



## Senate Community Affairs Legislation Committee Inquiry into the Mitochondrial Donation Law Reform (Maeve's Law) Bill 2021

The Australian Academy of Science and the Australian Academy of Health and Medical Sciences (jointly, 'the Academies') welcome the opportunity to provide a submission to the Senate Community Affairs Legislation Committee Inquiry into the *Mitochondrial Donation Law Reform (Maeve's Law) Bill 2021* (the Bill).

The Academies strongly support the passage of the Bill. The proposed legislation allows important research to proceed and is expected to enable affected families to increase their likelihood of having a healthy child unaffected by mitochondrial DNA disease. It does so while providing an appropriate regulatory environment with necessary safeguards.

The Bill's reforms are consistent with international standards and best practice. For example, the International Society for Stem Cell Research, the preeminent global science organisation in this field, recently recommended that research and clinical use involving mitochondrial donation is permissible but only when subject to strict regulatory oversight and limited to patients at high risk of transmitting serious mitochondrial DNA-based diseases to their offspring.<sup>1</sup> The licensing measures outlined in the Bill will provide the required oversight.

In keeping with the Academies' recommendations, the legislation's approach will allow mitochondrial donation to be introduced in a manner that gives full scope to evaluate relevant issues such as informed consent, at-risk population screening, service delivery, cost, safety, community concerns, genetic and epigenetic consequences, and impacts on individuals and families.

The Academies' position and recommendations on mitochondrial donation are discussed in detail in the following previous submissions:

- Joint Academies submission to the Department of Health consultation on mitochondrial donation in Australia (March 2021)
- Joint Academies submission to the National Health and Medical Research Council consultation on mitochondrial donation (November 2019).
- Australian Academy of Science submission to the Senate Community Affairs References Committee Inquiry into the science of mitochondrial donation and related matters (May 2018)

<sup>&</sup>lt;sup>1</sup> 2021 ISSCR Guidelines for Stem Cell Research and Clinical Translation – Recommendations 2.2.2.3 and 3.4.8.1. https://www.isscr.org/policy/guidelines-for-stem-cell-research-and-clinical-translation





The Academies highlight two additional considerations relevant to the implementation of mitochondrial donation. Firstly, the administrative and operational arrangements should allow for equity of access for all Australians. Secondly, the assisted reproductive technology service providers should ensure there is sufficient mitochondrial donation expertise available to ensure the highest quality advice and counselling are available to families seeking access to the technology.

As much as possible, these considerations should be captured in the Regulations accompanying the legislation.

If you have any questions about this submission, or to arrange an appearance before the Inquiry, please contact Stuart Barrow (<u>stuart.barrow@science.org.au</u>) or Amanda Rush (<u>amanda.rush@aahms.org</u>).