



everyone deserves  
a better chance

## FH Australasia Network Registry Members:

- Timothy Bates
- Damon Bell
- Warrick Bishop
- John Burnett
- Peter Clifton
- David Colquhoun
- Peter George
- Ian Hamilton-Craig
- David Hare
- Edward Janus
- Karam Kostner
- Andrew Martin
- Michael Metz
- Paul Nestel
- Richard O'Brien
- Jacqueline Ryan
- Leon Simons
- Shubha Srinivasan
- David Sullivan
- George Tallis
- Gerald Watts
- Frank van Bockxmeer  
(Registry Custodian)

### WATCH VIDEO

Introduction to the  
National FH Registry

LOGON TO  
FH REGISTRY TEST SITE  
Username: fhcurator  
Password: fhcurator

## Welcome to the first edition of the FH Registry News!

We will produce regular newsletters to keep all members informed of each site's activities.

As we know, the Registry is a crucial component of the comprehensive model of care for FH, which aims to provide a standardised, high-quality and cost-effective system of care that is likely to have a high impact on patient outcomes.

The FH Registry was developed by the **Centre for Comparative Genomics (CCG)** at Murdoch University using the Registry Framework. It is an open source, interoperable web-based tool that can be modified dynamically as registry requirements evolve.

The Registry was launched in September last year with **Prof Peter Clifton** speaking about the importance of FH and early identification and **Prof Matthew Bellgard** on the role of patient registries in clinical development, quality improvement and ultimately patient healthcare.

Patient consenting and data entry have commenced at Royal Perth Hospital, Flinders Medical Centre, Royal Adelaide Hospital and Calvary Hospital.

## Ethics and Governance

We now have ethics/governance approval at 12 sites across Australia, including the private sector (**Prof David Colquhoun** (QLD), **Prof Edward Janus** (VIC) and **Prof David Hare** (VIC)).

The public sector includes:

- Royal Perth Hospital, WA
- Royal Prince Alfred Hospital, NSW
- Flinders Medical Centre, SA
- Austin Health, VIC
- Calvary Health, TAS
- Fiona Stanley Hospital, WA
- Royal Adelaide Hospital, SA
- Mater Hospital, QLD
- The Children's Hospital at Westmead, NSW



The Women's and Children's Hospital (SA) and St John of God Hospital Midland (WA) are awaiting final governance approval.

## Future meetings

A series of teleconferences have been scheduled by site/state where ethics approval has been obtained, to ascertain how best the FHAN can assist each site in forging ahead with the task of consenting patients and entering the data onto the web-based registry.

These teleconferences, will be followed by site visits by the national coordinator and secretariat support staff to help develop and deliver individual plans of action including the appointment of state-based coordinators, to ensure the longevity and sustainability of this important initiative.

In due course, you will be invited to attend FH Registry board meetings to report your progress.

## Our industry supporters

The FH Registry board would like to acknowledge support from Sanofi and Amgen.

