

3 weeks to go before the 8th Annual FSHD Global Golf Tournament

The two day FSHD Global Golf Tournament is back.. so ask around the office, recruit your colleagues and friends to play a round of 18 holes, in the name of a good cause.

Beyond the golf itself, you will enjoy a hot breakfast, goodies on arrival, half way house treats and will conclude with a deluxe luncheon featuring entertaining stories from sporting legends;

Day 1: George Rose, Solomon Haumono, and Olympian ARU Sevens player Lewis Holland

Day 2: Brad Fittler & Andrew Johns,

This is a long standing Annual Golf Tournament within the Foundation, we appreciate your support to ensure this year's Tournament is a success, so please consider donating a prize, seeking sponsorship or recommending the event to those in your networks who enjoy a game of golf.

Teams can be reserved by clicking below or through the [website](#).

Day 2 Proudly sponsored by



September Science Meetings

FSHD Global is proud to announce we recently released \$1.4 million to fund world class medical research into areas of Therapeutics, Diagnostics and Infantile FSHD. This is an incredible feat, only possible with the support from our Corporate and FSHD community. This is also a reflection on the success of this year's Sydney Chocolate Ball. We look forward to announcing details of the new research grants in the coming weeks.

At the front line of global research, FSHD Global will bring several highly acclaimed researchers and clinicians to Australia in September, to travel across states educating and updating members of our community. We encourage you to save the date when we visit a place near you. These are really special evenings, a highlight of our year.

To reserve your seat [click here](#).

At the Edge of Research

FSHD Global Annual Science Week

Be part of a global conversation about FSHD research!

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

This year we are joined by:

Professor Silvere van der Maarel from The Netherlands who will be sharing insights from his ground breaking work in the discovery and characterisation of FSHD type 2.

Professor Yi-Wen Chen from the United states who will be discussing her significant work on infantile FSHD and the use of antisense oligonucleotides to treat FSHD.

Dr Davide Gabellini from Italy who will take you on a journey of discovery discussing new genetic mechanisms for FSHD.

Local speakers include Associate Professor Marnie Blewitt from the Walter and Eliza Institute of Medical Research and Dr Mark Cowley from the Garvan Institute of Medical Research.

Places are limited. Don't miss your chance to hear from our amazing line-up of researchers.



Annual Science Week Evening Seminars

Contact us or visit our website to reserve your seat at this free seminar.

www.fshdglobal.org
admin@fshdglobal.org
(02) 8007 7037

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| Sydney | Monday 5th September, 2016
6:00 pm - 9:00 pm
Garvan Institute
384 Victoria St (enter via Burton St)
Darlinghurst, NSW |
| Melbourne | Tuesday 6th September 2016
6:00pm - 9:00pm
Novotel on Collins - Australia Room 1
270 Collins Street
Melbourne, VIC |
| Brisbane | Wednesday 7th September 2016
6:00pm - 9:00pm
Novotel Brisbane - Kendall Room
200 Creek St
Brisbane City, QLD |
| Perth | Thursday 8th September 2016
5:30pm - 8:30pm
Harry Perkins Institute - Seminar Room G24
6 Verdun St
Nedlands, WA |



City to Surf - Join the FSHD Global team today



Sunday, August 14, 2016

The team from FSHD Global will be taking part in the City to Surf this year in Sydney. If you are taking part in this run, and would like to join our team please [register](#) and then go to [everyday hero](#) to join the team. We are excited to be taking part and will be running (or maybe walking!) to raise awareness for FSHD.

FSHD Global publishes clinical practice considerations for FSHD

Clinical practice guidelines are an important part of clinical practice for many health professionals. Health professionals need to know about, understand and critically appraise new evidence as it becomes available. The problem facing many health professionals is the pace at which new evidence is generated. It's estimated that 2.5 million scientific papers are published each year. Only some of these will be relevant to clinical practice, but health professionals need to know which ones are important and represent quality research, and which ones are not. This is where practice guidelines come in. Collating new research as it becomes available and systematically assessing it for quality before developing guidelines for clinical practice based on the available evidence.

Guidelines generate an accepted standard of care and create a benchmark for quality of care that clinicians can work to. Up until 2015 there were no guidelines for FSHD. Health professionals were essentially treating based on their own experience. In 2015 the American Neurological Association produced a guideline that covers aspects of diagnosis and management of FSHD. (1) However, this guideline was US focussed

and did not discuss who should be part of a care team, lifestyle management, respiratory function or options for rehabilitation.

In September 2015 FSHD Global convened a workshop of 13 leading international and Australian clinicians to expand on the US guidelines. (2) The guideline covers diagnosis and management of FSHD and sets out the standard of care that people with FSHD in Australia should expect from their care team.

The practice guidelines can be found [here](#)

The Foundation will be preparing a range of materials to support the guideline including factsheets and learning materials. These will be available soon.



1. [Tawil R, Kissel JT, Heatwole C, Pandya S, Gronseth G, Benatar M, et al. Evidence-based guideline summary: Evaluation, diagnosis, and management of facioscapulohumeral muscular dystrophy: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology and the Practice Issues Review Panel of the American Association of Neuromuscular & Electrodiagnostic Medicine. Neurology. 2015;85\(4\):357-64.](#)

2. [Tawil R, Mah JK, Baker S, Wagner KR, Ryan MM, Sydney Workshop P. Clinical practice considerations in facioscapulohumeral muscular dystrophy Sydney, Australia, 21 September 2015. Neuromuscular disorders : NMD. 2016;26\(7\):462-71.](#)

