

Progress



Tickets selling fast for 8th Annual FSHD Global Golf Tournament



This two day 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.

THE DETAILS

Dates:

Thursday 25 August 2016

Concord Golf Club, Concord, Sydney

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 two 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



Workplace Giving - How you can make a difference

The One Million donors campaign was launched in 2014 calling on Australian businesses to make a personal commitment to the charities they care about. Their goal is one million Australians giving to charity through their workplace by 2020.

Workplace Giving is a joint relationship between employers, employees and charities. By contributing a small portion of your pre-tax salary to charity, you will receive a tax benefit immediately rather than waiting until the end of the financial year. In many cases employers match staff donations, meaning your donation value doubles.

Here at FSHD we rely on our Monthly Givers to supply a steady stream of donations to fund our Medical Research, Medical Education and Investment.

Talk to your employer today about how you can start a Workplace Giving Program or if you are an employer, visit the [One million donors](#) website today to see how you can get started.

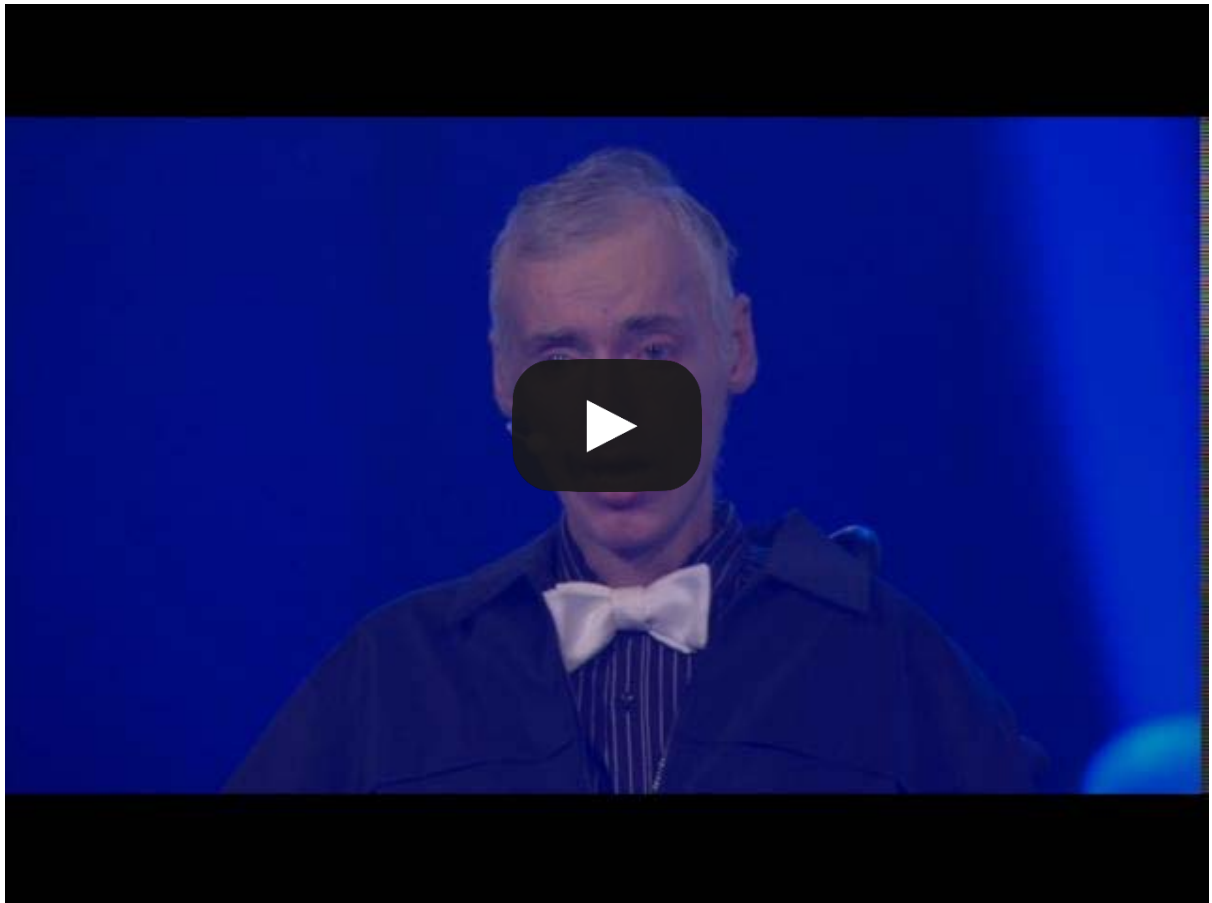


Medical Research Grant Update

2016 is an exciting year for research at the Foundation. Thanks to our communities continued support we were able to release \$1.3 million for three separate grants, diagnostics, therapeutics and the Monica Ellis Children's Medical Research Grant. We received 22 applications for our current round of grants, four from researchers that are new to the area of FSHD research. This means there are four labs from around the world who are bringing their expertise to FSHD research that we didn't have last year.

Applicants who made it through the first round of assessment are currently preparing their full applications, with successful projects announced in August.

We raised an amazing \$600,000 for medical research at this years Sydney Chocolate Ball, and will be announcing the next round of grants later this year. For those of you unable to attend the Sydney Chocolate Ball, we have included the highlights from the night along with Founder Bill Moss AM and Patrol Justin Reid's speeches from the night.



Guest Speaker & FSHD Global Patron Justin Reid inspires the 2016 Sydney Chocolate Ball crowd.



Highlights from the 2016 Sydney Chocolate Ball



Founder and Chairman Bill Moss AM speaks at the 2016 Sydney Chocolate Ball

Genetic Alliance Genome Sequencing

Genetic Alliance Australia is conducting research into the understanding of Australian patients and families on the use of genome sequencing in the healthcare system. It is open to anyone aged 18 years or older residing in Australia, and will help to gain a further understanding of genome sequencing. You can read more and take part in the survey [here](#).



FSHD: beyond muscles



For people with FSHD it will come as no surprise that this condition effects more than just muscles. Progressive muscle weakness leads to massive changes in the way people live their lives impacting how they get around, how they complete daily activities, whether they can work or care for children.

While this may seem logical there is actually very little known about the burden of FSHD. The variability in presentation and lack of research means we don't really know how people with FSHD experience the disease and what effect this has on their lives. This information is important. When someone gets a diagnosis of FSHD they need to be able to plan for their future. Will they need to move into an accessible house, will they be able to work and for how long? Information on burden can also help tailor management programs that includes all services people with FSHD require.

A study from Amsterdam in The Netherlands has provided some of the first evidence of personal burden of FSHD.⁽¹⁾ This study is what is called a 'qualitative' assessment, essentially, instead of measuring how much something is experienced they looked at the 'what' is experienced and the 'why'.

[Read more](#)

