

## FSHD Community Meetings

FSHD Global is taking to the road to visit our community. We are inviting people living with FSHD, their friends, and family to an informal community meeting. This is an opportunity to meet with other members of our community, hear an update on the Foundations vision and plans for 2017 including our events, in addition to finding out how you can become more involved in assisting us to find treatments and a cure for FSHD.

We also want to hear what is important to you!  
Please contact us if you wish to attend or would like more information.  
We look forward to seeing you there!

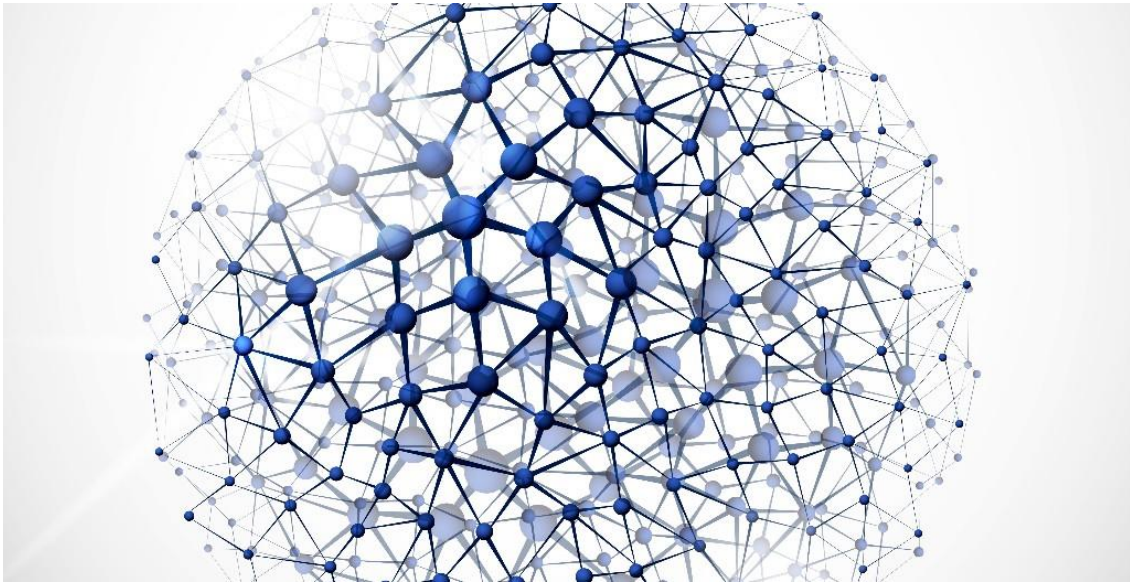
## FSHD COMMUNITY MEETINGS

**Melbourne:** Tuesday 4th April, 6:30 - 8:30 pm  
Novotel Melbourne on Collins

**Sydney:** Tuesday 11th April, 7:00 - 8:30 pm  
Rydges Parramatta

**Brisbane:** Tuesday 2nd May, 6:30 - 8:30 pm  
Novotel Brisbane

# FSHD Global Medical Research Update



## **Israel- Australia Collaborative Tender**

FSHD Global Research Foundation has issued a tender for an Israel-Australia Collaborative Medical Research Grant. Both Israel and Australia have strong academic ties and a similar heritage in biomedical research. The Foundation would like to foster research ties between the two countries and leverage respective expertise in order to advance the field of FSHD research. The Foundation has always encouraged scientific collaboration and is excited to see what international connections this tender inspires.

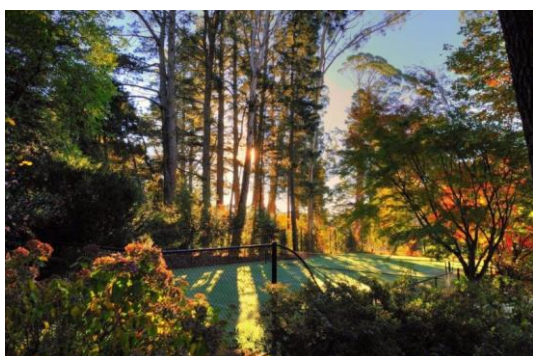
## **Therapeutics Tender**

Development of new therapies for people with FSHD is the principle aim of FSHD Global Research Foundation. Currently, there are no effective treatments and no cure. As part of the Foundations commitment to finding a cure for FSHD, we are calling for high-quality research projects that address this issue. Projects may be basic science, clinical or translational. However, all must demonstrate the potential for the discoveries to be developed into treatments for people with FSHD. In particular, we will be looking for projects where consideration about the path to commercialisation has been undertaken.

[Read more](#)

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# Mount Wilson Open Gardens



We are excited to announce that FSHD Global will be a charity partner for two upcoming open garden days. Enjoy the magical autumn colours of these world class gardens at Mount Wilson - Yengo Sculpture Garden and Dennarque Estate. Both gardens were designed in the 19th century by Charles Moore, Director of the Sydney Botanical Gardens and include many rare specimens of trees and native plants in the idyllic village setting of Mount Wilson. Don't miss out on this opportunity as these private Estates are rarely opened for public viewing.

## **WHEN:**

*Saturday 29th April 2017 - 9 am to 4 pm*

*Sunday 30th April 2017 - 9 am to 4 pm*

## **ENTRY:**

*Adult: \$20 per person for entry into both gardens*

*\$50 per person for entry into both gardens and a guided tour of Yengo Sculpture Garden by owners (must be pre-booked, subject to availability).*

*Children under 12: FREE*

*Coach Groups welcome*

**For more information and to purchase tickets, click [here](#).**



# FSHD Global Research Grant 23 Update



## Bone Health in FSHD

In a first for the FSHD field, a study has been published looking closely at the morbidity of low bone density and bone fracture risk in patients suffering from FSHD. The FSHD Global Research Foundation played a particularly proactive role in supporting this study beyond just financial support, including advocating for not only United States patients but also Australian patients from a Centre of Excellence in FSHD research at Concord Hospital in NSW to be included in the study. The findings are therefore of international significance. Moreover, a key member of the scientific committee of FSHD Global, Dr. Scott Baker, himself an endocrinologist provided expert comments on the design of the study which were acknowledged in the paper.

The study characterised 94 patients with FSHD. One of the key findings of the study was that there is a correlation between strength, physical function and bone density. This could have implications for the clinical management of FSHD patients, for example, it may be wise to use a lack of strength and physical function to prompt more frequent scans of bone density. It was also noted that there was a high prevalence of abnormal Vitamin D3 levels. Fascinatingly the risk of fractures was 48% in Australia versus 25% in the United States.

Overall the study indicated a high variability in bone density and other characteristics, and having FSHD does not automatically mean a patient has low bone density. However, the prevalence of mostly traumatic fractures in the patient group overall was high. It is the hope of the Foundation that this research paper will draw attention to this important clinical feature of FSHD patients and improve the standards of care not only in Australia but also in other countries.

<https://www.ncbi.nlm.nih.gov/pubmed/28214289>

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## Pearls Pearls Pearls!

This year, we officially welcome Australian Opal Cutters & Pearl Divers as a Corporate Partner of the Foundation. This family-run business has supported the Foundation for a number of years and is one of the world's leading producers of skillfully cut and polished Opals and carefully selected Australian South Sea Pearls.

Australian Opal Cutters & Pearl Divers is a family owned and run business with a long and successful history. 30+ years later the company is now run by Jason Blaiklock, (3rd generation family member) and has a global reach with exclusive cruise liners and a presence in over 38 countries.

We are thrilled to announce that Australian Opal Cutters and Pearl Divers will be a major sponsor at our upcoming Sydney Chocolate Ball, with a number of beautiful pieces being featured in our live and silent auctions. Further to that, the Foundation has the opportunity to host private Pearl Parties with a major portion of the proceeds supporting the Foundation. If you would be interested in hosting a private pearl party, please contact the Foundation at [admin@fshdglobal.org](mailto:admin@fshdglobal.org) or on (02) 8007 7037.

**Visit their website to learn more** [www.australianopalcutters.com.au/](http://www.australianopalcutters.com.au/)



## AFL Footy Tipping

The FSHD AFL footy tipping comp has started, but it is still not too late to sign up and be a part of this.

**1st Prize:** Mystery accommodation package for two

**2nd Prize:** \$200 dinner voucher in a CBD or town near you

**3rd Prize:** \$100 dinner voucher in a CBD or town near you



Entry fee is \$30 with all funds being donated to FSHD Global Research Foundation. To enter simply click the [link](#) and follow the directions to join. If you have any questions at all please contact Les Jones at [lesandclaire@bigpond.com](mailto:lesandclaire@bigpond.com)

# Sydney City Prestige Luxury Drive Day

We were thrilled to have partnered with Sydney City Prestige for a beautiful luxury drive day along the NSW Central Coast. On Sunday 26 March, the Foundation joined Sydney City Prestige along with VIP guests for a Charity Drive Day. With an incredible array of luxury vehicles to choose from we were blessed with beautiful weather making for a great driving day out.

Thank you to all involved in making this day possible.

Contact us for more information on how to be involved.

