PREGEN
ANTENATAL GENOMICS & NEWBORN CARE

Support and Information Resources

PreGen Antenatal Genomics and Newborn Care Study
Website: https://pregen.neura.edu.au/

If you have been enrolled in PreGen or are undergoing prenatal genomic testing, we acknowledge that you may be experiencing increased stress, anxiety and complex grief during and/or after your pregnancy. When a fetal abnormality is diagnosed in pregnancy, this is often associated with a lot of uncertainty. It may lead to conversations with your health professionals about the option of testing in pregnancy (eg. genomic testing), making new plans for delivering and caring for your baby after birth or you may be considering termination of pregnancy. Many people in this situation benefit from additional support. Below is a selection of resources that you might find useful. This list is not exhaustive but provides a safe starting point if you wish to seek more information.

Start with your Local Health Professionals

Your GP: Speak to your GP about a referral to a local support service such as a counsellor, psychologist or psychiatrist. Your GP will advise what Medicare support may be available to you. eg. Mental Health Care Plan.

Your Genetic Counsellor: Genetic counsellors will be able to direct you to local support services within hospitals and in private settings depending on your needs. Find your local genetic counselling service within Australia and New Zealand here.

Your Local Hospital Supports: Speak to your health professionals about support services available within your hospital. eg. Social workers and chaplain services.

Support Booklets

Diagnosis of abnormality in an unborn baby. The Impact, Options and Afterwards.

When your unborn baby has a problem. How to manage the weeks ahead.

Please note these booklets were created by NSW Health in 2006. The content remains relevant, however, the contact details of some support groups and services may have changed. For current contacts, speak to your local health professionals or visit The Centre for Genetics Education Website.

Supports for Genetic, Rare and Undiagnosed Conditions

Genetic Alliance Australia
Provides peer support and information for individuals and families affected by rare genetic conditions and rare disease.

Syndromes Without a Name (SWAN)
Provides information, support and systemic advocacy for families caring for a child with an undiagnosed or rare genetic condition.

Rare Voices Australia (RVA)
Provides a strong, unified voice to advocate for policy as well as health, disability and other systems that work for people living with a rare disease.

Genetic Support Network Victoria
Provides services to people in Victoria with genetic, undiagnosed and rare conditions, and those who support them.

Support Groups Queensland
Provides help for people, their families, and carers, with all kinds of health issues, including genetic conditions, grief and loss, and mental health challenges.

Rare Disorders NZ
Provides support for all New Zealanders who live with a rare condition, and the people who care for them. Provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare diseases.

Perinatal Mental Health Support

Pregnancy, Birth & Baby
24-hour support line: 1800 88 24 36
Supports Australian parents on the journey from pregnancy to preschool.

Centre for Perinatal Psychology
A national group of psychologists dedicated to mothers, fathers, infants, couples and families during the perinatal period which covers planning, pregnancy, postpartum and parenting.

Perinatal Depression and Anxiety Support

Perinatal Anxiety and Depression Australia (PANDA)
Supports women, men and families across Australia affected by anxiety and depression during pregnancy and in the first year of parenthood.

Gidget Foundation
Raises awareness of perinatal depression and anxiety and provides support for those in need.

Pregnancy Loss and Bereavement Support

Red Nose Grief and Loss / Sands
24-hour support line: 1300 308 307
Grief and loss support for miscarriage and early pregnancy loss, medical termination, stillbirth and newborn death, sudden infant death, young children and relationships. Sands is now part of Red Nose and provides peer-to-peer support services.

- **Terminating Pregnancy for Medical Reasons**

Bears of Hope
24-hour support line: 1300 11 HOPE (4673)
Pregnancy and infant loss support.

The Pink Elephants Support Network
Miscarriage, early pregnancy loss and termination for medical reasons support.

- **Termination For Medical Reasons (TFMR)**
- **The Turmoil of Termination due to Fetal Anomaly**

Pillars of Strength
Support for bereaved dads.

Terminating a Pregnancy For Medical Reasons (TFMR)
Information provided by Tommy's, the largest UK charity researching the causes and prevention of pregnancy complications, miscarriage, stillbirth, premature birth and neonatal death.

Pregnancy and Infant Loss (NEW SOUTH WALES)
A resource to support parents whose baby has died before, during or soon after birth.

Support After Fetal Diagnosis of Abnormality (SAFDA) (SOUTH AUSTRALIA)
Based at the Women's and Children's Hospital, offers counselling and resources for families before and after termination of pregnancy due to fetal abnormalities.

Sands New Zealand
Promotes awareness, understanding and support for those dealing with the death of a baby in pregnancy, birth or as a newborn, and due to medical termination or other forms of loss.

Additional Information about Genetic and Genomic Testing in Pregnancy

Testing in Pregnancy
An overview of screening and diagnostic testing available in pregnancy.
- **Prenatal Testing Booklet**
- **Prenatal Diagnostic Testing Fact Sheet (VCGS)**

Chromosome Microarray
- **Chromosome Microarray (CMA) Testing During Pregnancy Fact Sheet**

Genomic Testing
Including whole exome sequencing (WES) and whole genome sequencing (WGS).
- **Genetic and Genomic Testing Fact Sheet**
- **Genomic Testing Fact Sheet (VCGS)**
- **Genomic Information for you and your family (Australian Genomics)**
- **What is Genomic or DNA Testing? – Video**

Possible Results from Genomic Testing
- **Positive result**: *When the cause of the health condition is found. Your health professional team will discuss this in detail with you.*
- **Uninformative result**: *When the cause of the health condition has not been found.*
- **Variant of uncertain significance (VUS)**: *When the result is unclear. These results are usually not reported in prenatal testing.*
- **Incidental finding**: *When a genetic change is found but is not related to the reason for testing. These results may occur in prenatal testing and your health professional team may discuss them with you.*