



PREGEN

ANTENATAL GENOMICS
& NEWBORN CARE

Summary for Families

PreGen Antenatal Genomics and Newborn Care Study

Website: <https://pregen.neura.edu.au/>

PreGen is a research study that aims to understand the best way to support families who are having genomic testing in pregnancy. **Taking part in this study is voluntary and choosing not to take part will not affect your care with your health professional team.**

If you have had prenatal genomic testing organised already, you may be asked if you would like to take part in the PreGen research study.

What is involved in PreGen?

1. Two Interviews

PreGen would like your permission to conduct two interviews with a PreGen Genetic Counsellor via phone or zoom call. One interview would be conducted before your genomic results are ready and the second interview would be conducted after 6 months.

Information collected in the interviews will be deidentified. The interviews will help us to understand your hopes and expectations for prenatal genomic testing.

2. Permission to Access Medical Records

PreGen would also like your permission to collect Medicare (MBS), Pharmaceutical (PBS) and hospital medical record data for you and your baby. This will help to make prenatal genomic testing available for other families in the future.

If you give your permission, a PreGen Genetic Counsellor will contact you to provide more information and arrange written consent for the study.

More information for families can be found here:

<https://pregen.neura.edu.au/family-resources-support/>