



everyone deserves
a better chance

FH Australasia Network Registry Members:

- Walter Abhayaratna
- Justin Ardill
- Timothy Bates
- Damon Bell
- Warrick Bishop
- Andrew Black
- Edmund Brice
- 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
- Sam Mirzaee
- Allison Morton
- Christian Mussap
- Christopher Neil
- Paul Nestel
- Richard O'Brien
- Jay Ramanathan
- Jacqueline Ryan
- Leon Simons
- Shubha Srinivasan
- David Sullivan
- Gerald Watts
- Andrew Wilson
- Angela Worthington
- Frank van Bockxmeer
(Registry Custodian)

Site Updates

- We now have a total of **40** clinical sites around Australia!
- We welcome our new sites this year
 - Dr Angela Worthington (Newcastle Cardiology)
 - Dr Allison Morton (Heartcare WA Bunbury)
 - Dr Robert Justo (Queensland Children's Hospital)
 - Dr Andrew Black (Royal Hobart Hospital)
- We also welcome on board Drs Alison Colley, Christian Mussap and Jay Ramanathan who will soon be joining us from Liverpool Hospital.
- Our current aim is to audit all the core information for a first publication in the second half of 2019. This publication will focus on the gaps in the detection and management of FH in Australia. Ethics approval has been received to undertake this analysis.



FH Registry Platform Update

- On the 28th of May 2019, the Centre of Comparative Genomics (CCG, Murdoch University) transitioned the hosting of the FH Registry from physical servers to a third party cloud hosting (Amazon Web Services, AWS).
- Please be assured that all patient data collected in the Registry will remain in Australia and the cloud infrastructure has met strict security requirements, additional details can be found in the [Data Management Plan](#).
- Owing to patient consents across different sites (ie. patient seen at more than one clinic, or patient has moved to another clinic), the FH registry now allows a record to be accessed by multiple sites as long as a consent has been signed at each site.

FH Australasia Summit 2019

- Earlier this year, we had the first FH Summit 2019 in Melbourne. We had a fantastic program with international and local speakers.
- Prof David Wald highlighted complementary strategies to identify new FH individuals and their family members via child-parent cascade screening, Prof Brian Ference provided an international perspective on the value of genetic testing and Prof Christie Ballantyne covered old and new therapies for FH.
- Luke Elias shared his family's experience of being diagnosed with FH, the patient journey through the healthcare system and the importance of patient education.
- We hope to have a summit like this every year to improve FH care, raise awareness and emphasise the significant role of patient advocacy.

User Tips

- Please refer to the [FH Registry Manual](#) 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!](#)

