



## Life Saving Research – Mitochondrial donation

The Australian Government will commit \$4.4 million over 4 years (\$10.3 million over 10 years), to facilitate a staged implementation of mitochondrial donation in research and clinical settings in Australia. This will enable the introduction of a new assisted reproductive technology aimed at preventing children being born with severe, life-threatening mitochondrial disease – a devastating genetic disorder which has no cure.

On 24 March 2021, the Government introduced the Mitochondrial Donation Law Reform (Maeve's Law) Bill 2021 into Parliament.

- This initial investment will be for the first stage of implementation: **Stage 1** will introduce a regulatory and licensing framework for mitochondrial donation and establish a clinical trial to determine the safety, efficacy and feasibility of mitochondrial donation.
- The outcomes of this clinical trial will then inform an option for the Australian Government to move to **Stage 2**, where mitochondrial donation will be made available in clinical practice more broadly.

A competitive grant funding opportunity will be announced separately to engage a suitably qualified organisation to conduct the clinical trial.

### Why is this important?

Approximately one child each week is born in Australia with a severe form of mitochondrial disease, often with a life expectancy of less than 5 years. Symptoms include seizures, fatigue, heart problems, multiple organ failure and premature death. Mitochondrial donation has the potential to prevent children from being born with severe forms of this disease.

The Government's proposed legislation was inspired by Maeve Hood, a young Victorian girl who has struggled with mitochondrial disease, and the tireless work of her parents to raise awareness and build support for all those suffering from the disease.

### Who will benefit?

This investment will enable research that has the potential to change the lives of families, who have a high risk of passing on mitochondrial disease, and their children by providing a pathway to become biological parents without the risk of passing on the disease.

This will also enable Australian clinicians to advance Australia's position as a world leader in medical research and delivery.

### **How much will this cost?**

The Australian Government is investing \$4.4 million over 4 years, and a total of \$10.3 million investment over 10 years from 2021–22.