FSHD Global Research Foundation

Annual Report

THE AUSTRALIAN CHARITY AWARDS®

CHARITY OF THE YEAR WINNER 2017

2017

FSHD Global Research Foundation Ltd

Content

Our Story

FSHD Global Research Foundation was established in 2007 by Australian businessman, philanthropist and sufferer of FSHD Bill Moss AO. We fund world-class medical research and medical education to find treatments and a cure for Facioscapulohumeral Muscular Dystrophy (FSHD). This Foundation does not operate like your average not-for-profit. We allocate 100% of all tax deductible cash donations to current and future medical research investment, grants and education whilst the Foundation's operations are supported by non-tax deductible sponsorships. With no government support, this unique charity model offers great transparency and accountability in allowing us to fulfill our mission.

Mission

To advance global medical research, education and collaboration to improve quality of life and ultimately find a cure for Facioscapulohumeral Dystrophy. Through transparency, accountability, good governance and pure passion we aim to achieve results as quickly as possible.

Vision

A cure for FSHD to enable all people living with FSHD globally to live healthy and unrestricted lives.

Values

Transparency and accountability

We are clear and open about where your money goes, how we make decisions and how we run the Foundation. We take responsibility for our actions and openly communicate with our donors and sponsors.

Experimentation and Innovation

We encourage new approaches to solving problems and look beyond the boundaries of traditional disciplines and areas of specialty.

Community

We are committed to staying close to our community of people living with FSHD and their friends and families to ensure our research is in their interest. We leverage their skills, knowledge, experience and networks to advance closer to achieving our mission.

Passion

We are a family Foundation directly impacted by the disease, with a relentless drive to find a cure as quickly as possible.

FSHD Global would like to thank DibbsBarker for their ongoing support in housing our team and providing their valuable time, expertise and resources at no cost to the Foundation.

$9 MILLION

FSHD Global Research Foundation has successfully raised over $9 million dollars in tax deductible donations.

Founded in 2007, we have achieved this result in just 9 years.

This money has helped fund 42 world class medical research grants in 9 countries around the globe.

Message from the Chairman

Dear Friends,

Winning The Australian Charity of the Year, in the Australian Business Awards, is a prestigious honor. This award acknowledged our outstanding achievement in advancing FSHD global medical research and education.

Winning this Award is the beginning of a new era for the Foundation, we will strive to improving what we do, and how we do it.

In nine short years, the Foundation has raised over $9 million dollars, established 42 medical research grants across 9 countries.

Despite receiving no government support the Foundation remains one of the world's largest supporters of FSHD research.

As a result of our grants we have seen the publication of 53 papers in eminent journals. We also published what we believe to be the Australian first educational toolkit for allied health groups, patients and GP's providing a clinical consensus on diagnostics and management of the disease.

I would like to take this opportunity to thank all our research scientists, donors, corporate sponsors, volunteers and staff that have made the FSHD Global Research Foundation the Australian Charity of the Year.

This Foundation remains committed and focused on the future and will strive to fast track a cure for FSHD, and in the process unlock new scientific discoveries that affect muscles, bones and the respiratory system.

Bill Moss AO
Chairman and Founder
FSHD Global Research Foundation

Our Highlights

Winner of the Charity of the Year in The Australian Charity Awards 2017

42 ongoing Medical Research grants into Basic, Diagnostic and Therapeutic research areas

FSHD Global has raised over $9 million in 9 years funding medical research in 9 countries

We remain one of the largest contributors to FSHD medical research outside of the US Government

Our Board of Directors, Science Advisory Boards, Patrons and Ambassadors receive $0 remuneration

We proudly allocate 100% of all cash tax deductible donations to current and future medical research investment, grants and education

FSHD Global launched Australia's first FSHD educational toolkits for patients, GP's and allied health groups to better understand the impact of living with FSHD

The 'FSHD - Find the Cure' App is an innovative tool allowing donors to track exactly which medical research grant(s) their donation funded and follow the progress

Message from the Chief Executive Officer

It is with incredible pride and enthusiasm that I have joined FSHD Global as we approach our 10 year anniversary milestone with some outstanding achievements under our belt and a very exciting future ahead.

Our innovative charity model inspired by passion, energy and drive for a cure for FSHD continues to see us achieve recognition for our high level of transparency and accountability to donors in every aspect of our operations.

Being awarded Australian Charity of the Year in 2017 has been an incredible celebration of our efficient model and an organisational pinnacle that our dedicated staff and board have been collectively inspired by. It has motivated us to do even more to give hope to the 1 in 7500 Australians living with FSHD that a cure can be found quickly.

Fundraising is at the heart of what we do and ongoing funding is the key to driving the continued momentum of ground-breaking FSHD research across the globe.

Over the next few months I look forward to meeting each and every one of the amazing group of committed and generous individual and corporate supporters who have contributed so much to our success.

Our Charity of the Year status also gives me a great opportunity to start fresh conversations with potential new corporate and philanthropic partners who may wish to make us their charity of choice.

I am thrilled to be leading such a passionate, loyal and talented team of staff and volunteers at FSHD Global. I look forward to what we can achieve together as we set new benchmarks, welcome new partners and bring new ideas to life in our quest to raise funds for and awareness of the Foundation's great work.

Kate Ross
Chief Executive Officer
FSHD Global Research Foundation

Sophie's Story

I'm 10 years old and I want to tell you what living with FSHD is like for me.

How FSHD affects me every day

FSHD affects me every day. It stops me having a normal day like everyone else by giving me pains in my shoulders, neck and legs and other parts of my body. Every day I get really tired. Simple things can be really hard for me to do. My side muscles are too weak for me to sit on the floor to play games or watch TV. Its getting really hard to write because my muscles are getting weaker. I also have to sit down regularly because my legs get sore and I can't walk any more. I miss out on some things my family does, like walking or swimming at the beach. My family can't do some activities that they enjoy, like going bushwalking or going to the beach because they know it's really hard for me. Going on holidays is fun, but it's hard because I can't get to lots of the fun places because my wheelchair can't get through. Last year we went to Wet 'n Wild but I couldn't go on any of the waterslides because I couldn't get up the stairs. It sucked watching my sisters have a good time. Using my wheelchair in the house is a real hassle because the rooms are too small and I sometimes bang into the walls but Mum and Dad don't get angry. We are building a special bathroom to make it easier for me to wash.

FSHD affects the way other people see me and treat me

FSHD affects the way other people see me and treat me. There's only one other kid I know in our town who is in a wheelchair. People don't understand why I am in a wheelchair. When we go out kids and their parents stare at me because they don't understand my disability. Kids pull weird and disgusting faces at me. It makes me feel ashamed and embarrassed. It is the worst when I go out shopping or when we mix with other schools. It makes me feel like not going out anywhere. When I start High School and I'm really worried the kids will stare at me and tease me.

Some of the things I can't do, but I would like to do

Some of the things I would like to do but can't are athletics, cross country, walking with my family and many more things that normal kids do.

FSHD makes it hard to play with friends. Most of my friends like to play soccer at recess and lunch, but I find it too hard so I feel left out.

I can't do those things because my muscles get too sore. For example, last year I wanted to try to race in the cross country. I walked down to the starting line, started the race, but my legs got really sore and I needed to stop racing and go to my wheelchair. I felt really embarrassed and sad because everyone was watching. So I don't try to participate any more. When I get invited to play at a friend's party I worry that there is going to be lots of running around.

To change the future for children like Sophie, we are funding the world's first clinical trial in children with FSHD conducted by The Royal Children's Hospital in Melbourne through the Monica Ellis Children's Medical Research Grant.

Why I want a cure or treatment to be developed as soon as possible

I want a cure or treatment to be developed soon because I am worried about my FSHD getting worse and getting to the point that I can't walk anymore. That means I will need to be in my chair all the time which means that my Mum and Dad will have to spend more money on making the house bigger, buying hoists, shower chairs and toilet chairs and get changes done at school.

I will also need a helper for when I need to transfer into classrooms that don't have ramps and out into a different chair for doing simple things like going to the toilet.

The equipment I rely on

The equipment I rely on is my power wheelchair and my travel wheelchair. I also rely on specially made orthotics and that means I need special shoes that are very expensive. I rely on wheelchair accessible cars, ramps and lifts when I am getting somewhere. The equipment takes up most of the space in my room.

The worst part about having FSHD

Lately I've noticed that it is getting harder to get stand up when I'm on the ground. Eating some foods is hard. I have to get meat cut up for me. It can also get worse if you eat too much food and you're overweight. Or it can just get worse by itself eventually. I hate that I can't take short cuts around school but the teachers are good and they make everyone take the same path as I do.

The best thing about having FSHD

That you can get out of doing sports such as cross country and athletics carnivals. You can also play special sports for disabilities. Some of the sports are boccia, wheelchair basketball, wheelchair soccer and wheelchair rugby league and more. There are also kids camps that you can go to and meet other kids with similar conditions of muscular dystrophy and no one gets teased at those camps because most of the kid campers are in wheelchairs.

How you can help

You can help me and other kids out by donating to FSHD Global so that they can find a cure or treatment before my FSHD get worse. Please.

is a genetic disease with no treatments and no cure

does not discriminate by age, sex, race or religion

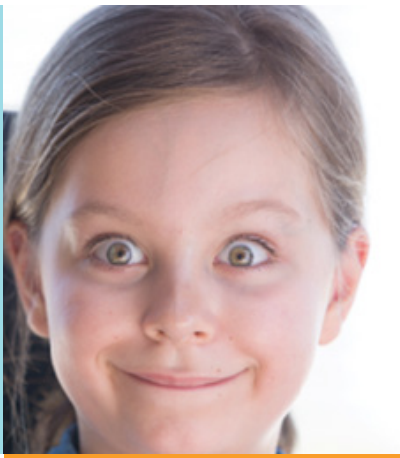
is one of the most common forms of muscular dystrophies affecting adults and children

is named for its affecting areas: face (facio), shoulder and back (scapula) and upper arm (humeral)

Facioscapulohumeral muscular dystrophy:

affects 1 in 7,500 Australians

demonstrates bursts of sudden muscle death



can manifest at any point in a person's life from infancy to late adulthood

is often misdiagnosed or misunderstood by doctors

Charity of the Year!

FSHD Global Research Foundation has been recognised as Charity of the Year in The Australian Charity Awards 2017. Now in their fifth year, The Australian Charity Awards are a partner program of The Australian Business Awards and have been established to identify, recognise and reward organisations for the exceptional work undertaken through their charitable initiatives.

"We are honoured to be recognised as the Australian Charity of the Year. This fantastic achievement highlights the calibre of the Foundation and recognises our innovation, transparency and commitment to funding world's best medical research and education of FSH muscular dystrophy on a global scale."

"Being praised for our 100% donor model, which sees every tax deductible dollar directed towards research, sheds light on the importance of transparency and accountability within the not for profit sector. Pairing today's technology with traditional modes of philanthropy gives the donor journey a stronger sense of impact and satisfaction, as we strive towards an ultimate cure", said FSHD Global Research Foundation, Natalie Moss, Managing Director.

This prestigious accolade will act as a tool for the Foundation to obtain exposure, recognition and acknowledgement for our distinctive and innovative charity model on a prominent and far-reaching scale. This will also provide a platform to increase the general public awareness for this genetic disease.

If you would like to partner with the Australian Charity of the year, please contact Kate@fshdglobal.org or on (02) 8007 7037

Our Board of Directors

The Foundation relies on the generosity, time and expertise of our community to continue to excel in our mission for a cure. We are fortunate to have an incredible support network made possible by our non-remunerated Board of Directors, Science Sub-Committees, Patrons, Ambassadors, Staff and Volunteers who each offer vast experience in their respective fields to support our quest for a cure.

Bill Moss AO
Chairman

James Wakim
Deputy Chair

Natalie Moss
Managing Director

Alan Watts
Head of Science

Andrew Rigney
Secretary / Director

Andrew Frost
Director

Barry Robinson
Director

Bechara Shamieh
Director

David Mackay
Director

Glenn Willis
Director

Malcolm Beville
Director

Nigel Virgo
Director

Pradnya Dugal
Director

Bev Baker
Alternate Director

James Harvey
Alternate Director

FSHD
Find the Cure
APP

FSHD Global Research Foundation does not operate like your average not-for-profit. FSHD Global is a believer of transparency in all areas of charity, with research and accountability being integral aspects of its organisational culture and structure. The Foundation views every tax deductible dollar donated as an investment into FSHD medical research and medical education worldwide, which is why we believe each donor is entitled to know exactly where and how their donation has been invested.

Download the award winning "FSHD - Find the Cure" App for free today to see the history of your donations and the specific research you have supported. Stay up to date with the latest scientific updates, Foundation's news, achievements and so much more.

Service Science Society AUSTRALIA

2014 AUSTRALIAN SERVICE INNOVATION AWARDS

Paul's Story

I'm 37 years old, married and have two beautiful children. My son Hunter is 10 and my daughter Allegra is 8.

My FSHD story began at around the age of 26. I began to get in shape for our wedding, and my wife noticed that my left pectoral muscle was developing but my right wasn't. It wasn't until I started experiencing back pain and migraines that I decided to see a chiropractor. This meeting resulted in me being referred to my GP, then to a rheumatologist and on to a neurologist. Each practitioner was truly perplexed by my symptoms. By this point I was also experiencing vision disturbances and tingling and numbness down my arm.

My wife and I were frustrated that I had these mystery symptoms and none of the medical experts had a clue why.

The next few months were a whirlwind or MRI's, scans and ultrasounds and a suggestion emerged that I had MS. Medical experts found my condition so puzzling that I was receiving completely conflicting information - one well known neurologist even suggested that there was nothing wrong with me and that I should just go home and live life because I could be hit by a bus tomorrow! My wife and I were enraged.

Finally I ended up at St Vincent's Hospital in Melbourne and the words Facioscapulohumeral Dystrophy first came up. The test results took 3 months to come back and it was the longest 3 months of my life. The results came back positive - I had FSHD. I was 30 years old.

On one hand I felt relieved to finally have an answer and on the other hand I felt totally overwhelmed by my shock diagnosis. I remember asking the question, what does this mean for my future and for my children's future? The doctor informed us that both our children have a 50% chance of inheriting the disease. I felt numb and my wife cried for a days. My world felt like it had been turned upside down. I was told not to lift anything over 10kg and that I would have to change my career as a plumber.

The diagnosis sent me into a deep depression. My small children both weighed over 10 kg, so the idea of not lifting them was unthinkable. I had also spent 10 years building up my plumbing business and there was no way that I wanted to give it up. My parents and siblings found it hard to discuss the diagnosis with me and this was very hard to deal with. There was no family history of the disease at the time of my diagnosis, and it took 3 years to get a definitive answer for my symptoms.

I shut down emotionally and went into denial phase which was very hard on my family.

My plumbing business suffered greatly as a result of the diagnosis. To be open with my clients I decided to let them know about my condition, but what happened next I never dreamt could be possible. Within 6 weeks I got the devastating news that my services were no longer required by my biggest client.

This meant that the business and my family's livelihood was in jeopardy. In the blink of an eye I felt I had lost nearly everything. I eventually decided that this disease was not going to define me and I worked harder than I've ever worked before in an attempt to build my business up while I still had the strength.

In hindsight this approach was probably not the best way to deal with it but I felt I had no other option. Four years on and FSHD has really progressed for me. I have experienced considerable loss of strength and a lot of pain. I try hard to push my body but am realising that it's no longer possible. This has had an enormous effect on me mentally. I think that I am still in denial about what is happening to my body and I refuse to accept that I can no longer do what once came so easily to me. I feel like I am losing control and failing. I suffer awful anxiety and panic attacks. I know that I really am lucky in the scheme of things and realise that there are others far worse off but I guess everyone's situation is relative to them and their lives.

I hold on to so much hope that there will be a cure in the near future, not just for me but for everyone suffering with this terrible disease.

Our Events

FSHD Global Annual Science Week

In September, FSHD Global toured some of the world's leading FSHD scientists across Sydney, Melbourne, Brisbane and Perth for the FSHD Global Annual Science Week. We would like to thank our International scientists; Professor Silvere van der Maarel, Professor Yi -Wen Chen and Doctor Davide Gabellini and the local speakers; Doctor Mark Cowley, Associate Professor Marnie Blewitt, Doctor Ian Woodcock and Hugh Dawkins for educating our Australian community, sharing insights and updating us on the most recent scientific breakthroughs for FSHD. It was an inspiring week or all who attended.

8th Annual FSHD Global Golf Tournament

Our annual FSHD Global Golf Tournament sponsored by Genworth was held in September at St. Michael's Golf Club. Whilst the competition was close, it was Wyndham Vacation Resorts Asia Pacific who took out the winning title. A special thank you to Genworth who were the Naming Rights Sponsor. With the success of the Tournament, we would also like to thank our corporate community, sponsors, players, volunteers and special guests; Brad Fittler, George Rose and Renee Gartner who entertained us over lunch.

Community Meetings

Across the year, our team took to the road to meet with the wider FSHD Global community. With meetings held in Sydney, Melbourne and Brisbane we set out to share our 2017 events calendar, fundraising goals, and how people can be involved in the Foundation. We are grateful for the support of everyone who attended and were thrilled to see the fundraisers that were held as a result.

Open Gardens

In April, FSHD Global held an Open Garden Fundraising Weekend at Mount Wilson, Blue Mountains. We were proud to be associated with two magnificent cold climate gardens that showcased the stunning colours of changing leaves, age-old trees and the serene and peaceful beauty of the Blue Mountains. Special thanks to Peter and Ann Pigott of Yengo Sculpture Garden who opened their gardens for the weekend and to our Chairman Bill Moss AO for opening Dennarque Estate.

8th Annual Sydney Chocolate Ball

In June, the Foundation held its most successful Chocolate Ball to date, and what a night it was! Guests were treated to fine champagne, decadent Lindt chocolate and incredible entertainment and an inspiring story from special guest Tracey Jackson on the impact of living with FSHD. The amazing Moulin Rouge themed event saw host Jamie Durie OAM and celebrity chef Luke Mangan join us again along with so many of our sponsors and friends who generously gave their time and support.

Save the Date!

9th Annual Sydney Chocolate Ball will be held on Saturday June 16th, 2018 at the Star Events Centre. This is a sold out events each and every year so be sure not to miss out!

events@fshdglobal.org
(02) 8007 7037

Our Finances

Where the money comes from

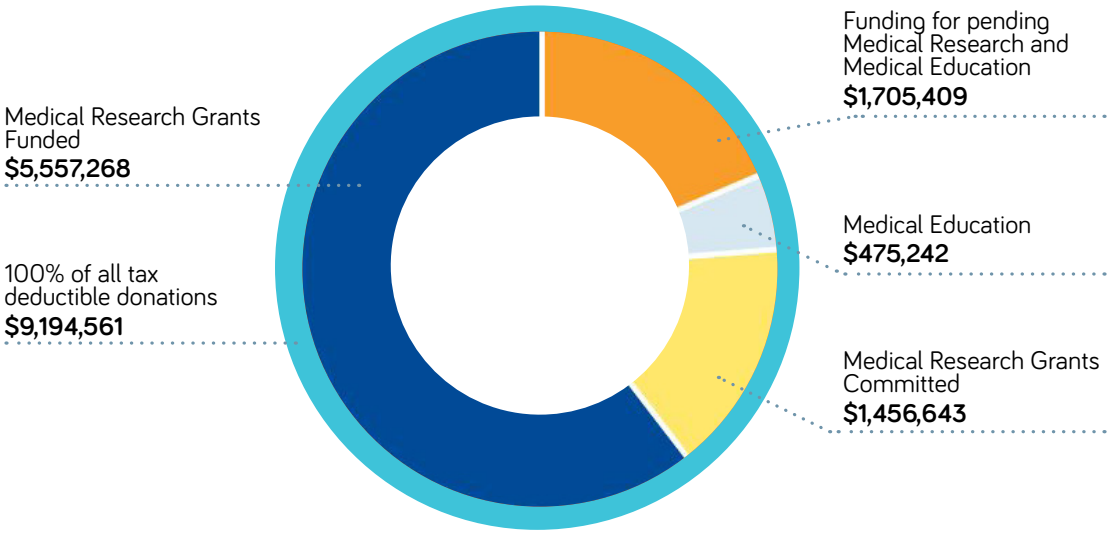
As at June 30 2017, the Foundation has successfully raised over $9.1 million in tax deductible donations and over $2.3 million in net non-tax deductible income. This has been achievable because of the support of our community and the hard work of our lean, dedicated team.

Where the money goes

The Foundation funds world class medical research, education and investments championing a cure for FSHD. We encourage collaboration in medical research, putting Australia in the middle of the global medical matrix of FSHD.

Allocation of Tax Deductible Donations

Inception - 2017 FY: As at 30th June



100% of all cash tax deductible donations are allocated to current or future medical research investment, grants and education.

FSHD Global continues to dramatically advance the global footprint of FSHD by increasing funds distributed to medical research, investment and education on a global stage. The Foundation funds each grant to full term (ranging from 1 – 3 years) with medical research distributions released when agreed scientific milestones are reached.

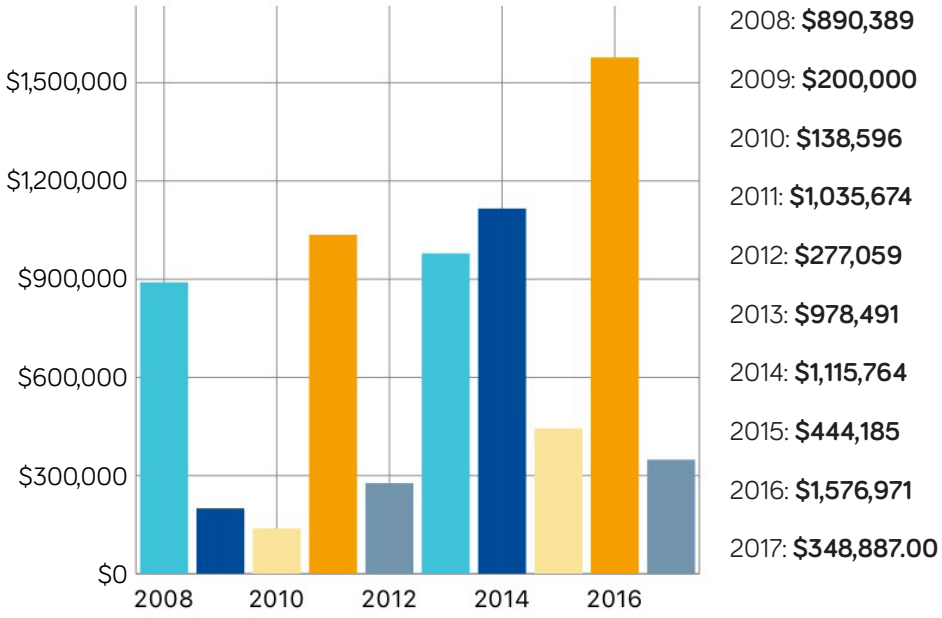
As part of our 100% model, the Foundation's operating expenses are covered by other Non-Tax Deductible fundraising activities such as sponsorships and auctions. It is through such transparency, accountability, good governance and pure passion we seek to find a cure for FSHD as quickly as possible.

Net Non-Tax Deductible Income vs Operational Expenses

2007 - 2017 FY: As at 30th June

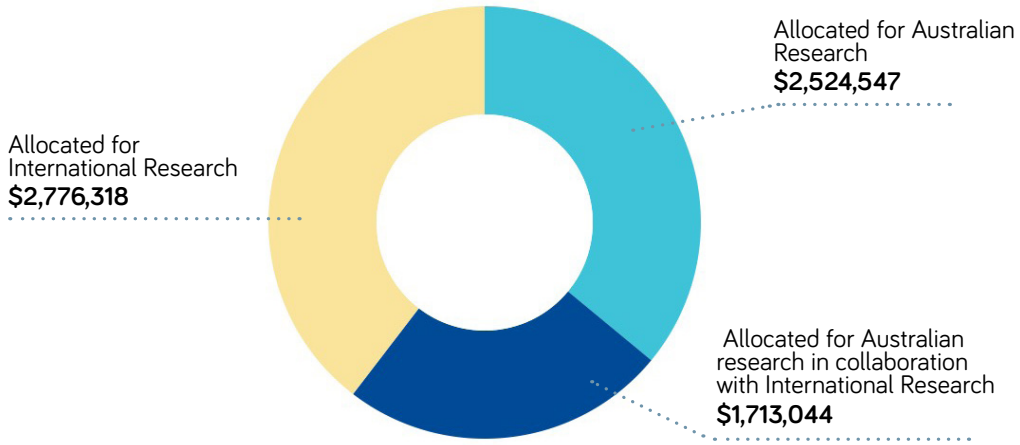
Medical Research Contracted

2007 - 2017: As at 30th June



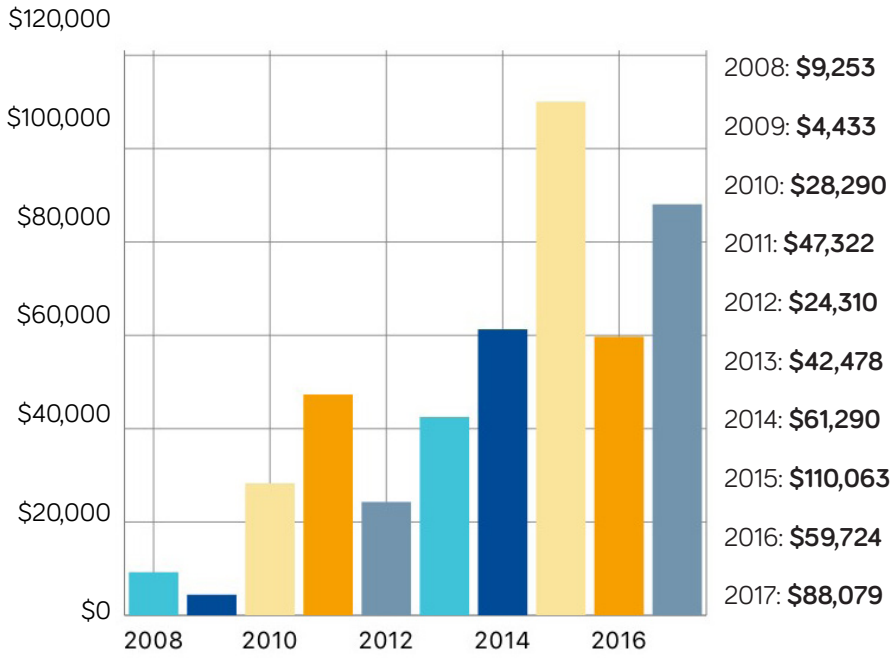
Medical Research Allocated

2007 - 2017 FY: As at 30th June



Medical Education Funded

2007 - 2017 FY: As at 30th June



Statement of Profit or (Loss) and Other Comprehensive Income

For the year ended 30 June 2017

	Notes	2017 $	2016 $
Donations	3	901,757	1,014,740
Other Fundraising Income	3	773,702	1,307,571
Other income	3	70,540	93,722
		1,745,999	**2,416,033**
Grants made	4	(987,982)	(850,648)
Fundraising expense		(503,389)	(660,084)
Education programs		(88,079)	(21,416)
Sponsorship		-	(38,308)
Employee expense		(271,243)	(424,119)
Other expenses		(52,727)	(40,781)
(Loss)/Surplus for the year		**(157,421)**	**380,677**
Other comprehensive income:			
Other comprehensive income		-	-
Other comprehensive (loss)/income for the year, net of income tax		-	-
Total comprehensive (loss)/income for the year		**(157,421)**	**380,677**

Statement of Financial Position

As at 30 June 2017

Assets	**Notes**	**2017** **$**	**2016** **$**
Current			
Cash and cash equivalents	5	1,726,011	2,765,966
Trade and other receivables	6	73,535	75,130
Financial assets	7	1,484,733	741,511
Other assets	8	43,306	37,321
Total Current assets		**3,327,585**	**3,619,928**
Non-current			
Investments	9	485,632	333,412
Property, plant and equipment	10	10,312	18,683
Total Non-current assets		**495,944**	**352,095**
Total assets		**3,823,529**	**3,972,023**
Liabilities			
Current			
Trade and other payables	11	22,649	5,902
Provisions	12	4,105	11,925
Total Current liabilities		26,754	17,827
Total liabilities		**26,754**	**17,827**
Net assets		**3,796,775**	**3,954,196**
Equity			
Retained earnings		3,796,775	3,954,196
Total equity		**3,796,775**	**3,954,196**

Download the full Audited Financial Report at goo.gl/CGJJcS

Help Make a Difference

One Off Gift

Donate a one-off amount to go towards finding a cure for FSHD. Take the opportunity to elect the particular grant or area of research you wish to support.

Flex your muscles for us

Walk, swim, run, cycle, paddle, climb or create your own active challenge! Get your friends along to participate or sponsor you and ask your employer to match the donations to make twice the impact.

Corporate Partnership

Become a corporate partner of FSHD Global and give your staff access to events and volunteering opportunities across the year. Your staff and executives can also make important business connections though our events and boardroom lunches.

Monthly Giving

Support us by making a regular monthly donation - all donations over $2 are tax deductible. A small monthly gift can make a huge difference to advancements in research as we move closer to finding a cure for FSHD.

Bequest

Leave a legacy that will change lives. Your gift can play a vital role in achieving tomorrow's medical breakthroughs that will change the future for people and families living with FSHD.

Become a part of the Family

Host your own fundraising event and fundraise on behalf of the Foundation. Whether it be a birthday, ladies lunch, comedy night or dinner, we encourage and appreciate all fundraising attempts – no matter how big or small.

Donation Boxes

Every dollar counts, and it doesn't always have to be from your own pocket. You can help raise funds by placing a donation box in your local cafe, workplace kitchen or business place. Donation boxes are an easy way to generate awareness within your community and offer a simple way your friends and family can get involved.

Speak to us about how you can Volunteer

Volunteer your time and skills to the Foundation. Whether it be through our internships, events or advisory boards – any help is hugely appreciated.

For more information please contact us at admin@fshdglobal.org or visit www.fshdglobal.org

What is FSHD

Facioscapulohumeral muscular Dystrophy (FSHD) is a genetic neuromuscular disease characterised by the progressive weakening and loss of skeletal muscles. FSHD places a significant burden on those affected by it and their families.

There is currently no cure and no effective treatments for FSHD.

FSHD is the most common form of muscular dystrophy affecting both adults and children. It is estimated to affect 1 in every 7,500 Australians, however, this number is probably higher as FSHD is commonly misdiagnosed or undiagnosed.

Despite the fact that FSHD affects around 3,200 people in Australia the government has never provided funding for FSHD research. Internationally the level of funding is minimal.

As a result, FSHD research is estimated to lag behind research into other forms of muscular dystrophy by about twenty years.

The symptoms of FSHD can manifest at any point from infancy to late adulthood, although the average age of diagnosis is around 30. Infantile FSHD is particularly severe and children affected tend to have more severe symptoms and added health complications.

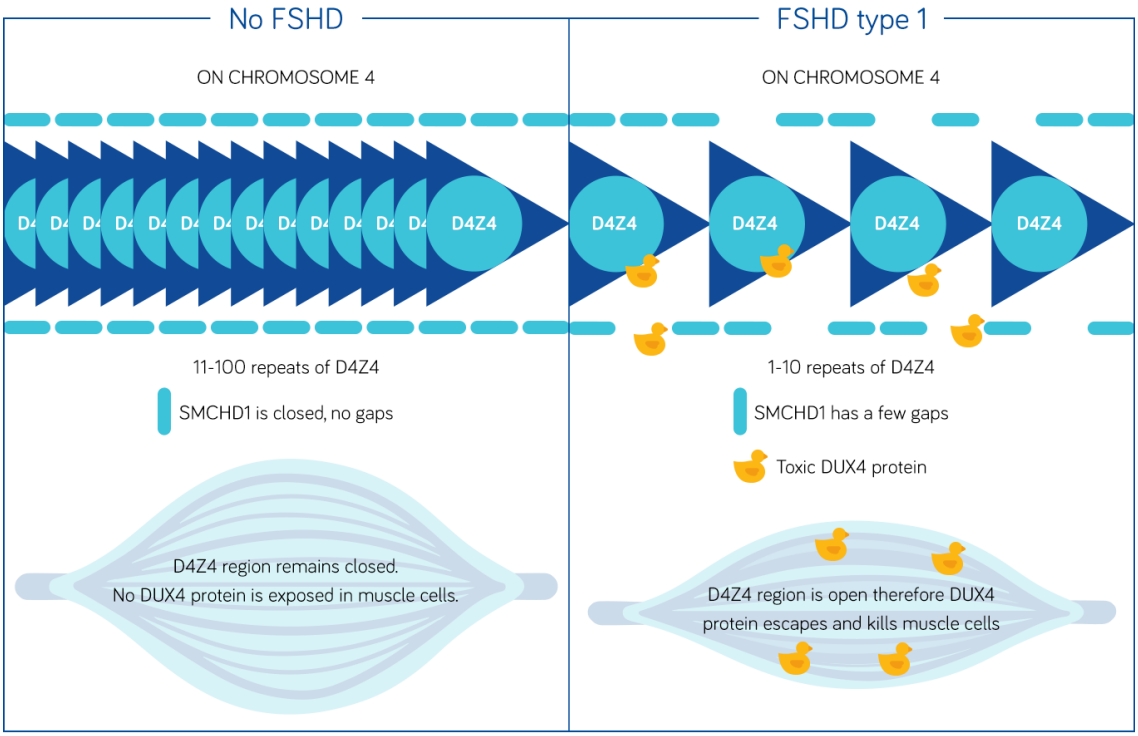
FSHD is commonly associated with progressive weakening of facial (facio), shoulder (scapulo) and upper arm muscles (humeral). However, this explanation does little justice to a disease that can rob people of their ability to walk, talk, smile or even eat. The progression is highly variable and often comes in bursts with sudden deterioration followed by periods of no change. Many people with FSHD may experience serious speech impediments caused to the weakening of facial muscles. 15% of patients have high-frequency hearing abnormalities and one in four also develop abnormalities in the blood vessels at the back of the eye with a small minority leading to vision problems.

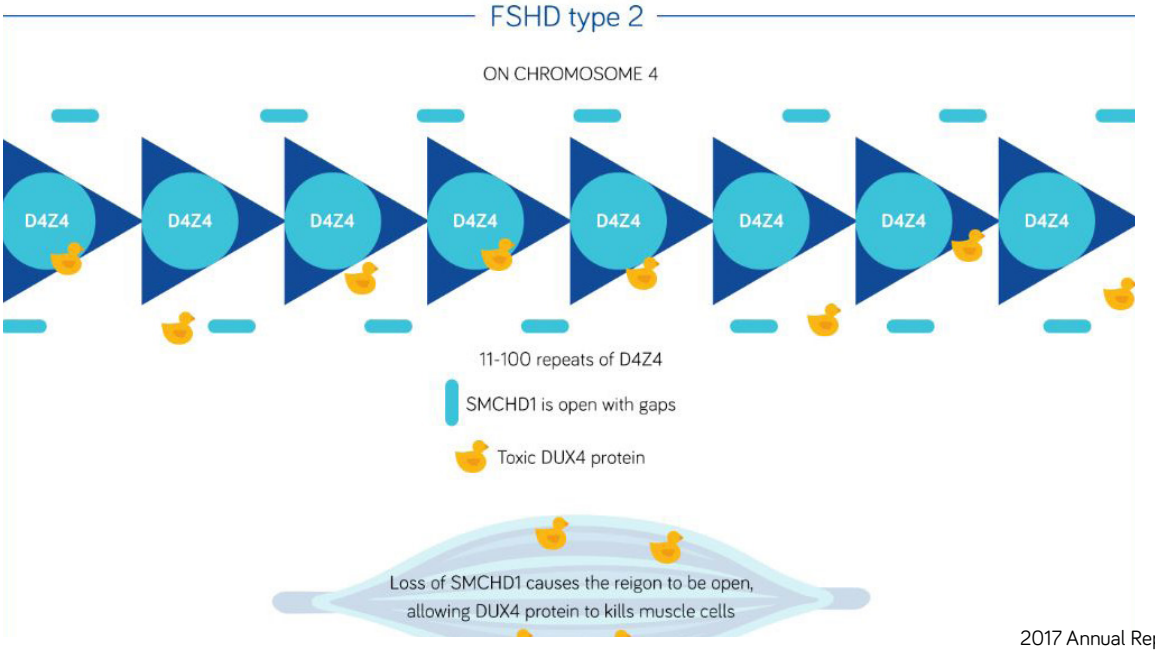
The symptoms of FSHD are caused by the production of a protein called DUX4.

This protein plays a normal role in early foetal development, but it is highly toxic when produced in adult muscle tissue. In people without FSHD, the DUX4 gene is repressed and levels of DUX4 protein are low. For people with FSHD, the DUX4 gene is not repressed and the toxic protein damages muscle cells.

While many hereditary diseases are caused by a single genetic defect, the production of DUX4 and the development of FSHD can actually result from defects in two different chromosomes. The majority of sufferers (95%) have what is called FSHD 1 which is caused by a defect on Chromosome 4. The remainder (5%) have FSHD 2 which is caused by a defect on Chromosome 18.

This scientific complexity, coupled with the shortage of research funding, makes the search for a cure even more challenging.


No FSHD
ON CHROMOSOME 4
D4Z4
11-100 repeats of D4Z4
SMCHD1 is closed, no gaps
D4Z4 region remains closed.
No DUX4 protein is exposed in muscle cells.
FSHD type 1
ON CHROMOSOME 4
D4Z4
D4Z4
D4Z4
D4Z4
1-10 repeats of D4Z4
SMCHD1 has a few gaps
Toxic DUX4 protein
D4Z4 region is open therefore DUX4
protein escapes and kills muscle cells


FSHD type 2
ON CHROMOSOME 4
D4Z4
D4Z4
D4Z4
D4Z4
D4Z4
D4Z4
D4Z4
D4Z4
11-100 repeats of D4Z4
SMCHD1 is open with gaps
Toxic DUX4 protein
Loss of SMCHD1 causes the reigon to be open,
allowing DUX4 protein to kills muscle cells

The Science

Facioscapulohumeral muscular dystrophy is arguably one of the most complex genetic conditions currently known. It is convoluted and complicated.

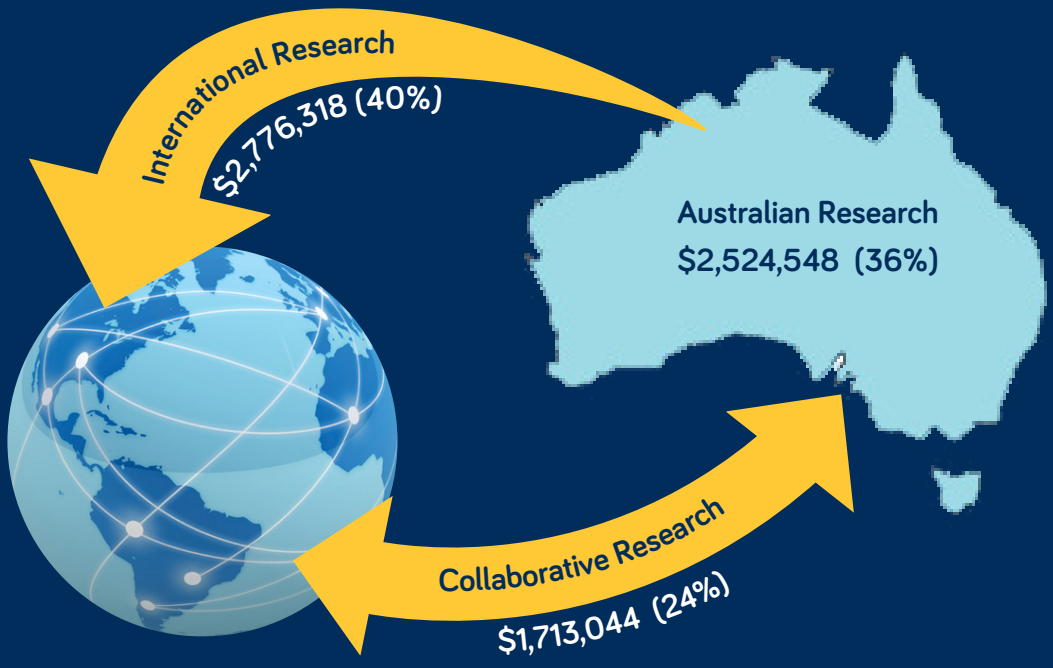
Within nine years, the Foundation has established 42 world class medical research grants, with each project acting as a stepping stone towards identifying treatments and a cure for FSHD.

In 2017, the Foundation allocated $1.5 million, creating 5 new research grants.

As the Foundation works towards finding a cure, it became more and more evident that we needed to focus on effective treatments and therapeutic initiatives to aid quality of life for people currently living with the disease.

2017 saw the publication of a world first bone health study between Australian and America looking at the morbidity of low bone density and bone fracture risk in patients suffering from FSHD. A respiratory sleep study was established to look at lung volume, breathing and cough effectiveness aimed at developing evidence-based guidelines for assessment and monitoring in FSHD. Following this push to improve clinical care, we published what we believe to be the world's first educational tool kit for Allied Health Groups, Patients and GPs, providing a clinical consensus on diagnostics and management of the disease.

In our search for a cure, the Foundation recently funded world class medical research including; an Australian first Infantile FSHD grant aimed at strengthening muscle mass in children, advancements of pharmaceutical therapies through small molecule inhibitors, an analysis of genetic verification of FSHD and its subtypes, as well as new drug target discovery in human FSHD well lines and tissue biopsies.



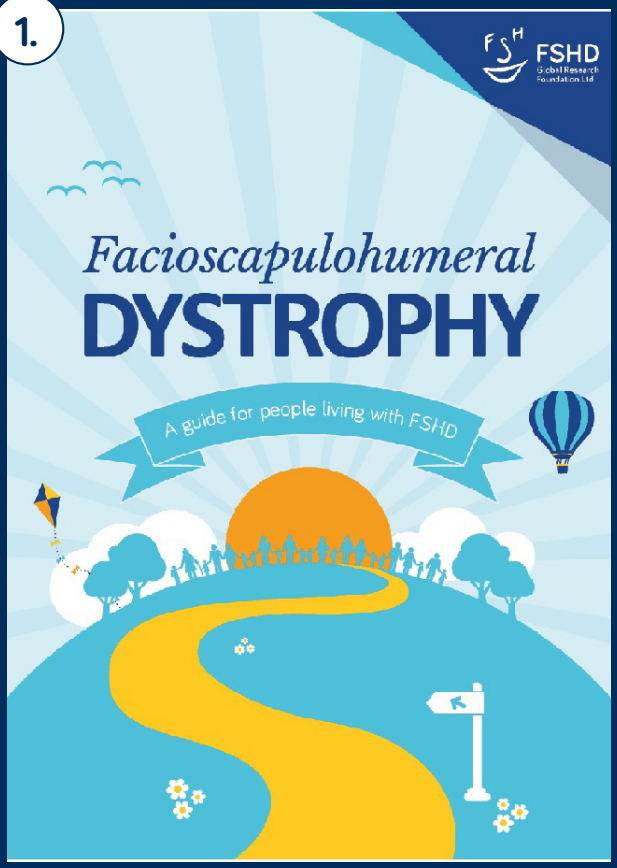
FSHD Educational Toolkits

The Foundation was thrilled to release a range of educational toolkits for Patients, GP's and Allied Health Professionals. We set out with the goal to empower our community when championing for support within the medical world.

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, the Foundation created a set of free and accessible Educational Toolkits 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, 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 for your health care providers to help them better understand the genetics of this disease, symptoms, prognosis and the effective management of FSHD.

1.



These global resources are available to download and share at www.fshdglobal.org/news/fshd-educational-toolkits/

Contact the Foundation to receive your hard copy or learn more on how these resources can benefit you!

admin@fshdglobal.org
(02) 8007 7037

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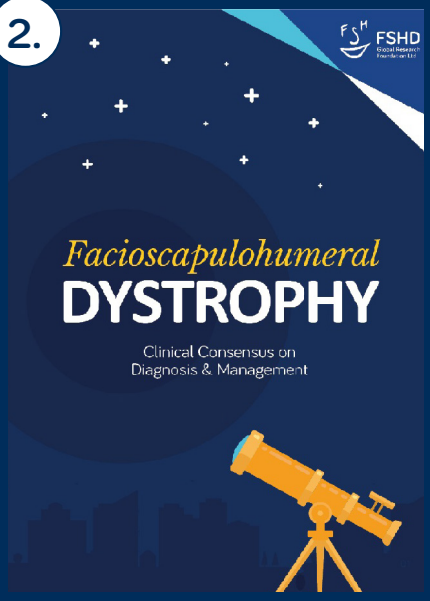

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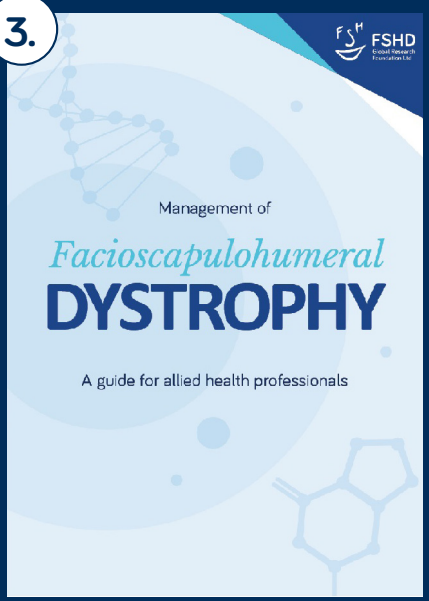

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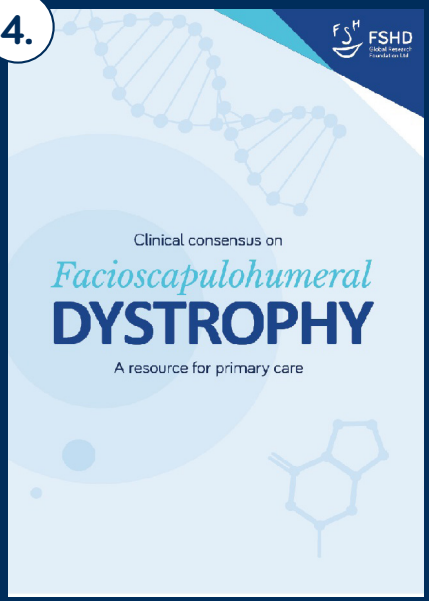


BASIC

Basic research covers the scientific discovery side of research. From understanding what the genes involved in FSHD are doing, to how they interact with the environment to lead to progressive muscle weakness.

Grant 1: Investigation into the role of FHL1, Calcineurin and NFAT in reducing muscle wasting in FSHD

Grant 2: Derivation of human embryonic stem cells to aid medical research in FSHD

Grant 3: Biomarkers in FSHD, a metabolome study in blood, urine and muscle

Grant 4: Comparing the DnaselHypersensitive Chromatin Landscape at 4q35 of FSHD and Control Cells

Grant 5: Defining the mechanism controlling muscle-specific gene expression in FSHD

Grant 6: Deciphering the longdistance interactions of the D4Z4 array in control and FSHD cells

Grant 7: Molecular Genetic Basis of Facio Scapulo Humeral Dystrophy

Grant 8: Title: Dysregulated Pathways in FSHD: Recreating the FSHD Phenotype

Grant 9: Investigation of the role of FHL1 as a novel therapeutic target to reduce muscle wasting

Grant 10: Title: Study of DUX4 and DUX4c gene expression in human embryonic stem cells

Grant 11: The development of an antiDUX4 therapeutic based on chemical inhibitors of DUX4

Grant 12: Culture and Expansion of DUX4 in Human Embryonic Stem Cells Carrying FSHD

Grant 13: Bill Moss AO Fellowship for Dr Leslie Caron

Grant 14: Tissue-specific silencing of the Planar cell polarity gene FAT1 as a causal mechanism for FSHD

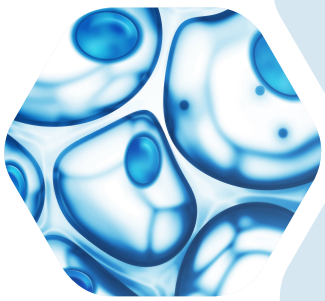
Grant 19: FSHD drug discovery based on chemical inhibitors of DUX4

Grant 20: Identification of drugs for the normalization of aberrant FSHD candidate gene expression

Grant 21: Drugtargeting of myoblast fusion as a treatment for FSHD

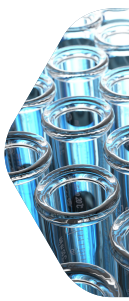
Grant 25: Enhancing BMP signaling to treat FSHD

Grant 28: Application of novel isoflavones in an FSHD hESC model system



Grant 30: HDL based therapy is a potential treatment for FSHD

Grant 31: Development and synthesis of AO transporter



Grant 32: A multicenter natural history and biomarkers study of infantile onset FSHD

Grant 35: The Consensus

BIOTECH INVESTMENT

Grant 40: Living life with FSHD: who is affected and how.

Grant 37: The next wave of whole genome sequencing-based FSHD diagnostics, and clinical measures of progression

Grant 29: Training Agreement to The Netherlands

Grant 33: Facio Therapies Biotech

DIAGNOSTICS

Diagnostics are the tools used to tell if someone has a certain condition. This could be a blood test, an imaging test or a genetic test. Diagnostics are usually built around a particular aspect of a condition that most people have.

Grant 15: DUX4 inhibition as a therapeutic strategy for FSHD

Grant 16: Recreating the human chromosomal genetic defect responsible for FSHD in a mouse

Grant 17: Evaluation of antisense strategies to suppress DUX4 expression in FSHD

Grant 22: Increasing SMCHD1 Levels as a Therapy for FSHD1 & FSHD2

Grant 23: Clinical Study on Possible Increased Risk of Bone Fracture

Grant 26: Functional study of a novel candidate gene for FSH (LRIF)

Grant 28: Application of novel isoflavones in an FSHD hESC model system

Grant 24: Generation of Drosophila-Based Biomedical Models of FSHD

Grant 27: Preclinical Studies of Fisetin and VBP15 in Facioscapulo-humeral Muscular Dystrophy

Grant 34: Targeting DUX4 using gene-silencing oligonucleotides in FSHD models

Grant 36: Effect of creatine monohydrate on strength and muscle mass in children with FSHD

Grant 38: Small molecule inhibitors of DUX4 as FSHD therapeutics

Grant 39: High throughput chemical screens for activators of SMCHD1, as potential therapeutics for FSHD

THERAPEUTICS

Therapeutics is the area of creating treatments for conditions. These can be medicines or physical therapies to help improve quality of life. Research in this area may also include trying to get a better understanding of what people with FSHD go through in their lives to help develop treatments that alleviate their symptoms.

Active Grant Updates

Grant 16

Research Institution: Division of Regenerative Medicine, San Raffaele Scientific Institute, Milano, Italy

Principal Investigator: Dr Davide Gabbelini and Dr Robyn Fitsimmons

Type: Collaborative

Project Title: Re-creating the human chromosomal genetic defect responsible for FSHD in a mouse model.


Our main goal is to develop an accurate animal model of facioscapulohumeral muscular dystrophy (FSHD) in order to better understand how the disease develop and to have an informative system to test possible therapeutic approaches. FSHD is a complex disease that has been only partially understood. For example, while the genetic lesion associated with the disease is present in all the cells of the body, the pathological signs develop mainly in the muscles of the patients. Moreover, not all muscles of the FSHD patients are damaged or are damaged at the same level, while certain muscles are spared. Other unexplained features of the disease are the frequent asymmetric distribution of muscle wasting, the gender bias with males usually more affected than females, why identical twins could be discordant for the disease, and why the onset of the disease is in most cases in the second decade of life despite the fact that the genetic cause is present at conception.

Obtaining an explanation to the above questions could provide ways to develop treatments for FSHD. For example, if we understand why tissues outside of muscle are usually not affected in FSHD or why some type of muscle is spared, we could develop ways to "protect" muscles from the disease.

Since for ethical and practical reasons it is not possible to conduct experiments on patients, the way to address the above issues will be to study an animal model that faithfully recapitulate the human disease. Unfortunately, such model does not exist yet. The main limitation in generating such model is that the genetic material affected in FSHD (D4Z4 repeats) is present only in humans, so the traditional transgenic approach envisaging the manipulation of mice in the case of FSHD is not possible.
To solve the problem, we decided to construct a "humanized" mouse model of FSHD by inserting the relevant human genetic material (in the form of artificial chromosomes or MACs) in mice. While this is a challenging and lengthy process, to have an appropriate in vivo system for testing targeted therapies for the disease will be priceless.

During the last six months, we achieved a key milestone. Indeed, we were able to obtain stem cells containing MACs with human chromosome 4 modification present in healthy or FSHD muscle cells. This is the last step before generating the animal model. Currently, we are transferring the stem cells with the healthy- or FSHD MACs to mice.

Once ready, mice with control or FSHD MACs will be used to investigate the features of the FSHD region in several tissues to learn how the disease develops and to test possible therapeutic options.

Grant 20

Research Institution: San Raffaele Scientific Institute, Italy

Principal Investigator: Dr Davide Gabellini

Type: Collaboration

Project Title: Identification of drugs for the normalization of aberrant FSHD candidate gene expression

Despite the genetic problem responsible for FSHD is known since more than 25 years, no effective treatment or cure is currently available for the disease.

One of the aspects of FSHD that complicates the development of a cure is that aberrant activity for as many as 18 different genes encoding for proteins localized near the FSHD region (locus) on chromosome 4 has been reported in the disease. Thus, FSHD could be caused by the cumulative pathogenic effects of several proteins encoded by genes located on chromosome 4. As a result, targeting the pathogenic effect of just one FSHD protein would be unlikely to address all the symptoms in the disease complicating the development of therapeutic approaches.

A treatment allowing for a general normalization of the expression of all genes mapping on chromosome 4 and showing aberrant activity in FSHD would have much better chances to ameliorate all the FSHD symptoms.

We have identified a non-protein-coding controlling element (called DBE-T) that behaves as a master regulator of the expression of the FSHD locus. Our results strongly suggest that by controlling the activity of DBE-T it is possible to normalize the aberrant expression of all the candidate genes in FSHD muscle cells.

Our goal is to obtain a drug to block DBE-T activity. To this aim, we are characterizing the fine details of the mechanism of action of DBE-T in order to develop molecules that can block the aberrant activity of DBE-T. This will allow us to identify effective therapeutics (drugs) preventing the aberrant protein production by the FSHD locus for the treatment of the disease.

Grant 25

Research Institution: Baker IDI Heart and Diabetes Institute

Principal Investigator: Doctor Paul Gregorevic

Type: Australian

Project Title: Enhancing BMP signalling to treat FSHD

The Team's first objective was to develop a new mouse model in which to study how muscles are affected by FSHD, which can be used to test new therapeutic strategies. To achieve this, the Team designed a gene delivery tool that enables controllable expression of the FSHD-related gene Dux in the muscles of mice. This mouse model has a number of advantages over existing approaches including a) the ability to express Dux at extremely low levels as reported in human FSHD muscles and b) to profile the earliest changes that occur in response to low-levels of Dux expression in the muscles of a mammal, using time points that precede any disease pathology. Having designed and validated the tunable Dux expression system during the initial months of the project, the Team has used this model to show that Dux can activate genes that promote skeletal muscle pathology. Based on these findings, they have developed a specific inhibitor against one of these genes that they show can block the development of FSHD-like symptoms in the Team's mouse model. Current studies are exploring the underlying mechanisms driving this effect to elucidate novel strategies that could be employed to treat FSHD symptoms.

Grant 26

Research Institution: University of Massachusetts Medical School

Principal Investigator: Professor Rossella Tupler

Type: International

Project Title: Functional study of a novel candidate for FSHD (LRIF)

FSHD is considered an autosomal dominant disease associated with changes of DNA or chromatin of a region located at the very end of the long arm of chromosome 4. Studying FSHD for over 25 years we understood that FSHD does not always present as an autosomal dominant trait with affected people in all generations of a family tree. Instead we found families in which two sibs have FSHD with healthy parents and healthy children. This type of setting is suggestive of an autosomal recessive mode of inheritance. In this case genetic counselling is different because parent and children are carriers of only one mutated gene and have no risk of developing disease. Moreover, the study of these families can bring more knowledge to understand FSHD.

With these considerations in mind we studied a family in which FSHD seemed to be transmitted as autosomal recessive disease. The two sisters with FSHD presented a rapid progression and very severe outcome. Both sisters presented severe reduction of muscle mass and respiratory difficulties. We found they carry homozygous mutations in one gene encoding a protein that might play a role in chromatin conformation. We demonstrated that the two identical mutations present on both copies of this gene causes the lack of one of the two forms of the protein that the cell can produce. We think that the absence of this specific form can trigger a cascade effect and interfere on the function of several genes with severe consequences for the muscle.

Our studies may facilitate the understanding of the complex mechanisms underlying FSHD and have important repercussions for clinical practice, genetic counselling and research in this disease.

Grant 32

Research Institution: University of Calgary, Calgary, Alberta, Canada and Royal Children's Hospital, Melbourne, Australia

Principal Investigator: Dr, Jean Mah in collaboration with Prof. Monique Ryan

Type: Collaboration

Project Title: A multicentre natural history and biomarkers study of infantile onset FSHD

To date, the early onset FSHD study have enrolled 16 participants across the globe as part of a long term follow-up study. We hope to understand the rate of change in motor function and other health-related quality of life measures among the participants with early onset FSHD. Further enrollment is on hold, pending on review of preliminary data from the follow up assessments. In addition, using blood samples from the participants, we have been looking for biomarker candidates for FSHD. A biomarker is a biological characteristic that can be objectively measured and evaluated as an indicator of normal biological processes, pathogenic processes, or pharmacologic responses to a therapeutic intervention. A major advantage of having measurable biomarkers from blood samples is to provide safer and low-cost means to determine whether a potential treatment is effective in clinical studies.

We have been using several methods to identify different types of molecules in the blood samples, which can potentially be used as biomarkers. At this moment, we screened proteins in the blood samples and found 19 candidates. One of the protein, glutathione peroxidase 3 (GPX3), was further investigated using more samples and the results confirmed the difference between samples from individuals with FSHD and healthy controls. In addition, we used cutting-edge technologies to determine RNA changes in the blood samples and identified activities associated with specific types of immune cells that were different between samples collected from affected individuals and controls.

This finding may provide important insights to the disease mechanisms in FSHD. The study will also collect blood sample to look at markers of disease progression for FSHD. We will need to obtain additional funding for the follow-up studies. We hope to find unique clinical and molecular profile that can be used to measure disease progression in FSHD.

Grant 34

Research Institution: Centre for Genetic Medicine Research, Children's National Health System, Washington DC, USA

Principal Investigator: Dr Yi-Wen Chen

Type: International

Project Title: Targeting Dux4 using gene-silencing oligonucleotides in FSHD models

Gene-silencing oligonucleotides (GSOs) produced by Idera Pharmaceutical are designed to reduce the expression of the pathogenic DUX4 expression in FSHD. The goal of this study is to determine their efficacy using both human cell and mouse models of FSHD. In the first part of the study, we have tested five GSOs using FSHD muscle cells and showed that the GSOs reduced DUX4 levels in the cells. In addition, the FSHD cells behaved more similar to the healthy cells after the treatments. In this report period, we started animal studies to determine whether we can successfully deliver GSOs to muscles and whether the GSOs reduce expression of DUX4 and genes regulated by DUX4. To allow us visualize the GSOs, we added a florescent tag to the GSO compounds before we injected them into the mice. Our results showed that GSOs were able to enter muscle cells after intramuscular injection (direct injection into muscle), as well as after the subcutaneous injection (injection under the skin which allows systemic delivery).

The results showed that the GSOs entered the muscles after either intramuscular or subcutaneous injection. Higher amount of GSOs was observed in muscles when the GSOs were delivered by intramuscular injection. We also showed that a gene regulated by DUX4 reduced its expression level after systemic delivery of GSOs for 12 days (6 subcutaneous injections).

Our next step will be to increase the number of injections of GSOs to determine the efficacy of GSOs when delivered for longer period of time. We thank the FSHD Global Research Foundation for supporting this work.

Grant 36

Research Institution: Royal Children's Hospital, Melbourne, Australia

Principal Investigator: Dr Ian Woodcock and Prof. Monique Ryan

Type: Australian

Project Title: Effect of creatine monophosphate on strength and muscle mass in children with FSHD

FSHD is a clinically diverse condition and to date has not been widely studied in children.

We are pleased to announce that on 3rd July 2017 we received ethical approval to proceed with the first clinical trial in paediatric FSHD. We are finalising governance approval at The Royal Children's Hospital Melbourne, setting up at other sites and aim to start patient recruitment in August or September 2017.
As this is to be the first clinical trial worldwide in paediatric FSHD there are no specific validated outcome tools. As such, we have carefully assessed and selected outcome measures to ensure best possible trial design. We have chosen the Motor Function Measure in Neuromuscular Disease as our primary outcome measure to effectively capture changes in clinical condition.

We have also included several secondary outcome measures to assess the sensitivity of measures in this population for future clinical trials. We aim to gather more information on response to treatment for these patients and obtain validation data for more specific adult FSHD outcome measures (FSH-COM and FSH-HI) for future use in the paediatric population.

Grant 37

Research Institution: Concord Hospital and Garvan Institute of Medical Research, Sydney Australia

Principal Investigator: Prof. Garth Nicholson

Type: Australian

Project Title: The next wave of Whole Genome Sequencing – based FSHD diagnostics, and clinical measures of progress

Fascioscapulohumeral dystrophy (FSHD) is the third most common muscle disorder and causes progressive wasting and weakness particularly of the face (fascio), shoulder (scapulo) and arm (humeral).

The genetics of FSHD are complex, and up until now, obtaining a genetic diagnosis for this condition has been difficult, labour intensive and involved multiple laboratory tests. A new diagnostic method, Whole Genome Sequencing (WGS) is able to diagnose many genetic disorders, and may offer a new paradigm for diagnosing FSHD. This project seeks to develop a WGS-based method to diagnose all forms of FSHD and facilitate novel disease gene identification. To overcome the challenging genetics of FSHD pathogenesis, we will develop novel bioinformatic methods, and utilise the brand new Chromium platform from 10x genomics, to help resolve the "D4Z4 repeat" length in FSHD patients. This will also provide valuable insights into the genetic basis and disease mechanisms underlying this disorder.

We are also looking at ways to monitor the natural history and disease progression including specialised MRI scans. This will in turn allow design of treatment trials in the future. This project brings together experts in FSHD genetics, diagnostic testing, with clinical WGS and bioinformatics to develop this new test.

Grant 38

Research Institution:` Minneapolis, USA and Icagen Tuscon Innovation Centre, Tuscon, USA

Principal Investigator: Dr Michael Kyba

Type: International

Project Title: Small molecule inhibitors of DUX4 as FSHD therapeutics

The objective of this collaborative project between the Kyba Laboratory and the biotech company Icagen is to discover and develop new small molecule inhibitors of DUX4 as potential therapeutics for FSHD. In this stage of the grant, we have performed a preliminary screen on a set of compounds enriched for known biological activities. This demonstrated that the screening protocol is suitable to automated 384-well screening and identified compounds with relatively weak, possibly indirect, biological activity. To further enhance the screening capabilities, we have developed improved high throughput screening cell lines and are currently validating these.

Grant 39

Research Institution: Walter and Eliza Hall Institute of Medical Research, Melbourne, Australia

Principal Investigator: A/Prof. Marnie Blewitt

Type: Australian

Project Title: High throughput chemical screens for activators of SMCHD1, as potential therapeutics for FSHD

The molecule SMCHD1 has been shown to play an important role in FSHD, where it keeps the specific DNA element that causes FSHD in check, by ensuring that it goes unnoticed in the cell i.e. it is switched off. Our project is to identify drug-like chemicals that boost SMCHD1's activity, as potential therapeutics to treat FSHD. To achieve this aim, we will screen more than 117,000 chemicals, then characterise those that enhance SMCHD1 function for how they achieve this enhanced activity and for their role in the context of living cells. In the first 6 months of the project, we have established all of the systems required to screen the large library of chemicals, and have performed a pilot screen of just over 4000 chemicals. From this pilot we have already identified 40 hits, that potentially activate SMCHD1. We are now keenly working on these molecules to validate their effect on SMCHD1, then study their interaction with SMCHD1. Alongside this preliminary work on the hits from our pilot screen, we will now screen the full library of around 113,000 chemicals, to find more such hits for future validation, with the clear aim of identifying, characterising and developing drug-like molecules that activate SMCHD1 as potential treatment for FSHD.

Grant 40

Research Institution: Auckland University of Technology

Principal Investigator: Associate Professor Alice Theadom

Type: International

Project Title: Living life with FSHD: who is affected and how.

This study aims to identify who is affected by FSHD in New Zealand by age, gender and ethnicity. Data for 123 people will be analysed to gain greater understanding of genetic verification of FSHD and its subtypes. Data for 83 people and 47 of their significant others will be analysed to increase our understanding on living life with FSHD. The effects on people's ability to complete everyday activities, obtain work and performance in employment, social relationships and quality of life will be explored. The study will also identify areas where services could be improved through finding out what resources people need and what they are able to access.

Our dedicated and passionate Patrons, Ambassadors and State Branches across Australia are vital to our success in growing awareness and funding for our work. We extend our heartfelt thanks for their generous contributions and time.

Patrons

Jamie Durie OAM

Justin Reid

Luke Mangan

Prof. John Rasko
Patron of Science

Ambassadors

Ben Schultz

Carol Major

Charlotte Caslick

Emma Weatherley

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GET POSITIVE!

A piece by FSHD Patron Justin Reid

You hear it a lot. "Just stay positive." It's definitely good advice but sometimes I feel like yelling, "Well OBVIOUSLY!!!". If it was easy, if I could just flick a switch and be positive I'd do it!

So how do you get positive when you're feeling overwhelmed and defeated? At the age of 14 I certainly felt like my world had fallen apart. When I was 13 my father left the family. 6 months later I was diagnosed with FSHD.

At that age I didn't really understand what the diagnosis meant. From the faces of my family and the doctors I knew it was serious and it was bad. The specialist explained the nature of my condition and what it meant for my future. He painted a picture of continuous and inevitable physical decline. On a chart you would see the line always falling, with some plateaus where the condition is dormant, but always falling again as the Dystrophy became active. The future was all downhill. How do you get positive about that?

The short answer is that you can't. I spent a lot of years being angry and fighting the physical decline. It was a war I could never win. Eventually I asked myself "Why am I fighting this war?" The answer came, "To find peace." I worked with a counsellor and did some reading, including a book on Buddhist philosophy. One sentence in this book changed my life. It said,"The causes of suffering contain within them the means of release from suffering.". Somehow this seemed like the answer I was looking for.

I thought about that sentence a lot. What was the secret that lay hidden in those words ? Eventually I decided they were telling me to stop blindly fighting and look inside myself with fresh eyes. To see my life as more than just a physical process. To see my life as a journey of personal evolution where adversity drives healing, learning and growth.

With this realisation I saw that as my life progressed over time and the FSHD took its inevitable course the difficult times offered rich opportunities for self evolution. Opportunities to find within myself strength, courage, wisdom and compassion. Now the chart of my life became a continuous and inevitable upward line. Now I had something to really get positive about.

Of course it sounds great in theory but living it in the real world is a different story. I still get frustrated and feel down when things are difficult and seem unfair. I still react to situations and have to catch myself before I spiral down into negativity. But now I'm always looking for the lesson, for the opportunity to be wiser and stronger. To be a bigger person. The opportunity is always there.

So now when someone says to me, "Just stay positive.", I smile and say, "Yeah, thanks." and think to myself, "I'm already there buddy, I'm already there!".

Community Fundraisers

We are very grateful to have such an active community of supporters and friends. The past year has seen some wonderfully imaginative fundraising take place in a range of events across Australia which has seen our community fundraising more than double to $115K. Thank you to our event champions and everyone involved! If you would like to receive information on how you can host your own fundraiser, please get in touch with us at admin@fshdglobal.org or call us on (02) 8007 7037.

Hustle for Muscle

Held by Dizzy Heights on June 4th 2017 at the Yarraville Club, Hustle for Muscle was a night of laughs raising funds for FSHD Global. Showcasing some of Australia's most popular and talented stand up comedians including Lawrence Mooney, Judith Lucy, Lehmo, Hannah Gadsby, Bob Franklin, Anne Edmonds and Dave Thornton, this comedy fundraiser was successful in raising over $3,000.

City2Surf

Emily Hunt ran in Perth's City to Surf 2016 in support for FSHD Global. Emily ran the Marathon in 4 hours and 30 minutes through the wind and rain - "It was a tough but enjoyable race". Emily was inspired after FSHD Ambassador Claire Anderson said to her "I wish someone would find a cure for this disease." Emily's efforts raised over $600 for medical research into FSHD.

WA Bunnings BBQ

The FSHD Global WA State Branch hosted their very first Bunnings sausage sizzle! Held on Sunday 20th November at the East Victoria Park Bunnings WA, the community effort was successful in raising over $600 for the Foundation. Led by FSHD Global State President Claire Anderson, the group pulled together and organised a successful day of fundraising and awareness of FSHD.

60th Birthday Roast

This year community member Michael Weston celebrated his 60th birthday in style while raising money for FSHD Global. His "Celebrity Roast" themed party saw an array of colourful characters from his past turn up to reminisce and celebrate his Birthday. Michael shared his experience living with FSHD and gave his "right of reply" to the guest roasters. The night was finished off with a side splitting performance by local comedian Tom Green. A great night of fun and laughs was had by all. Michael's party successfully raised over $2,200!

Blackmore Marathon

Dane Knight ran in the 2016 Blackmore's Sydney Marathon in an official finishing time of 4 hours, 59 minutes and 5 seconds! Dane had planned for a sub-4 hour finish and was holding that pace until the 25km mark when an Achilles injury from a few months ago came back to bite him. Nevertheless he pushed on and limped over the line. Dane was successful in raising $2,700!

Corporate Surf Challenge

We were thrilled to once again be included as a charity partner at the Wyndham Resorts and Brisbane Airport Corporate Surf Challenge. Proudly supported by Wyndham Ambassador Layne Beachley, the event saw teams come together with over $6,000 raised on the day supporting the Foundation. Congratulations to the team from Stellar Recruitment who were the overall winners. Thank you to both Wyndham and Sydney Airport for their continued support of the Foundation and to all who took part in this incredible event.

ASX Thomson Reuters Charity Foundation

This year, the Foundation was welcomed back as a benefiting charity in the ASX Thomson Reuters Charity Foundation. By partaking in their charitable events and selling raffle tickets, we received an outstanding $70,000. We look forward to being a part of this charity program again in 2018.

Chop Chop Changs

Every month, Pan Asian street food restaurant Chop Chop Chang's ask their customers through Facebook to nominate a charity to receive the proceeds from their fabulous Karma Cookies. Thanks Emma Weatherley for nominating us to raise $350 for the Foundation.

Muscles for Muscles

Danielle Salvatore pledged to do one hour of exercise every day for eighty days, to build as much muscle as she can! Fundraising for her husband who lives with the disease, Danielle's muscles for muscles fundraiser raised over $3,000.

AFL Footy Tipping Competition

President of the Victorian State Branch Les Jones, once again ran an annual AFL footy tipping competition raising over $1,000 for the Foundation. This year's winner will enjoy a holiday getaway with second and third place winning a $200 and $200 dining voucher.

SwimRun

FSHD Global Board Director Bechara Shamieh and teammate Daniel Caine took part in Australia's first ever SwimRun - a challenging event where teams of two compete by running and swimming on a challenging course covering trails, beaches, ocean, cliffs, rocks, and paths. After weeks of training and preparation along with fundraising, Bechara and Daniel successfully completed the gruelling course raising over $6,000

Entertainment Books

WA community member Stacie on sold the 2017 | 2018 Entertainment Book to her network in Western Australia. Stacoe raised $700 in book sales for the Foundation.

WORLD FSHD DAY

Unite to find a cure

The Foundation received an enormous amount of support for the second World FSHD Day. June 20th saw community members across Australia come together to raise funds and awareness for FSHD. We would like to thank everyone who changed their social media display pictures to the World FSHD Day logo and shared our posts with their networks.

A special mention to those who hosted their own fundraisers, collectively raising over $5,000! See what great ideas they came up with and start thinking about what you can do for World FSHD Day 2018.

Free Dress Day

Mentorne Primary School held a Free Dress Day and collected gold coin donations.

Cupcakes for a Cure

Community member Bridget Brischetto sold beautiful cupcakes in the kitchen of her workplace.

Dinner

Community member Mary Garrett charged an additional $10 per person for a three course meal.

Movies for Muscles

FSHD Ambassador Emma Weatherley hosted her friends and family as she hired out a movie theatre and on-sold tickets to Despicable Me 3.

Afternoon tea

Victorian Branch President Les Jones hosted an afternoon tea at his work place.

Social Media

Community members shared their stories and the Foundation's work ith their networks which resulted in multiple donations.

Thank you to all our Individual and Corporate Supporters

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Thank you to each and every one of the generous donors who supported the Foundation this year.

If you would like to help change the world for people living with FSHD, start today by contacting us.

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