



# WA launch for National Familial Hypercholesterolaemia Registry

**Oct 15 21** A National Familial Hypercholesterolaemia (FH) Registry has been officially launched in Perth – and WA Health has been the driving force in getting it off the ground.

FH is an inherited condition in which the liver's ability to remove low-density lipoprotein (bad cholesterol) from the blood is severely impaired, raising blood cholesterol (a major determinant of heart disease). Without treatment, affected individuals are at greatly increased risk of coronary artery disease, heart attack and early death.



Professor Gerald Watts, Head of the Lipid Disorders Clinic at Royal Perth Hospital

The new registry will become an important tool for researchers and health professionals in tackling the disorder.

Championed by Professor Gerald Watts, Head of the Lipid Disorders Clinic at Royal Perth Hospital, and the Office of Population Health Genomics, the registry becomes the latest in a series of WA Health-led initiatives designed to improve health outcomes for people with FH, about 80 per cent of whom are not even aware they have the disorder.

“Those who consent to join the registry will be helping us gain new insights into the care of people with FH, paving the way for new and better treatments and improved services – ultimately helping us save lives,” he said.

The National FH Registry will be open to individuals diagnosed with – or suspected of having – FH, as well as the children and undiagnosed relatives of these individuals.

“Without timely detection and treatment, about 50 per cent of men with FH will have coronary heart disease by the time they are 50 years and 30 per cent of women by the time they are 60,” he said.

“Early detection is a key to managing FH because a person who knows they have FH can manage it by making healthy lifestyle choices and taking statins, with the addition of other cholesterol-lowering medication in the most severe cases.

“Unfortunately, however, awareness of the condition is limited even among experienced health practitioners so many affected individuals remain undiagnosed and as a consequence miss the chance to take preventative measures.”

Professor Watts is confident the registry will help raise awareness of FH in both the medical and wider community, saying it would also:

- provide valuable demographic and clinical information for researchers and health

service planners

- enable developments and breakthroughs in FH management to be more easily communicated to patients and their GPs
- give registrants information about clinical trials, for which some may be eligible.

He said the National FH Registry would complement other measures to improve detection and management of FH which included encouraging:

- general practitioners to be alert to potential FH cases and to use data extraction tools to review existing medical records to detect cases that may have been overlooked previously
- “cascade testing” of relatives of people already diagnosed with FH
- pathology laboratories to routinely alert general practitioners to individuals with elevated LDL results that would put them at high risk of having FH.

Professor Watts said rigorous protocols had been developed to protect registrants’ privacy. He stressed that registration was voluntary and that registrants were free to withdraw their consent at any time.

Anybody seeking to join the registry should speak to their doctor, specialist or lipids clinic in their state.

FH affects about one in 300 people. An estimated 77,000 Australians have the condition.

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