




Speech By
Hon. Shannon Fentiman

MEMBER FOR WATERFORD

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ASSISTED REPRODUCTIVE TECHNOLOGY BILL

Second Reading

 **Hon. SM FENTIMAN** (Waterford—ALP) (Minister for Health, Mental Health and Ambulance Services and Minister for Women) (11.22 am): I move—

That the bill be now read a second time.

I want to acknowledge the work of the Community Safety and Legal Affairs Committee and its staff in conducting its inquiry into the Assisted Reproductive Technology Bill 2024. I thank the committee for its detailed consideration of the bill and its report. The committee made one recommendation—that the bill be passed. I appreciate the committee's support of the bill.

I would also like to thank everyone who made submissions to the committee, participated in the public hearings and contributed to the development of the bill, so many of whom have joined us in the gallery today. Last year I had the privilege to meet with a number of these incredible advocates, including Anastasia, Lexie, Danielle and Shannon, and to hear from many more families. After hearing their stories, I asked Queensland's Health Ombudsman to undertake a systemic investigation into the health services offered by providers in Queensland.

To all of the donor-conceived people, advocates and families, I know it took courage to speak up and expose how the fertility industry's self-regulation has, in some instances, failed to protect Queensland families. Donor-conceived people courageously shared their stories, describing the unique stress and anguish that can come from finding out that you may have many siblings or from not being able to know your background or medical history. Some described finding out they were donor conceived as a traumatic experience that left them feeling like they had lost their identity. Others described the richness that being able to develop meaningful relationships with their donor siblings and the donor can bring to their lives. Parents of donor-conceived children shared their sometimes painful experiences and explained how they will feel the effects in their families for years to come. People undergoing fertility treatments shared how they have felt misled and unheard during a highly emotional and stressful time. Thank you for your bravery and resilience in sharing your personal stories. We have heard you. Your rights are enshrined in this bill, which will protect the welfare and interests of people who use assisted reproductive technology and who are born as a result. The bill will improve confidence in Queensland's fertility industry by providing greater oversight, transparency and protections for Queenslanders. For donor-conceived people, your welfare and interests throughout your lives will be of paramount importance in the administration and operation of the legislation.

I would also like to thank the Health Ombudsman and her team for their intensive and detailed work throughout their investigation into the fertility industry. The final report, which was published on 1 July 2024, identified a range of systemic issues and made recommendations to government and industry. The final report confirmed the need for robust legislation to regulate the fertility industry in Queensland. The bill puts into action a range of recommendations that the Health Ombudsman made for legislation, including the need for robust industry oversight, a family limit on the use of donor

gametes, informed consent and prohibiting sex selection. The committee supported the introduction of a licensing scheme and noted strong stakeholder support for regulating the fertility industry. The licensing framework will give Queensland Health powers to oversee providers and enforce compliance.

Some industry stakeholders expressed concern that the penalties for offences in the bill are too punitive. Queensland Health will have a range of regulatory actions that can be applied before pursuing an offence, including the ability to impose licensing conditions, issue an improvement or prohibition notice, or suspend or cancel a licence. However, it is important that the bill takes a strong stance on serious ethical and clinical breaches. When there are instance of such conduct, the penalties are proportionate to the impacts which are significant and at times can be lifelong.

The bill includes a range of requirements that will govern the ethical conduct of the industry. The committee found that while stakeholders often raised competing views, the bill has struck the appropriate balance. This is particularly the case for the family limit, time limits for use of donor gametes and withdrawal of consent. The bill will legislate a maximum number of Australian families that may be created from a single donor. It will be an offence for a provider to perform an assisted reproductive technology procedure knowing that it would result in more than 10 families being created in Australia from the same donor. This is in line with several other jurisdictions in Australia. The limit responds to the concerns we heard from donor-conceived people about the impacts of having many siblings. It strikes a balance between limiting the number of families that may be created without unduly restricting the availability of donor gametes.

The bill also sets a maximum time limit of 15 years for the use of donated gametes and embryos. Assisted reproductive technology providers seeking to use materials after this period must apply to the chief executive of Queensland Health. Some stakeholders raised concerns that this provision could pressure people into extending their families sooner than they otherwise would have, for example, if the gametes had already been in storage for some time. This is not the intent of the provisions. It is to ensure that providers are acting ethically with respect to materials stored over many years. This is particularly important to donor-conceived people given the impacts of potentially having an age difference of many years between a person and their genetic parent or genetic siblings.

The bill includes provisions around the counselling and information that must be provided to ensure patients are able to make informed decision about their options. Stakeholders were generally supportive of the role of counselling in the provision of assisted reproductive technology services, provided that it was appropriate and of high quality. Following providing the information and counselling and obtaining consent, providers must act in accordance with a person's consent. This also applies if consent is withdrawn or modified.

The bill will also prohibit the use of a person's gametes in procedures after that person has died. There are two exceptions to this. The first is when the person specifically consented to the use after their death. The second is if the gametes are retrieved under the new processes established by the bill.

The Health Ombudsman's report identified record keeping as another critical area where legislation is needed. During consultation, many donor-conceived people shared their experience of approaching a provider for information about their conception and genetic history only to learn that those records had been destroyed or lost. One donor-conceived person said—

By adulthood I had resigned myself to the fact that I would never know the identity of my father or siblings, I would never know the family that genetically I was a part of. I did not know my cultural background or the medical conditions I might need to watch out for.

The bill will require providers to collect information and retain records for at least 99 years and not destroy records.

The bill also requires providers to collect donors' relevant medical history information, which will also be recorded in the donor conception information register for access by genetically linked people. The ability to share emergent information about serious health conditions is so important to donor-conceived people and their families. I have heard firsthand from people who have a health condition that may have a genetic component and want to warn their siblings, only to find the relevant fertility clinic is unable or unwilling to provide that warning.

The Health Ombudsman's report details similar concerns. A parent of a donor-conceived child told the ombudsman of spending three years pushing to share their child's health issues with donor siblings. They were repeatedly reassured by the clinic that any health issue would be shared immediately, no matter the severity, but families of donor siblings say that no disclosure was made. The bill makes it clear that providers are authorised to pass on health information that may come to light after a gamete or embryo is donated where a medical practitioner has certified a serious risk of harm. I note the committee considered that these provisions will benefit donor-conceived people.

The bill addresses the critical gaps and risks identified in the Health Ombudsman's report. Some of the more clinical matters will be dealt with through licence conditions and implementation activities. During consultation and the committee's inquiry, some providers suggested that legislating protections could increase costs to patients and their families. The new regulatory framework will avoid unnecessary red tape for clinics as much as possible, and providers should already be doing the things in the bill under the current self-regulatory model.

The bill will also respond to recommendations made by the former Legal Affairs and Safety Committee following its inquiry into matters relating to donor conception information by establishing the donor conception information register in the Registry of Births, Deaths and Marriages. When I was attorney-general, the member for Toohey and I met with Professor Katharine Gelber, who was a key advocate pushing for this inquiry to occur. Professor Gelber and other stakeholders demonstrated that there was strong support for the establishment of the register and that it will 'make a real difference to the lives of donor-conceived people and their families'.

Many donor-conceived people stressed the importance of knowing their genetic origins and the beneficial impact of being able to access information about a person's donor-conceived siblings and donor. The bill establishes an access-to-information framework that will allow all donor-conceived people, regardless of when they were born, to access identifying and non-identifying information about a donor where the information is held on the register. Donors and parents of donor-conceived people will also be able to access certain information through the register.

Under the bill, donor-conceived people aged 16 years or older will be able to apply for and access information on the register, including identifying information about the donor. Access from 16 years of age is intended to support donor-conceived people to know important information about their genetic origins from an age of relative maturity. This is consistent with a person 16 years or older being able to apply to alter their records under the Births, Deaths and Marriages Registration Act 2023. The bill allows the parents of a donor-conceived person or a person with parental responsibility for a donor-conceived person under 16 years of age to apply for and access information about the donor, including identifying information if the donor consents to its release. This is intended to facilitate sharing of this information with the donor-conceived person in an age-appropriate manner.

Some stakeholders submitted that retrospective operation of the register will disproportionately impact upon the privacy rights of donors who donated prior to 2004 on the condition of anonymity or who otherwise did not consent to their identifying information being released. Retrospective operation of the register was strongly recommended by the committee. It was their view that a donor-conceived person's right to know identifying information about a donor outweighs the donor's right to anonymity. The bill will require providers to disclose historical donor conception records to the register, regardless of whether the donor donated on the condition of anonymity. If a donor's identifying information is held on the register, a donor-conceived person will be able to access it upon application. Retrospective operation of the register will ensure donor-conceived people can access important information about their genetic origins.

The bill also provides for addendums to be issued to the birth certificates of donor-conceived people born in Queensland. The addendum will outline that further information about the person's birth is available in a register kept by the registrar. The addendum model outlined in the bill is intended to provide an independent avenue for donor-conceived people to become aware that they are donor-conceived. The model is intended to maintain the privacy of a donor-conceived person, as the method of the person's conception will not be noted on the birth certificate itself and inadvertently disclosed when the birth certificate is used as an identity document.

The Assisted Reproductive Technology Bill will protect Queenslanders and their families now and into the future, along with providing certainty and confidence for Queensland's fertility industry. Once again, I would like to thank the families and individuals who have spoken up about these issues and have fought tirelessly to bring about these reforms. I commend the bill to the House.