

## World Leading Scientists visit Australia

The September Scientific meetings being hosted by the FSHD Global Research Foundation will bring together some of the world's leading FSHD clinicians and researchers as they present on the latest advances in FSHD research. Held across three days in Sydney, Melbourne and the Gold Coast it will be the first time Australia has had a dedicated global research group come together to establish world best practices for diagnostics and treatment.

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## Grant 23 Bone Density Trial - Update

We are proud to present the success and share the results from our Bone Health Study in cooperation with Professor Alastair Corbett at Concord Hospital in Sydney. It is truly amazing that we recruited nearly 50 participants who travelled across the whole of Australia at their own expense to take part in this exciting study. We cannot thank you enough for your support. This pre-clinical study is certainly one step closer to developing important knowledge for management of this cruel disease. Results from the study showed that many of the participants remain able to work and lead full and busy lives and many have not attended a hospital clinic for several years. The most exciting news that came out from the study was the fact that 2 people who were previously diagnosed with FSHD almost certainly do not have FSHD. Professor Alastair Corbett is working closely with Dr Kathryn Wagner who is a Director of the Centre of Genetic and Muscle disorders at Kennedy Krieger Institute and associate Professor of Neurology and Neuroscience at the John Hopkins School of Medicine in Baltimore, Maryland, United States. Dr Kathryn Wagner is also one of the guest speakers presenting at our Patient Information Evenings held in Sydney, Melbourne and the Gold Coast. The study will complete in October and we are looking forward to reviewing the full report and sharing the information with the greater FSHD community.



## Shaun's video on living with FSHD



One of our valued FSHD Global community members Sean Jones was kind enough to share his story as he navigates life living with FSHD. Sean is an 18 year old living in QLD and from his video we can see that he has such strength and support surrounding him.

