

## Open Garden Weekend

On April 29 & 30, FSHD Global was a proud charity partner of an Open Gardens weekend at Mount Wilson in the Blue Mountains. We were proud to be associated with Dennarque Estate and Yengo Sculpture Gardens - two magnificent cold climate gardens. Blessed with the beautiful crisp autumn weather, both properties showcased the stunning colours of changing leaves, age-old trees and the serene and peaceful beauty of the Blue Mountains.

Thank you to our Chairman Bill Moss AO for opening Dennarque Estate to the public for the first time in over three years and who generously hosted the team in their beautiful Estate cottages for the weekend. Special thanks also to Peter and Ann Pigott of Yengo Sculpture Garden who opened their gardens for the weekend to assist in raising money for the Foundation. This weekend would not have been possible without the kindness and preparation of the owners of both these properties.

We would also like to thank everyone who travelled to Mount Wilson to support this event. We were successful in raising over \$4000.



## Community Fundraising

FSDH Global Board Director Bechara Shamieh and teammate Daniel Caine took part in Australia's first ever SwimRun event. After weeks of training and preparation along with fundraising, Bechara and Daniel successfully completed the gruelling course, raising over \$6k for medical research into FSDH.



SwimRun is a unique and challenging adventure sport where teams of two compete by alternating between running and swimming on a challenging course covering trails, beaches, ocean, cliffs, rocks, and paths. Teams must complete the entire course together and help each other through tough terrain to beat the course and reach the finish line.

Congratulations Bechara and Daniel on such an incredible effort. There is still time to support this fundraiser, simply click below.

[Donate](#)

## Community Meetings

Our team took to the road last month to meet with the wider FSDH Global community. With meetings held in Sydney, Melbourne and Brisbane we set out to share our 2017 events calendar, fundraising goals, and how people can be involved in the Foundation. With over 60 people attending, they were a huge success. We are excited to see the fundraisers that are currently being arranged and are grateful for the support of everyone who attended.

If you would like information about how you can help the Foundation, please contact Vanessa at [vanessa@fshdglobal.org](mailto:vanessa@fshdglobal.org)





## Science Grants



We are proud to have funded a joint study between Concord Hospital and the Garvan Institute of Medical Research in a study looking at The next wave of Whole Genome Sequencing-based FSHD diagnostics, and clinical measures of progression.

The genetics of FSHD are complex, and up until now, obtaining a genetic diagnosis for this condition has been difficult, labour intensive and involved multiple laboratory tests. A new diagnostic method, Whole Genome Sequencing (WGS) is able to diagnose many genetic disorders and may offer a new paradigm for diagnosing FSHD. This project seeks to develop a WGS-based method to diagnose all forms of FSHD and facilitate novel disease gene identification. To overcome the challenging genetics of FSHD pathogenesis, this collaboration will develop novel bioinformatics methods, and utilise the brand new Chromium platform from 10x genomics, to help resolve the "D4Z4 repeat" length in FSHD patients. This will also provide valuable insights into the genetic

basis and disease mechanisms underlying this disorder. They are also looking at ways to monitor the natural history and disease progression including specialised MRI scans. This will, in turn, allow the design of treatment trials in the future. This project brings together experts in FSHD genetics, diagnostic testing, with clinical WGS and bioinformatics to develop this new test.

This study will be conducted over 2 years and we are excited to see watch it progress.

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## Help us Find a Cure

From its establishment in 2007, the Foundation has raised over \$8.6 million in tax-deductible donations to find a cure for FSHD. 100% of this money has been allocated to current or future research grants and education. To date, we have funded 40 research grants in 9 countries, which at this stage has resulted in 44 publications in medical journals.

We are making progress towards finding a cure!

However, the closer we get to finding a cure means that more money for research is required.

In 2017 we aim to establish an FSHD Centre of Excellence with a post-doctoral fellow dedicated to FSHD research. Patients are still encountering significant hurdles in the diagnostic process, and we are exploring ways of bringing cutting edge technology to this Centre to transform FSHD diagnosis in Australia and facilitate research that will move us towards clinical trials.

Secondly, in the hope of improving the lives of FSHD patients in real and tangible ways, we will fund therapeutic research involving human clinical trials of devices to improve airway function, to alleviate widespread respiratory difficulties.

This end of financial year, please consider making a donation to support FSHD Global as we continue to fund medical research into treatments and an ultimate cure for FSHD.

[Donate](#)



## World FSHD Day



World FSHD Day is held on **June 20** and aims to raise public awareness for FSHD. Few members of the public have ever heard of FSHD, and many affected individuals don't know that they have the condition. This international day aims to bring awareness of this debilitating disease to the general public and decrease the misdiagnoses within the medical industry not only in Australia but across the globe. Join people all around the world as we come together on June 20th and unite to raise awareness and find a cure for FSHD.

Initiated in 2016 by the [FSHD Champions](#), an international alliance of FSHD advocacy organisations around the world, this day is a fantastic platform for the global FSHD community to unite and create a global footprint for FSHD.

On June 20th, we encourage all of our supporters to change their social media profile pictures to the World FSHD Day logo and use the official hashtags [#WorldFSHD](#) and [#CureFSHD](#). Click [here](#) to download the official World FSHD logo.

This year we ask you to join us in spreading awareness of FSHD and to raise funds by hosting your own fundraiser. No matter how big or small, every effort counts! For more information on how to host your own fundraising event or for ideas on how you can be involved, please contact [admin@fshdglobal.org](mailto:admin@fshdglobal.org)

[Download your World FSHD Day fundraising toolkit.](#)