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Human Genetics Society of Australasia

ARBN 076 130 937 (Incorporated Under the Associations Incorporation Act)
The liability of members is limited

14th July 2021

Senate Community Affairs Legislation Committee
community.affairs.sen@aph.gov.au

RE: Inquiry into the Mitochondrial Donation Law Reform (Maeve's Law) Bill 2021

The Human Genetics Society of Australasia (HGSA) was formed in 1977 to provide a forum for the various disciplines represented under the title of Human Genetics and is the leading professional body for health professionals working in the fields of genetics and genomics. Our members include clinical geneticists, genetic counsellors, diagnostic scientists, researchers and academics.

We welcome the opportunity to provide a submission to the Committee on the inquiry into the above legislation and make the following comments:

- We support the intent of the legislation to provide appropriate choice for families at risk of passing mitochondrial disease on to their children.
- The phases proposed in establishing a clinical service are supported, including the clinical trial phase which will be important to provide an opportunity to families to access mitochondrial donation as soon as possible whilst informing the suitability of the technology for routine clinical practice.
- We support the proposed licensing arrangements.
- We support the proposed oversight of the Licensing Committee and would hope they would be supported by appropriate clinical expertise in this complex area of medicine.

Yours sincerely,

Dr Kevin Carpenter, CEO HGSA

Chief Executive Officer: Dr Kevin Carpenter

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References

1. Bagnall et al., 2018 <https://doi.org/10.1016/j.jacc.2018.04.078>
2. Wu et al., 2021 <https://doi.org/10.1038/s41431-021-00916-8>
3. Stark et al., 2017 <https://doi.org/10.1038/gim.2016.221>
4. The changing landscape of the genetic counselling workforce (2017) <https://www.health.nsw.gov.au/workforce/alliedhealth/Documents/gsw-final-report.pdf>
5. <https://www.australiangenomics.org.au/reports/professional-status-survey-of-genetic-counsellors-and-clinical-geneticists/>