JH Registry News



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)

Site Updates

We now have a total of 26 sites across Australia:

- ACT Canberra Hospital, Prof Walter Abhayaratna
- **NSW** Royal Prince Alfred Hospital, The Children's Hospital at Westmead, Concord Hospital, Prof Leonard Kritharides, Prof Leon Simons
- **QLD** Mater Hospital, Prof David Colquhoun
- **SA** Flinders Medical Centre, Royal Adelaide Hospital, The Women's and Children's Hospital, Dr Shahid Hafeez
- TAS Calvary Health

How to find the **Specialist Resources** page:

- VIC Austin Health, The Alfred Hospital, Monash Health, Dr Justin Ardill, Prof David Hare, Prof Edward Janus, A/Prof Richard O'Brien
- WA Royal Perth Hospital, St John of God Hospital Midland, Fiona Stanley Hospital, Dr Edmund Brice, Mrs Jacqueline Ryan

Data entry has commenced at 16 sites, with over 1000 participants registered.

FHAN Website and Specialist Brochure

We have updated the FH Specialist page on the FHAN website and finalised the Specialist brochure which is located on a Specialist Resources page. This page will be a 'one stop shop' for all resources.



FHAN website > Health Professionals > Specialist Resources If your details are incorrect, please contact fhwa@health.wa.gov.au asap.

National FH Registry Patient Newsletter

We have produced the inaugural National FH Registry patient newsletter – suggestions for improvement are welcome. The newsletter features an excellent scientific communication by Prof Paul Nestel re: Fourier trial. **Thank you Prof Nestel!** And an Amgen sponsored patient survey re: high cholesterol treatments. The survey can be viewed via the test site. The eligibility criteria are: total cholesterol level >5 mmol/L and FH or coronary event/revascularisation. Your non-FH patients are also welcome to complete the survey. The link to the live site is http://bit.ly/2o234wB. The electronic newsletter will be sent to all National FH Registry participants in early May. **If you do not wish your site to receive the newsletter** please let us know **before the end of April.**

Registry User Tips

- Where possible please complete all fields. If some information is not known, choose 'Unknown' so we know that you have attempted to complete the field
- Treatment is asked in the 'Clinical data' and the 'Medications' module. In the 'Clinical data' module, the treatment reflects the treatment the patient was on at the time of the lipid profile. In the 'Medications' module, the treatment reflects the treatment the patient was on at the time of the assessment for eligibility/consent for the Registry. The treatment may be the same in both cases.
- A patient may not have 'premature' coronary disease (has occurred after 55 in males and after 60 in females), but we would still like information on non-premature coronary events and revascularisation (and the age), otherwise please select 'No' for both questions so we know that the patient has not had any coronary events and/or revascularisation.

April 2017