FSHD Global Annual Science Week

The Foundation is gathering world-class scientists and clinicians to meet with the FSHD community in Australia and New Zealand. This is your invitation to hear what research is happening, to share your stories about living with FSHD, and to make connections with clinicians and support networks.

One of the most important aspects of research is telling people about it. The researchers the Foundation fund lead the world in FSHD basic, therapeutic and diagnostic investigation. The Annual Science Week is your chance to hear what they have achieved with FSHD Global funding, and what this means for progress into treatments and an ultimate cure for FSHD.

Auckland
Date: Friday 15 September 2017
Venue TBC

Sydney
Monday 18 September 2017
Children's Medical Research Institute, Westmead

Brisbane
Tuesday 19 September 2017
Novotel, Brisbane

Perth
Wednesday 20 September 2017
Venue TBC

Melbourne
Thursday 21 September 2017
Novotel on Collins, Melbourne

This year we are joined by:

Scott Q Harper, PhD
Scott Harper is an Associate Professor of Pediatrics at The Ohio State University College of Medicine and Principal Investigator in the Centre for Gene Therapy at the Research Institute at Nationwide Children's Hospital, Columbus, Ohio, USA.

From 1996 to 2002, Dr Harper earned a PhD in Cellular and Molecular Biology from

the University of Michigan, where he worked on developing gene therapy approaches to treat Duchenne Muscular Dystrophy (DMD). Following that, from 2002 - 2007 he trained as a post-doctoral fellow at the University of Iowa. During this time, a new field of biology - gene silencing - was emerging, and Dr Harper worked to develop gene silencing techniques to treat dominant brain diseases, including Huntington's Disease (HD).

In 2007, Dr Harper started his own laboratory with the goal to combine his two areas of training - gene therapy for muscular dystrophy and gene silencing strategies - and develop a new research program in an area that had long been understudied: FSHD. During the last decade, the Harper lab has been working to create models of FSHD and develop therapies for the disease.

Paul Gregorevic, PhD
Dr Paul Gregorevic gained his PhD from the University of Melbourne in 2001. He subsequently trained as a postdoctoral research fellow at the University of Washington Department of Neurology, Seattle USA where he acquired expertise in molecular biology and the design of recombinant viral vectors as gene delivery technologies for studying and treating muscle diseases.

In 2008 Dr Gregorevic relocated his research program to the Baker Heart and Diabetes Institute, Melbourne, where he is Head of the Laboratory for Muscle Biology and Therapeutics Development, and Director of the Recombinant Viral Vector Core. His research interests focus on elucidating the mechanisms underlying the development and regulation of the skeletal muscle phenotype and the development of novel therapeutic interventions to combat loss of muscle function associated with heritable and acquired diseases and the ageing process.

Local Speakers include Associate Professor Marnie Blewitt from the Walter and Eliza Institute of Medical Research and Dr Richard Roxburgh from Auckland City Hospital.

Register Now

Join us at the 9th Annual FSHD Global Golf Tournament

Tickets are now on sale for our 9th Annual FSHD Global Golf Tournament. Set on the beautiful St. Michael's Golf Course, this Ambrose Tournament will see players come together in a fun and friendly environment to play golf with clients, friends or colleagues networking among an echelon of Australian businesses. Grab a massage on the massage hole, a drink on the tasting holes and participate in many on field games throughout the day.

To secure your team, or become a corporate sponsor, please contact the Foundation. This networking event is one not to be missed.

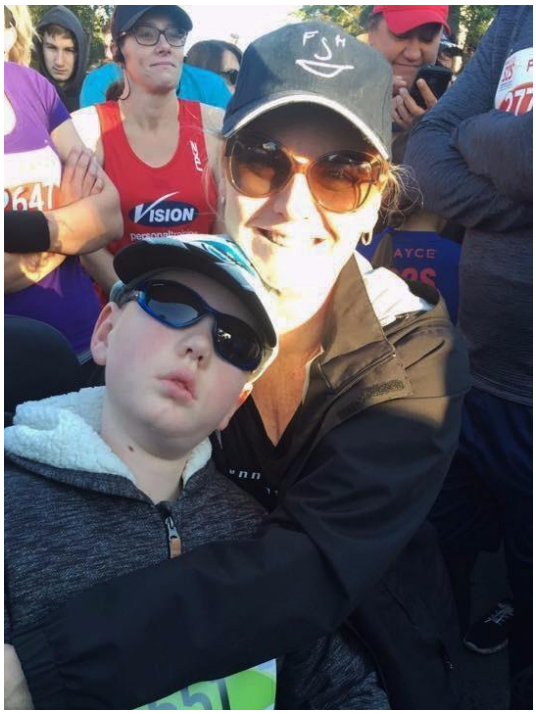
Support FSHD Global in the 2017 City2Surf!

Our team is getting out of the office for this year's City2Surf! The FSHD Global team will be getting active in the sun to highlight how important muscles are in our bodies. Join or support our team here as we prepare to hit Heartbreak Hill next weekend! The countdown is on and the anticipation is rising. Keep an eye out on our social media on the 13th of August for live updates.

If you have any friends or family participating in this year's City2Surf, encourage them to join our team and raise much-needed funds for FSHD.

Sutherland2Surf Fundraiser

Huge thanks to the Albert and Barnes families for taking part in the Sutherland2Surf on the 23rd of July, raising money to support medical research into FSHD. They were successful in raising over $2,500! We are grateful to our community members who are continuously finding ways to raise funds for FSHD Global, allowing us to support medical research into FSHD. Contact the Foundation today to register your next fundraising activity!



Sophie's Story

I’m 10 years old and I want to tell you what living with FSHD is like for me.

How FSHD affects me every day

FSHD affects me every day. It stops me having a normal day like everyone else by giving me pains in my shoulders, neck and legs and other parts of my body. Every day I get really tired. Simple things can be really hard for me to do. My side muscles are too weak for me to sit on the floor to play games or watch TV. It's getting really hard to do handwriting because my muscles are getting weaker. I also have to sit down regularly because my legs get sore and I can’t walk anymore. I miss out on some things my family does, like walking or swimming at the beach. My Mum and Dad don’t do some activities that they enjoy, like going bush walking or going to the beach because they know it’s really hard for me. Going on holidays is fun, but it’s hard because I can’t get to lots of the fun places because my muscles are too weak or my wheelchair can’t get through. Last year we went to Wet ‘n' Wild but I couldn’t go on any of the water slides because I couldn’t get up the stairs. It sucked watching my sisters have a good time. Using my wheelchair in the house is a real hassle because the rooms are too small and I sometimes bang into the walls but Mum and Dad don’t get angry. We are building a special bathroom to make it easier for me to wash.

Read more of this story