
Genetic services in Victoria

Summary

- Genetic services in Victoria cover diagnosis, screening and testing.
 - Genetic services provide counselling and information for individuals and families with, or at risk of, particular birth defects and inherited disorders.
 - The Genetic Support Network of Victoria (GSNV) supports many groups that provide a point of contact for parents and people with the same genetic condition.
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Genetic services can help people who are affected by, or at risk of, inherited conditions or birth defects to make informed choices about their healthcare. Services provided include genetic diagnosis, screening and testing, counselling, information, advocacy and support.

You may choose to access a genetic service for a variety of reasons. You may be concerned about a family history of a specific condition, or want peace of mind when deciding to have a baby. You may be referred to a genetic service if certain symptoms arise, or if a family member receives a diagnosis of a genetic condition.

The precision of genetics and the ease of accessing and undergoing genetic testing has improved significantly within the last decade.

Knowledge about genetics

Our understanding of genetics is expanding rapidly. It's an exciting field. New advances in technology have greatly improved our understanding of the role of inheritance in health and disease, and our ability to test for genetic and chromosomal conditions.

As our knowledge of genetics increases so does our understanding of the role genes play in conditions and diseases. This increased knowledge has allowed the expansion of genetic services. The number of medical conditions known to be associated with genes is growing. So more families and individuals are accessing genetic services for a wider variety of genetic conditions. Testing is now available across a wide range of healthcare settings.

Types of genetic services available in Victoria

Genetic services currently available in Victoria include:

- **carrier screening** – which can tell you whether you and your partner 'carry' a genetic change for the same **recessive** condition such as **cystic fibrosis**. If both parents are carriers, they do not have the condition, but their children are at a higher risk of inheriting that condition
 - **prenatal screening tests** – can tell you if you are at a higher risk of your baby being affected by a chromosomal condition such as Down syndrome. Examples of these tests include non-invasive prenatal testing (NIPT), combined first trimester screening and second trimester serum screening
 - **newborn screening** – all newborn babies are screened for **phenylketonuria (PKU)**, **hypothyroidism**, **cystic fibrosis** and other metabolic disorders
 - **diagnostic testing** – can identify or rule out a specific genetic condition. You may be offered a diagnostic test in pregnancy such as an **amniocentesis** or **chorionic villus sampling (CVS)** if you receive a high risk result on your prenatal screening test or an abnormal ultrasound
 - **predictive testing** – if an individual in your family is diagnosed with a genetic condition, you may be offered predictive testing, to find out whether you are likely to develop this condition later in life
 - **risk assessment** – of relatives who may carry or be at risk of a genetic condition. In some cases, families may carry genetic changes that can increase their risk of **cancer**. Family cancer clinics can help assess your
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individual risk and whether genetic testing may be useful

- **genetic counselling** – can help you navigate through the process and your future healthcare planning. Your GP or healthcare team can also support you with advice and help you plan for the future
- **information, advocacy and support** – the **Genetic Support Network of Victoria (GSNV)** is connected with a wide range of support groups throughout Victoria and Australia and can:
 - connect you with individuals and families affected by a genetic condition.
 - provide information and counselling for people having IVF who are considering pre-implantation genetic diagnosis
 - provide general information for individuals, health professionals and the community about genetic conditions and birth anomalies.

If appropriate, your healthcare professional (for example, your general practitioner or medical specialist) can refer you to a publicly funded genetic service. The healthcare professional will tell you what's involved.

Clinical genetic services

In Victoria, public genetic services are available at three metropolitan hub hospitals that provide outreach clinics to other metropolitan, regional and rural centres. All three of these 'hubs' are multifaceted in their healthcare approach and offer counselling alongside genetic testing.

The three metropolitan hubs are:

- **Austin Health** offers genetic services through:
 - **the Austin Hospital**
 - **the Mercy Hospital for Women**
 - **the Northern Hospital**
- **Monash Medical Centre Genetics Clinic**
 - Parkville precinct:
 - **Royal Melbourne Hospital**
 - **Royal Children's Hospital/Victorian Clinical Genetics Services**
 - **Royal Women's Hospital**
 - **Peter MacCallum Cancer Centre.**

Some clinics are general, covering all genetic conditions. Others are equipped to address specific conditions such as familial cancer, cardiology or neurogenetics.

Some health services may offer the option of **telehealth** video consultations. This connects you to your clinician via a videolink. Contact your health service to find out if this is available to you.

Genetic diagnostic laboratory services

Laboratory services include a range of genetic techniques to diagnose and help in managing particular genetic conditions. Once a genetic condition is identified in an individual, genetic testing to confirm a diagnosis can be offered to family members who would like to know their risk of being affected or being a carrier of that condition.

Note that not all conditions can be genetically tested for, and sometimes performing genetic tests may not result in an answer.

Genetic testing is provided by a number of public and private providers and is accessed through a clinical genetic service or some medical specialists.

Genetic testing usually involves taking a sample of body tissue. The tissue type needed depends on the test, but usually involves a blood or saliva sample.

If a genetic test is not available in Victoria, a sample may be sent interstate or overseas for testing. Be sure to use accredited genetic tests to which you are referred by your doctor. 'Send away' tests that you can perform yourself

over the internet are not assessed for quality, and you cannot be certain that the results you receive are accurate.

Providers of genetic diagnostic laboratory services in Victoria include:

- **Victorian Clinical Genetics Services**
- **Monash Medical Centre**
- **Peter MacCallum Cancer Centre**
- **Victorian Cancer Cytogenetic Service at St Vincent's Hospital.**

Support groups for genetic disorders

The **Genetic Support Network of Victoria (GSNV)** aims to make sure that all people with a genetic disorder in Victoria have appropriate and accurate information and support to be able to manage the challenges to their health and wellbeing. GSNV provides information, resources and help to support a number of existing **genetic support groups** and to aid the development of new groups.

Where to get help

- Your **GP (doctor)**
- **Genetic Support Network of Victoria** Tel. (03) 8341 6315
- **Cancer Council for familial cancer services** Tel. (03) 13 11 20
- **Murdoch Children's Research Institute newborn screening program** Tel. (03) 8341 6200
- **Victorian Clinical Genetics Services** Tel: 1300 11 8247

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