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App - FSHD - Find the Cure

# FSHD Global Research Foundation Annual Report 2019

#### Company Name :

FSHD Global Research  
Foundation Ltd

#### Company Address

PO Box A296, Sydney South,  
NSW, 1235, Australia  
+61 (2) 8007 7037



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OUTSTANDING  
ACHIEVEMENT  
WINNER 2019



**FSHD**  
Global Research  
Foundation Ltd



Welcome to the  
FSHD Global Research Foundation  
Annual Report

# Our Highlights



## Multi-award winning Charity

Winner of Outstanding Achievement in the  
Australian Charity Awards 2019 and 2018  
Winner of the Charity of the Year in 2017.



## \$0 remuneration

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



## On going Medical Research grants

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



## 100% of all cash tax deductible donations

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



## \$10 million in 11 years

FSHD Global has raised over \$10 million in 11  
years funding medical research in 10 countries



## FSHD educational toolkits

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



## Largest contributors to FSHD medical research

We remain one of the largest contributors to  
FSHD medical research worldwide



## Find the Cure' App

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

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FSHD Global Research Foundation  
PO Box A296, Sydney South,  
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# About us

## Our Story

The FSHD Global Research Foundation was established in 2007 by Australian businessman, philanthropist and sufferer of FSHD, Bill Moss AO.

Our mission is to find a cure for Facioscapulohumeral muscular dystrophy (FSHD) within five years. A disease that affects an estimated one million people globally. It is caused by an overexpression of a protein called DUX4, which is toxic to muscle.

The true prevalence of this disease is still unknown. Due to poor diagnostics and misdiagnosis, many people live unaware they carry the genetic gene, at risk of passing down generations.

The Foundation's aim is to increase awareness and fund national and international researchers to undertake both clinical and basic research projects that can lead to identifying the cause and a future cure for FSHD. We also aim to increase the knowledge and awareness of FSHD among medical practitioners, researchers, patients, donors and the general community.

FSHD Global invests directly into well managed Biotechs that have a major focus on technology which has a prospect of leading to clinical trials in patients with any muscular dystrophy that can:

- Grow muscle cells in human tissue
- Improve muscle wellness
- Develop wearable technology to assist in movement

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 fulfil our mission.

## 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.

### 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.

### Experimentation and Innovation

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

### Passion

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

# Message from the Chairman



## Bill Moss AO

Founder and Chairman  
FSHD Global Research  
Foundation

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

Over the past 12 months, the FSHD Global Research Foundation has invested time and resources to redefine our strategy in terms of where the focus of our funding should align. Whilst we continue our mission to find a cure for Facioscapulohumeral Muscular Dystrophy (FSHD), we have identified the need to expand our funding of medical research to include therapies for muscle wellness and muscle technology.

The future strategy of FSHD Global is to encourage clinical development of many novel medicinal compounds which can be used in clinical trials to stop FSHD. In parallel with this strategy we are working on ways to increase muscle wellness to keep peoples muscles healthier until a cure is available and encourage research into futuristic combinations of robotics and artificial intelligence that will be able to help people regain mobility after a lifetime of muscle deterioration.

The aim of funding this research is to find ways that all people suffering from muscle weakness caused by neuromuscular disorders, muscle trauma and aging will benefit.

In support of our new strategy, the Foundation continues to invest directly into well managed Biotech companies that have a major focus on technology. In this regard the Foundation invested \$624,401 into Biotech research.

In the financial year ended 30 June 2019, the Foundation received revenue of \$1,468,675 of which \$766,447 was received from donations, \$644,180 was received from fundraising activities and \$58,047 was received from investment income. We funded 10 projects located in Australia, USA, Italy, Netherlands and Israel.

As at 30 June 2019 the Foundation held cash deposits of \$914,529 of which \$820,261 was held to fund current approved projects and projects under consideration for future funding. During the year the Foundation also committed \$17,369 to education and awareness of FSHD.

We would like to thank all our Donors, Supporters, Volunteers, Patrons, Ambassadors and Board Members for their commitment and continued support.

## Contact Us

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## Our Journey

**10**  
MILLION

FSHD Global Research Foundation has successfully raised over \$10 million dollars in tax deductible donations.

**11**  
YEARS

Founded in 2007, we have achieved this result in just 11 years.



**10**  
COUNTRIES

This money has helped fund 48 world class medical research grants in 10 countries around the globe.

**We continue to receive no government support or funding**

# Message from the Chief Executive Officer



## Danielle Thomson

Chief Executive Officer  
FSHD Global Research  
Foundation

The past 12 months has seen an incredible shift in strategy, momentum and determination for FSHD Global.

We continue to deliver on our mission to fund medical research to find a cure for FSHD, however we are excited to broaden our scope by acknowledging the need to invest in muscle wellness and muscle technology which will assist all people who are affected by all muscle weakness disorders.

As a result of our revised strategy, we are proud to have expanded our core team with enhanced resources and skill sets in marketing, fundraising, partnerships and events, which will grow, strengthen and build new relationships and nourish our existing partnerships.

Our success relies heavily on the support of our generous sponsors, supporters,

community and team to continue to believe in our vision, our mission, our purpose and passion in providing much needed funding to accelerate the ground breaking research into FSHD across the globe.

I look forward to working with our strong, committed and long standing supporters and community, and welcoming new corporate and philanthropic partners who want to become a part of our journey as we work together to achieve new benchmarks in raising funds and creating awareness of the Foundation's work.

## Contact Us

FSHD Global Research Foundation

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# What is FSHD?

## Facioscapulohumeral Muscular Dystrophy

Facioscapulohumeral muscular dystrophy (FSHD) is a highly complex and progressive muscle wasting disease causing weakening and loss of skeletal muscles. FSHD is one of the most common forms of muscular dystrophy in adults and children. Often referred to as a 'slow death' disease, it is aggressive and does not discriminate, affecting young and old from all ethnic groups.

The Global footprint of this disease is enormous, with an estimated 1 million people living with FSHD.

FSHD is commonly associated with progressive weakening of facial, shoulder and upper arm muscles. 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 often comes in bursts with sudden deterioration followed by periods of no change.

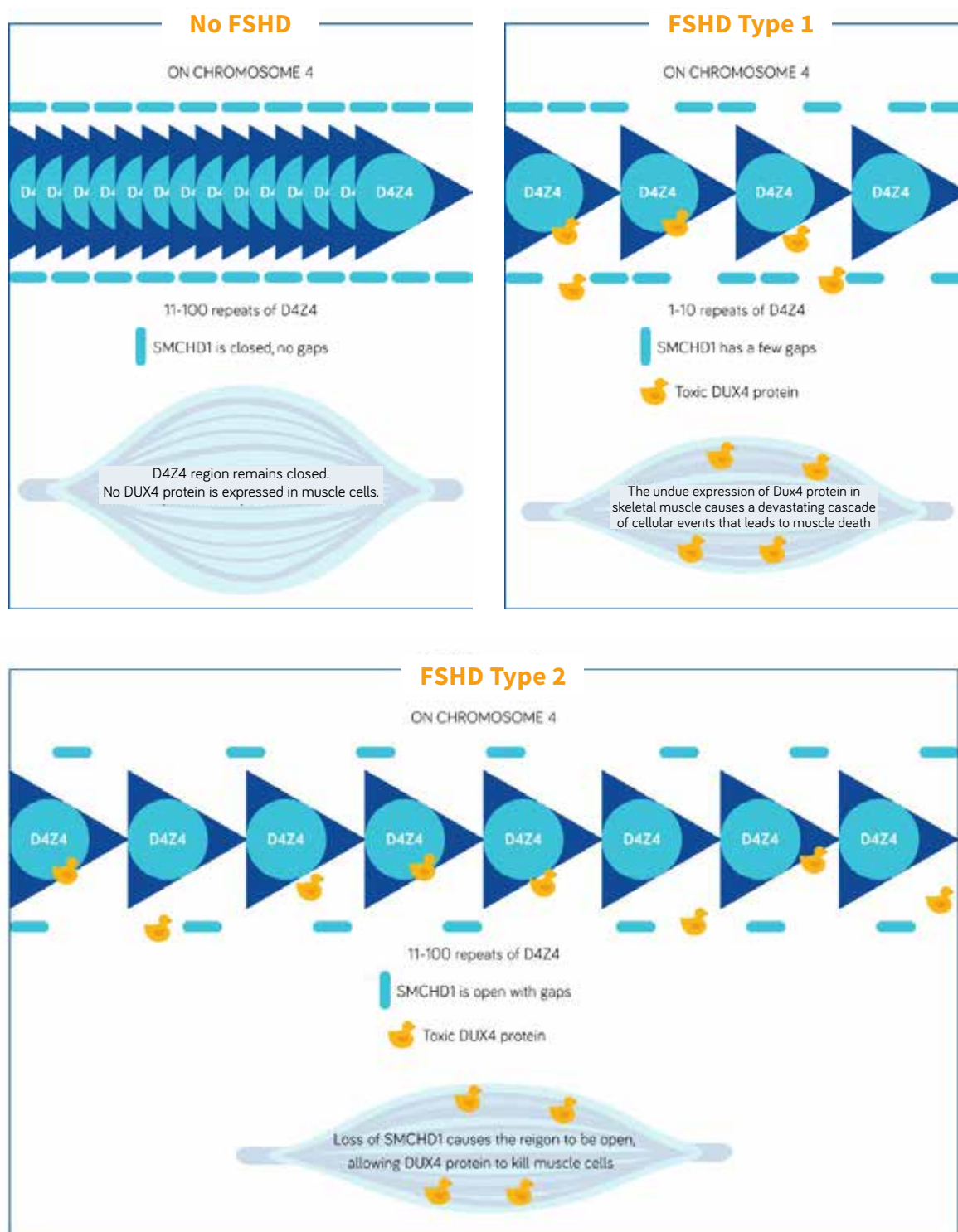
The loss of skeletal muscle has a huge impact on daily life making even simple

tasks complicated. Living with FSHD means living with pain, fatigue and the social isolation that comes from being reliant on mobility aids. The future for someone with FSHD is uncertain because there is so much variability in how FSHD manifests in people.

People with FSHD live with no known cure and few treatments currently available. The FSHD Global Research Foundation is working to change this and gives hope to those living with this disease that something is being done to fight for a cure.



There are more than 30 muscular dystrophies currently known and FSHD is thought to be one of the most common affecting both adults and children and is arguably one of the most complex.





World FSHD Day is held on **June 20** and aims to raise public awareness for FSHD. Few members of the public have heard of FSH muscular dystrophy, and many affected individuals don't know that they have the condition. This International day aims to bring awareness of this debilitating disease to the general public and decrease misdiagnoses within the medical industry.



## UNITE TO FIND A CURE

On June 20th, we encourage every one of our supporters to change their Social Media profile pictures to the World FSHD Day logo and use the official Twitter hashtags **#WorldFSHD** and **#CureFSHD**.



# About the Foundation

The FSHD Global Research Foundation focuses on finding treatments and a cure for FSHD. In doing so, we fund world-class medical research, awareness and education. We are also committed to complete transparency and accountability in our operations.

The Foundation was established in 2007 by Bill Moss AO, a well-known Australian businessman and philanthropist who lives with FSHD. Since then, we have been addressing the chronic lack of medical funding and awareness of FSHD, both in Australia and globally.

The true prevalence of this disease is still unknown. Due to poor diagnostics and misdiagnosis, many people live unaware they carry the genetic gene, at risk of passing down generations.

The Foundation undertakes a wide range of medical research focused on; slowing this disease, muscle wellness and muscle technology. The aim of this research is not only to find a cure for FSHD, but to find ways that all people suffering from muscle weakness caused by neuromuscular disorders, muscle trauma and ageing will benefit.

Since 2007, the Foundation has committed over \$10 million to fund 48 ongoing medical research grants in 10 countries; the USA, Canada, the Netherlands, Israel, Italy, France, Belgium, Spain, New Zealand and Australia.

The FSHD Global Research Foundation does not operate like an average not for profit. We allocate 100% of cash tax deductible donations we receive to current and future medical research grants. The Foundation's operations are supported by non-tax deductible sponsorships.

This pure charity model offers great transparency and accountability to our mission. Proud of our innovative structure, we offer all donors via the 'FSHD – Find the Cure' mobile APP the opportunity to track exactly which research programs their money has been allocated to, with updates on the latest milestones of those programs.

With no government support the main sources of our funding for FSHD research are individuals afflicted by FSHD, their friends, supporters, as well as corporate sponsors. All funds donated are invested through careful consideration, guided by our Scientific Advisory Boards, Board of Directors and International Research Committees, ensuring FSHD Global remains a leader in discovering world's best science.

# Our Patrons, Ambassadors and State Branch Presidents

Our dedicated and passionate Patrons, Ambassadors and State Branch Presidents 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 OAM**



**Prof. John Rasko AO**

Patron of Science

## Ambassadors



**Ben Schultz**



**Charlotte Caslick**



**Emma Weatherley**



**Julie Wood**



**Kerry-Anne Johnston**



**Lewis Holland**



**Paul Gallen**



**Rochelle Collis**



**Danny Chronopoulos**



**Carol Major**

## State Branch Presidents



**Claire Anderson**

Western Australia President



**Leona Luke**

Queensland President



**Les Jones**

Victoria President



**Tania Spagnolini**

New South Wales President

# 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



**Nigel Virgo**  
Deputy Chairman



**Alan Watts**  
Director



**Andrew Frost**  
Director



**Andrew Rigney**  
Director



**Anne Paton**  
Director



**Barry Robinson**  
Director



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Director



**David Mackay**  
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**Glenn Willis**  
Director



**Malcolm Beville**  
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**Natalie Cooney**  
Managing Director



**Pete Ratcliffe**  
Director



**Pradnya Dugal**  
Director



**Scott Baker**  
Director



**Bev Baker**  
Alternate Director

# AT THE EDGE OF RESEARCH

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In a short period of time, the Foundation has successfully generated 48 medical research grants across 10 countries, funding all types of research to help drive discoveries that may lead to effective treatments and an ultimate cure for people living with FSHD.

With clinical trial readiness around the corner we need your help to fast track treatments and increase the quality of life for those living with FSHD.

## OUR FOCUS

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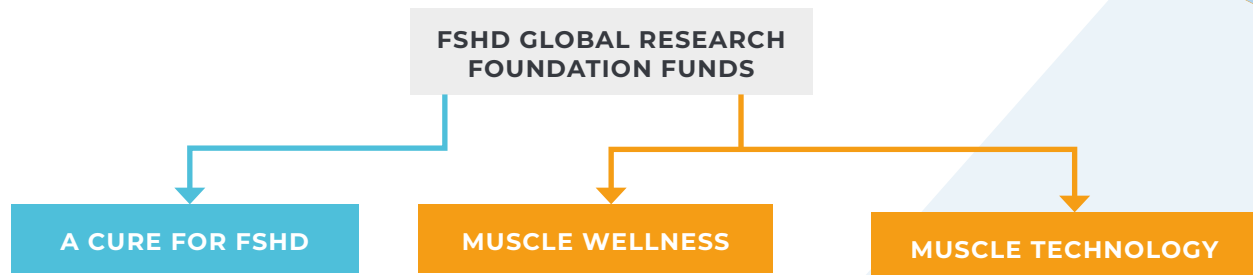
Our mission is to find a cure for Facioscapulohumeral muscular dystrophy (FSHD). A disease that affects an estimated one million people globally. It is caused by an overexpression of a protein called DUX4, which is toxic to muscle.

The true prevalence of this disease is still unknown. Due to poor diagnostics and misdiagnosis, many people live unaware they carry the genetic gene, at risk of passing down generations.

The Foundation undertakes a wide range of medical research focused on; slowing this disease, muscle wellness and muscle technology. The aim of this research is not only to find a cure for FSHD, but to find ways that all people suffering from muscle weakness caused by neuromuscular disorders, muscle trauma and ageing will benefit.



## FSHD GLOBAL FUNDING PILLARS



## OUR JOURNEY TO A CURE

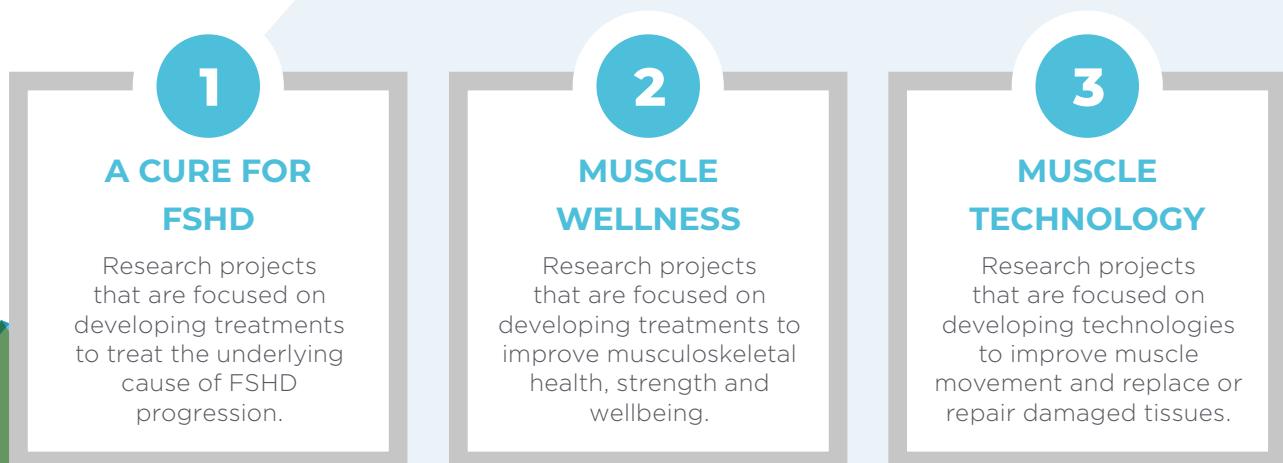
Finding a cure for FSHD has been a long and complex process. It was necessary to unlock the mechanism for the disease, understand the cell biology, and commence the long journey towards drug development.

Along the way, we also had to focus on human FSHD cells and tissue, biomarkers, diagnostics and prepare for clinical trial readiness.

The future strategy for this Foundation is to encourage clinical development of many novel

medicinal compounds which can be used in clinical trials to stop this disease.

In parallel with this strategy we are working on ways to increase muscle wellness to keep peoples' muscles healthier until a cure is available, and encourage research into futuristic combinations of robotics & artificial intelligence that will be able to help people regain mobility after a lifetime of muscle deterioration.



# Grants Snapshot

## A CURE FOR FSHD

Research projects that are focused on developing treatments to treat the underlying cause of FSHD progression.



**Grant 1**  
Inco  
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**Grant 2**  
Grant  
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Grant 2  
health

**Grant 3**  
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of F

**Grant 4**  
Identifica  
for the n  
of aber  
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### Grant 3

Biomarkers in FSHD, a metabolome study in blood, urine and muscle

### Grant 2

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

### Grant 4

Comparing the DnaseI Hypersensitive Chromatin Landscape at 4q35 of FSHD and Control Cells

### Grant 6

Deciphering the long distance interactions of the D4Z4 array in control and FSHD cells

### Grant 8

Title: Dysregulated Pathways in FSHD: Recreating the FSHD Phenotype

### Grant 11

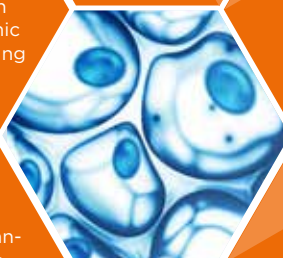
Deciphering the long distance interactions of the D4Z4 array in control and FSHD cells

### Grant 12

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

### Grant 26

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



### Grant 13

Bill Moss AO Fellowship for Dr Leslie Caron

### Grant 16

Bill Moss AO Fellowship for Dr Leslie Caron

### Grant 27

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

### Grant 28

Application of novel isoflavones in an FSHD hESC model system

### Grant 7

Molecular Genetic Basis of Facio Scapulo Humeral Dystroph

### Grant 14

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

### Grant 17

Evaluation of antisense strategies to suppress DUX4 expression in FSHD

### Grant 29

Training Agreement to The Netherlands

### Grant 5

Defining the mechanism controlling musclespecific gene expression in FSHD

### Grant 15

DUX4 inhibition as a therapeutic strategy for FSHD

### Grant 18

Study on the clinical features, expression profiling, and quality of life of infantile onset FSHD

### Grant 30

HDL based therapy is a potential treatment for FSHD

### Grant 31

Development and synthesis of AO transporter

### Grant 19

FSHD drug discovery based on chemical inhibitors of DUX4

### Grant 21

Drug targeting of myoblast fusion as a treatment for FSHD

### Grant 32

A multicenter natural history and biomarkers study of infantile onset FSHD

### Grant 34

Drug targeting of myoblast fusion as a treatment for FSHD





# Active Grant Update

## Grant 36

### Research Institution:

Murdoch Children's Research Institute, The Royal Children's Hospital, Melbourne, Australia

### Principal Investigator:

Dr Ian Woodcock

### Type:

Australian

### Project Title:

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

At present, there are no treatments proven to improve strength or delay loss of functional abilities in paediatric and adult patients with FSHD. Therapeutic interventions with proven efficacy in children with other muscle diseases, such as corticosteroid therapy, have been shown to be ineffective in patients with FSHD. Creatine monohydrate has been shown to have some effect on strength and function in adult patients with muscle diseases.

This study aims to assess the effects of dietary supplementation with creatine monohydrate on muscle strength and function, and body composition, in children with FSHD. The study will also assess the activities of daily living, mood and general wellbeing of children with FSHD, as determined by patient- and parent-reported outcome measures. Safety data will also be collected throughout the study period. The study will assess the efficacy of creatine supplementation on improving muscle bulk and strength in children with FSHD, and will establish valuable baseline data on quality of life in paediatric FSHD. To the best of our knowledge, this will be the first therapeutic trial to be undertaken in paediatric FSHD.



## Grant 37

### Research Institution:

ANZAC Research Institute, Concord Hospital and Garvan Institute of Medical Research, Sydney, Australia

### Principal Investigator:

Professor Garth Nicholson

### Type:

Australian

### Project Title:

The next wave of whole genome sequencing-based FSHD diagnostics and clinical measure of progression.

The Team's first objective was to develop a new mouse model in which to study the acute consequences in muscles following Dux activation, with the aim of identifying new therapeutic strategies.

To achieve this, the Team designed a gene delivery tool that enables tunable and reversible 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 and b) to profile the earliest changes that occur in response to low-levels of Dux expression using time points that precede any muscle pathology.

Following careful design and validation steps, the Team has gone on to use this model to define the acute changes in global gene expression that occur following Dux activation prior to the onset of pathology in mouse limb muscles.

Extending these studies, the Team has developed AAV vectors to express the human DUX4 protein to validate these findings in human skeletal muscle cell culture models. The team plans to profile gene expression changes that occur in human muscle tissue following acute DUX4 exposure and contrast these to previous work in mouse limb muscles to identify conserved mechanisms of action.

These findings will aid our understanding of the processes that contribute to muscle pathology, and help to identify possible treatment strategies for further development.



## Grant 39

### Research Institution:

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

### Principal Investigator:

Assistant Professor 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 the systems required to screen the large library of chemicals and have performed a pilot screen of just over 4,000 chemicals. From this pilot we have identified 40 hits, that potentially activate SMCHD1. We are now keenly working on these molecules to validate their effects on SMCHD1, then study their interaction with SMCHD1. Alongside this preliminary work of 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 treatments for FSHD.



## Grant 41

### Research Institution:

The Hebrew University of Jerusalem, Israel

### Principal Investigator:

Assistant Professor Nir Kalisman

**Type:** International

### Project Title:

Characterisation of DUX4 protein-protein interactions in FSHD cell lines and tissue biopsies by cross linking and mass spectrometry

Our project aims to study the interactions of DUX4 with other proteins by a powerful experimental technique – cross-linking and mass spectrometry – that will chart these interactions in unprecedented detail. A first round of experiments, which was performed in cell cultures, identified several interactors of DUX4, most notably the nuclear proteins: C1QBP, XRCC5 and XRCC6. We also localised the DUX4-C1QBP interaction to the second homeobox domain of DUX4. We are now in the middle of a second round of experiments that will localise these interactions in more detail. Our next aim is to use the great sensitivity of mass spectrometry to verify these findings directly in human muscle tissue, thus demonstrating their clinical relevance.



## Grant 43

### Research Institution:

The University of Melbourne, Australia

### Principal Investigator:

Associate Professor Paul Gregorevic

### Type:

Australian

### Project Title:

Targeting Dux4 using gene-silencing oligonucleotides in FSHD models

Our proposal seeks to expand our understanding of the mechanisms that lead to the development of skeletal muscle degeneration in FSHD and to test multiple interventions that we propose could be used to prevent and/or limit disease progression. Combining our expertise in skeletal muscle biology and gene therapies, we have developed new animal based and human-cell-based models of FSHD. Here, we will use these models to demonstrate that skeletal muscle from individuals with FSHD uses fats and carbohydrates differently to healthy individuals and that this is critical for the progression of disease pathology. We believe that the strategies outlined to manipulate these vital pathways are viable approaches that could be rapidly deployed to improve outcomes for individuals with FSHD.



## Grant 44

### Research Institution:

Murdoch Children's Research Institute, The Royal Children's Hospital, Melbourne, Australia

### Principal Investigator:

Ms Katy de Valle

### Type:

Australian

### Project Title:

Physical function outcome measures in paediatric FSHD

This study will investigate two promising outcome measures that can be used in children diagnosed with FSHD. The Facioscapulohumeral Dystrophy-Composite Outcome Measure (FSH-COM) and Facioscapulohumeral Dystrophy Health Index (FSH-HI) are two FSHD-specific outcomes that have been used in adults with the condition, however their usefulness in children with the condition are less well known. The FSH-COM evaluates physical function (what the person

can do), while the FSH-HI measures a person's perception of disease burden (the impact the condition has on their life). This study will specifically look at the reliability and validity of these two outcomes measures in children aged 5-18 years with a genetic diagnosis of FSHD. As well as looking at how consistent these outcome measures are over a short time period, we will also compare these FSHD specific measures with two other measures of physical functioning and quality of life, the Motor Function Measure (MFM), and the Paediatric Quality of Life (PedsQL™) neuromuscular module. A better understanding of the reliability and validity of these measures in children with FSHD will enhance their readiness for use in future clinical studies, improving our ability to rapidly and effectively assess the efficacy (or lack thereof) of therapeutic agents for FSHD in children.



## Grant 45

### Research Institution:

University of Minnesota, United States of America

### Principal Investigator:

Associate Professor Michael Kyba

### Type:

International

### Project Title:

Crystal structure of DUX4 protein domains

FSHD has no specific therapy. The genetic mutations that cause FSHD all lead to mis-expression of the DUX4 protein, thus potential therapies center around inhibiting DUX4 activity. The DUX4 protein functions in the nucleus of the cell where it turns on a set of genes that are not compatible with healthy muscle. Our previous work has shown that one end of the protein binds DNA, while the other end of the protein interacts with various cofactors to regulate gene expression. We have recently determined the atomic structure of the DNA binding part of the DUX4 protein, and the current grant focuses on obtaining an atomic resolution structure of the part of the protein that regulates gene expression. Our work has shown the DUX4 interacts with two protein cofactors named p300 and CBP and that this interaction is central to the function of DUX4. We will probe the molecular structure of this part of DUX4 and determine how it interacts with p300 and CBP. This molecular detail about DUX4 will be valuable for designing and developing small molecule inhibitors of DUX4 function that could be developed into therapies for FSHD.



## Grant 47

### Research Institution:

University of Nevada, Reno School of Medicine, United States of America

### Principal Investigator:

Associate Professor Peter Jones

### Type:

International

### Project Title:

Pre-clinical testing for FSHD CRISPR-inhibition therapy

CRISPR technology provides an avenue for targeting and correcting virtually any sequence in the human genome, with long-term or permanent beneficial effects. Thus, it has the potential to cure the root cause of a disease such as FSHD, rather than merely treating symptoms. Although typically used for gene editing (in which DNA is cut and replaced, allowing conversion of a disease-causing mutation to the normal sequence), CRISPR can also be used to change the expression level of a disease-causing gene (e.g., CRISPR inhibition turns a gene off) without cutting the genome. FSHD is caused by mis-expression of the DUX4 gene in skeletal muscle, and could potentially be cured by either CRISPR editing or CRISPR inhibition. Because FSHD is associated with highly repetitive DNA sequences, there are a number of concerns with a CRISPR editing approach that introduces many cuts into the genome. CRISPR inhibition circumvents these problems and is a viable approach for FSHD. The goal of this project is to test the efficacy, specificity, and stability of this approach in two novel mouse models of FSHD, including a xenograft model that will allow us to study the effects of CRISPR inhibition in human muscle derived from FSHD patient cells.



## Grant 48

### Research Institution:

Hubrecht Institute, The Netherlands

### Principal Investigator:

Professor Neils Geijsen

### Type:

International

### Project Title:

Muscle-in-a-dish, development of an in vitro platform of human skeletal muscle

Facioscapulohumeral dystrophy (FSHD) is the most common autosomal dominant form of muscular dystrophy, affecting approximately 1 in 8000 individuals worldwide. FSHD is a human-specific disease and current in vitro and in vivo models do not fully recapitulate the genetic and pathophysiologic aspects of the disease. Therefore, the rationale of this project is to create an in vitro model that mimics the human pathophysiology of FSHD as close as possible. The ability to grow skeletal muscle in a 3D environment coupled with electrostimulation of the muscle tissue allows improved maturation of the in vitro-derived skeletal muscle tissue and provides a new platform on which to test functional parameters of human muscle physiology and test new therapeutic approaches to treat FSHD. In this project, we aim to generate human 3D muscle tissue in vitro to model the natural physiological state and pathogenesis of FSHD, and enable the assessment of the efficacy of different gene editing approaches for the treatment of this disease.





# 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 stay up to date with  
the latest scientific developments,  
Foundation's news, achievements  
and so much more.**



 Service  
Science  
Society  
AUSTRALIA

2014 AUSTRALIAN  
SERVICE INNOVATION  
AWARDS



## 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.

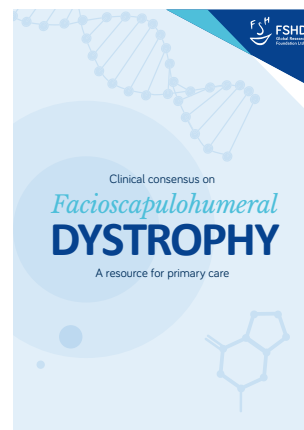
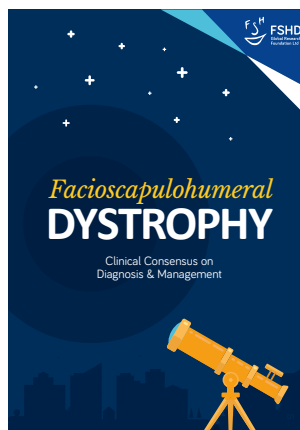
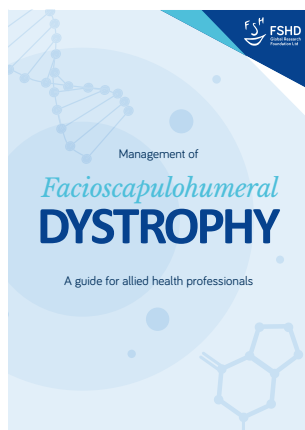
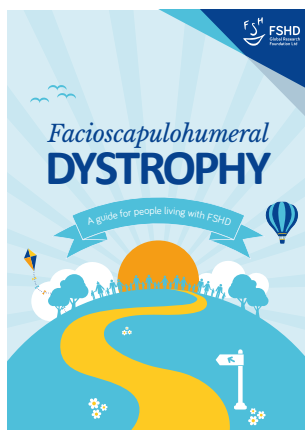
FSHD Global convened a workshop of 13 leading International and Australian clinicians to develop a clinical practice guideline on FSHD. The guideline covers diagnosis and management of FSHD and sets out the standard of care that people with FSHD in Australia should expect from their care team.

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.

These global resources are available to download and share at [www.fshdglobal.org/news/fshd-educational-toolkits/](http://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](mailto:admin@fshdglobal.org)  
(02) 8007 7037



# 11TH ANNUAL SYDNEY CHOCOLATE BALL

## INVITATION

Join us for an evening of celebration

**Saturday 9 May 2020**

The Star Event Centre, Sydney

Time: 6.00 pm

Dress: 'Black & White' Tie

## The Event

Join us for an elegant night of everything chocolate as we celebrate our 11th Annual Sydney Chocolate Ball! Hosted by Jamie Durie OAM, this extravagant night will feature world class entertainment, a chocolate inspired menu designed by celebrity chef Luke Mangan, and an abundance of champagne. Traditionally a sold out event, this is one gala dinner not to be missed!

## The Cause

The FSHD Global Research Foundation is dedicated to finding a treatment and cure for Facioscapulohumeral Dystrophy – an aggressive disease causing irreversible weakening and wasting of muscles. Your support and our transparency enables us to be at the forefront in funding world class global research, providing hope to those affected and their families.

### FSHD Global Research Foundation Ltd

Phone: (02) 8007 7037

Fax: (02) 8007 7038

Email: [admin@fshdglobal.org](mailto:admin@fshdglobal.org)

Web: [www.fshdglobal.org](http://www.fshdglobal.org)

PO Box A296, Sydney South NSW 1235

### Follow us:

Twitter: @FSHD

Facebook: /FSHDGlobal

Instagram: @fshdglobal

Hashtag: #SydneyChocolateBall





# Our Events



## 10th Annual Sydney Chocolate Ball

On 15 June 2019, FSHD Global held its 10th annual Sydney Chocolate Ball! With over 600 guests in attendance, this amazing event was held at The Stars Event Centre, Sydney. Raising over \$1.25 million, guests were treated to a decadent Lindt chocolate menu, exclusively designed by celebrity chef and FSHD Global Patron – Luke Mangan OAM, whilst delighting in free flowing Moët Hennessy champagnes.

With FSHD Global Patron and regular host of the Ball away filming television commitments, we were excited to have travel extraordinaire and television presenter Catriona Rowntree host our night of nights. The Ball was also headlined by FSHD Global Ambassador Emma Weatherley and her 10 year old daughter Hannah, who's personal, inspirational and emotional speech was one of the many highlights of a truly spectacular evening.

As we celebrate 10 years of the Sydney Chocolate Ball, it is important to acknowledge that Lindt have been our proud chocolate sponsor since day one, having donated; 800kg of cooking chocolate, 13,000 Lindt balls and 5,000 gift bags for our guests filled with decadent chocolates... all of which has been 100% donated.

Another cornerstone sponsor of the Ball is Moët Hennessy Australia, who have supported over 13,000 bottles of divine champagnes providing; Krug, Dom Perignon, and Moët & Chandon for us to enjoy year after year.

We have auctioned and raffled more than \$3.5 million dollars' worth of prizes, and seen over 1,000 volunteers donate their time, to ensure we have a good night.

We have welcomed over 5,000 guests to our Ball, who have all helped support, donate and contribute to raising over \$10 million of which has helped fund the vital medical research into finding a cure or treatment for FSHD.

We look forward to welcoming you to our 11th Annual Sydney Chocolate Ball, which will be held on Saturday 9 May 2020 at The Star Event Centre in Sydney. Tickets are now on sale, so please contact our office on 02 8007 7037 or visit our Sydney Chocolate Ball website – [www.sydneychocolateball.com.au](http://www.sydneychocolateball.com.au) to secure your tickets today!



FSHD Global is proud to have an active and engaged community of supporters and friends. Thank you to our 2019 event champions!



### Wyndham Destinations Corporate Surf Challenge

Wyndham Destinations has been a long and loyal support of FSHD Global for over 9 years. The 2018 Corporate Surf Challenge was the 5th event hosted by Wyndham which raised over \$15,500 for FSHD Global. Proudly supported by Wyndham Destinations Ambassador Layne Beachley and attended by a fantastic group of corporates who came together to not only surf but raise much needed money for our cause. Thank you again to Wyndham for their continued and valued support of our Foundation.



### AFL Footy Tipping Competition

President of the Victorian State Branch, Les Jones, once again ran the annual AFL footy tipping competition, raising over \$1,500 for FSHD Global.



### Madison Marcus

Madison Marcus were once again big supporters of the Foundation at two separate events over the last year. Denis Hall participated in the City to Surf and David Voet in the 2019 SMH Cole Classic at Manly. Both gentlemen contributed over \$1,000 in donations for our cause. Thank you so much for your continued support of FSHD Global.



### 80th Birthday Fundraiser

Congratulations to Bev Stidworth from Victoria on your 80th Birthday and thank you so much for making a wonderful fundraising event for the Foundation. Bev asked her birthday party guest to donate to the Foundation rather than receiving gifts, raising an amazing \$984. Thank you Bev for your selfless generosity.



### World FSHD Day

FSHD Global initiated World FSHD Day – a day uniting all FSHD organisations around the world to bridge the gap of education across government, families and media on the effects of the disease and raising greater awareness and funding opportunities worldwide. This initiative continues to grow each year with our communities hosting their own events to raise awareness and funding for FSHD Global. Thank you to 10 year old Hannah Weatherley who raised over \$500 and spoke at her school assembly to educate and create awareness for FSHD. No matter how big or small your event is, every dollar counts and is invested directly into medical research for FSHD.



June 20th 2019



# OUR COMMUNITY



## » Entertainment Books

Once again, Stacie Cunliffe from Western Australia raised money for FSHD Global by selling Entertainment books to the community. Stacie was able to raise over \$850 and continue to raise awareness for FSHD. Awesome work Stacie!

## » 2019 Christmas Appeal

Our annual Christmas appeal saw many within our community hold fundraising events to help support the Foundation, including Jacobs \$615, Dentons \$4,540 and Nanda Albert who raised \$225 in her gym class. The Foundation also received many individual donations from our valued supporters, donors and sponsors.



## » End of Financial Year Appeal

Our End of Financial year campaign was a great success raising over \$9,200. Thank you to everyone who donated to the Foundation and for your continued support of the important work that we continue to do in finding a cure for FSHD.

## » FSHD Global Monthly Giving Program

Have you signed up for our Monthly Giving Program? We are fortunate to have a very generous community, who have donated over \$35,000 via our giving program. If you would like to be part of this important program, you can sign up at [fshdglobal.org](https://fshdglobal.org)



## » Crossfit Bondi

Danny and the team at Crossfit Bondi are inspired by the work of FSHD Global and again, have raised money for our cause. The team created a sponsored Marathon Row event and had their colleagues, friends and family support this initiative. Thank you Crossfit Bondi for doing your bit to make a difference to the lives of those suffering with FSHD.



# Heathers Story

My name is Heather and I am 57 years old. I have four children and seven beautiful grandchildren. I was diagnosed with FSHD seven years ago and as far as I know, I am the only one in my family with FSHD. I came to Australia from England 37 years ago and have never been back.

With the knowledge I have of FSHD now, I know I had a few minor symptoms as a child, such as not being able to whistle or blow up a balloon, I was uncoordinated at any sport and became tired easily. I had sloping shoulders in my 20s and so I loved the 80s fashion of wearing shoulder pads!! It meant my shoulders looked a better shape and the strap of my handbag would not keep slipping off my shoulders!!

At the age of 35 I had a car accident from which I got whiplash and a few other minor injuries. I now look back and wonder if my FSHD would have been picked up earlier if I hadn't had that accident because for the following few years all my shoulder, back and neck pain were put down to having had that accident!! I went through several years of tests in those years but nothing was picked up and my pain was becoming more severe and my upper arm movement more restricted!!

Then one day I had a Nerve Conduct Study done and a Neurologist was in the room. She watched me move different ways then she asked me if I could walk on my heels, which I couldn't do! In fact I couldn't do any of the things she asked! I was then asked to have a blood test, a DNA test which would



take 6 weeks to come back. I said yes but I wanted to know what she thought I had! Her answer was FSHD, she explained it was a type of Muscular Dystrophy. I had the blood test done and rushed home to Google it. I know everyone always says don't google medical conditions or you will think you have everything wrong with you, well this was one time I'm glad I did! As I read, I was thinking, this is me, this is what I do etc, it was amazing!

Six weeks later the blood test came back positive! My first thought was relief! I had all sorts of dreadful diseases and conditions running through my mind! At that point I had no idea how awful FSHD was!

Since being diagnosed I have been learning as much as I can about FSHD so I can educate the Drs I go to!!! As well as trying different ways of managing my pain as it increases and adjusting to the constant and often sudden changes in my body that cause more restriction in my movement.

My arms are so weak, so everyday tasks are difficult - dressing, preparing meals. If I carry anything over 2-3 kgs it causes pulling on my shoulders and neck and a lot of pain. This also means that I can't pick up my youngest grandchildren, I can't sit on the floor to play with them because I can't get up. In the last 3 months I have had several falls due to my foot drop. The last one was in a shopping centre, which was embarrassing! Gardening has been one

of my passions but I can't lift, bend or dig and I haven't got the energy most days. My pain is ALWAYS there, it is a matter of how bad it is. Fatigue is a daily problem, there are times when I have been out for a day and need two days to recover!!

Every morning when I get up, I smile at myself in the mirror, to check whether my mouth muscles have got weaker! I use facial expressions a lot so I dread the thought of not being able to. I have severe dry eye problems due to weak facial muscles, I don't blink much and I sleep with my eyes partially open.

I know I am slowly getting worse, but I will not give up! I can't walk far and stairs are a battle but I want to keep doing as many things as I can! The one thing I would love to do is to travel, especially in Australia.

I am so thankful for my FSHD friends, they are all at different stages of this disease, many are in wheelchairs, (which is something I will need to deal with at some stage). These people are amazing, they are supportive, helpful and willing to listen after a hard day and share ideas on how to do things as our bodies change. They are also hopeful that one day a cure will be found! It is so important to teach people about FSHD and to raise money to be used towards finding a cure. FSHD is a horrible, painful, debilitating disease!

WE ARE PROUD TO BE RECOGNISED AS

# THE AUSTRALIAN CHARITY OF THE YEAR

## 2017 Charity of the year

**“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.”**

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.

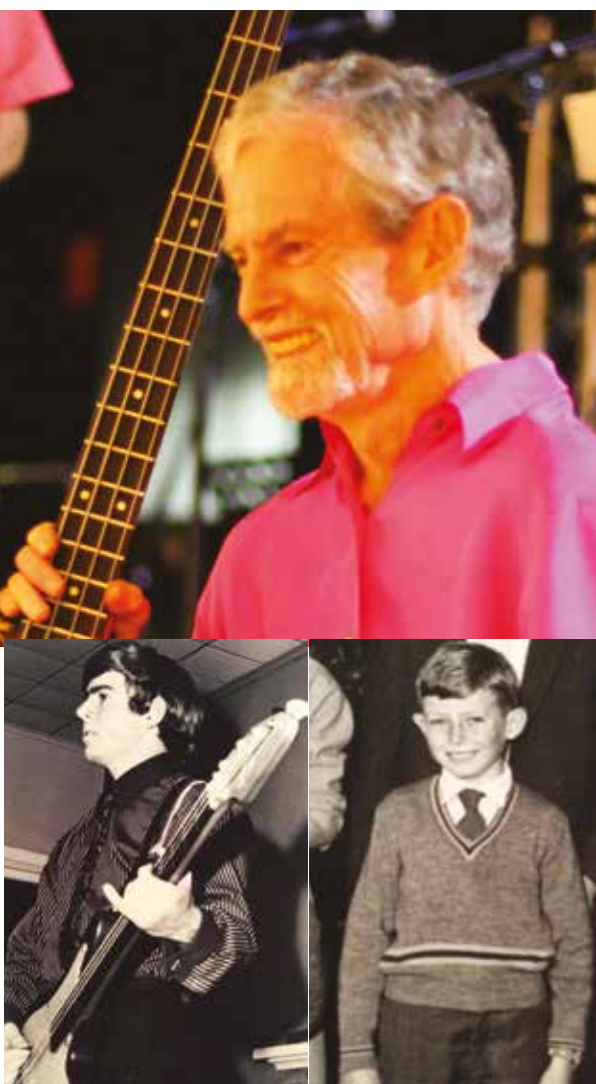
“Being praised for our 100% donor model, which sees every tax deductible dollar directed towards research, sheds light on the importance of transparency and accountability within the not for profit sector. Pairing today’s technology with traditional modes of philanthropy gives the donor journey a stronger 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 [danielle@fshdglobal.org](mailto:danielle@fshdglobal.org) or on (02) 8007 7037

# Rob's Story



I was diagnosed as having Polio during my primary school days. This was regularly assessed by doctors at the Department of Health, Poliomyelitis Division Melbourne. My symptoms were poor posture, weakness, pain and lack of stamina. I was fitted with a steel back brace to try and improve my posture.

After leaving school, I worked in an office for the Public Service but my back and shoulder pains prevented me from continuing. I remember having several episodes of exhaustion and lying in bed in the sick bay for hours. Later I luckily was offered a job as a trainee draughtsman. After a while I was unable to continue standing at the drawing board due to pain so was transferred to the test department where I eventually could not go on. I then joined a 2 customs agents in the city for a few years but that also did not last to the effects of "Polio".

During these years I played in weekend pop bands and now was the time to go full time.

A great adventure awaited. Then there were years of success and touring, however the pain and weakness and fatigue continued until this too became impossible.

I left Melbourne and came to Sydney to study electronics with the help of the Dept of Rehabilitation and I subsidized my income backing cabaret shows in big clubs. After completion I was offered a job in Antarctica, but realized I wouldn't cope so I took a position in a Government Communications Station but pain, shift work and fatigue

finally saw the end of that. After a few years I became an officer on ships on overseas voyages for 15 years, all the while battling with my "Polio".

When I left the sea I became married and started family. I got a job with a printing company doing shift work. I was unable to cope. My symptoms worsened and I went to see a Specialist for Post Polio Syndrome. I was diagnosed with Congenital Myopathy and that was that.

I saw on the internet the symptoms of FSHD and somehow was sent to Concord Hospital for review. I had one of the first DNA Southern Blot Tests in Australia and after 9 months, yes 9 months my results came back positive, FSHD. It was always FSHD. I have been under the care of Concord Hospital ever since.

I joined a Danish Scientific company in Sydney working in the field in Biomedical Engineering, and other scientific instrumentation. Yet again my symptoms worsened so I was taken off the road to do remote specialist problem solving until I eventually could not continue and retired in 2014 after 21 years service.

I have just started playing music again but must stop regularly due to FSH issues.

So the above is my story of a long term battle with the insidious disease. I never had Polio after all.

We with FSH do hope that a cure can be found, especially to help the younger people make their way in life.

Rob Matthews Age 70



# FSHD Global is a little organisation doing very big things!

FSHD Global Research Foundation is leading the charge to change the future for people living with FSHD by funding world class medical research and medical education. FSHD Global is doing all it can to fast track treatments and a cure, and in doing so needs your help. We hope to see the day where FSHD is treatable, curable and even preventable.

 <p>FSHD Global established Australia's first clinical trial for Infantile FSHD</p>			<p>100%</p> <p>100% of all cash tax deductible donations have been allocated to current or future medical research investment, grants and education</p>		 <p>We are committed to bring clinical trials to Australians affected with FSHD</p>
	 <p>Within 11 years we have funded 48 successful medical research grants across 10 countries</p>				 <p>The Foundation receives no government funding, we rely on charitable donations</p>
 <p>The Foundation remains committed to fund every grant to full term</p>		 <p>The Foundation supports innovative and socially responsible biotech's to fast track therapies and clinical trials</p>	 <p>We successfully generated a world first FSHD embryonic stem cell line fast tracking global research</p>		
	 <p>The Board and its Scientific Advisors receive no remuneration, volunteering their expertise to the cause</p>		 <p>Aimed at empowering awareness and clinical care we developed treatment guidelines and toolkits for patients, GP's and Allied Health groups</p>		 <p>The Foundation was honored to be named The Australian Charity of the Year, in the 2017 Business Awards.</p>

It remains our mission to advance global medical research, education and collaboration to improve quality of patients 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.

Connect with us: [www.fshdglobal.org](http://www.fshdglobal.org)  
Facebook: /FSHDGlobal  
Twitter: @FSHD  
Instagram: @fshdglobal



# Andrews Story



Having FSHD sucks. Being unable to do some of the simplest of things that everyone takes for granted is annoying and unfair. It has, however, made me think about things differently. From finding unusual ways to perform tasks, to considering alternative viewpoints.

Looking back, I am grateful for having a normal childhood, something that those born with a disability often don't experience. I was able to ride a bike, play sports, explore and be curious – be a normal kid. Always tall & skinny, my shoulder blades stuck out and wearing a t-shirt made it look like I had boobs on my back. Bullies would grab me by the upper arm and show others how their fingertips would touch their thumb, able to grip all the way around. I hardly ever went shirtless and P.E. was the class I would always dread.

At school, in my early teens, I was told I was the right height to be on a basketball team but soon found that I didn't have the triceps to shoot the ball properly. My doctor suggested going to a gym to beef up a bit, but after six months the change was negligible so the doctor sent me to a neuromuscular specialist. I was spared a muscle biopsy but subjected to other unpleasant tests which indicated FSHD. The specialist looked at mum and said she had it too and I'd inherited from her, which later led to the realisation that my great grandmother also had minor symptoms. I found out the progression

would probably be slow, but it would be inevitable of not being able to walk in my distant future.

My gradual decline resulted in only being able to climb one step at a time by age 18 and difficulty getting up out of a chair by my late 20s. One time on a secluded beach with surfer mates, I was knocked over by wave and couldn't get back onto my feet without being knocked down again by each following wave. After several minutes of struggling I was frustrated and worn out. A mate helped me up, and I haven't been back into the surf since.

Daily difficulties with simple movements, a couple of falls and reduced social interactions was leading towards potential depression. Unable to live alone, I moved back in with mum & dad. They've been wonderful and supportive my whole life and have made me into the person I am. My partner Carol, my everything, is an inspiration for making the most of life regardless of how difficult it can be.

I could see that my strength was continuing to decline and really wanted to be able to keep driving, even if from a wheelchair. I found a newly designed chair that perfectly fit my needs including allowing me to drive. I kept walking as much as I could at home and work and used my chair to be able to go places which had previously been too difficult. It was the best of both worlds.

After my leg broke due to osteoporosis, I ended up with a titanium nail in my tibia and spent several weeks in hospital. I wasn't sure if I'd ever walk again. I pushed myself with physiotherapy and was able to walk just like before. I decided that using my wheelchair was inevitable and another fall could result in serious injury with ongoing pain, so I started using my chair full time. I'd already had the bathroom modified to remove the bathtub and make the shower accessible which was the last obstacle. Home isn't what you'd call easily accessible with some tight corners and narrow doorways but with a manoeuvrable chair and some precision driving I don't think I hit the walls too often (Carol might disagree).

I found out about FSHD Global through my friend Tania. I've been to a few information sessions and this is the second time I've been to the incredible Sydney Chocolate Ball. FSHD Global is an amazing charity in that 100% of ALL donations go directly to medical research to find a cure, an uncommon philosophy that has not only resulted in it being selected as charity of the year, but also accelerating improvements and resulting in a cure being almost within reach, an achievement that should be proudly celebrated by everyone here tonight.

# Our Finances

## Where the money comes from

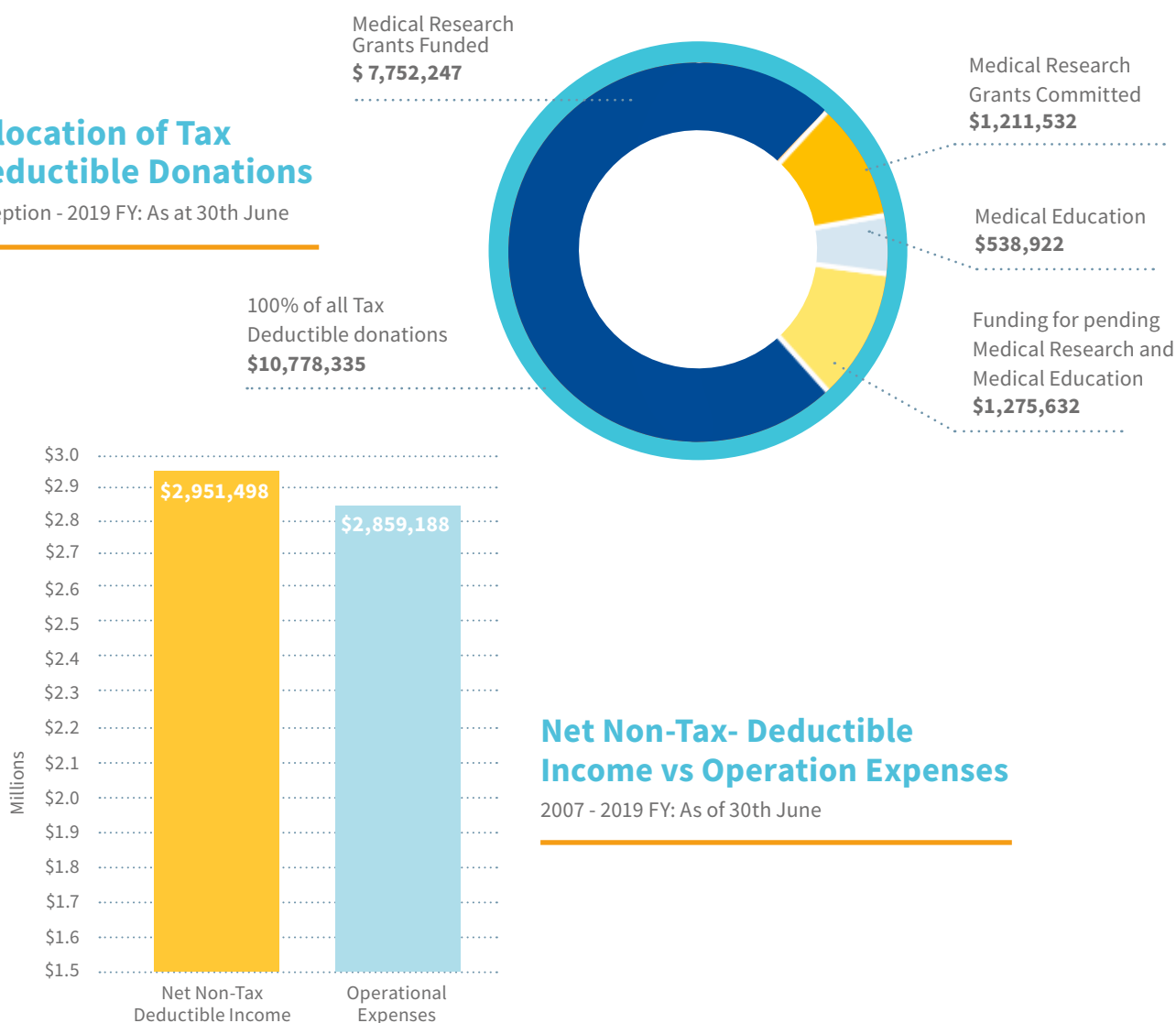
As at June 30 2019, the Foundation has successfully raised over \$10.7 million in tax deductible donations and over \$2.9 million in net non-tax deductible income. This has been achievable because of the support of our community and the hard work of our lean, dedicated team.

## 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 - 2019 FY: As at 30th June



## Net Non-Tax- Deductible Income vs Operation Expenses

2007 - 2019 FY: As of 30th June



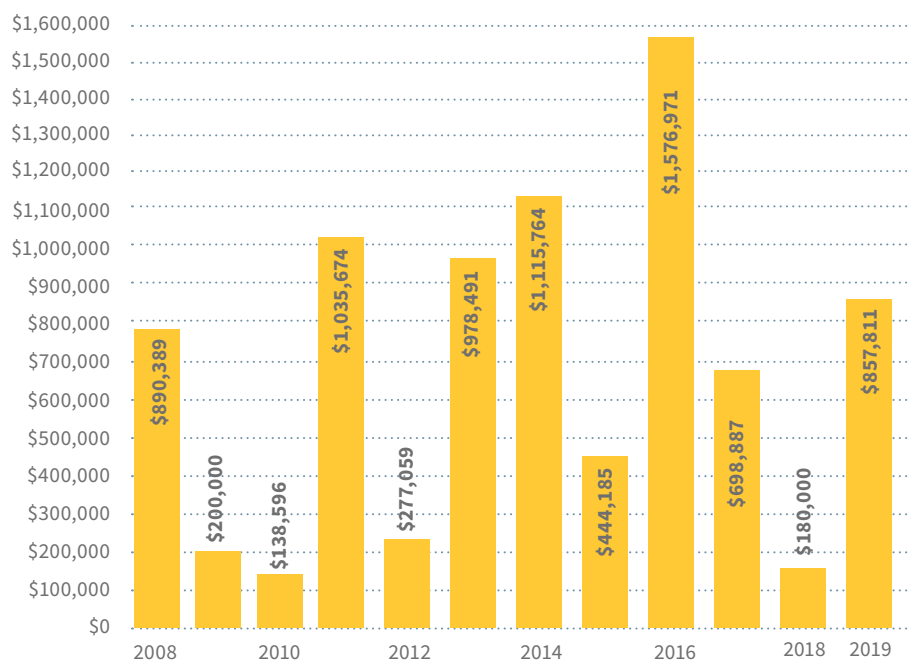
100% of all cash tax deductible donations are allocated to current or future medical research investment, grants and education.

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.

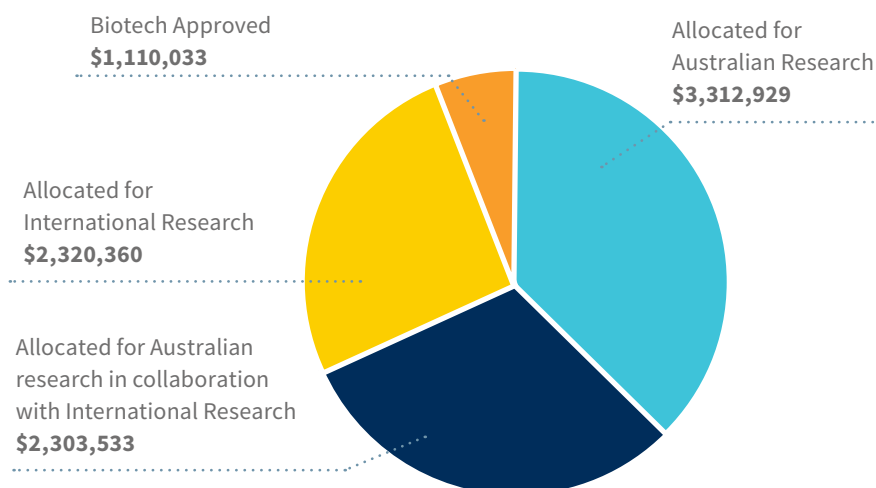
## Medical Research Contracted

2007 - 2019: As at 30th June



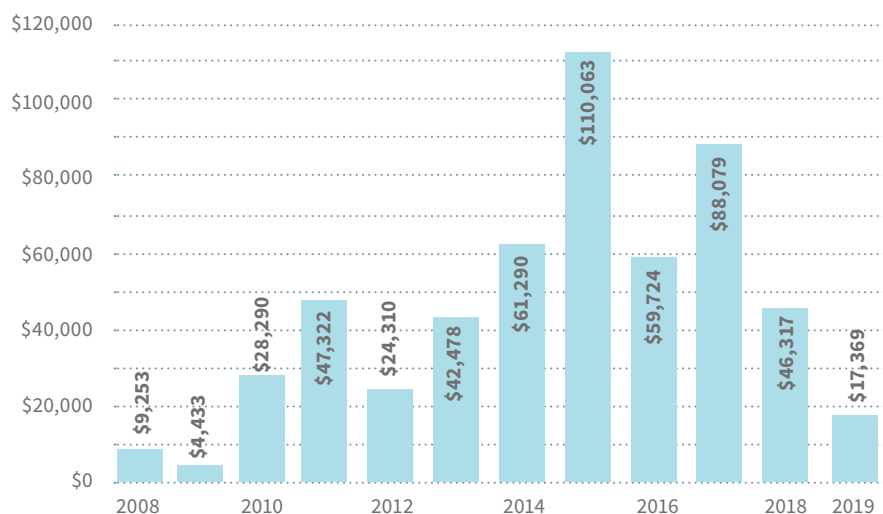
## Medical Research Allocated

2007 - 2019: As at 30th June



## Medical Education Funded

2007 - 2019: As at 30th June



	2019	2018
Donations	\$757,448	\$813,013
Donations in Kind	\$9,000	
Other Fundraising Income	\$644,180	\$748,435
Other income	\$58,046	\$56,434
	<b>\$1,468,674</b>	<b>\$1,617,882</b>
Grants made	(688,911)	(833,505)
Fundraising expense	(377,478)	(486,768)
Education programs	(17,369)	(46,312)
Employee expense	(319,584)	(261,528)
Other expenses	(54,810)	(26,653)
<b>(Loss)/Surplus for the year</b>	<b>10,522</b>	<b>(36,884)</b>
<b>Other comprehensive income:</b>		
<b>Other comprehensive (loss)/income for the year, net of income tax</b>	<b>-</b>	<b>-</b>
<b>Total comprehensive (loss)/income for the year</b>	<b>10,522</b>	<b>(36,884)</b>

## Statement of Profit or (Loss) and Other Comprehensive Income

Available at [acnc.gov.au](http://acnc.gov.au)

This statement should be read in conjunction with the notes to the financial statements.

ASSETS	2019	2018
<b>CURRENT</b>		
Cash and cash equivalents	914,529	1,667,530
Trade and other receivables	18,981	101,829
Financial assets	1,754,493	1,523,170
Other assets	1,952	9,954
<b>Total Current assets</b>	<b>2,689,955</b>	<b>3,302,483</b>
<b>NON-CURRENT</b>		
Investments	1,110,033	485,632
Property, plant and equipment	4,910	6,675
Total Non-current assets	1,114,943	492,307
<b>Total assets</b>	<b>3,804,898</b>	<b>3,794,790</b>
<b>LIABILITIES</b>		
<b>CURRENT</b>		
Trade and other payables	22,003	30,794
Provisions	12,482	4,105
Total Current liabilities	34,485	34,899
<b>Total liabilities</b>	<b>34,485</b>	<b>34,899</b>
<b>Net assets</b>	<b>3,770,413</b>	<b>3,759,891</b>
<b>EQUITY</b>		
Retained earnings	3,770,413	3,759,891
<b>TOTAL EQUITY</b>	<b>3,770,413</b>	<b>3,759,891</b>

## Statement of Financial Position

Available at [acnc.gov.au](http://acnc.gov.au)

This statement should be read in conjunction with the notes to the financial statements.

# How You Can Help!



## Volunteer

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



## Workplace giving

Commit to supporting our Foundation by donating as little as \$2 each month. Simply include FSHD Global as one of your favourite charities for workplace giving.

Workplace giving is an easy way for employees to contribute a small portion of their pre-tax salary to charity.



## Matching

Rally together some colleagues to participate in corporate giving. Then double your company's social impact by matching their donations!



## 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.



## End of Financial Year Donation

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



## Boardroom luncheons

Let us liven up your boardroom! FSHD Global provides engaging and prominent speakers from our networks of scientists, business leaders and people living with FSHD to speak on topics such as the latest FSHD research, philanthropy and the gift of giving. You put on the lunch and we put on the show.



## Invoice rounding

Consider appointing FSHD Global as your preferred charity for invoice rounding. When issuing invoices to your clients simply round up the amount and donate the difference to FSHD Global. This small gesture goes a long way in helping us advance treatments and finding a cure for FSHD.



## Corporate partnerships

Become a Corporate Partner of our Foundation and be involved in all events throughout the entire year. Let us connect you to pioneers of industry to create prosperous relationships for all parties.



## Create your own fundraiser

Host your own fundraising event and raise money on behalf of the Foundation. Whether it be a Christmas party, birthday, ladies lunch, comedy night or dinner, we encourage and appreciate all fundraising activities - no matter how small. We can provide volunteers, collateral and amazing prizes so all you need to do is send out invites.

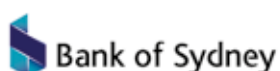
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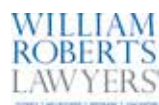


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# Thank you

## FSHD Global Research Foundation Ltd

© FSHD Global Research Foundation is an Australian based charitable organisation raising funds and awareness into FSHD.

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