

Genetic and Rare Disease Network
Genetic Support Council WA (Inc)
PO Box 1023
BOORAGOON WA 6954

The Program Manager
Reproductive Technology Unit
Patient Safety and Clinical Quality
Clinical Excellence Division
Department of Health
189 Royal Street
PERTH WA 6004

Re: Submission to the Review of the *Western Australian Human Reproductive Technology Act 1991* and the *Surrogacy Act 2008*

This submission from the Genetic and Rare Disease Network (GaRDN) is made on behalf of the over one hundred-patient support organisations we represent who provide support and services to thousands of Western Australians and Australians who live with genetic and rare conditions.

On behalf of our members we would like to state our support of the need for laws in Western Australia to allow citizens to make reproductive choices. We are supportive of nationally consistent legalisation that is up to date and meets the needs and advance in practices happening across Australia; and as consistent with the *NHMRC Ethical guidelines on the use of assisted reproductive technology in clinical practice and research*.

Rare diseases affect approximately 8% of the Western Australian population (some 200,000 people) and approximately 60,000 of those people are under the age of six years. These conditions are often complex and multi-systemic and have a significant impact on a person's quality of life and require complex care. For people that are known to be at risk to carry or to be predisposed to a genetic condition, disease or abnormality there is a specific requirement to have access to assisted reproductive technology and practices, including:

- Preimplantation genetic testing (PGT) and the techniques of preimplantation genetic diagnosis (PGD) and preimplantation genetic screening (PGS). This needs to be combined with access to robust genetic and psychological counselling to support well informed choices.
- Access to ethically acceptable and equitable surrogacy arrangements.
- To ensure access to these services for those people with children who already have a rare condition.

More generally we would encourage consideration of education for both the public and clinical staff who are in a position to support couples about the availability of assisted reproductive technology and surrogacy. We would also encourage consideration of equity

and access issues that may impact the reproductive choices of Western Australians, including:

- Socio-economic and education status – choices should not be limited by this.
- Regional and remote locations – people in these locations should be supported to access services that support their reproductive choice.

Finally, we are supportive of a review which considers the advances in technology, knowledge, access and awareness of assisted reproductive technology and the specific considerations for those people who themselves or with family members that are known to be at risk to carry or to be predisposed to a genetic condition, disease or abnormality.

Thank you for the opportunity to provide a submission. Further information can be obtained via the details below.

Contact details

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[Redacted contact information]