of the child.

23. Enforcement of contractual terms that purport to transfer legal parentage is not consistent with the best interests or human rights of a child.

Posthumous Use of Gametes

24. Gametes or embryos which a) have been retrieved posthumously from a person, or b) are stored by a clinic on behalf of a person who has since died must never be used in donor conception or surrogacy arrangements, regardless of whether any consent had been given by the person from whom those gametes were obtained prior to their death.

Commentary:

The Principles express the common view of the members of the November 2019 UN presentation on The Rights of the Child in the Age of Biotechnology as part of the 30th anniversary conference on the UNCRC.

The Principles recognise that, pursuant to the UNCRC, donor-conceived people and people born of surrogacy have a fundamental human right to:

- as far as possible, know and be cared for by their parents (Article 7);
- preserve their identity, nationality and family relations, to not be deprived of any elements of their identity, and to seek State assistance to re-establish their identity (Article 8);
- maintain personal relations and direct contact with both parents on a regular basis (Article 9);
- express their views in all matters affecting them (Article 12); and
- seek, receive and impart information and ideas affecting them (Article 13).

Most importantly, ALL children have a fundamental human right not to be bought or sold.

Donor-conceived people and people born of surrogacy also have the right to:

- have their rights in the Convention respected by States Parties without discrimination of any kind, irrespective of the child’s birth or other status (Article 2); and
- have the best interests of the child as the primary consideration in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies (Article 3).

States Parties should undertake all appropriate legislative, administrative and other measures for the implementation of these human rights as recognised in the UNCRC (Article 4).

As noted in the background to this document, all policy-making, both national and international, must henceforth include meaningful consultation with a broad representation of donor-conceived and surrogacy-born persons, as they are the population overwhelmingly affected by the practice of third-party reproduction.

The full United Nations Presentation by Donor-Conceived and Surrogacy-born People for the 30th Anniversary of the Convention on the Rights of the Child can be viewed here: https://www.youtube.com/watch?v=GEP3ZGPFdeQ

The transcript of the presentation can be found here: https://www.donorkinderen.com/speeches-united-nations

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