

# Mitochondrial Donation in Australia – Q&As

## **What are mitochondria?**

Mitochondria are small DNA-containing structures in human cells. The mitochondria produce 90 per cent of the energy that the body needs to function. They are inherited almost exclusively through the maternal line (passed from a mother to her children) through the mitochondria present in the mother's egg cells.

## **What is mitochondrial disease?**

Mitochondrial disease is a genetic disorder caused by mutations in an individual's nuclear or mitochondrial DNA. Mutations in mitochondrial DNA are passed directly from a mother to her children.

Mitochondrial disease is difficult to diagnose. Currently, there is no known cure, and treatment options are limited largely to the management of symptoms.

While mitochondrial disease varies in presentation and severity, common symptoms include developmental delays, seizures, weakness and fatigue, muscle pain, vision and hearing loss, multiple organ failure and heart problems, leading to morbidity and in severe cases, premature death.

## **How many Australians are affected by mitochondrial disease?**

In Australia, between one in 5,000 and one in 10,000 people are likely to develop severe mitochondrial disease during their lifetime<sup>1</sup>, with approximately one child per week born with a severe form of the disease. The prognosis for these children is that most will die within their first five years, although, some individuals do not develop symptoms until adulthood.

## **What is mitochondrial donation?**

Mitochondrial donation has the potential to change the lives of parents and their children by providing a pathway to have children who will not inherit and suffer from this devastating genetic disorder.

Mitochondrial donation is an assisted reproductive technology which can help some parents to avoid transmitting mitochondrial DNA disease to their biological children. The term collectively refers to techniques aimed at ensuring only healthy mitochondrial DNA is passed on to an embryo.

Used in conjunction with in-vitro fertilisation (IVF), mitochondrial donation techniques allow for an embryo to be produced using the nuclear material from a man and woman and the mitochondria in an egg donated by another woman. This approach minimises the risk of transmission of the abnormal mitochondria from the mother to her child.

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<sup>1</sup> Source: Mito Foundation, <https://www.mito.org.au/mito-info/>, How Common is it?

### **Can mitochondrial donation help people with mitochondrial disease?**

Mitochondrial donation cannot be used to cure existing mitochondrial disease. However, for some prospective mothers, mitochondrial donation may represent the only option for them to have a genetically related child without passing on mitochondrial DNA disease.

### **Is legalising mitochondrial donation supported in Australia?**

There is strong support for legalising this procedure in Australia from the community and from experts in the field. Most of those who support the procedure also support a cautious and highly regulated introduction.

Further information can be found in the findings of the [2018 Senate Inquiry](#) and the [NHMRC consultation activities](#) undertaken in 2019-20.

### **Is mitochondrial donation legal in any other countries?**

Yes. For example, in 2015, regulations were passed in the United Kingdom approving mitochondrial donation to be used for human reproductive purposes to prevent the transmission of serious mitochondrial DNA disease.

### **When will mitochondrial donation be implemented?**

The Government is proposing that mitochondrial donation be implemented in Australia under a two stage process, which will provide for a cautious introduction of the technology. This includes legalising mitochondrial donation for use in research settings and through an initial pilot site, before permitting it in clinical practice more broadly.

This aligns with the approach undertaken in the United Kingdom, where mitochondrial donation has already been legalised for the purpose of minimising the risk of transmitting serious mitochondrial disease from a mother to her child.

### **Is there scientific evidence to show that mitochondrial donation in a human works?**

Whilst the introduction of mitochondrial donation will be new for Australia, the science behind these techniques is not new and has been the subject of extensive research and scientific review since the 1990s.

However, scientific evidence to support this procedure in humans is limited, due to the small number of human births globally and patient privacy.

Implementing mitochondrial donation through a staged approach, based on existing practice in the UK, will allow Australian experts to build appropriate expertise and knowledge around the safety and efficacy of mitochondrial donation before it is implemented more broadly.

### **Does mitochondrial donation alter the personal characteristics of a person?**

No, mitochondrial donation techniques do not alter personal characteristics and traits. This is because mitochondrial DNA only contains genes that are essential for mitochondrial function. In contrast, personal characteristics and traits are derived from the nuclear material.

### **Is mitochondrial donation ‘three parent IVF’?**

Mitochondrial donation is not ‘three parent IVF’. The dominant DNA (the nuclear DNA) in any child born using this method would be that of the mother and the father. In line with current arrangements for sperm and egg donors in Australia, mitochondrial donation egg donors will not be considered as legal parents under legislation.

The 2018 Senate Community Affairs References Committee inquiry into the *Science of mitochondrial donation and related matters* similarly concluded that mitochondrial donation techniques do not lead to children having three genetic parents.

### **Has the public been consulted on the introduction of mitochondrial donation before?**

Yes. To date, two public consultations have been undertaken in Australia on the introduction of mitochondrial donation. This has included a [Senate Inquiry](#) and work undertaken by the [National Health and Medical Research Council](#).