



# Speech By Hon. Shannon Fentiman

## MEMBER FOR WATERFORD

Record of Proceedings, 22 May 2024

## ASSISTED REPRODUCTIVE TECHNOLOGY BILL

## Message from Governor

**Hon. SM FENTIMAN** (Waterford—ALP) (Minister for Health, Mental Health and Ambulance Services and Minister for Women) (11.52 am): I present a message from Her Excellency the Governor.

**Mr DEPUTY SPEAKER** (Mr Lister): The message from Her Excellency recommends the Assisted Reproductive Technology Bill. The contents of the message will be incorporated in the *Record of Proceedings*. I table the message for the information of members.

#### MESSAGE

ASSISTED REPRODUCTIVE TECHNOLOGY BILL 2024

Constitution of Queensland 2001, section 68

I, DR JEANNETTE ROSITA YOUNG AC PSM, Governor, recommend to the Legislative Assembly a Bill intituled-

A Bill for an Act to provide for the regulation of the use of technology to assist human reproduction and for a donor conception information register, and to amend this Act, the Anti-Discrimination Act 1991 and the Births, Deaths and Marriages Registration Act 2023 for particular purposes

GOVERNOR

Date: 22 May 2024

*Tabled paper:* Message, dated 22 May 2024, from Her Excellency the Governor recommending the Assisted Reproductive Technology Bill 2024 <u>838</u>.

## Introduction

**Hon. SM FENTIMAN** (Waterford—ALP) (Minister for Health, Mental Health and Ambulance Services and Minister for Women) (11.52 am): I present a bill for an act to provide for the regulation of the use of technology to assist human reproduction and for a donor conception information register, and to amend this act, the Anti-Discrimination Act 1991 and the Births, Deaths and Marriages Registration Act 2023 for particular purposes. I table the bill, the explanatory notes and a statement of compatibility with human rights. I nominate the Health, Environment and Agriculture Committee to consider the bill. I also table a summary report into the investigation of assisted reproductive technology providers in Queensland by the Office of the Health Ombudsman.

Tabled paper: Assisted Reproductive Technology Bill 2024 839.

Tabled paper: Assisted Reproductive Technology Bill 2024, explanatory notes 840.

Tabled paper: Assisted Reproductive Technology Bill 2024, statement of compatibility with human rights 841.

*Tabled paper:* Office of the Health Ombudsman report, undated, titled 'Section 81—Investigation of ART providers in QLD— Summary report: Phases 1 and 2' <u>842</u>. Today I am proud, as the Minister for Health, Mental Health and Ambulance Services and Minister for Women, to introduce the Assisted Reproductive Technology Bill 2024 into this House. The bill will establish a robust framework to regulate assisted reproductive technology providers and services and will establish a donor conception information register in Queensland. This legislation will ensure that the wellbeing and interests of people receiving fertility treatments are central to the delivery of assisted reproductive technology services and that the welfare and interests of people born as a result of these services are of paramount importance.

The journey to becoming a parent is different for everyone. Those who struggle to conceive can experience stress and heartache. Assisted reproductive technology includes treatments such as artificial insemination, IVF and gamete intra fallopian transfers that can help those with fertility issues, genetic risks, and diverse genders and sexualities become parents. This is an increasingly common part of people's fertility journey. However, recently there have been concerning reports of failures involving providers in Queensland.

I would like to thank the families and individuals who have spoken up and brought these issues to light, many of whom are with us in the gallery today. I want to thank these advocates for their bravery, their resilience and their tenacity in sharing their stories and highlighting the need for this industry to improve its practices and provide more person-centred care. We have heard the heartbreaking stories of alleged donor mix-ups resulting in lifelong impacts for the families involved. We heard from many donor-conceived people and recipient parents that some clinics used sperm from the same donor many more times than what the community would consider appropriate, resulting in some donor-conceived people having potentially hundreds of genetic siblings. We have heard from the donor-conceived community about the ripple effects the search for answers and secrecy has throughout their lives: the questions about their medical history and ancestry, the yearning to understand that unknown part of themselves.

After hearing these concerning stories and noting the serious questions that were raised about the conduct of the fertility industry in Queensland, I asked Queensland's Health Ombudsman to undertake a systemic investigation into the health services offered by providers in Queensland. The investigation has focused on identified areas of concern, such as the handling of gametes and embryos, the use of donor material, screening techniques and record keeping. As one person identified to the Health Ombudsman, there needs to be more communication between clinics to prevent donors from donating to multiple clinics and to prevent donors who donate under an alias. The Health Ombudsman has made a number of preliminary recommendations that have informed the development of the bill. I thank the Health Ombudsman and her team for their extensive work on the investigation to date and I look forward to receiving the final report in June.

This bill creates a strong state-based framework to ensure appropriate oversight of the industry. It ensures there are proper enforcement powers to deal with noncompliance and adverse events and appropriate record keeping. I want to take this opportunity to thank the ongoing work of the Assisted Reproductive Technology Regulation System Policy Branch at Queensland Health. I will now outline some of the key features of the bill.

The bill adopts a key preliminary recommendation from the Health Ombudsman by establishing a licensing framework to ensure robust oversight of providers. Under the bill, providers will be required to obtain a licence to be able to operate in Queensland. It will be an offence to provide services without one. Where it is necessary for a provider to rectify a particular matter to prevent or minimise a risk to the health, safety or welfare of patients or people born as a result of those services, Queensland Health will have the ability to issue an improvement notice. They will also have the power to suspend or cancel a provider's licence. To ensure transparency of services, the bill requires licensed providers to give written notice of certain events within prescribed timeframes. Noncompliance of this requirement will be an offence. Inspectors will be appointed under the bill to investigate, monitor and enforce compliance with the act and will have a range of powers, including to enter premises, inspect and seize things and require production of information.

The bill includes requirements that providers must meet before providing treatment and will ensure that clinics are enabling the patient to make an informed decision about their treatment. Providers must make counselling available to people seeking treatment using their own gametes or embryos and ensure mandatory counselling has been undertaken by people involved in donor conception programs. People will be able to choose their own counsellor, given many people will have an existing relationship with a particular counsellor.

The bill introduces safeguards against the misuse of gametes and embryos by prohibiting or restricting uses that are considered unacceptable. Sex selection procedures, which seek to produce a child of a particular sex, are also banned, except where it is necessary to reduce the risk of transmitting

a genetic abnormality or disease. To prevent donated gametes being used across many decades, the bill prohibits the use of donated gametes and embryos that were obtained more than 15 years before the procedure. The bill does not impose any time limit on the use of a person's own gametes, which must be used only in accordance with their consent. The bill also prohibits the use of a gamete or embryo after the gamete provider has died, unless specific exceptions apply.

In response to the concerns raised regarding large numbers of families being created using the same donor, the bill makes it an offence for a provider to use donor material if they know it would result in more than 10 families within the country. Providers will be required to exercise appropriate due diligence to check this. The 10-family limit includes the donor's raised family as well as families who use donated gametes to conceive. This reflects the Health Ombudsman's preliminary recommendation. The bill ensures this limit is clear and enforceable, and will safeguard the rights of donor-conceived people against the psychological impacts of having many genetic siblings. The limit of 10 families seeks to find a balance between reducing the impacts on donor-conceived people and ensuring that regulation does not unduly restrict the supply of donors.

One of the key themes of the Health Ombudsman's investigation has been on the quality of record keeping and the provision of information to people accessing services and to donor-conceived people. One person told the Health Ombudsman that no meaningful improvements will be possible until records are fully and reliably maintained. The bill requires providers to collect and keep information about gamete providers, including donors, and people who undergo procedures for at least 99 years. The bill also makes it an offence to destroy records. This offence will carry a maximum penalty of 400 penalty units. This reflects the enormous impact on donor-conceived people of having records about their genetic origins destroyed and the importance of ensuring providers take their role as custodians of this information very seriously.

The bill also includes information-sharing provisions, which also support the establishment of the donor conception information register by the Registry of Births, Deaths and Marriages. The bill will establish the donor conception information register in the Registry of Births, Deaths and Marriages. The establishment of the register was considered by the then parliamentary Legal Affairs and Safety Committee following its inquiry into matters relating to donor conception information. As part of its inquiry, the committee heard from donor-conceived people and their families that access to information about a donor can be fundamental in informing their identity and a sense of self and can help them, importantly, to manage their health and wellbeing.

Donor-conceived people shared their stories of being refused access to donor records and information by providers and what this meant for their sense of identity. One person stated, 'Not having knowledge of one's genetic origins is like having the first chapter missing from one's life story.' Having access to information about their donor, such as ethnicity, medical history and family history, can resolve unanswered questions and help donor-conceived people develop a deeper understanding of who they are. Having access to the medical history of donors is also important. Enabling this sharing of medical information can be lifesaving.

It is for these reasons that the committee recommended the establishment of a retrospective register so that all donor-conceived people can be legislatively provided with the right to access identifying information about a donor regardless of when they were born. Whilst it is acknowledged that the establishment of a retrospective register will impact on the right to privacy of donors, the right of donor-conceived people to know their genetic origins outweighs the competing right to privacy. Making the register operate retrospectively creates information access equality for all donor-conceived people regardless of when a donor-conceived person was born and ensures all donor-conceived people are treated equally before the law.

The bill establishes a register that will hold available information about all donor conception procedures carried out in Queensland that resulted in the birth of a donor-conceived person. The bill will require providers or other people who carried out fertility treatments in the past to provide all historical donor conception information in their possession or control to the register within six months. From commencement of the bill, providers will be required to collect and provide relevant information about donors, donor-conceived people and their parents to the register within three months. Information on the register will be held by the Registrar of Births, Deaths and Marriages in perpetuity.

The bill establishes an access to information framework that will allow donor-conceived people, their parents, donors and other individuals to apply to access information held on the register. All donor-conceived people will be provided with the right to access identifying and non-identifying information about donors when the donor-conceived person turns 16. All applicants to the register will be provided with access to counselling support services. To provide an independent avenue for donor-conceived

people to become aware of the fact that they are a donor-conceived person, the bill provides for the addition of an addendum to birth certificates of donor-conceived people that outlines that further information about them is held by the Registrar of Births, Deaths and Marriages.

By regulating providers and establishing a donor conception register, the Queensland government is demonstrating a commitment to protecting the welfare and interests of people who use assisted reproductive technology and those born as a result of such treatments. This bill demonstrates that the Queensland government's commitment to improving health care for families and for women forms part of our landmark Queensland Women and Girls' Health Strategy 2032.

I thank the Attorney-General and her department for their support in making this bill possible. I again take the opportunity to thank the many individuals, organisations and groups who advocated for this historic reform. This bill balances an appropriate level of regulation on providers with robust protections for Queenslanders. I commend the bill to the House.

## First Reading

**Hon. SM FENTIMAN** (Waterford—ALP) (Minister for Health, Mental Health and Ambulance Services and Minister for Women) (12.05 pm): I move—

That the bill be now read a first time.

Question put—That the bill be now read a first time.

Motion agreed to.

Bill read a first time.

#### **Referral to Health, Environment and Agriculture Committee**

**Mr DEPUTY SPEAKER** (Mr Krause): Order! In accordance with standing order 131, the bill is now referred to the Health, Environment and Agriculture Committee.