

FSHD Global Golf Tournament. Secure your place and purchase your tickets now!

The count down has begun with only three weeks to go until the 8th Annual FSHD Global Golf Tournament teeing off at St Michael's Golf Club. With only two teams left, get in and purchase your tickets before you miss out!



This Ambrose Tournament is a fun and friendly environment to play golf with clients, friends or colleagues networking among an echelon of Australian businesses.

Enter your team today and help advance much needed medical research, medical education, treatment plans and ultimately a cure for the most common form of muscular dystrophy, Facioscapulohumeral Dystrophy.

All guests will enjoy breakfast on arrival, 18 holes of golf with complimentary electric carts, games along the green, drinks on the field, food at the half way house and will conclude with a deluxe luncheon during the Awards Ceremony.

We look forward to welcoming you and your guests, and thank you in advance for your support in our quest to find a cure for FSHD.

Proudly sponsored by Genworth 

THE DETAILS

Date:

Friday 30 September 2016
St. Michaels Golf Club, Little Bay, Sydney

Time:

7 am - Registration & Breakfast
8 am - Tee off
1 pm - Lunch & Awards Ceremony
3 pm - Formalities conclude

Format:

Enter a team of four to play 18 holes of golf in Ambrose format across a one day Tournament.

Dress:

Metal spikes, sandals, jeans, tracksuits or cords are not permitted

RSVP by 28 July 2016 to

events@fshdglobal.org or
phone (02) 8007 7037

2016 Annual Science Meetings

We are excited to have embarked on our annual Science Week for 2016 on Monday night in Sydney, with the speakers both entertaining and educating our local community. Traveling to Melbourne, Brisbane and Perth, be sure to come along to this free information night.

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.

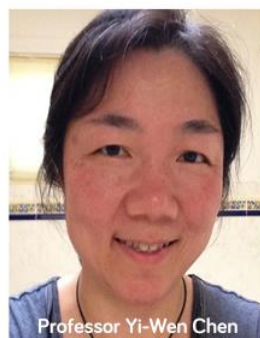
[Doctor Davide Gabellini](#) from Italy who will take you on a journey of discovery discussing new genetic mechanisms for FSHD.

In Sydney, we were joined by [Doctor Mark Cowley](#) is a local speaker from the Garvan Institute of Medical Research who spoke in Sydney about the role of diagnostics in Australia and how it is changing.

In Melbourne, we will be joined by [Associate Professor Marnie Blewitt](#) from the Walter and Eliza Institute of Medial research to talk about new treatments for FSHD 2.

In Perth, we will be joined by [Doctor Hugh Dawkins](#) from the Office of Population Health will talk about registries in Australia.

Don't worry if you are unable to attend, a video will be uploaded in the coming weeks of these incredible guest speakers and their updates on FSHD.



Facio-Therapies Announce Breakthrough

This week we are proud to announce that FSHD Global's Biotech Investment Medical Research Grant 33, Facio-Therapies, announced a breakthrough development in FSHD drug discovery.

What is it?

Facio-therapies have developed a high through-put screening platform that uses muscle cells from people with FSHD and actually measures DUX4 protein levels.

Why is it a breakthrough?

Most screening platforms use cells that are not specific to the disease and readouts that are not biologically relevant as fluorescence. This is because it is easier to use these cells and measure these outputs.

Facio-therapies have developed this platform to be more similar to human FSHD. It is hoped that by using this platform the potential drugs, or 'hits' will be more likely to progress through drug development.

What does this mean for FSHD treatments?

It is an exciting time for FSHD research. There are numerous teams around the world working on drug discovery using various different platforms. This platform from Facio-therapies is innovative and will add to the field of drug discovery for FSHD.

Facio-therapies is the world's first biotech company dedicated to drug discovery for FSHD and a recipient of the first biotech investment from FSHD Global.



Exercise & FSHD

The Latest Study

The role of exercise in muscular dystrophy has long been controversial and advice has oscillated from promoting exercise to counselling people with muscular dystrophy to avoid it entirely.

A recent [review](#) of the available evidence concluded that exercise was not harmful for people with FSHD, but was unable to conclude any benefit. This was based on the studies available which were short duration, or contained a mix of dystrophies or outcome measures. Now a [new study](#) may help build the case that exercise is an important part of management for FSHD.

This study was only 16 people but over 24 weeks they managed to show that a home-based program of cycling 3 times weekly for 35 minutes (combination of strength, high-intensity interval, and low-intensity aerobic) at home resulted in improvements in general fitness and muscle strength. They also showed improvements in the six minute walk test, a test commonly used to see if an intervention is effective in people with muscular dystrophy.

The Foundation recently published a clinical consensus statement that addresses the role of exercise in the management of FSHD. The statement along with support materials can be found [here](#) under treatment guidelines. Seek advice from a health professional before you embark on any exercise program.

What are your experiences of exercise? Do you find it helpful? Do you struggle with fatigue and muscle pain following exercise? We would love to hear your stories. Please email admin@fshdglobal.org



Racing to find a cure

Dane Knight is “running for those who can’t” in this year’s Blackmores Sydney Running Festival by attempting his first ever full marathon.

Dane attended this year’s FSHD Global Research Foundation annual ball and was inspired by the stories he heard and the struggles endured by those with the severe muscle wasting disease. Dane is taking steps towards helping the Foundation to find a cure; 42.195km of steps to be exact!

Dane is hoping to raise \$100 for each kilometre of the marathon and needs your support. Please [donate](#) to Dane's everyday hero page and support the Foundation.

Lets get behind him on this incredible run!

