

How has the National FH Registry been developed?

The FH Australasia Network (sub-committee of the Australian Atherosclerosis Society) has established the National FH Registry in partnership with the Office of Population Health Genomics, Government of Western Australia (Department of Health) and the Centre for Comparative Genomics.

www.athero.org.au/patients/fh-registry

CENTRE FOR
COMPARATIVE GENOMICS



Western Australia

Contact

NSW FH Registry Coordinator:

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E: RPAHGene.Clinic@sswahs.nsw.gov.au

WA FH Registry Coordinator or for general enquiries about the Registry:

E: fhwa@health.wa.gov.au



*everyone deserves
a better chance*

*You can't change your family's
history, but you can change your
family's future...*



*everyone deserves
a better chance*

The National

fH
Registry



What is a Registry?

A patient Registry is a place where medical information, family history and other related information from individuals are collected and stored for medical research. The National FH Registry collects information on people with FH and their family members which can be used to improve treatment and quality of care for people with FH and future generations.

Why Should I Join?

By joining the FH registry, you will be helping the entire FH community. The ultimate goal of the FH Registry is to improve treatment options and care for people with FH and this will only occur if significant numbers of people join.

Information collected from family members will be used as a benchmark for evaluating new methods of care and to improve treatments for FH.

What information will be in the National FH Registry?

The Registry will record demographic and clinical information such as family history of FH, history of cardiovascular disease and cardiovascular disease risk factors, treatment, cholesterol and other results. These will be provided by your treating doctor and recorded. If genetic testing has been done, these details will also be included.

What about privacy, security and access?

Your personal identifying details (name, address etc.) will be stored as an individual electronic record. This individual record will be assigned a Unique Identification Number. This process of hiding your information is called 'de-identifying' because all personal identifiers have been removed.

All information will be stored in a secure and confidential manner in order to prevent a person from being identified by anyone other than those directly involved with your clinical care. No unauthorised person will be able to gain access to any information about you.

How Do I Join?

Joining the National FH Registry is simple!

- Ask your FH Physician or Genetic Counsellor
- Contact your FH Registry coordinator, see contact details on the back of this pamphlet, or
- Visit the Registry website:
www.athero.org.au/patients/fh-registry

You will be asked to read and sign a consent form which will give you further details on how the data is stored, who has access to your data and data security and privacy.

To update or withdraw details from the Registry, contact the FH Registry coordinator.

