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To Whom It May Concern.
Submission regarding the Mitochondrial Donation Law Reform (Maeve's Law) Bill 2021.

My name is Dr Suzanne Sallevelt and I am a Clinical Geneticist from the Netherlands, currently working in Adelaide in the Paediatric and Reproductive Genetics Unit. I have been in Australia since 2020.

I am making a submission as I have expertise in the field of mitochondrial genetics, and more specifically in preventing transmission of mitochondrial diseases. This is evidenced by my PhD entitled "Preventing the transmission of mitochondrial diseases" obtained in 2017 in Maastricht, The Netherlands, containing 8 chapters of original research which have been published as 7 peer-reviewed articles in high-impact journals. After this I have remained involved in work and activities related to this topic. For example, in 2018 I went on an exchange visit for 2 months to the world-renowned lab of Professor Mary Herbert, the main driver of mitochondrial donation in the UK. In 2019 I was invited as a young clinician scientist to participate in the European Neuromuscular Centre (ENMC) workshop "Developing guidelines for management of reproductive options for families with maternally inherited mtDNA disease" with a total of 23 participating scientists from all over the world, including Australia.

Mitochondrial donation is the missing item in the portfolio of reproductive options currently available to women with an increased risk of offspring with mitochondrial disease caused by a mutation in the mitochondrial DNA. For a subset of such women the currently available reproductive options are not suitable. Therefore, it is wonderful that Australia is undertaking steps to legalise mitochondrial donation.

In reviewing the legislation, I fully support the position that the Mito Foundation has reached regarding the legislation, which is as follows:

- The legislation provides appropriate choice to Australian families who wish to avoid the risk of passing mitochondrial disease onto their children;
- It does this in a considered and sensible manner, including the various phases provided for;
- The 'clinical trial' proposed will enable eligible parents to access mitochondrial donation as soon as possible whilst also permitting the introduction of mitochondrial donation into clinical practice in the future;
- The licensing requirements appear reasonable;
- The Mito Foundation welcomes the fact that families will not require licenses but acknowledges the need for individual approval to ensure that mitochondrial donation only occurs in

appropriate circumstances. Providing individual approval must be done in a timely manner. This is particularly important given the experience in the UK where the approval or licensing process for each couple has sometimes caused considerable delays and potentially discrepant outcomes for women who have similar risk profiles; and

- The relevant committees and expert groups proposed to oversee mitochondrial donation are appropriate and proportionate. It is important however to ensure that the Licensing Committee either includes or has access to the support and advice of a clinician expert in mitochondrial medicine, given the broad range of medical issues that can be involved in patients with mitochondrial disease.

In summary I feel the legislation is appropriate and fulfilling the intended goal. It will be of great value to help families in need.

Yours sincerely,

Dr Suzanne Sallevelt, MD, PhD
Clinical Geneticist