FSHD
Global Research
Foundation Ltd

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FSHD GLOBAL RESEARCH FOUNDATION | ANNUAL REPORT 2021

Company Name :
FSHD Global Research
Foundation Ltd

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

THE AUSTRALIAN CHARITY AWARDS® OAA OUTSTANDING ACHIEVEMENT WINNER 2021

Welcome to the FSHD Global Research Foundation Annual Report

Our Highlights

Multi-award winning Charity

Winner of Outstanding Achievement in the Australian Charity Awards 2021, 2020, 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

Ongoing Medical Research grants

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

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

$18 million in 13 years

FSHD Global has raised over $18 million in 12 years funding medical research in 10 countries

FSHD Medical Education Portal

The FSHD Medical Education Portal is a 'one stop shop' for people living with FSHD. This platform provides education on advancements in the disease, access to clinical trial readiness programs and the Australian FSHD Registry.

Table of Content

FSHD Global Research Foundation

PO Box A296, Sydney South,
NSW, 1235, Australia

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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

Until 2020 and the challenges of COVID-19, FSHD Global proudly allocated 100% of all tax deductible cash donations to current and future medical research grants, investment and education, whilst the Foundation's operations are supported by non-tax deductible sponsorships and revenue. We hope to return to this proud point as soon as possible. With no government funding or support, our operating model continues to offer great transparency and accountability in allowing us to continue 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 Chairperson

Natalie Cooney

Chairperson
FSHD Global Research Foundation

Dear Friends,

Despite another year of challenges from the COVID 19 pandemic, the FSHD Global Research Foundation achieved several milestone moments, building upon our mission to find a cure for facioscapulohumeral muscular dystrophy (FSHD).

Looking back on 2021, continued COVID restriction saw the postponement of our major fundraising event, The Sydney Chocolate Ball. While we were disappointed to not have the opportunity for our community to connect and drive support to our cause for a second year, our digital fundraising strategy saw the launch of a global 'Muscle for Muscle' campaign, a 'Double Your Donation' campaign and a digital auction. We were truly grateful for the generosity seen from our supporters, during another difficult year.

Despite the challenges, the Foundation funded of over $400,000 establishing three new medical research grants, aimed at improving the diagnostic journey and disease data, to help Australians prepare for FSHD clinical trial readiness programs.

Since our inception, the Foundation has awarded over $18 million to 55 global medical research and educational grants, which has significantly contributed to today's understanding of the disease. With clinical trial readiness programs launching overseas, it has become evident Australia's diagnostic technology and disease awareness for FSHD are behind that of global standards.

To overcome this roadblock in May 2021 the Foundation successfully launched the 'Parliamentary Friends of FSHD' at Parliament House with co-chairs Dr Michael Freelander MP and Dr Fiona Martin MP. A non-partisan forum for all political representatives to raise awareness of FSHD, requesting fairness and equality for FSHD among other neuromuscular disorders the government supports.

Another milestone moment saw the Foundation form a multi-institutional Australian FSHD Research Alliance to launch Australia's first fully characterised FSHD Tissue Cell Bank, donated from adults and children within the Australian FSHD community. Capturing these FSHD genetic packages will unlock critical opportunities to advance medical research for both FSHD1 and FSHD2 and will be made available to researchers within Australia and abroad.

I'm incredibly proud of the Foundation's ability to adapt to the challenges of 2021 and seek the opportunities in strategically advancing therapeutics and treatments for FSHD, muscle technology and muscle wellness programs. 2021 concluded with the Foundation winning the Outstanding Achievement Award for the X year in a row.

I would like to take this opportunity to thank the Foundation's dedicated staff, board of directors, committee members, donors, volunteers, ambassadors, corporate sponsors and members of the FSHD community who have continued to support and inspire the Foundation to continue to provide hope and much needed research and change for thousands of Australians living with this debilitating disease.

I encourage you to follow our journey and partake in any small way you can, as every idea, connection or ounce of support to this global community does make a difference.

Warmest Regards,
Natalie Cooney

Our Journey

11
MILLION

FSHD Global Research Foundation has successfully raised over $11 million dollars in tax deductible donations.

13
YEARS

Founded in 2007, we have achieved this result in just 13 years.

2007 2008 2009 2010 2011 2012 2013 2014 2015 2016 2017 2018 2019 2020 2021

10
COUNTRIES

This money has helped fund 55 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

2021 has been nothing short of another challenging and extraordinary year. As a result of COVID-19, we saw the cancellation for the second year of our blue ribbon major fundraiser – the Sydney Chocolate Ball which essentially provides funding not only for medical research but our annual operational and fundraising costs.

Whilst most of the world paused its operations, FSHD Global set out to revise its operational and fundraising strategy by delivering virtual campaigns and streamlining operations. With the loss of the Sydney Chocolate Ball and a challenging economy, our financial results remained positive.

We still continue to deliver on our mission to fund medical research to find a cure for FSHD, and invest in muscle wellness and muscle technology - assisting all people who are affected by all muscle weakness disorders.

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 as we pave the way towards clinical trials for this debilitating disease.

Thank you to our community and sponsors who continued to support FSHD Global this year by way of monetary donations or the donation of goods and services, which enabled us to deliver our successful virtual fundraising campaigns and donation drives.

The future remains bright for FSHD Global and I look forward to working with our strong, committed and long standing supporters and community in 2022, as we work together to achieve new benchmarks in raising funds and creating awareness of the Foundation's work.

Contact Us

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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 aof 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.

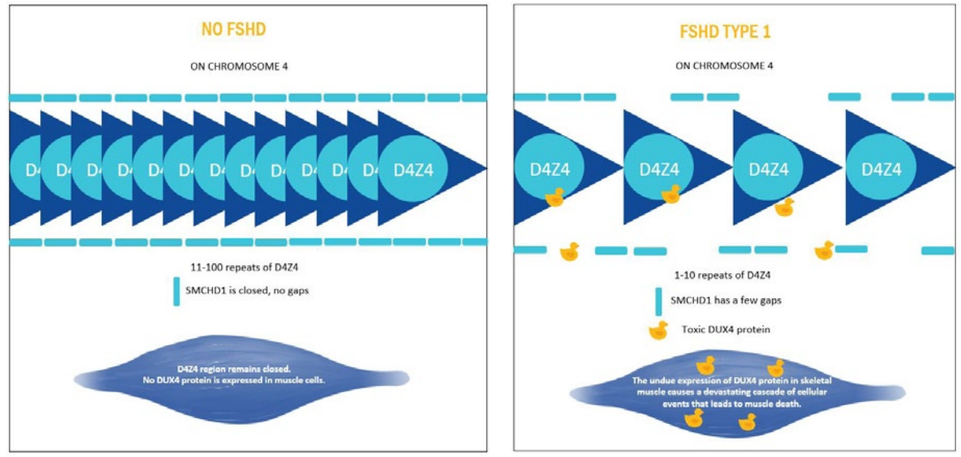
The Global footprint of this disease is enormous, with an estimated 1 million people living with FSHD.

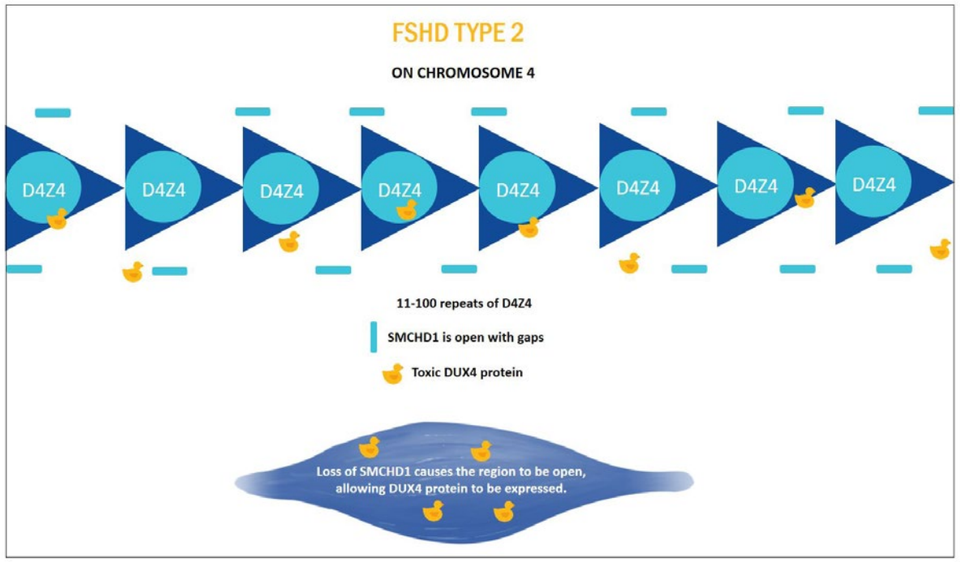
FSHD is commonly associated with progressive weakening of facial, shoulder and upper arm muscles. However, this explanation does little justice to a disease that can rob people of their ability to walk, talk, smile or even eat. The progression often comes in bursts with sudden deterioration followed 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.





BUILDING MUSCLES FOR THOSE WHO CAN'T!

The FSHD Global Research Foundation "Muscles for Muscles" campaign will be returning in 2022. The aim of this campaign is to drive awareness, empathy and support towards finding treatments and a cure for FSHD muscular dystrophy. As a genetic disease, FSHD affects people of all ages, religion, sex and body type. It does not discriminate, and neither does this campaign!

Muscles for Muscles encourages people of all fitness levels to partake. It also gives people living with this debilitating disease an opportunity to engage with their friends and loved ones to compete and raise awareness around the importance of having functional muscle and movement. This challenge is bigger than just fundraising, it is personal to the one million people and their families living with FSHD.

Stay tuned for more information about the 2022 challenge!

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 $11 million to fund 55 ongoing medical research grants in 10 countries; the USA, Canada, the Netherlands, Israel, Italy, France, Belgium, Spain, New Zealand and Australia.

Until 2020 and the challenges of COVID-19, FSHD Global proudly allocated 100% of all tax deductible cash donations to current and future medical research grants, investment and education, whilst the Foundation's operations are supported by non-tax deductible sponsorships. : We hope to return to this proud point in the very near future.

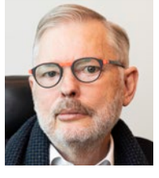
FSHD Global has always been an innovator and a disruptor. The Foundation has launched another innovative milestone for the field of FSHD with the new FSHD Medical Education Portal. This Portal will bridge the gap from archaic diagnostic methods which commonly causes misdiagnoses, and will provide education, assistance and knowledge to people and their families in their own home.

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.

Meet 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



Bill Moss AO
Founder and Patron

Jamie Durie OAM

Justin Reid

Luke Mangan OAM

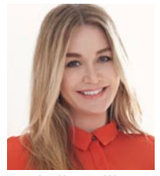
Prof. John Rasko AO
Patron of Science

Ambassadors

Ben Schultz

Julie Wood

Kerry-Anne Johnston



Rochelle Collis

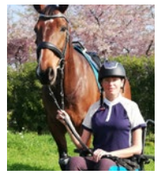
Danny Chronopoulos

Carol Major

Phil Harding

Kerry Armstrong

Bev Baker



Jodie Thorne

State Branch Presidents

Claire Anderson
Western Australia President

Leona Luke
Queensland President

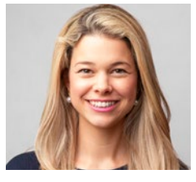
Les Jones
Victoria President

Tania Spagnolini
New South Wales President

Meet 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
Founder and Director



Natalie Cooney
Chairperson

Nigel Virgo
Deputy Chairman

Natalie Pidgeon
Director

Shaun McMenamin
Director

Andrew Rigney
Director

Ross Nicholas
Alternate Director

Barry Robinson
Director

Bechara Shamieh
Director

David Mackay
Director

Glenn Willis
Director

Malcolm Beville
Director

Scott Baker
Director

Emma Weatherley
Executive Director

Thank you to departing Directors of 2020 who have provided their time, expertise and commitment to FSHD Global. We acknowledge Alan Watts, Andrew Frost, Anne Paton, Pete Ratcliffe and Pradnya Dugal.

AT THE EDGE OF RESEARCH

In a short period of time, the Foundation has successfully generated 55 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.

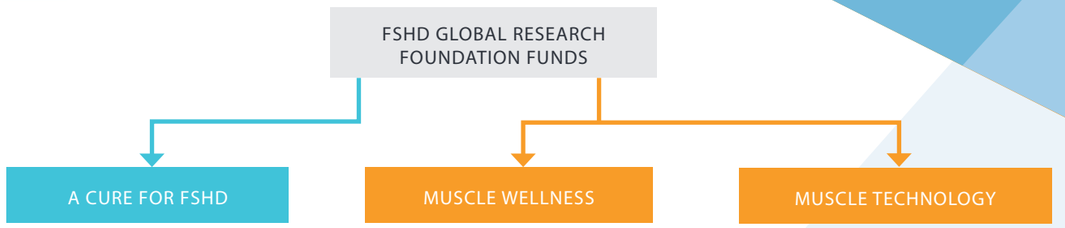
OUR FOCUS

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



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

Research projects that are focused on developing treatments to improve musculoskeletal health, strength and wellbeing.

Research projects that are focused on developing technologies to improve muscle movement and replace or repair damaged tissues.

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.

FSHD MEDICAL EDUCATION PORTAL

FSHD Global has always been an innovator and a disruptor. This year, the Foundation has launched another innovative milestone for the field of FSHD with the new FSHD Medical Education Portal. This Portal will bridge the gap from archaic diagnostic methods which commonly causes misdiagnoses, and will provide education, assistance and knowledge to people and their families in their own home.

This Portal centres on establishing a FSHD Registry, collating information on disease evolution and connecting our community with diagnostic platforms and furthermore clinical trial readiness programs.

Members of the Portal will be encouraged to participate in the FSHD Saliva Research Test to better understand their own DNA sequencing relating to FSHD, which is complimentary and available worldwide.

FSHD MEDICAL EDUCATION PORTAL

FSHD Global Research Foundation funds the world's best medical research into Facioscapulohumeral muscular dystrophy.

As we work towards finding treatments and a cure, the FSHD Medical and Education Portal focuses on encouraging our community to join the FSHD Global Registry, and furthermore connects people living with FSHD to medical research institutions and biotechs researching and/or recruiting for clinical trial readiness programs.

Explore

The FSHD Medical Education Portal not only provides education, professional services and resources about FSHD, it also offers complimentary Saliva Research Test for participants wanting to sequence and check their DNA for any FSH mutations – making them eligible to partake in the FSHD Medical Research & Clinical Trial Readiness Program.

- A Complex Introduction
- Diagnostic Technology
- FSHD Global Registry
- FSHD Saliva Research Test
- Clinical Trials
- Professional Services
- Research & Publications

FSHDmedicalportal.org

FSHD Saliva Research Test

As global medical research advances, so too does our knowledge and understanding of FSHD. While this Portal helps to educate and share resources with our community, it also encourages people living with FSHD to be part of the **FSHD Global Registry**, and be a catalyst for change.

In addition, the Portal assists people and their families to order a complimentary FSHD Saliva Research Test delivered to their home, to better understand their own DNA sequencing relating to FSHD, and furthermore offers these participants an opportunity to then join the **FSHD Medical Research & Clinical Trial Readiness Program**.

To be eligible to participate in the FSHD Medical Research & Clinical Trial Readiness Program, you must complete the following three steps;

STEP 1

Join the FSHD Global Registry

(Note your personal information will be securely and privately stored on our HIPPA compliant database)

STEP 2

Order a FSHD Saliva Research Test to your home

(By clicking here, you will be connected directly with the Peter Jones Lab (University of Nevada, Reno School of Medicine, USA) to facilitate your private test and receive your results).

STEP 3

Donate your results

Donate your Saliva Research Test results to join the FSHD Medical Research & Clinical Trial Readiness Program

- You can request to remove your results at any time.
- Results may be anonymously shared to support and advance medical research.
- When biotech's require participants, and/or a clinical trial is recruiting you will be contacted.
- Note: Your results will be stored in a highly secure HIPAA compliant cloud database, and will be deemed as confidential information.

- FSHD Global is not involved in performing the Saliva Research Test and does not have access to your results unless you choose to provide them.
- This is a research test and not considered an official diagnostic.
- You do not have to have prior genetic testing for FSHD to participate.

Grants Snapshot

A CURE FOR FSHD

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

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

Grant 6
Deciphering the long distance interactions of the D4Z4 array in control and FSHD cells

Grant 4
Comparing the Dnasel Hypersensitive Chromatin Landscape at 4q35 of FSHD and Contol Cells

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 51
FSHD Medical Education Portal

Grant 52
Large animal model for FSHD

Grant 11
Deciphering the long distance interactions of the D4Z4 array in control and FSHD cells

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

Grant 7
Molecular Genetic Basis of Facio Scapulo Humeral Dystroph

Grant 5
Defining the mechanism controlling musclespecific gene expression in FSHD

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

Grant 25
Enhancing BMP signaling to treat FSHD

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

Grant 13
Bill Moss AO Fellowship for Dr Leslie Caron

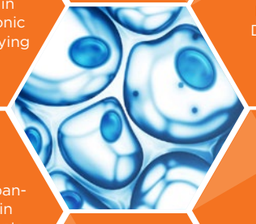
Grant 14
Tissue-specific silencing of the Planar cell polarity gene FAT1 as a causal mechanism for FSHD

Grant 15
DUX4 inhibition as a therapeutic strategy for FSHD

Grant 19
FSHD drug discovery based on chemical inhibitors of DUX4

Grant 23
Grant 23A – current description Grant 23B - Bone health in FSHD

Grant 43
Targeting Dux4 using gene-silencing oligonucleotides in FSHD models



Grant 26
Culture and Expansion of DUX4 in Human Embryonic Stem Cells Carrying FSHD

Grant 27
Functional study of a novel candidate gene for FSH (LRIF)

Grant 16
Bill Moss AO Fellowship for Dr Leslie Caron

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

Grant 18
Study on the clinical features, expression profiling, and quality of life of infantile onset FSHD

Grant 21
Drug targeting of myoblast fusion as a treatment for FSHD

Grant 24
Generation of Drosophila-Based Biomedical Models of FSHD

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

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

Grant 30
HDL based therapy is a potential treatment for FSHD

Grant 29
Training Agreement to The Netherlands

Grant 34
Drug targeting of myoblast fusion as a treatment for FSHD

Grant 31
Development and synthesis of AO transporter

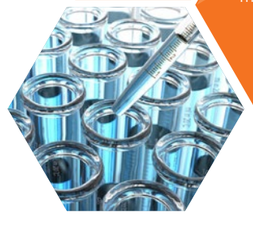
Grant 28
Application of novel isoflavones in an FSHD hESC model system

Grant 50
Facio Therapies Biotech

Grant 35
The Consensus

Grant 33
Facio Therapies Biotech

Grant 49
FSHD cell characterisation project – exome sequencing



MUSCLE WELLNESS

Research projects that are focused on developing treatments to improve musculoskeletal health, strength and well being.

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

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

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

Grant 46
Developing a systemic myostatin-inhibiting gene therapy approach to improve muscle weakness in a new FSHD mouse model

Grant 44
Physical function outcome measures in paediatric FSHD

Grant 45
Crystal structure of DUX4 protein domains

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

Grant 38
Small molecule inhibitors of DUX4 as FSHD therapeutics

Grant 47
Pre-clinical testing for FSHD CRISPR-inhibition therapy

Grant 41
Characterisation of DUX 4 protein – protein interactions in FSHD cell lines and tissue biopsies by cross-linking and mass-spectrometry

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

Grant 48
Muscle-in-a-dish, development of an in vitro platform of human skeletal muscle

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

Grant 55
Target small molecules to inhibit protein-protein interactions by DUX4

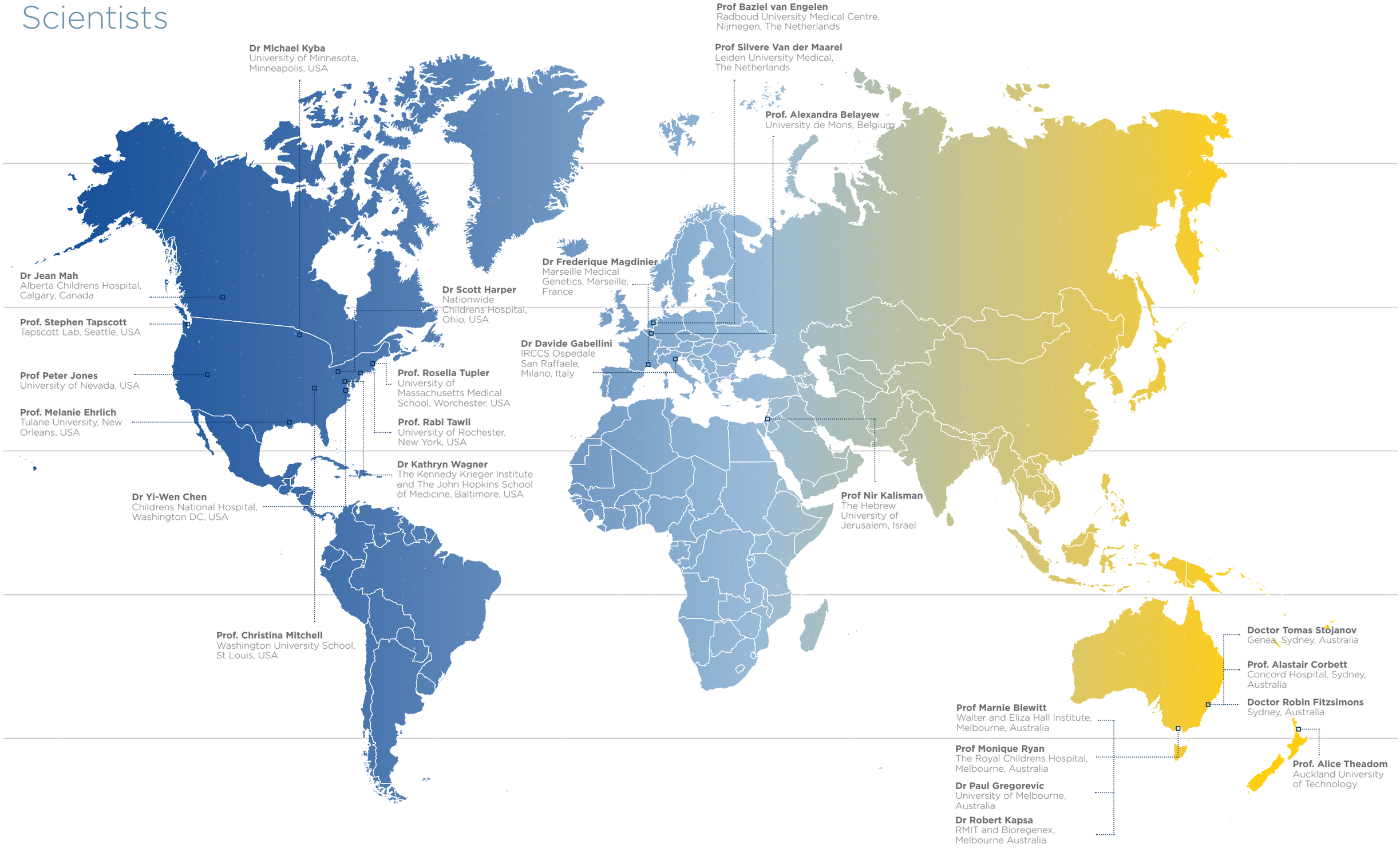
Grant 53
Muscle-in-a-dish, Development of BRGX' proof-of-principal to edit the 4q35A gene locus that causes DUX4 gain of function underlying FSHD pathology

Grant 54
characterised FSHD tissue cell bank

MUSCLE TECHNOLOGY

Research projects that are focused on developing technologies to improve muscle movement and replace or repair damaged tissues.

Meet the Scientists



Active Grant

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.

Grant 39

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

Principal Investigator:
Assiatant Professor Marnie Blewitt

Type: Australian

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

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Grant 43

Research Institution:
The University of Melbourne, Australia

Principal Investigator:
Associate Professor Paul Gregorevic

Type: Australian

Project Title:
Testing novel therapeutic strategies to combat the metabolic disturbances underlying the muscle pathology of FSHD.

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.

Grant 50

Research Institution:
Facio Therapies, The Netherlands

Type: International

Project Overview:
Facio Therapies multi-tier R&D strategy towards a therapy for FSHD is exceptional. The year 2021 will see full implementation of this strategy. They plan to select a fully optimized DUX4 gene repressor for animal toxicology studies – another key value inflection point. These government-mandated studies (if completed successfully) will be the last building block of an application to start a first-in-human study, we will be submitted in 2022. In parallel, Facio plan to further advance their second series of DUX4 gene repressors as well as engage in discovering novel direct DUX4 "disablers" in 2021.

Grant 53

Research Institution:
Royal Melbourne Institute of Technology (RMIT) and St Vincents Hospital Melbourne

Principal Investigator:
Dr Robert Kapsa

Type: Australian

Project Overview:
FSHD Global is collaborating with the Royal Melbourne Institute of Technology (RMIT) and St Vincents Hospital Melbourne (SVHM) to fund the development of biotech BioRegenex' proof of concept' to edit the 4q35A gene locus that causes DUX4 gain of function underlying FSHD pathology.

Grant 54

Research Institution:
Westmead Hospital, Sydney

Principal Investigator:
Dr Michel Tchan

Type: Australian

Project Overview:
: Establishing an Australian – first fully characterized FSHD tissue cell bank made available to national and global researchers will help fast track advancements for the field of FSHD. The Tissue Cell Bank will be created from fully characterized FSHD cells donated from adults within the Australian FSHD community. The cells will be ethically taken via a skin biopsy and sotred at Westmead Hospitals Cell Bank Facility. This Tissue Cell Bank project will quickly become an essential tool in advancing medical research for FSHD1 and FSHD2 and will be available to reserachers within Australia and abroad.

Our Fundraising

Christmas Campaign

Our 2020 Christmas Campaign encouraged our community and supporters to use our online auction platform for the Christmas shopping list. The Foundation was fortunate to have received many generous items to auction, providing 100% of all proceeds to our cause. This campaign raised over $6,500.

End of Financial Year Campaign

Our End of Financial Year Campaign was led by our Founder and Chairman, Bill Moss AO, as a Double your Donation matching campaign. Mr Moss generously donated $150,000 which was the catalyst in driving another $150,000 in donations. With thanks to our generous community, sponsors and supporters, FSHD Global was successful in raising over $405,000 in donations.

Giving Tuesday

On the first Tuesday in December each year – we celebrate Giving Tuesday! This is a global initiative that invites communities to give to their chosen charity. Thank you to our amazing supporters for your continued support!

Muscles for Muscles Squat Challenge

During the 2020 financial year, The Foundation ran two Muscles for Muscles Squat Challenge campaign. The aim of the campaign is to build muscles for those who can't and importantly generate awareness, expand our network into new audiences and drive donations.

The Squat Challenge was launched in August 2020 and held again in May 2021. As a collective result, there were over 500 participants globally, over 500,000 squats completed, and over $110,000 raised. The Squat Challenge was a true global campaign with participants and donors from USA, Brazil, the UK, New Zealand and Australia.

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 almost $33,000 via our giving program. If you would like to be part of this important program, you can sign up at fshdglobal.org

Our Community

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. This year our community raised over $1,500. No matter how big or small your event is, every dollar counts and is invested directly into medical research for FSHD.

AFL Footy Tipping Competition

President of the Victorian State Branch, Les Jones, once again ran the annual AFL footy tipping competition, raising over $1,400 for FSHD Global.

NRL Footy Tipping Competition

For the first time, FSHD Global ran an NRL Footy Tipping competition within our network. We had over 30 tippers join in the fun and raised over $900.

Entertainment Books

Once again, our community raised money for FSHD Global by selling Entertainment books to the community. From these books, our community was able to raise almost $500 whilst continuing to raise awareness for FSHD. Awesome work!

Social Media, Birthday and School Fundraisers

Thank you to the many supporters who hosted their own social media, birthday fundraisers, community or school events in raising awareness and donations for FSHD Global. We were grateful to have received over $5,000 in donations via these events, including international fundraising events.

Hannah's Story

I'm 12 years old and I live in Brisbane with my Mum, Dad, sister and our dog, Mitsy. In 2019 I came to the Sydney Chocolate Ball and it was the best night of my whole life. I met lots of new friends and it was the first time that I felt excited to have FSHD. I spoke with my Mum on stage about FSHD and everyone there wanted to help us.

I'm still finding out whether I have FSHD for sure. About three years ago, my Mum and Dad noticed my arms seemed weaker than they should be and she has FSHD, so they took me to the doctor to talk to him about my muscles. My doctor said he thought I had FSHD and I've been having testing ever since to try to find out whether I have FSHD or something else. For now, my neurologist has told me that she is sure I have FSHD like my Mum, but it has been a long wait to find out. I mainly just want to know what to expect into the future because it might change my career choice if I do know I have FSHD. At the moment I think I will be a bio-engineer because I love maths and science, but I do also really love art so I might be an artist.

I can still dance and walk and even run, but I get tired and sore and sometimes just can't keep up with my friends. I have stopped doing things like riding my bike and riding a normal scooter because it just makes me too tired and sore and I have to stop really quickly. I got an electric scooter last year and my Dad and sister got one too, so we all ride together. I like it much better that we are all riding the same type of scooters. Mum comes along on her wheelchair and leads our dog but she is a lot slower than we are so we wait for her and do some laps.

My physiotherapist has been telling me to use a wheelchair to help save my energy, but I feel silly using a wheelchair when I can still walk. One day, I went on a school excursion to Australia Zoo with my school and the zoo is really big so I used a wheelchair. It was the first time I have been in a chair in front of my friends and I was really nervous.

But they pushed me and had lots of fun with me in my chair – even accidentally letting me roll down a hill and into a garden bed! I had so much energy saved up after that day that I could jump on the jumping pillow with my friends and I made it around the whole zoo. Everyone else was tired and for once, I was fine! So that helped me make my decision to get my first wheelchair.

It's not really a Christmas present but my electric wheelchair is arriving just before Christmas. I picked blue wheels because I'm starting high school next year and the blue wheels will match my uniform and I will blend in. I don't like being different from my friends, and I'm a bit nervous meeting so many new people in high school with my new wheelchair, but I will have my sister with me and I know people will understand that it helps me get around. Plus, it will mean that I will be able to skip lines for rides at theme parks – that's my favourite thing about wheelchairs!

I love dancing. I do ballet, jazz, contemporary, acro, hip-hop and musical theatre. My dance teacher makes sure I am feeling ok and let's me skip activities that are too hard for me or when I get tired. I do everything that my friends do, I just sometimes do it a different way.

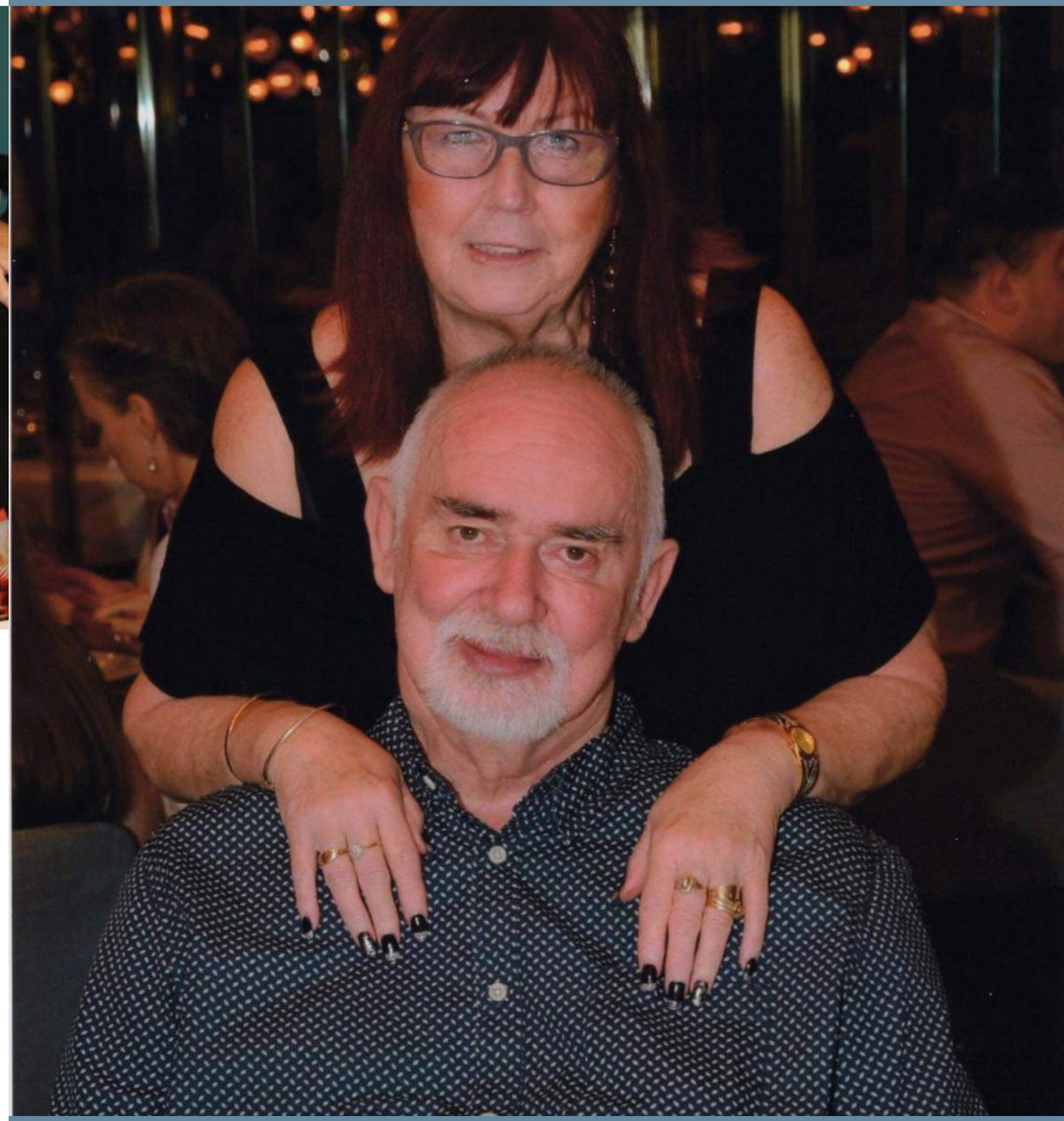
I have a horse called Bailey and love riding on our farm. Dad built a ramp for my Mum and I so that we can get on our horses easily without having to lift our legs up because it is too hard for both of us to do that. The ramp is just the same height as my stirrup, and I can just put my foot in and lift my leg over. Bailey stands very still for me and lets me get on. We do barrel racing and muster cattle together.

Seeing my Mum have FSHD, I know that I'm not alone and there is always someone who understands how I feel. It can be scary seeing how FSHD affects my Mum because I know that will be me one day, but Mum tells me that by the time I'm an adult there will be a treatment for both of us to make us better. I can't wait for that day. I want to be like Mum because every time she can't do something because of her FSHD, she just finds a different way to do it. She never gives up and neither will I.

To help a treatment come sooner, I help raise money for FSHD Global by speaking to my school at assembly and organising everyone to donate for World FSHD Day. My friends at school all wore orange to support me and it felt amazing to see orange everywhere at school. I went to Parliament house with my family and the FSHD Global Research Foundation this year to ask the government for help for our disease. They listened to us and Dr Fiona Martin MP waved to me in Question Time when we went to watch her in Parliament. She said she wanted to help people with FSHD.

Sometimes it is hard to talk about FSHD because it makes me sad. I think the saddest thing about FSHD is knowing that it gets worse and worse and that not even the best doctors in the world can make us better. It makes me sad to think about what might happen as I get older and as my Mum gets older but I just hope that before we are too old we can have medicine to stop our muscles from being weak. But I try to talk about it because if people don't know about FSHD then no one will help us find a treatment for it. Maybe the next person I tell might be the one that helps, so I keep telling everyone that will listen.

Michael's Story



I was born in 1951 in Nowra NSW, my mother was from Scotland and my father was a West Australian. From an early age I was aware my mother had significant health issues, but unfortunately the doctors could not diagnose her problem and for a while they believed she had Polio. Regardless of this my mother went on to have two more children, and we had a great life with loving parents.

I married my wife when I was in my early 20s, and felt as fit and normal as my mates, Shirley and I had children and really enjoyed life. However in the mid 70s Dr Patricia Hurst asked my mother about screening the family, as by this time she had been diagnosed with Facioscapulohumeral Dystrophy (FSHD), which was a genetic disease.

Unfortunately I was diagnosed with FSHD, and although not showing many signs and still quite fit, it was a shattering diagnosis, I had watched my mum deteriorate over the years to a point where she now used a wheelchair fulltime, this was my future.

In 1990 my mother passed away aged 60.

I had decided to keep as active as I could to prolong my independence and mobility, however by my late 50s life was becoming difficult mainly around walking and getting up and down from chairs. At the time I was working for the WA state government and they were extremely supportive, but by the age of 62 I had enough I had several falls my back was causing considerable pain and I was constantly tired. Following discussions with my wife I took early retirement, and my working life of 44 years came to an end.

Progression of this disease increases with age, I now require an electric wheelchair to get around, an electric lift chair to sit in, an electric bed, and a modified bathroom to allow me some independence.

This disease quietly destroys your body you slowly lose the ability to walk, stand, lift your arms , it affects your motor skills and causes significant pain through your body. It also impacts your life socially, unfortunately Australia still has a long way to go to improve accessibility for the disabled.

During my life journey one problem constantly reoccurs, and that is a lack of understanding by the general medical profession, they are quick to put any issue I have down to my FSHD, and frankly admit they know little about the disease.

I am hopeful they will find a treatment for FSHD if not for me then for the next generation.

Michael Truscott.

FSHD Global is a little organisation doing very big things!

FSHD Global has established an FSHD Medical Research & Clinical Trial Readiness Program

Within 13 years we have funded 55 successful medical research grants across 10 countries

The Foundation receives no government funding, we rely on charitable donations

We successfully generated a world first FSHD embryonic stem cell line fast tracking global research

The Board and its Scientific Advisors receive no remuneration, volunteering their expertise to the cause

Aimed at empowering awareness and clinical care we developed treatment guidelines and toolkits for patients, GP's and Allied Health groups

The Foundation supports innovative and socially responsible biotech's to fast track therapies and clinical trials

The Foundation was honored to be named The Australian Charity of the Year, in the 2017 Business Awards.

We are committed to bring clinical trials to Australians affected with FSHD

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.

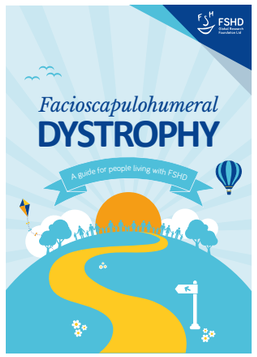
FSHD Global convened a workshop of 13 leading International and Australian clinicians to develop a clinical practice guideline on FSHD. The guideline covers diagnosis and management of FSHD and sets out the standard of care that people with FSHD in Australia should expect from their care team.

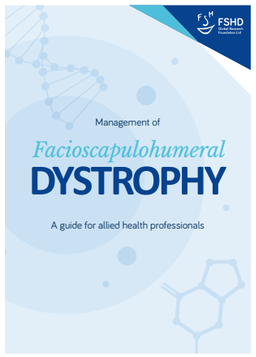
From this, the Foundation created a set of free and accessible Educational Toolkits for people living with FSHD and health care providers. The "Living with FSHD" booklet covers the care that you should expect from your healthcare team, steps for diagnosis, understanding test results, guidance on communicating 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.

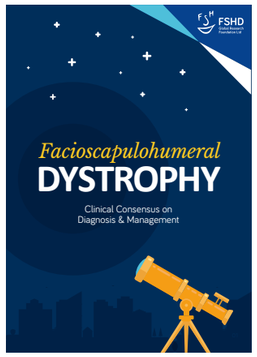
These global resources are available to download and share at www.fshdglobal.org/news/fshd-educational-toolkits/

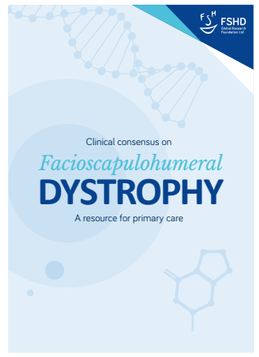
Contact the Foundation to receive your hard copy or learn more on how these resources can benefit you!

admin@fshdglobal.org
(02) 8007 7037







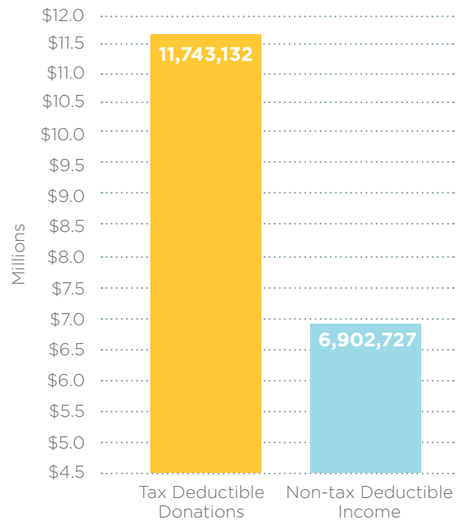


Our Finances

Where the money comes from

Since inception, we have raised over $18 million. As at June 30 2020, FSHD Global successfully raised over $11.3 million in tax deductible donations and over $6.7 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.

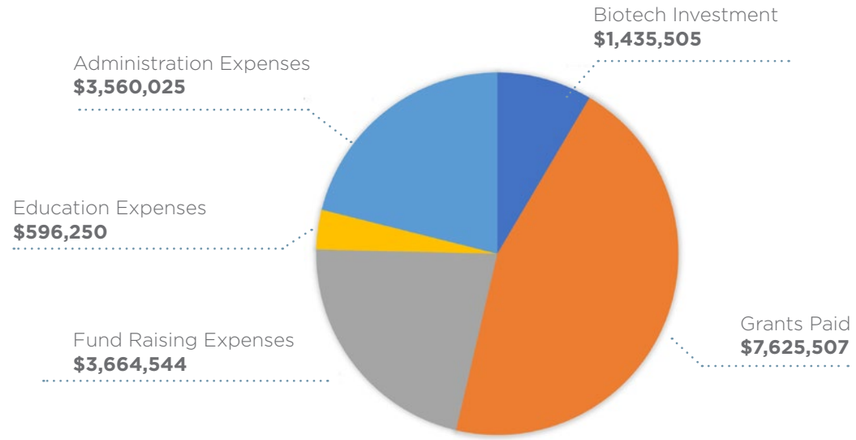
Total Income



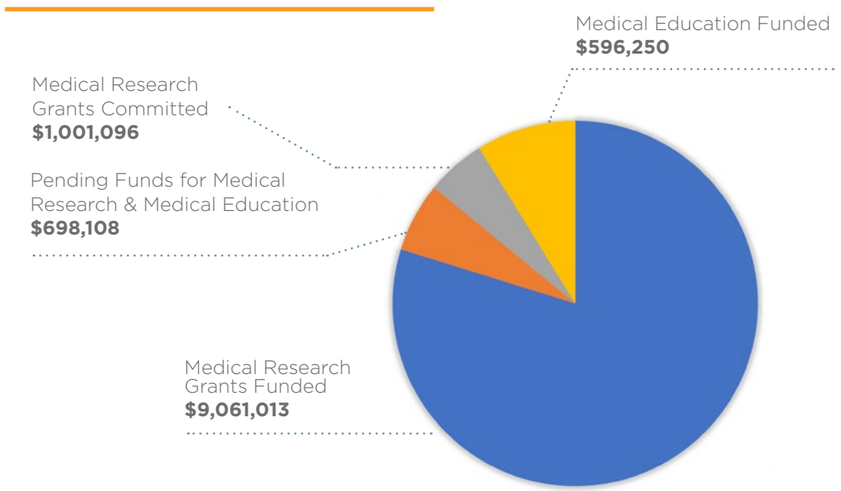
Where the money goes

FSHD Global 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.

Total Expenditure



Allocation of Tax Deductible donations since 2007



Statement of Profit or Loss and Other Comprehensive Income

For the year ended 30 June 2021

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

	2021	2020
Donations	$389,849	$606,846
Bequests	$6,194	
Donations in Kind		-
Other Fundraising Income	$20,711	$104,351
Government Subsidy	$128,030	$34,563
Other income	$11,662	$41,913
	$556,446	$787,673
Grants made	(414,330)	(552,518)
Fundraising expense	(28,330)	(29,464)
Education programs	(16,720)	(40,607)
Employee expense	(273,950)	(369,725)
Investment Losses	(4,716)	(31,900)
Other expenses	(19,132)	(21,710)
(Loss)/Surplus for the year	**(200,732)**	**(258,250)**
Total comprehensive income/(loss) for the year	(200,732)	(258,250)

Statement of Financial Position

As at 30 June 2021

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

ASSETS	2021	2020
CURRENT		
Cash and cash equivalents	809,991	928,252
Trade and other receivables	12,978	120,058
Financial assets	1,068,451	1,056,890
Other assets	-	-
Total Current assets	1,891,420	2,105,200
NON-CURRENT		
Investments	1,435,505	1,435,505
Property, plant and equipment	1,705	2,986
Total Non-current assets	1,437,210	1,438,491
Total assets	3,328,630	3,543,690
LIABILITIES		
CURRENT		
Trade and other payables	1,526	21,325
Provisions	15,672	10,202
Total Current liabilities	17,198	31,527
Total liabilities	17,198	31,527
Net assets	3,311,432	3,512,164
EQUITY		
Retained earnings	3,311,432	3,512,164
TOTAL EQUITY	3,311,432	3,512,164

Notes to the Financial Statements

1 General information and statement of compliance

FSHD Global Research Foundation Ltd (the "Foundation") has elected to adopt the Australian Accounting Standards – Reduced Disclosure Requirements (established by AASB 1053 Application of Tiers of Australian Accounting Standards and AASB 2010-2 Amendments to Australian Accounting Standards arising from Reduced Disclosure Requirements).

These financial statements are general purpose financial statements that have been prepared in accordance with Australian Accounting Standards – Reduced Disclosure Requirements and the *Australian Charities and Not-for-profits Commission Act 2012.*

The company is a not-for-profit entity for financial reporting purposes under Australian Accounting Standards. The Foundation is a company limited by guarantee, incorporated and domiciled in Australia.

Australian Accounting Standards set out accounting policies that the AASB has concluded would result in financial statements containing relevant and reliable information about transactions, events and conditions. Material accounting policies adopted in the preparation of these financial statements are presented below and have been consistently applied unless otherwise stated.

The financial statements have been prepared on an accruals basis and are based on historical costs. A statement of compliance with International Financial Reporting Standards cannot be made due to the Foundation applying the not-for-profit sector specific requirements contained in the Australian Accounting Standards.

The financial statements for the year ended 30 June 2021 were approved and authorised for issue by the Board of Directors on Monday 1 November 2021.

2 Summary of accounting policies

2.1 Overall considerations

The significant accounting policies that have been used in the preparation of these financial statements are summarised below.

The financial statements have been prepared using the measurement bases specified by Australian Accounting Standards for each type of asset, liability, income and expense. The measurement bases are more fully described in the accounting policies below.

2.2 Revenue

Revenue recognition policy for revenue from contracts with customers (AASB 15) requires revenue to be recognised when control of a promised good or service is passed to the customer at an amount which reflects the expected consideration.

Revenue is recognised by applying a five-step model as follows:

1. Identify the contract with the customer
2. Identify the performed obligations
3. Determine transaction price
4. Allocate the transaction price
5. Recognise the revenue

Generally the timing of the payment for sale of goods and rendering of services corresponds closely to the timing of satisfaction of the performance obligations, however where there is a different, it will result in the recognition of a receivable, contract asset or contract liability.

None of the revenue streams of the company have any significant financing terms as there is less than 12 months between receipt of funds and satisfaction of performance obligations.

Interest

Interest income is recognised on an accrual basis using the effective interest method.

Donations and Fundraising

Donations and fundraising collected, including cash and goods for re-sale, are recognised as revenue when the Foundation gains control, economic benefits are probable and the amount of the donation can be measured reliably.

2.3 Operating expenses

Operating expenses are recognised in profit or loss upon utilisation of the service or at the date of their origin.

2.4 Income taxes

No provision for income tax has been raised as the Foundation is exempt from income tax under Div 50 of the Income Tax Assessment Act 1997.

2.5 Cash and cash equivalents

Cash and cash equivalents comprise cash on hand and demand deposits, together with other short-term, highly liquid investments that are readily convertible into known amounts of cash and which are subject to an insignificant risk of changes in value.

2.6 Property, plant and equipment

Each class of property, plant and equipment is carried at cost less, where applicable, any accumulated depreciation and impairment losses.

Depreciation

The depreciable amount of all fixed assets are depreciated on a straight-line basis over their useful lives to the Foundation commencing from the time the asset is held ready for use. The estimated useful life of all property, plant and equipment is 5 years.

The assets' residual values and useful lives are reviewed, and adjusted if appropriate, at each reporting period date. An asset's carrying amount is written down immediately to its recoverable amount if the asset's carrying amount is greater than its estimated recoverable amount.

Gains and losses on disposals are determined by comparing proceeds with the carrying amount. These gains or losses are included in the statement of comprehensive income.

2.7 Employee benefits

Short-term employee benefits

Short-term employee benefits are benefits, other than termination benefits, that are expected to be settled wholly within twelve (12) months after the end of the period in which the employees render the related service. Examples of such benefits include wages and salaries, non-monetary benefits and accumulating sick leave. Short-term employee benefits are measured at the undiscounted amounts expected to be paid when the liabilities are settled.

Other long-term employee benefits

The Foundation's does not have any present or expected obligations in relation to long service leave.

Defined contribution plans

The Foundation pays fixed contributions into independent entities in relation to several state plans and insurance for individual employees. The Foundation has no legal or constructive obligations to pay contributions in addition to its fixed contributions, which are recognised as an expense in the period that relevant employee services are received.

2.8 Financial instruments

Recognition, initial measurement and de-recognition

Financial assets and financial liabilities are recognised when the Foundation becomes a party to the contractual provisions of the financial instrument, and are measured initially at fair value adjusted by transactions costs, except for those carried at fair value through profit or loss, which are measured initially at fair value. Subsequent measurement of financial assets and financial liabilities are described below.

Financial assets are derecognised when the contractual rights to the cash flows from the financial asset expire, or when the financial asset and all substantial risks and rewards are transferred. A financial liability is derecognised when it is extinguished, discharged, cancelled or expires.

Classification and subsequent measurement of financial assets

Except for those trade receivables that do not contain a significant financing component and are measured at the transaction price, all financial assets are initially measured at fair value adjusted for transaction costs (where applicable).

For the purpose of subsequent measurement, financial assets other than those designated and effective as hedging instruments are classified into the following categories upon initial recognition:

- amortised cost
- fair value through profit or loss (FVPL)
- equity instruments at fair value through other comprehensive income (FVOCI)

All income and expenses relating to financial assets that are recognised in profit or loss are presented within finance costs, finance income or other financial items, except for impairment of trade receivables which is presented within other expenses.

Classifications are determined by both:

- The entities business model for managing the financial asset
- The contractual cash flow characteristics of the financial assets

All income and expenses relating to financial assets that are recognised in profit or loss are presented within finance costs, finance income or other financial items, except for impairment of trade receivables, which is presented within other expenses.

Trade receivables
Trade and other receivables are categorised as financial assets at amortised costs. The carrying value of trade and other receivables are deemed to be materially consistent with their fair values given their short-term nature, and after adjustment for expected future credit losses.

Management also considers whether any external factors, such as macro-economic changes are expected to have an impact on future credit losses expected and where applicable overlay this into the assessment of future credit losses.

Balances are deemed to be in default, and therefore written off when reasonable attempts to recover the balances have been exhausted.

Trade and other receivable balances are unsecured.

The Foundation makes use of a simplified approach in accounting for trade and other receivables, and records the loss allowance at the amount equal to the expected lifetime credit losses. In using this practical expedient, the Foundation uses its historical experience, external indicators and forward-looking information to calculate the expected credit losses using a provision matrix.

The Foundation assesses impairment of trade receivables on an individual basis as they possess credit risk characteristics based on each creditor. There is minimal default on payment given majority of payments are made by way of donation.

Subsequent measurement financial assets
Equity instruments at fair value through other comprehensive income (Equity FVOCI) Investments in equity instruments that are not held for trading are eligible for an irrevocable election at inception to be measured at FVOCI. Under Equity FVOCI, subsequent movements in fair value are recognised in other comprehensive income and are never reclassified to profit or loss. Dividend from these investments continue to be recorded as other income within the profit or loss unless the dividend clearly represents return of capital.

Impairment of Financial assets
AASB 9's impairment requirements use more forward-looking information to recognise expected credit losses - the 'expected credit losses (ECL) model'. Instruments within the scope of the new requirements included loans and other debt-type financial assets measured at amortised cost and FVOCI, trade receivables and loan commitments and some financial guarantee contracts (for the issuer) that are not measured at fair value through profit or loss.

The Foundation considers a broader range of information when assessing credit risk and measuring expected credit losses, including past events, current conditions, reasonable and supportable forecasts that affect the expected collectability of the future cash flows of the instrument.

In applying this forward-looking approach, a distinction is made between:

- financial instruments that have not deteriorated significantly in credit quality since initial recognition or that have low credit risk ('Stage 1') and
- financial instruments that have deteriorated significantly in credit quality since initial recognition and whose credit risk is not low ('Stage 2').

'Stage 3' would cover financial assets that have objective evidence of impairment at the reporting date.

'12-month expected credit losses' are recognised for the first category while 'lifetime expected credit losses' are recognised for the second category.

Measurement of the expected credit losses is determined by a probability-weighted estimate of credit losses over the expected life of the financial instrument.

Classification and subsequent measurement of financial liabilities
The Foundation's financial liabilities include trade and other payables.

Financial liabilities are initially measured at fair value, and, where applicable, adjusted for transaction costs unless the Company designated a financial liability at fair value through profit or loss.

Subsequently, financial liabilities are measured at amortised cost using the effective interest method except for derivatives and financial liabilities designated at FVPL, which are carried subsequently at fair value with gains or losses recognised in profit or loss (other than derivative financial instruments that are designated and effective as hedging instruments).

All interest-related charges and, if applicable, changes in an instrument's fair value that are reported in profit or loss are included within finance costs or finance income.

2.9 Goods and Services Tax (GST)
Revenues, expenses and assets are recognised net of the amount of GST, except where the amount of GST incurred is not recoverable from the Tax Office. In these circumstances the GST is recognised as part of the cost of acquisition of the asset or as part of an item of the expense. Receivables and payables in the statement of financial position are shown inclusive of GST.

Cash flows are presented in the statement of cash flows on a gross basis, except for the GST components of investing and financing activities, which are disclosed as operating cash flows.

2.10 Investments
Investments are initially recognised at cost, and subsequently carried at cost less accumulated impairment at each reporting date.

At each date, the Foundation assesses whether there is objective evidence that the investment has been impaired. Impairment losses are recognised in the statement of comprehensive income.

2.11 Significant management judgment in applying accounting policies
When preparing the financial statements, management undertakes a number of judgements, estimates and assumptions about the recognition and measurement of assets, liabilities, income and expenses.

Significant management judgment:
Impairment of investments:
In assessing impairment, management estimates the recoverable amount of each investment based on certain valuation techniques. This involves developing estimates and assumptions consistent with how market participants would price the investment. Management bases its assumptions on observable data as far as possible, but this is not always available. In that case, management uses the best available information to calculate the recoverable amount.

3 Revenue

	2021	2020
Donations		
Founder	$212,000	$262,000
General	$3,742	$16,754
Events	-	$26,690
Corporate	-	$15,380
Monthly Giving Program	$31,438	$33,470
CAF Good2Give	$1,460	$1,690
Campaign Donations	$141,208	$250,862
	$389,848	**$606,846**
Bequests		
Bequests	$6,194	-
	6,194$	-
Fundraising		
Chocolate Ball	-	$79,462
Corporate Surf Challenge	-	$8,575
Other	$20,711	$16,314
	$20,711	**$104,351**
Government Subsidy		
Jobkeeper and Jobsaver subsidies	$98,850	$18,000
Original Cashflow Boost	$20,133	$16,563
	$9,047	-
	$128,030	**$34,563**
Other income		
Interest income	$11,662	$41,913

4 Grants made

	2021	2020
Australian Research Grants	$219,404	$171,898
Collaborative Research Grants	$11,165	$13,305
International Research Grants	$183,762	$367,315
Total Grants Paid	**$414,330**	**$552,518**

5 Cash and cash equivalents

	2021	2020
Cash at bank	$809,991	$928,252
Total cash and cash equivalents	**$809,991**	**$928,252**

6 Trade and other receivables

	2021	2020
Current		
Trade receivables	$12,978	$120,058
Total trade and other receivables	**$12,978**	**$120,058**

7 Financial assets

	2021	2020
Current		
Term deposits	$11,068,451	$1,056,890
Total financial assets	**$11,068,451**	**$1,056,890**

8 Investments

During the year ended 30 June 2021 shares in Facio Therapies the Director related entity were held

	2021	2020
Biotech Portfolio – at cost	$1,435,505	$1,435,505
Total investments	**$1,435,505**	**$1,435,505**

9 Plant and equipment

	2021	2020
Low value pool		
At cost	$2,194	$2,195
Less accumulated depreciation	-$2,194	-$2,078
	$0	**$117**
Software		
At cost	$25,387	
At cost	-$23,682	-$22,516
	$1,705	**$2,871**
Total property, plant & equipment	**$1,705**	**$2,986**

10 Trade and other payables

	2021	2020
Current:		
Other payables	$1,526	$21,325
Total trade and other payables	**$1,526**	**$21,325**

11 Provisions

	2021	2020
Current:		
Annual leave	$15,672	$10,202
Total Provisions	**$15,672**	**$10,202**

12 Contingent liabilities
There are no contingent liabilities that have been incurred by the Company in relation to 2021 or 2020.

13 Post-reporting date events
No adjusting or significant non-adjusting events have occurred between the reporting date and the date of authorisation.

14 Member's guarantee
The Company is incorporated under the Corporations Act 2001 and is a Company limited by guarantee. If the Company is wound up, the constitution states that each member is required to contribute a maximum amount of $20 towards meeting any outstanding obligations of the entity. At 30 June 2021, the total amount that members of the Company are liable to contribute if the Company wound up is $320 (2020: $320).

15 Related party transactions
Key management personnel include the directors and the Chairperson (previously Managing Director). No income was paid or payable to non-executive directors during the year.

The directors and other key management personnel may be members of FSHD Global Research Foundation Ltd and may donate to the Foundation.

16 Commitments
The Foundation has 12 active research grants and has commitments to fund 2021: $1,001,096 (2020: $1,069,967) in research projects over the next three years. There have been no significant changes in the nature of these activities during the year.

17 Charitable Fundraising Act 1991 Disclosures

	2021	2020
Donations		
Founder	$212,000	$262,000
General	$3,742	$16,754
Events	-	$26,690
Corporate	-	$15,380
Monthly Giving Program	$31,438	$33,470
CAF Good2Give	$1,460	$1,690
Campaign Donations	$141,208	$250,862
	$389,848	**$606,846**
Bequests		
Bequests	$6,194	-
	6,194$	-
Fundraising		
Chocolate Ball	-	$79,462
Corporate Surf Challenge	-	$8,575
Other	$20,711	$16,314
	$20,711	**$104,351**
Gross aggregate income received from donations and fundraising	**$416,753**	**$711,197**
		-
Total Fundraising Expenditure	**$28,330**	**$29,464**
Net Surplus from fundraising appeal	**$388,423**	**$681,733**

Any donations received where the use of those funds is restricted under the conditions of the contribution to specific Any donations received where the use of those funds is restricted under the conditions of the contribution to specific purposes are applied for those specific purposes.

Costs of fundraising include all direct fundraising costs in accordance with the Act. The costs also include costs for processing unsolicited donations and the planning and development of future fundraising activities.

Any surplus arising from fundraising appeals is applied to the charitable purposes of the Company.

Our Sponsors and Supporters

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Bill Moss AO

Boston Global

Canterbury

Credit Suisse

David & Michelle Dodd

David & Michelle Mackay

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Frank Pace

Glenn Willis

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luke mangan & COMPANY

MADISON MARCUS LAW FIRM

Malcolm & Julie Beville

RBW CHARTERED ACCOUNTANTS

WILLIAM ROBERTS LAWYERS
SYDNEY | MELBOURNE | BRISBANE | SINGAPORE

Facioscapulohumeral Muscular Dystrophy (FSHD) Facts

FSHD affects an estimated **3,500 Australians – one of the most common forms of muscular dystrophy.**

FSHD is a highly complex and **progressive muscle wasting disease** causing weakening and loss of skeletal muscle in adults and children, robbing the ability to **walk, talk, smile, blink or even eat**.

FSHD is often described as a **slow death** disease and does not discriminate against **gender, race, religion or ethnicity**.

FSHD is a **genetic** disease that is either passed down through generations or caused by a **spontaneous gene mutation**, which can mean that **any family** can be impacted without warning.

There is currently no treatment or cure.

Parliamentary Friends of FSHD

A collaboration between Parliamentary representatives, the FSHD community, scientific researchers and pharmaceutical and medical industry to ensure Australians living with FSHD have access to improved diagnostic technologies, education and future clinical trials.

Join the Parliamentary Friends of FSHD and proudly wear your ribbon to raise awareness and start important conversations for FSHD.

Scan the QR code to learn more abour our work

fshdglobal.org

How can you help?

Education

- Currently, there are no educational programs or diagnostic advocacy for FSHD in Australia, resulting in misdiagnosis and delayed diagnosis.
- **Patients, medical professionals and providers require support and education programs to better understand the disease.**

Diagnostics

- Australia uses outdated technology, resulting in expensive and unreliable diagnostics.
- There is currently no option for pre-natal screening of FSHD, despite existing capability and funded screening of other less prevalent conditions.
- **Providing world class diagnostic technology would bring Australia into alignment with the United Kingdom, America, Europe and China.**
- Diagnostics are key to understanding prevalence of FSHD in Australia and enabling Australians to participate in future clinical trials.

Clinical Trial Readiness

- Since 2007, FSHD Global Research Foundation has privately funded world's best medical research using Australian donations. Clinical trials are commencing globally, however, without change, Australians with living FSHD will not be able to participate or benefit from them.
- **A comprehensive patient registry is required to collect data and enable Australians to participate in local and international clinical trials.**
- Clinical trials give hope to Australians living with FSHD that a treatment and cure are in sight.

We ask for your help to bring fairness and equality to current and future Australians living with FSHD. We ask to work through the challenges together to bring quality of life to the thousands of Australians silently suffering.

Contact Us | fshdglobal.org

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natalie@fshdglobal.org

Danielle Thomson
CEO
0408 640 891
danielle@fshdglobal.org

FSHD Global
A multi – award winning Charity

2013
- 2013 WINNER OUTSTANDING ACHIEVEMENT – FSHD GLOBAL RESEARCH FOUNDATION

2014
- THE AUSTRALIAN CHARITY AWARDS – OUTSTANDING ACHIEVEMENT 2014
- 2014 AUSTRALIAN SERVICE INNOVATION AWARDS

2015

2016
- THE AUSTRALIAN CHARITY AWARDS – OUTSTANDING ACHIEVEMENT WINNER 2016

2017
- THE AUSTRALIAN CHARITY AWARDS – CHARITY OF THE YEAR WINNER 2017

2018
- THE AUSTRALIAN CHARITY AWARDS – OUTSTANDING ACHIEVEMENT WINNER 2018

2019
- THE AUSTRALIAN CHARITY AWARDS – OAA – OUTSTANDING ACHIEVEMENT WINNER 2019

2020
- THE AUSTRALIAN CHARITY AWARDS – OAA – OUTSTANDING ACHIEVEMENT WINNER 2020

2021
- THE AUSTRALIAN CHARITY AWARDS – OAA – OUTSTANDING ACHIEVEMENT WINNER 2021

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.

Thank you

FSHD Global Research Foundation Ltd

ABN 79 128 037 614

Contact Us

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