

## What will happen in the appointment?

### Family history

The clinical geneticist or the genetic counsellor will ask you about your family's health history and record it in a genetics file. They may ask about your relatives, including their names, dates of birth and death, causes of death and general health.

### Examination

The clinical geneticist may wish to physically examine you or your child.

Draw their attention to any feature you may think is relevant. They may also wish to examine the parents or other family members present to compare family features. If your examination requires undressing and you would prefer a doctor of the same sex as you, do ask.

### Photos

Sometimes, with your permission, photos of you or your child will be

taken to help diagnosis, or for research purposes. The doctor must ask you to sign a permission form to have photos taken, and it is OK to ask what these will be used for, or to say NO.

### Blood

You may be asked to have a blood test following your appointment. This can usually happen within the same building.

## How long will it take?

### Clinic waiting time

Sometimes appointments can take longer than expected. You may have to wait up to an hour.

### The appointment

Each appointment usually takes approximately 1 hour. You may be asked to have a blood sample, x-rays, photos taken following your appointment, so it is best to allow a total of two hours.

## What are my rights?

### Respect and Autonomy

You have a right to expect that you and your family members will be treated with respect. Genetic Health is committed to providing you with accurate information and support to enable you to make the best decisions for yourself at the time.

### Protection of information

Genetic Health is committed to protecting client privacy and confidentiality. We have developed policies for the protection of client privacy in compliance with privacy legislation. To obtain a copy of the client privacy policy pamphlet contact Genetic Health Services Victoria, on (03) 8341 6201 or visit our website, [www.genetichealthvic.net.au](http://www.genetichealthvic.net.au)

### Informed choice

Genetic Health is committed to facilitating informed choice. Therefore

- Ask for clarification if you are not sure of the meaning or implications of what was said
- If you are still not sure, ask them to say it another way.
- Ask for information in writing which you can read afterwards. Hospitals have medical translators for this

purpose, if you need translation.

- If you are unclear why you are being asked for specific information, ask for clarification.

### Taking tests

- Clarify what is involved and how long test results take
- Ask how your results will be returned to you and do state your preference

## What will happen afterwards?

### Waiting for results

You can ask when you can expect to receive the results, and how you will get them (e.g. by phone or in person).

### Written information

A letter will be written summarising your appointment and sent to you and your referring doctor.

### Living with a diagnosis

To be given a diagnosis that you have a particular genetic condition can be

a life-altering experience. Support is available if you need.

### Living without a diagnosis

This can be frustrating for some people not having a diagnosis may lead them to other services or more questions about their health.

### Support groups

The Genetic Support Network of Victoria can put you in touch with the most relevant group for you and your family. The Genetic Support Network

## What if I am not satisfied?

of Victoria facilitates an information, support and advocacy network, which empowers people to overcome genetic challenges. You can contact the GSNV on (03) 8341 6315 Voice/TTY or [info@gsnv.org.au](mailto:info@gsnv.org.au)

### You have a choice

If you see a doctor at clinic and do not feel comfortable seeing that particular doctor again, you can request to see someone else at that clinic, or at another clinic at a different hospital.

### Opportunities for Improvement

If you are concerned or not satisfied with the consultation feel free to contact Genetic Health Services Victoria on 8341 6201. Your written complaint can be addressed to Professor Agnes Bankier, Director.

## Some frequently asked questions

[www.genetichealthvic.net.au](http://www.genetichealthvic.net.au)



Genetic Health is committed to providing quality health care. This booklet aims to give you an overview of the types of services Genetic Health provide and what you and your family can expect

## Why do people come to genetics?

Some examples of reasons for referral include:

- For information on a particular genetic condition and the likelihood of other members of a family being affected.
- For information on testing for adult onset conditions such as Huntington Disease before symptoms appear.
- To find out if a person is a carrier of a gene that could cause a genetic condition in future generations.
- For screening and/or diagnostic tests before or during pregnancy.
- To try to find out the underlying cause of a collection of signs and symptoms in a person.

Although genetic diagnosis is available for an increasing number of conditions, technology is not at a point yet where every condition can be identified, so it is important to be aware that you may not get a diagnosis.

The genetic health team may use a combination of information about:

- Your family's history
- Your own health history
- A physical examination of the person that is affected, and perhaps their family members
- Results of x-rays, or blood tests that show a person's genes or chromosomes and chemicals in the blood.

Not all of this information will lead to a diagnosis, and sometimes there is no blood test that can be done, or the results of a blood test are not useful in getting to the cause of the problem.

In some instances, even after a thorough investigation, there may not be an answer to what the underlying cause of a condition is. This may be frustrating for the person or family involved.

## How should I prepare for my appointment?

### Ask questions about family health history

Ask both sides of your family about your relatives' health, death, miscarriages, ages, and even photographs if possible, as these can often provide clues.

### Do I have to pay

Your consultation is free of charge. You may need a test which is not currently available in Victoria, in which case you may be asked to contribute or pay for the test.

### Make a note of things you want to ask

Leading up to your appointment, write down questions as they occur to you, and bring these along. A written list will help to make sure your questions are covered.

Bring your child's Health Centre book and available records as appropriate.

## What should I bring?

### Information about family history

#### Your (or your child's) medical history

It can help to keep the whole medical history together in one folder and bring it to every appointment.

#### Family member

A family member can provide moral support, and help with information about family health history.

### Friend for support

A friend could be your preferred support person and can help you to recall information that was discussed in the appointment, or you may choose to bring a tape recorder.

### Interpreters

If English is not your first language, the hospital you are visiting is able to arrange an interpreter.

## Where are genetic clinics held?

Clinic Location	Clinic Specialty	Contact details
Albury/Wodonga Genetics Clinic	General genetics	Albury/Wodonga Genetic Counsellor (02) 6056 0451
Alfred Hospital	Adult neuro-genetics Cystic Fibrosis, Haemophilia	(03) 8341 6201
Austin & Repatriation Hospital	Cancer genetics	(03) 8341 6201
Ballarat Genetics Clinic	General genetics	(03) 8341 6224
Bendigo Genetics Clinic	General genetics	(03) 8341 6224
Frankston Genetics Clinic	General genetics	(03) 8341 6201
Geelong Genetics Clinic	General genetics	(03) 8341 6224
Mercy Hospital for Women	Perinatal clinic	Genetic Counsellor (03) 9270 2394
Monash Medical Centre	General genetics Cancer genetics Neuro-genetics	(03) 9594 2026
Peter McCallum Cancer Institute	Cancer genetics Familial Cancer	(03) 9656 1064

Clinic Location	Clinic Specialty	Contact details
The Royal Melbourne Hospital	General genetics Cancer genetics Neuro-genetics	(03) 8341 6201
Royal Children's Hospital	General genetics Metabolic, Neuro-genetics Skeletal dysplasia Cystic Fibrosis Huntington Disease	(03) 8341 6201
The Royal Woman's Hospital	Perinatal genetics General genetics	(03) 9344 2121
Sale Genetics Clinic	General genetics	(03) 8341 6224
Shepparton Genetics Clinic	General genetics	(03) 8341 6224
St. Vincent's Public Hospital	Neuro-genetics	(03) 8341 6201
Traralgon Genetics Clinic	General genetics	(03) 8341 6224
Warragul Genetics Clinic	General genetics	(03) 8341 6201
Warrnambool Genetics	General genetics	(03) 8341 6224

## Who might I meet at the clinic?

### Clinic Co-ordinator

The clinic co-ordinator's role is to arrange your appointments and make sure things run smoothly while you are at the clinic.

### Clinical Geneticist

A Clinical Geneticist is a specialist doctor (or consultant) who has spent many years studying genetics after training in another speciality, such as paediatrics.

### Fellow

A genetics fellow is a fully qualified doctor

who is training to be a clinical geneticist.

### Certified Genetic Counsellor

A Genetic Counsellor is a fully qualified health professional who has specialist training in genetics and counselling and will help you to understand the medical information you have been given and its effects on you and your family.

### Associate Genetic Counsellor

An Associate Genetic Counsellor is a professional who is in the process of completing their training and will help you

to understand the medical information you have been given and its effects on you and your family.

### Social Worker

A social worker can provide emotional support for you in your situation, as well as practical help in finding community resources to assist you.

### Other specialists

Depending on the specific condition, the genetics specialists may require the help of other specialists, such as cardiologist

(heart), orthopaedic surgeon (bones) or a dietician.

### Students

Medical students, genetic counselling students or social work students may occasionally ask to sit in on appointments. If you are not comfortable with having another person in the room, it is OK to say no.

Ask to be introduced to all of the health professionals who see you, and make sure you know their names and their roles.