

ART Secretariat  
PO Box 8172  
Perth Business Centre  
PERTH WA 6849

ART.Secretariat@health.wa.gov.au

5 September 2022

Dear Ministerial Expert Panel members,

**Re: Targeted consultation on discussion paper *Contemporary Assisted Reproductive Technology and Surrogacy Legislation for Western Australia***

Thank you for the opportunity to provide comments on the discussion paper. The purpose of Mito Foundations is to end the suffering from mitochondrial disease (mito). Prevention is one of our key objectives and we support equitable access to assisted reproductive technologies (ART) and surrogacy to all Australians living with mito.

Mito Foundation encourages the Ministerial Expert Panel to recommend:

- Legislation that can regulate mitochondrial donation and other emerging technologies
- Equitable access to ART and surrogacy
- Access to surrogacy for people who face significant health risks in pregnancy
- Reliance on NHMRC Ethical Guidelines to regulate access to preimplantation genetic diagnosis (PGD)
- Safeguarding of health information related to mitochondrial donation.

This submission contains further information about each of these items. We have not considered other aspects of the discussion paper and their exclusion from this submission is not intended to be interpreted as agreement or endorsement.

## Background

The Mito Foundation<sup>1</sup> supports patients with mito and their families, funds essential research into the prevention, diagnosis, treatment and cures of mito, and increases awareness and education about these devastating diseases. The Mito Foundation was founded in 2009 by Doug and Margie Lingard, their friends, and experts in the field of mito. Doug and Margie have tragically lost a son and daughter to mito.

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<sup>1</sup> Incorporated as the Australian Mitochondrial Disease Foundation Limited ABN 841 353 243 91

The Mito Foundation's work is informed by our Mito Community Advisory Panel, and regular engagement with the wider mito community through specific projects. This submission has been informed by members of the mito community based in Western Australia as well as key medical and scientific advisors to Mito Foundation.

Mitochondrial disease can be caused by genetic changes in either mitochondrial DNA or in nuclear DNA. Fertility can also be affected by mito. This means that a variety of assisted reproductive technologies are used by the mito community including pre-conception genetic carrier screening, in vitro fertilisation (IVF), PGD, and prenatal testing.

On Wednesday 30 March 2022, the ***Mitochondrial Donation Law Reform (Maeve's Law) Bill 2021*** passed the Australian Senate by a convincing vote of 37 in favour and 17 against. This followed multiple Australian inquiries and consultations regarding legalising mitochondrial donation, including those that focussed on social and ethical issues.

Maeve's Law introduces a licensing system that enables a multi-year pilot program to be undertaken into mitochondrial donation. The law allows affected individuals the opportunity to have genetically related children without the risk of them inheriting mitochondrial DNA defects which can drastically limit their life.

We support the Australian Government Department of Health's approach to allowing affected families to access mitochondrial donation in an appropriate and regulated manner. The program, funded by the Medical Research Future Fund, will also build the evidence base to determine the safety, efficacy and feasibility of implementing mitochondrial donation reproductive technology in clinical practice settings.

### Mito Foundation supports reforms in WA to regulate mitochondrial donation

Mito Foundation, on behalf of the Australian mito community, encourages the Ministerial Expert Panel (MEP) to consider how the new legislation will support the introduction of mitochondrial donation into clinical practice in WA.

We are encouraged by the discussion paper's focus on the importance of the new legislation being able to regulate new and emerging technologies, including mitochondrial donation. We support an approach that would provide for the introduction of mitochondrial donation in a way that:

- Provides timely access to Western Australian families;
- Provides options within Western Australia that reduce or eliminate the need for families to travel to access the technique; and
- Ensures safe and high quality services

Ultimately, we hope that the legislation will support Western Australian families impacted by mito to have healthy children. When we discussed this submission with mito community members, they told us that they consider future access to mitochondrial donation as an issue of equity and fairness. They drew parallels between mitochondrial donation and other proposals in the discussion paper seek to reduce discrimination.



Mito has taken so much from my life. My hope for the future is that I could take back some of my power to decide to have children unaffected by this grueling and relentless disease.



Western Australian Mito Community Member

Mito Foundation supports making WA legislation consistent with Commonwealth legislation so that research to improve mitochondrial donation techniques could be conducted in WA. This would contribute to improved access to mitochondrial donation for Western Australian families after the conclusion of the national pilot program by supporting training of embryologists to perform the technique in Western Australian reproductive services.

### Mito Foundation supports equitable access to ART and surrogacy

The mito community is diverse. Many families with a history of mito are using assisted reproductive technologies, such as IVF and pre-implantation genetic testing, to build their families. Mito Foundation supports access to ART regardless of sex, relationship status, gender identity, intersex status or sexual orientation.

### Mito Foundation supports access to surrogacy for people who face significant health risks in pregnancy

The discussion paper describes a set of criteria for access to ART (page 6). These criteria do not seem to support access to ART, particularly surrogacy, for people with mito for whom the risks to their health posed by pregnancy are significant. We encourage the MEP to consider the New South Wales (NSW) access criteria. The Surrogacy Act 2010 (NSW) s 30 specifically defines eligible women as including people for whom their health will be significantly affected by a pregnancy or birth.

People with mito are likely to have high risk pregnancies due to their increased chances of pre-term delivery and of developing gestational diabetes and pre-eclampsia<sup>2</sup>. Some medications taken by women with mito, including anti-epilepsy medications, may further complicate pregnancy management. In addition to these, the increased metabolic demands of pregnancy, particularly close to delivery, may accelerate a person's symptoms of mito, such as mitochondrial cardiomyopathy and respiratory dysfunction. Risks will vary between individuals with mito, but for a minority of people with mito planning to have children, surrogacy

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<sup>2</sup> Amel Karaa, Ibrahim Elsharkawi, Mark A. Clapp, Cristy Balcells. Effects of mitochondrial disease/dysfunction on pregnancy: A retrospective study. *Mitochondrion*. Volume 46. 2019, Pages 214-220, <https://doi.org/10.1016/j.mito.2018.06.007>.

And Newcastle Mitochondrial Disease Guidelines Pregnancy in Mitochondrial Disease. Available at <https://www.newcastle-mitochondria.com/wp-content/uploads/2016/03/Pregnancy-Guidelines.pdf>

will be an important option. We believe that surrogacy, in addition to other assisted reproductive technologies, should be available to them.

We encourage the MEP to ensure that the new legislation provides for access to surrogacy by people with mito for whom a pregnancy and/or birth will pose a significant health risk.

### Mito Foundation supports reliance on NHMRC Ethical Guidelines to regulate access to PGD

Mito Foundation supports the recommendations in the Allen Review to remove the current requirement in WA for preimplantation genetic diagnosis (PGD) approval by the Reproductive Technology Council (RTC). Reliance on the NHMRC Ethical Guidelines regarding the use of PGD will help to ensure national consistency, reduce the time taken to access PGD in WA, and reduce unnecessary hurdles that can cause stress for people wanting to access PGD.

### Mito Foundation asks the MEP to consider safeguarding of health information related to mitochondrial donation

The discussion paper proposes that WA adopts a disclosure approach for donor details that is similar to the current approach in Victoria. As we understand the planned legislation, this would be the approach to storage of information about families who access mitochondrial donation. Any information specifying that a mitochondrial donor has been used is effectively storing and disclosing health and genomic information about the mother of a donor-conceived person and likely multiple other family members. This information may have implications for health care and insurance.

Mito Foundation encourages the MEP to consider how this health and genomic information will be safeguarded. We suggest that lessons learnt from Victoria's experience will be informative and that WA should consider approaches that limit the information stored by the Registry of Births, Deaths and Marriages.

### Further information

Clare Stuart, Mito Foundation's Policy and Advocacy Manager, is available for further discussion regarding this submission: [clare.stuart@mito.org.au](mailto:clare.stuart@mito.org.au) or 0410 685 181.

Yours faithfully,

A handwritten signature in black ink, appearing to read "S. Murray".

**Sean Murray**  
Chief Executive Officer