# /H Registry News

#### July 2018



#### 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
- Elif Ekinci
- Brett Forge
- Peter George
- Shahid Hafeez
- Christian Hamilton-Craig
- David Hare
- Edward Janus
- Karam Kostner
- Leonard Kritharides
- Andrew Martin
- Michael Metz
- Sam Mirzaee
- Christopher Neil
- Paul Nestel
- Richard O'Brien
- Jacqueline RyanLeon Simons
- Leon Simons
  Shubha Srinivasan
- David Sullivan
- Gerald Watts
- Andrew Wilson
- Frank van Bockxmeer (Registry Custodian)

## Site Updates

We now have 35 sites across Australia.

We welcome Dr Brett Forge (VIC) on board! Additionally, Perth Children's Hospital will be joining the Registry, led by Dr Andrew Martin.

Data entry has commenced at 22 sites, with over 1,300 participants registered. The big challenge now is the auditing process to ensure high quality data collection at all sites.

Ctrl + Click on the map to see FH Registry locations. Please check your pin is correct.



### **FH Registry Updates**

Some minor changes have been made to the registry to improve usability.

1. Questions indicated with a red asterisk \* have always been core data elements and are required to be answered in order to save the form.

A green asterisk \* has been added to core data elements that are **required as a minimum**, but are not required to be answered for the form to save.

Please enter additional data if available.

An updated data entry form is available.

2. Lp(a) and CRP will be moved to the bottom of 'Other CVD Risk Factors' when possible.



### **New FH Brochures (DRAFTS)**

Drafts of two new FH brochures:

- <u>Women and Pregnancy</u>
- Lipoprotein Apheresis

are available for comment.

Please forward comments to <a href="mailto:fhwa@health.wa.gov.au">fhwa@health.wa.gov.au</a>

### **User Tips**

Please refer to the <u>FH Registry Manual</u> for guidance in using the online Registry; please contact the national coordinator if there are any issues with the online Registry platform.

