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To whom it may concern

Genetic Alliance Australia welcomes this Inquiry and the opportunity to respond to the proposed legislation for Mitochondrial Donation Law Reform (Maeve's Law) Bill 2021.

Genetic Alliance Australia was formed in 1988 in response to the need for peer support for those with rare genetic conditions. We provide support to individuals and families affected directly and indirectly by rare genetic conditions providing information, resources and peer support. For support groups, Genetic Alliance provides support and education with quarterly meetings with a topic of interest and concern. Our organisation provides community representation to state, federal and research bodies on projects, social need and health services.

Genetic Alliance Australia supports the draft legislation based on the following:

Personal Participation and Privacy

Most importantly this legislation supports the individual decision to participate voluntarily at all stages of use of mitochondrial donation and any subsequent follow up actions.

Further, it supports parents to avoid a clinically established risk of mitochondrial diseases being passed on to their offspring.

That provides security of personal information of those participating in mitochondrial donation and the recipients.

Staged Approach

Applaud the staged approach of this legislation to accommodate the development of this science and ensuring ART service and safety for the Australian community.

Clinical Trial.

That a clinical trial will provide scientific rigour of mitochondrial donation, combined with the careful notification and monitoring of adverse events.

Recognises the role clinical trials have in providing the initial availability of new technology and ART services to the Australian community.

Licensing Committee

The Licensing Committee has access to knowledgeable clinicians of mitochondrial disease and specialists in the mitochondrial donation technology.

It is important that the Licensing requirements are not unnecessarily onerous. It follows that the proposed safeguards and protections are not out of step with other health licensing processes.

That the Licensing provision for mitochondrial donation is done in a timely, sensitive and appropriate manner for families, with the family needs foremost.

Provision of committees and expert groups.

These groups shall provide the guidance in this process necessary for scientific rigour of a clinical trial and to establish the benefits of this technology for the Australian community. It is also critical that proposed committees and expert groups are composed of individuals well versed in the clinical presentation of mitochondrial disease, the technology involved in mitochondrial donation and associated social perspectives.

It is important that the selection of a Data Monitoring and Safety Committee be independent to the trial to reduce any potential or perceived bias, and to have the criteria of expertise as described above.

Jan Mumford

Executive Director
Genetic Alliance Australia