



Cardiac Genetic Counselling

Statement of service

As part of the process of a cardiac genetic test, it is highly recommended that you participate in genetic counselling both before and after undertaking the test. This is provided by Sonic Genetics at no additional cost to you. This leaflet outlines what you can expect from a genetic counselling session.

What is genetic counselling?

Having been diagnosed with a genetic heart condition, you may be offered genetic testing. Genetic testing is used to determine the underlying genetic cause of your condition.

The outcome of a genetic test may have medical and psychological ramifications for both the person tested and for their relatives. It is important that these issues are discussed and considered before the test is undertaken.

Genetic counselling facilitates these discussions, giving you the opportunity to ask questions and to understand the implications of this test for you and your relatives.

What can I expect from a genetic counselling session?

During your phone consultation, your genetic counsellor will discuss with you:

- ▶ Your family history
- ▶ The process of genetic testing
- ▶ The potential outcomes/results of testing
- ▶ The limitations of a genetic test
- ▶ Consent for testing
- ▶ The implications of your result for you and your family
- ▶ Links will be provided to appropriate clinical services

All genetic counselling is conducted in accordance with the guidelines of the Human Genetics Society of Australasia, ensuring that high ethical and professional standards of clinical practice are maintained.

After each counselling session, a written record of your discussion will be sent to both you and your doctor by your genetic counsellor.

What is the process of genetic counselling?

Genetic counselling will be divided into two phone sessions.

- 1. Pre-test counselling**, which will occur prior to the genetic test
 - ▶ Upon receipt of payment by Sonic Genetics, a genetic counsellor will contact you to arrange a mutually convenient time. Consultation takes approximately 30 minutes.
 - ▶ During this session, your genetic counsellor will answer any questions and address any concerns you may have.
 - ▶ At the end of the session, should you decide to go ahead with the testing, you will be asked to sign a consent form.
 - ▶ This consent form will be sent to Sonic Genetics, and they will then proceed with testing your blood sample. Please note that should you choose not to proceed with genetic testing, the test fee will be refunded in part.
- 2. Post-test counselling**, occurs once you have received the genetic test result from your cardiologist
 - ▶ During this session, we will review your result, discuss the possible implications of your result for you and your family and offer advice on further screening if relevant.
 - ▶ You will also be provided with a list of clinics should your relatives wish to seek their own advice.

What is a genetic counsellor?

A genetic counsellor is an accredited allied health professional. This requires a Masters Degree in Genetic Counselling together with supervised clinical experience. Genetic counsellors are accredited by the Human Genetics Society of Australasia and comply with the relevant professional and legal obligations of healthcare providers in Australia.

Who are the genetic counsellors?

Genetic counselling is provided by experienced cardiac genetic counsellors independently affiliated with the Australian Genetic Heart Disease Registry in Sydney.

Charlotte Burns is an associate genetic counsellor currently undertaking her third year of her PhD focused on genetic testing within the genetic heart disease field. Charlotte graduated with her Masters in Genetic Counselling from the University of Sydney in 2014. Since that time, she has worked within the genetic heart disease field as a cardiac genetic counsellor.

Laura Molloy is an experienced HGSA certified genetic counsellor who has a breadth of clinical experience across cardiac, general and prenatal genetics. Laura graduated with her Masters in Genetic Counselling from the University of Melbourne in 2011. She has an interest in cardiovascular genetics, having worked at The Victor Chang Cardiac Research Institute, the Molecular Cardiology Program at The Centenary Institute and the High Risk Familial Hypercholesterolaemia Service.