



FACT SHEET

National Genetic Heart Disease Registry

The Centenary Institute aims to enrol every family in Australia with an inherited heart disease into the Registry.

The National Genetic Heart Disease Registry is the first in the world to cover all forms of genetic heart disease. For the first time a database will be able to provide an accurate picture of genetic heart diseases in Australia, providing a key foundation for further research breakthroughs and personalised treatment of patient populations.

The Registry has only been possible due to co-operation between cardiologists and genetic research centres across Australia.

Creating a single database of information will allow researchers to rapidly increase their knowledge of inherited heart diseases in Australia, including:

- The severity of symptoms of disease experienced by people;
- The effectiveness of medications and therapies;
- The ability to better estimate the number of at-risk relatives who should be seeing a cardiologist regularly, and;
- The opportunity to identify families which may benefit from genetic testing options.

The more people who are enrolled on the Registry, the more informative the database will be and this will ensure Australian researchers remain at the forefront of genetic heart disease research.

The aims of the National Genetic Heart Disease Registry are to:

- Collect data about families with inherited heart diseases.
- Create awareness and provide a reliable source of information to families and health professionals.
- Establish a database for use by approved Australian research groups, with the ultimate goal of improved treatment options and patient care.

Key facts

1. The Registry will provide an effective way for health professionals to keep in touch with families who are at risk of developing heart disease, and keep patients updated on medical advances and new treatment options, as well as opportunities to participate in research programs.
2. The Registry will be a valuable resource to families, health professionals and research groups and will provide accurate information about genetic heart disease in Australia.
3. Most current data about genetic heart disease comes from the United States and Europe and is limited in its scope. The Registry will provide comprehensive, in-depth data on Australian families with genetic heart diseases.
4. Currently 300 Australian families have enrolled in the Registry and that number is expected to reach more than 1000 families within the next 3 years.
5. Developing a large patient database will mean researchers can address many of the unanswered questions surrounding genetic heart disease, with the ultimate goal of improving treatment options and patient care.

6. As a requirement of the National Health and Medical Research Council, an Advisory Committee governs the Registry. The Registry Advisory Committee determines how the Registry functions and also how data is to be used.