JH Registry News

September 2019



FH Australasia Network Registry Members:

- Walter Abhayaratna
- Justin Ardill
- Timothy Bates
- Damon Bell
- Warrick Bishop
- Edmund Brice
- Andrew Black
- John Burnett
- Peter Clifton
- Alison Colley
- David Colquhoun
- Anthony Dart
- Elif Ekinci
- Brett Forge
- Shahid Hafeez
- Christian Hamilton-Craig
- David Hare
- Laurie Howse
- Edward Janus
- Robert Justo
- Karam Kostner
- Leonard Kritharides
- Stephen Li
- Andrew Martin
- Allison Morton
- Sam Mirzaee
- Christian Mussap
- Christopher Neil
- Paul Nestel
- Richard O'Brien
- Jay Ramanathan
- Jacqueline Ryan
- Leon Simons
- Shubha SrinivasanDavid Sullivan
- Gerald Watts
- Andrew Wilson
- Angela Worthington
- Frank van Bockxmeer (Registry Custodian)

Site Updates

- We now have a total of 43 clinical sites around Australia!
- We welcome on board Prof Laurie Howse who has joined us from the Gold Coast Hospital.
- A first publication of the Registry data is currently in preparation. This publication will focus on the gaps in the detection and management of FH in Australia and a draft will be circulated shortly.
- Relevant to the upcoming MBS Item on genetic testing for FH, there are several gaps to address and particularly in states where genetic testing is not normally requested:



MBS Item on Genetic Testing for FH

- A public summary document detailing the Government's Medical Services Advisory Committee (MSAC) consideration of genetic testing for FH was released earlier this year.
- MSAC supported the listing of genetic testing for heritable mutations associated with FH in affected individuals meeting defined eligibility criteria, and targeted cascade testing.
- "Think and Do Tank" meetings will be held in Sydney, Adelaide, Melbourne and Brisbane between now and early 2020 to consolidate implementation strategies to address the release of the new MBS Item to specialist and primary care physicians.

FH Awareness Day

• Every year, FH Awareness Day is September 24th. If you would like to share any local awareness-raising activities, please let the national coordinator know so the news can be shared via FHAN's facebook and twitter!

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.

All previous newsletters and FH resources can be found here!

