

We won Best Community Impact!

FSHD Global were proud to receive the award for Best Community Impact at the Australasian Business Excellence Awards. We were thrilled to be nominated for this award and even happier to have won. Here at FSHD Global, so much of what we do is about the impact we have both on and for the community. This award is as much for us as it is for you.



Welcoming John Rasko AO as Patron



We are thrilled to announce that John Rasko AO is now a Patron of Science for FSHD Global. Having previously served on the Board of Directors, Professor Rasko is an Australian pioneer in the application of adult stem cells and genetic therapy. He directs the Department of Cell and Molecular Therapies at Royal Prince Alfred Hospital and heads the Gene and Stem Cell Therapy Program at the Centenary Institute, University of Sydney.

John Rasko is a clinical hematologist, pathologist and scientist with a productive track record in gene and stem cell therapy, experimental haematology and molecular biology. In over 150 publications, he has

contributed to the understanding of stem cells and haemopoiesis, gene transfer technologies, oncogenesis, human aminoacidurias and non-coding RNAs.

He serves on Hospital, state and national bodies including Chair of GTTAC, Office of the Gene Technology Regulator – responsible for regulating all genetically-modified organisms in Australia - and Chair of the Advisory Committee on Biologicals, Therapeutic Goods Administration. He is a founding Fellow of the Australian Academy of Health and Medical Sciences. He is the recipient of national (RCPA, RACP, ASBMB) and international awards in recognition of his commitment to excellence in medical research, including appointment as an Officer of the Order of Australia.

An update on Justin Reid

Late last year we were saddened to hear that our Patron and dear friend Justin Reid was in hospital. We are happy to report that whilst Justin is still in hospital, he has made an improvement on his condition. Justin is in good spirits and is concentrating his efforts on being well enough to attend this year's Sydney Chocolate Ball.

His sister Gaenor tells us that "He questions everything; the doctor's advice, the medication, his time at the gym in rehab." This only highlights the importance of the Foundation's fight to educate Doctors on this disease. Justin is a fighter and a survivor. He looks forward to going home and living independently again and has asked to have someone to transcribe his thoughts. He wants to write, the first piece being "How to Survive Hospital"

We hope to see you out of hospital soon Justin.

Farewell to Glenn Pilkington & welcome to our new MSL Olivia Hibbitt



It is with much sadness that we farewell Glenn Pilkington from his role within the Foundation. Glenn has been with the Foundation since 2007 when he commenced as our Manager, Grants & Research Development. Over the last 9 years this has seen Glenn play an integral role in the Grant development and allocation of Grant money. We are so grateful to Glenn for

all of his hard work and time spent with the Foundation. Glenn will remain on as a Scientific Advisor serving on our science boards in a volunteer capacity.

As Glenn departs the Foundation we welcome Dr Olivia Hibbitt to the team as the new Medical Science Liaison. We are so happy to have Olivia join the team in a full time capacity to advance our Medical Research and Medical Education grants.

"I'm Liv Hibbitt, the Foundation's new Medical Science Liaison. My role in the Foundation will be to act as a key liaison point for all the amazing clinicians and researchers who are working hard to find treatments for FSHD. I'm going to be working hard to drive the research forward!

My background is in research, gene therapy for familial hypercholesterolemia. I spent 11 years in research before I decided to change focus somewhat and moved into medical writing. I have been working at NPS MedicineWise in a role that encompassed medical education, public health, advocacy, policy, and medicines management. I will be using all the skills I gained from research and medical communications to further the mission of the foundation.

I feel very privileged to be able to work at the Foundation and with the FSHD Global community more broadly."

