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To: Senate Committee on Community Affairs – Legislation Committee
Re: Mitochondrial Donation (MD)

Thursday, July 15th, 2021

MitoCanada is pleased to provide this submission letter to share our insights and express our support of the draft legislation for Mitochondrial Donation Law Reform (Maeve's Law) Bill 2021.

MitoCanada is Canada's only registered national charity focused on mitochondrial disease. Our mission is to transform the outlook and quality of life for people impacted by mitochondrial disease through education, awareness, patient/family support, and transformational patient-focused research.

MitoCanada has highlighted the following sections, which we believe will build strong legislation that provides appropriate choices to Australian families who wish to avoid the risk of passing mitochondrial disease onto their children.

MitoCanada believes there is great strength in the following sections of the draft legislation and fully supports:

- The 'clinical trial' process proposed, which will enable parents seeking access to mitochondrial donation to do so expeditiously while facilitating the introduction of mitochondrial donation into clinical practice
- Parents and families not requiring licences but individual approval will be required to ensure mitochondrial donation is employed in the most appropriate circumstances and done so without unnecessary delay.
- Support and see great value in providing this section: Sec 29A: Children born using MD will be able to apply for identifying information about the mitochondrial donor when they turn 18
- Authorization of mitochondrial donation under five different licenses, we feel this is reasonable as it furthers research and develops expertise in this area.
- Future clinical practice licenses to be subject to further amendments to legislation.
- Assembling committees and expert groups to oversee mitochondrial donation; however, we strongly believe committees should include a clinician expert in mitochondrial medicine. Mitochondrial diseases are complex, and the range of medical issues affecting patients can be extensive.

Section to reconsider revising:

- During the initial discussions, it was said that Australia would give parents the option of sex selection. However, under Sec 28Q (ii), for clinical trial and clinical practice licenses, it is stated that "only male embryos are selected for implantation." if ... the woman and her spouse (if any) **so request.**

**MitoCanada**: We find this section of the draft legislation to be a bit unclear. We could assume the interpretation is in support of sex selection, but some of the language suggests this is only in instances where the risk of mitochondrial mutation inheritance is high; selecting a male embryo reduces the risk of mutation inheritance. We strong urge rephrasing this section to avoid ambiguity. We would like to clearly state, MitoCanada would not support enforced male preferential sex selection and prefer the UK's approach to this section.

MitoCanada appreciates the rigorous discussions and consultations that have taken place at all levels to introduce mitochondrial donation in Australia; we believe the draft legislation is appropriately cautious, avoids any unanticipated or unwanted consequences, and will positively impact Australian mitochondrial patients and their families.

MitoCanada wishes the very best of success with the next steps in this process and appreciates the opportunity to contribute.

Sincerely,

Kate Murray
CEO and President
MitoCanada Foundation