

MEDIA RELEASE

28 June 2018

**Senate Committee recommendations offer hope that
future Australian babies won't suffer mitochondrial disease**

Australian women at risk of having babies suffering severe mitochondrial disease may soon be able to have healthy children, following the Senate Community Affairs References Committee recommendations to the Government on mitochondrial donation, a ground-breaking IVF technique that replaces energy-generating DNA in the mother's egg with donor material.

The Committee's 27 June report was welcomed by the Mito Foundation (formerly the Australian Mitochondrial Disease Foundation), the peak body supporting Australians with mitochondrial disease, a serious and potentially fatal genetic disorder that starves the body's major organs of energy.

Mito Foundation Chairman Dr Doug Lingard thanked the Senators for their hard work inquiring into mitochondrial donation, and called on the Australian Government to act on the Committee's recommendations as soon as possible.

"At least 60 Australian babies each year could be prevented from suffering severely disabling and potentially fatal forms of mitochondrial disease if mitochondrial donation was available here. It offers the first practical hope for future generations to live free of maternally inherited mitochondrial disease," Dr Lingard said.

"In the Mito Foundation's experience engaging with the Australian public, politicians and other stakeholders, including a Citizens' Jury in 2017, mitochondrial donation receives overwhelming support when people understand the procedure and its ramifications.

"By acting promptly to change our laws, Australia could become the second country in the world to establish a regulated system to provide mitochondrial donation to families affected by this devastating disease.

"After ten years of scientific research, ethical review and consultation, in 2015 the UK made pioneering legislative changes to allow mitochondrial donation; these were endorsed in 2016 by the Human Fertilisation and Embryology Authority, and the first clinic and patient licences were issued in 2017.

"The Senate Committee clearly recognises that the UK's strict regulatory system for mitochondrial donation provides a sound basis for Australia, with only minor changes likely to be required to reflect our local context.

"The Mito Foundation supports the pathway recommended by the Committee. We stand ready to help in the public consultation process and urge the Australian Government to seek the advice of the National Health and Medical Research Council as soon as possible," he said.

Background

Mitochondrial donation involves replacing the faulty mitochondrial DNA in the mother's egg (0.1% of its genetic material) with healthy donor mitochondrial DNA so the resulting baby will not suffer mitochondrial disease.

The mother's and father's nuclear DNA contributes more than 20,000 genes or 99.9 per cent of the baby's genetic make-up and determines its appearance, intelligence, behaviour and other personal characteristics. The 0.1 per cent contribution (37 genes) from the donor egg means the resulting baby's cells can effectively convert food and oxygen into the energy needed to power its organs.

Depending on which parts of their bodies are most affected and to what extent, people with mitochondrial disease can lose their sight or hearing, be unable to walk, eat or talk normally, have strokes or seizures, develop liver disease or diabetes, suffer cardiac, respiratory or digestive problems, or experience developmental delays or intellectual disability.

For interviews with the AMDF, experts and affected families, please contact:

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For further media information:

- **The Mito Foundation Media Resources Dropbox:** <https://tinyurl.com/MitoFoundationMedia>
- **Senate Standing Committee on Community Affairs**
Science of mitochondrial donation and related matters
https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/MitochondrialDonation
- **Scimex Expert Reaction, 28 June 2018:** Senate report on allowing 'three person IVF' to prevent mitochondrial disease
<https://www.scimex.org/newsfeed/expert-reaction-senate-to-report-on-allowing-three-person-ivf-to-prevent-mitochondrial-disease>
- **Scimex Expert Background Briefing, 15 June 2018**
<https://www.scimex.org/newsfeed/background-briefing-senate-to-report-on-allowing-three-person-ivf-to-treat-mitochondrial-disease>

A recording of the expert briefing is in the Attachments at the bottom of the page, featuring:

- Professor Carolyn Sue: Professor and Director of Mitochondrial Research, Royal North Shore Hospital, Kolling Institute, University of Sydney; Founding Director, Australian Mitochondrial Disease Foundation; Co-Chair, AMDF Scientific & Medical Advisory Panel.
- Professor David Thorburn: Head, Mitochondrial Research Group, Murdoch Childrens Research Institute; Co-Chair, AMDF Scientific & Medical Advisory Panel
- Dr Ainsley Newson: Associate Professor of Bioethics and Deputy Director, Sydney Health Ethics, The University of Sydney