Response ID ANON-1NXK-ANA1-3

Submitted to **Mitochondrial Donation in Australia**
Submitted on **2021-03-15 08:25:05**

Introduction

Survey questions

1 What is your name?

Name:
Nicole Millis

2 What is your email address?

Email:
nicole.millis@rarevoices.org.au

3 What is your organisation?

Organisation:
Rare Voices Australia

4 Why are you interested in providing feedback/comments on the consultation paper?(medical professional, lived experience with mitochondrial disease, member of the public etc)?

Type response here:

Rare Voices Australia (RVA) is the peak body for Australians living with a rare disease. The Mito Foundation is a RVA Partner organisation. RVA is interested in providing input to this consultation paper that is aligned with the Australian Government's National Strategic Action Plan for Rare Diseases (Action Plan). RVA led the collaborative development of the Action Plan which has been developed by the rare disease sector for the rare disease sector.

5 What is your feedback or comments on the Government’s staged approach to legalising mitochondrial donation in Australia?

Type response here:

The consultation paper describes measures that are aligned with international best practice (the UK) and is a cautious introduction of mitochondrial donation in a well regulated framework with ongoing monitoring.

While a staged approach is understandable, the needs of families impacted by mitochondrial disease must always be prioritised. It is encouraging that the Government's approach does indicate that all impacted Australian families who are ready to start a family would have access to mitochondrial donation in Stage 1. This is in line with the Action Plan which has 'Person-centred' as a foundation principle. Similarly a Priority Population of the Action Plan is: Australians with an increased chance of developing a rare disease or of having a child with a rare disease. It is vital that this proposed approach to mitochondrial donation continues to "embed the voice of people living with a rare disease" (mitochondrial disease) throughout.

This proposed policy will implement for the mitochondrial disease community, key Action Plan priorities and actions:
Priority: 2.3 Facilitate increased reproductive confidence
Priority 2.4 Enable all Australians to have equitable access to the best available health technology; and
Action 2.4.1 Develop policy that supports people living with a rare disease to have timely and equitable access to new and emerging health technologies.

The Action Plan specifically highlights this issue of mitochondrial donation in its call for "ongoing review of health technology policy in line with advancements in health technology. For example, mitochondrial donation involves removing the nuclear DNA from a woman’s egg containing faulty mitochondria and inserting it into a healthy donor egg, which has had its nuclear DNA removed. This prevents mitochondrial DNA defects from being inherited by a genetically related offspring. Mitochondrial donation is not yet legal in Australia." (Implementation 2.4.1.5)

https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-rare-diseases

Submitting documents

6 Would you like to upload a submission or additional supporting documents? If so, please follow the prompts below.

Upload file here :
No file uploaded