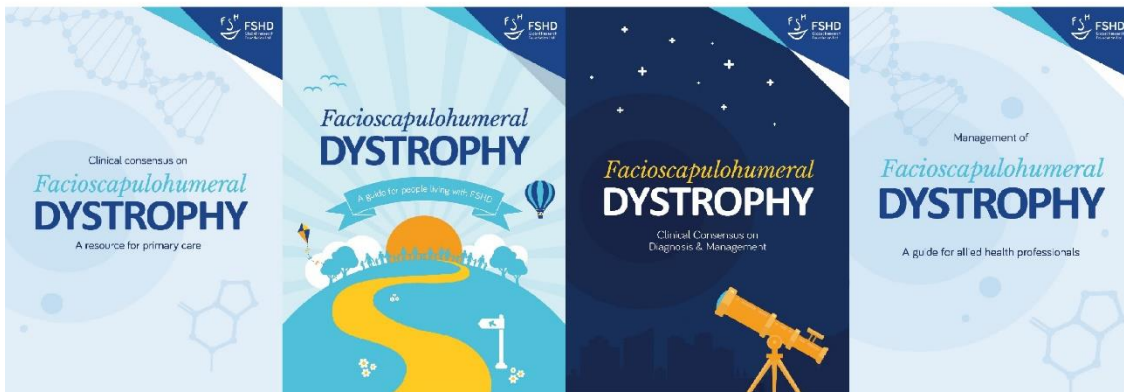


FSHD Educational Toolkits



Getting the support you and your health professionals need

The Foundation is thrilled to release a range of educational toolkits for patients, GP's and Allied Health Professionals. Our goal is to empower our community when championing for support within the medical world.

In September 2015 FSHD Global convened a workshop of 13 leading international and Australian clinicians to develop a [clinical practice guideline](#) on FSHD. 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.

From this, FSHD Global has created a set of free and accessible educational tool kits for people living with FSHD and health care providers.

The “Living with FSHD” booklet covers the care that you should expect from your healthcare team, steps for diagnosis and understanding test results, guidance on communicating with health professionals and some handy tools that may help make appointments more productive.

The other booklets are great resources to take to your health care providers to help them better understand the genetics of this disease, symptoms, prognosis and the effective management of FSHD.

Download and share:

[Clinical Consensus on Diagnosis & Management](#)

[A guide for people living with FSHD](#)

[A resource for primary care](#)

[A guide for Allied Health Professionals](#)

Facio Therapies



Arising from the FSHD community, Facio is translating breakthrough results of 25 years of basic research into a therapy that stops the progressive muscle wasting caused by FSHD. That is Facio's product mission. Facio also aims to make its therapy widely available by using a transparent model for fair and reimbursable pricing. That way, Facio aims to generate sustainable profits to fund additional quality-of-life projects for people with FSHD and to provide liquidity to its shareholders. That is Facio's socio-economic mission.

Facio Therapies announced at the end of December that it has screened approximately 34,000 compounds for their ability to repress the production of the muscle-toxic DUX4 protein in cultured muscle cells derived from FSHD patient biopsies. As planned, a variety of compounds with the desired effect (known as “hits”) have been identified.

In September 2016, Facio announced that, together with its drug discovery partner, German-based Evotec, it had established the first-ever screening platform that enables reliable quantification of naturally occurring DUX4 protein in cultured FSHD-affected muscle cells. Undue production of DUX4 is the cause of FSHD. When produced in muscle tissue, DUX4 is highly toxic due to a cascade of events eventually resulting in the devastating effects of FSHD. In people without FSHD, the production of DUX4 is repressed by regulatory mechanisms in the muscle cell. Facio's single goal is to pursue a therapy that restores this repression as much as possible.

“This is the very first large scale FSHD screening campaign on record that quantifies the naturally occurring DUX4 in patient derived skeletal muscle cells”, noted David Dasberg, Facio's Managing Director. He added: “Hits are the foundation for the development of our FSHD drug candidates, so we have to be very thorough. That's why we are now subjecting all our hits to a battery of additional tests to weed out false positives. We look forward to completing this process in the months ahead.”

Facio Therapies are now seeking interest from people interested in investing in their next round of funding. For more information please [contact](#) the Foundation.

Open Gardens



We are excited to announce that 2017 will see FSHD Global being a charity partner with 2 of Sydney's most incredible cold climate gardens for an open weekend. For just \$20 entry, 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 a rare 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](#).

Community Fundraising

We are thrilled to hear that FSHD Global Director Bechara Shamieh will be raising funds for FSHD as he challenges himself in this May's SwimRun event. SwimRun is a unique and challenging adventure sport where teams of two compete by alternating between running and swimming on a challenging course covering trails, beaches, ocean, cliffs, rocks, and paths. Teams must complete the entire course together and help each other through tough terrain to beat the course and reach the finish line.

Help Bechara and team mate Daniel make a difference by raising funds for medical research into finding treatments and a cure for FSHD. **Donate** [here](#).



Rare Disease Day

February 28th marked the 10th annual Rare Disease Day. This year's theme was research. At FSHD Global we have funded \$8.3 million dollars in global research to find treatments and a cure for FSHD, but we still have a way to go.

To celebrate this day and increase awareness for FSHD, we held an afternoon tea with our corporate partner [DibbsBarker](#). DibbsBarker have graciously hosted the Foundation for the past 8 years and have played a major role in the Foundation maintaining its 100% charity model.

This afternoon tea was a success in raising funds and increasing awareness of FSHD. We would like to thank everyone who came along to learn more about this disease and the Foundation.



Last Chance to Win!

The ASX Thomson Reuters Charity Foundation Art Union is drawn on the 16th March. Don't miss out on your last chance to purchase your tickets into this great raffle. With your ticket proceeds going to FSHD Global, get in with a chance to win one of outstanding prizes on offer. Win a new Lexus RX200T valued at over \$80k, a beautiful set of diamond and pearl earrings or a cruise down the Murray River.

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Purchase your tickets [here.](#)

