

Mito Foundation welcomes government response to recommendations from Senate Inquiry on mitochondrial donation in Australia, whilst recognising the need for swift action for those impacted by mitochondrial disease

The Mito Foundation welcomes the Government's response to the Senate Community Affairs Committee's Report into The Science of Mitochondrial Donation and Related Matters, tabled on 20 February 2019.

Changing the law to enable Australian parents access to mitochondrial donation is critical given that one child every week is born who will develop an avoidable form of mitochondrial disease and many of these children will die.

The Foundation **welcomes the commitment to develop a process for public consultation by the end of April and trusts that its implementation can then be expedited.**

The Foundation is also confident, having undertaken significant stakeholder engagement over the last few years, including with politicians and members of the community that Australians will support giving parents the choice to have children free from mitochondrial disease. In addition, other research including a Citizens' Jury completed by the University of Sydney, reflect the attitudes shown in other jurisdictions, including the UK.

This is also demonstrated by the submissions to last year's Senate Inquiry in which the overwhelming majority supported legislative change to enable mitochondrial donation.

Underpinning the public consultation is the Government's commitment to consult with scientists and other experts about mitochondrial donation before April. The Foundation looks forward to contributing to this work and notes that **the timeframe reflects both the urgency of the task and the work done in other jurisdictions**, notably the UK where mitochondrial donation is already legal. Beginning this work immediately is of critical importance.

The Foundation also appreciates the Government's decision to progress engagement with the COAG Health Council on mitochondrial donation and trusts that this can be expedited to enable Australian families access to mitochondrial donation as soon as possible.

The Foundation also acknowledges the approach taken by the Government to the recommendation regarding access to international services for those Australians desiring to access mitochondrial donation in the short term. This approach recognises **the challenges facing those members of our**

community who are running out of time in their quest to have healthy, genetically-related children of their own whilst balancing this against the desire for local consultation and review.

The Mito Foundation **implores the Government to commence the required groundwork on accessing international services in parallel to ensure that, after consultation, when the decision to progress is taken there are no untoward delays for parents.**

We also appreciate the fact that access to international services has been identified only as a 'short term solution' whilst consultations progress regarding our own legislative change. Sending Australian patients overseas for treatment, whilst timely and welcome in this instance, is not a feasible long-term solution for Australian families.

The Foundation thanks the Government and the Senators who undertook the Inquiry for recognising the impact that mitochondrial disease has on the lives of people in the mito community and looks forward to continuing working towards access to mitochondrial donation for our community.

To view the full *Science of Mitochondrial Donations and Related Matters* report [click here](#).

Summary of Recommendations from *Science of Mitochondrial Donation and Related Matters*:

Recommendation 1

5.99 The committee notes the strong potential of mitochondrial donation to address the debilitating effects of inheriting mitochondrial disease. The committee recommends that public consultation be undertaken regarding the introduction of mitochondrial donation to Australian clinical practice. To facilitate this consultation, the committee further recommends the Australian Government prepare a consultation paper, including options for legislative change that would be required. The Minister for Health should seek advice from the National Health and Medical Research Council on the most appropriate timing and format for this consultation.

Recommendation 2

5.100 The committee recommends that the Australian Government task the National Health and Medical Research Council with advising on the following questions:

- *Whether mitochondrial donation is distinct from germline genetic modification.*
- *Is there any new information to indicate that research findings from the United Kingdom, that the science of mitochondrial donation is safe for introduction into controlled clinical practice, cannot be applied in an Australian context?*

- *Whether other approaches to inheriting mitochondrial disease should also be the focus of Australian research.*

5.101 *The committee recommends the findings be used to inform future legislative process.*

Recommendation 3

5.103 *The committee recommends the Minister for Health take the findings of this report to the Council of Australian Governments (COAG) Health Council to progress the implementation of this report's recommendations with the states and territories.*

Recommendation 4

5.104 *The committee recommends, noting the need for community consultation and scientific review, the urgency of treatment for current patients and the small number of patients seeking this treatment, that the Australian Government initiate dialogue with the relevant authorities in the United Kingdom to facilitate access for Australian patients to the United Kingdom treatment facility as an interim measure.*