H Registry News

6 February 2017



FH Australasia Network Registry Members:

- Walter Abhayaratna
- Justin Ardill
- Timothy Bates
- Damon Bell
- Warrick Bishop
- Edmund Brice
- John Burnett
- Peter Clifton
- David Colquhoun
- Anthony Dart
- Peter George
- Shahid Hafeez
- Ian Hamilton-Craig
- David Hare
- Edward Janus
- Karam Kostner
- Leonard Kritharides
- Andrew Martin
- Michael Metz
- Sam Mirzaee
- Paul Nestel
- Richard O'Brien
- Jacqueline Ryan
- Leon Simons
- Shubha Srinivasan
- David Sullivan
- Gerald Watts
- Frank van Bockxmeer (Registry Custodian)

WATCH VIDEO Introduction to the National FH Registry

LOGON TO FH REGISTRY TEST SITE Username: fhcurator Password: FHcurator1*

Site Updates

We now have a total of 24 sites across Australia, including 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), St John of God Hospital Midland (WA) and The Alfred Hospital (VIC), Canberra Hospital (ACT), as well as 11 sites in the private sector: Prof David Colquhoun (QLD), Prof Edward Janus (VIC), Prof David Hare (VIC), Prof Leon Simons (NSW), Dr



Edmund Brice (WA), A/Prof Richard O'Brien (VIC), Prof Walter Abhayaratna (ACT), Prof Leonard Kritharides (NSW), Dr Justin Ardill (VIC), Dr Shahid Hafeez (SA) and Mrs Jacqueline Ryan (WA).

Monash Heart (VIC) will soon be joining the Registry, led by Dr Sam Mirzaee.

Data entry has commenced at 15 sites, with 800 participants registered.

Publication Plans

The first papers on the design and rationale of the Registry have been communicated locally in Heart, Lung and Circulation and internationally in the Journal of Atherosclerosis and Thrombosis.

Once the Registry has complete data on 1500 registrants, plans are to produce the first publication to describe the clinical characteristics, diagnosis and treatment gaps of FH patients in Australia.

Specialist brochure

Please check your details on the attached draft copy of the Specialist brochure. This is for patient use, so do not include personal contact details. Hospital/surgery contact details are welcome. If your details require updating or you wish to opt out, please contact fhwa@health.wa.gov.au.



User Tips

Hopefully everyone has had a chance to look at the FH Registry Manual since the last newsletter.

A few user accounts have been deactivated over the last few months. Please note that for security reasons, accounts that are not active after 3 months will be deactivated. You will need to email the National Coodinator to arrange reactivation.

For those who have noticed that the 'Doctors' they want to enter are not on the drop-down list, please refer to page 19-20 of the manual. Doctor's details only need to be added once to the database and will appear in the drop-down list for all future entries.







