

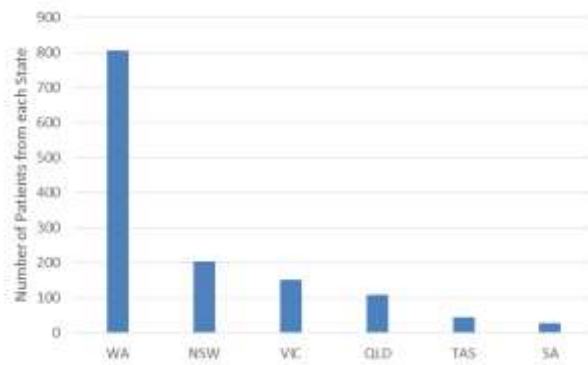
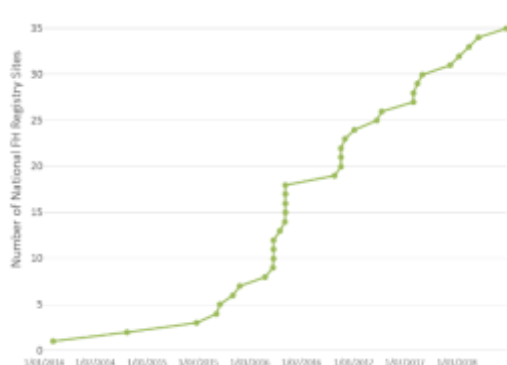


everyone deserves  
a better chance

## 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
- Stephen Li
- Edward Janus
- Karam Kostner
- Leonard Kritharides
- Andrew Martin
- Michael Metz
- Sam Mirzaee
- Christopher Neil
- Paul Nestel
- Richard O'Brien
- Jacqueline Ryan
- Leon Simons
- Shubha Srinivasan
- David Sullivan
- Gerald Watts
- Andrew Wilson
- Frank van Bockxmeer  
(Registry Custodian)

## Site Updates



- The number of FH Registry sites have been increasing over the last 5 years.
- Data entry has commenced at 25 sites with over 1,500 participants registered in total; over 400 genetically confirmed FH and 80 children.
- For the first time, we are including data from primary care as part of an [NHMRC partnership grant](#) project led by Prof Tom Brett and A/Prof Diane Arnold-Reed (University of Notre Dame).
- We also welcome on board Dr Stephen Li who will soon be joining as our lead investigator at Westmead Hospital (Sydney, NSW).
- Our big challenge is to constantly audit all the core information to ensure high quality data is being collected at all sites and also the timely processing of reimbursements.

## FH Registry - Server Transition

- The FH Registry platform is currently hosted on physical servers at the Centre of Comparative Genomics (CCG), Murdoch University.
- The CCG is planning to transition the hosting 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.
- The AWS cloud infrastructure will meet the same strict security requirements that are currently in place for the hosting of the Registry.
- A Data Management Plan has been put together to address this and to cover the recent revision of Section 3 of the National Statement.
- The Patient Information Sheets are also currently being amended and the national coordinator is working through all current sites.
- The transition will only occur once all sites have approved the Data Management Plan and the amended Patient Information Sheets.
- The transition should not affect the way we currently use the Registry platform.

## 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!](#)

