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www.fshdglobal.org

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App - FSHD - Find the Cure

FSHD Global Research Foundation Annual Report 2018

Company Name :
FSHD Global Research Foundation Ltd

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

FSHD
Global Research Foundation Ltd

Welcome to the
FSHD Global Research Foundation
Annual Report

Our Highlights

Charity of the Year

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

$0 remuneration

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

On going Medical Research grants

42 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 10 years

FSHD Global has raised over $10 million in 10 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

Table of Content

FSHD Global Research Foundation

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

+61 (2) 8007 7037

About us
Our Story

FSHD Global Research Foundation was established in 2007 by Australian businessman, philanthropist and sufferer of FSHD, Bill Moss AO. We fund world class medical research and medical education to find treatments and a cure for Facioscapulohumeral Muscular Dystrophy (FSHD). This Foundation does not operate like your average not-for-profit.

We allocate 100% of all tax deductible cash donations to current and future medical research investment, grants and education whilst the Foundation's operations are supported by non-tax deductible sponsorships. With no government support, this unique charity model offers great transparency and accountability in allowing us to fulfil our mission.

Mission

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

Vision

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

Values

Transparency and accountability

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

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

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

Bill Moss AO
Founder and Chairman
FSHD Global Research Foundation

Dear Friends,

Since its inception in 2007, the Foundation has received $10,020,888 in donations, all of which has been committed to either current or future medical research projects, that are focused on finding a cure for FSHD (Facioscapulohumeral muscular dystrophy), or educational programs to educate the Australian community, Doctors and Specialists on the disease.

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

In the financial year ended 30th June 2018, the Foundation received revenue of $1,617,882 of which $813,013 was received from donations, $748,435 was received from fundraising activities and $56,434 was received from investment income.

We funded 9 projects located in Australia, USA, Italy and Israel. The Foundation continued its policy of encouraging international applicants for funding to collaborate with Australian researchers and scientists.

During the year the Foundation continued to invest in its strategy to discover compounds that will reduce Dux4 and encourage muscle cell growth that can ultimately lead to a cure. In this regard the foundation invested $485,632 into Biotech research.

As at 30th June 2018 the Foundation held cash deposits of $1,667,530 of which $833,505 was held to fund current approved projects and projects under consideration for future funding. During the year the Foundation also committed $46,312 to education and awareness of FSHD.

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.

$10,000,000

10
YEARS

Founded in 2007, we have achieved this result in just 10 years.

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

10
COUNTRIES

This money has helped fund 42 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

The past year has seen FSHD Global reach some significant milestones. We proudly celebrated our 10 year anniversary which also coincided with the Foundation surpassing $10 million in donations.

Danielle Thomson

Chief Executive Officer
FSHD Global Research Foundation

As a result of these achievements, FSHD Global continues to shift the global and local medical landscape of FSHD and increase our pace and footprint in seeking treatments and an ultimate cure for FSHD.

We are making progress! We have recently seen amazing results come from the Biotech space which has rapidly shifted the momentum in research. This makes us even more eager and committed to continue our mission to raise funds and support the research which is quickly gaining traction and results.

Our award winning charity 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

www.fshdglobal.org
admin@fshdglobal.org

THE AUSTRALIAN CHARITY AWARDS
CHARITY OF THE YEAR WINNER 2017

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.

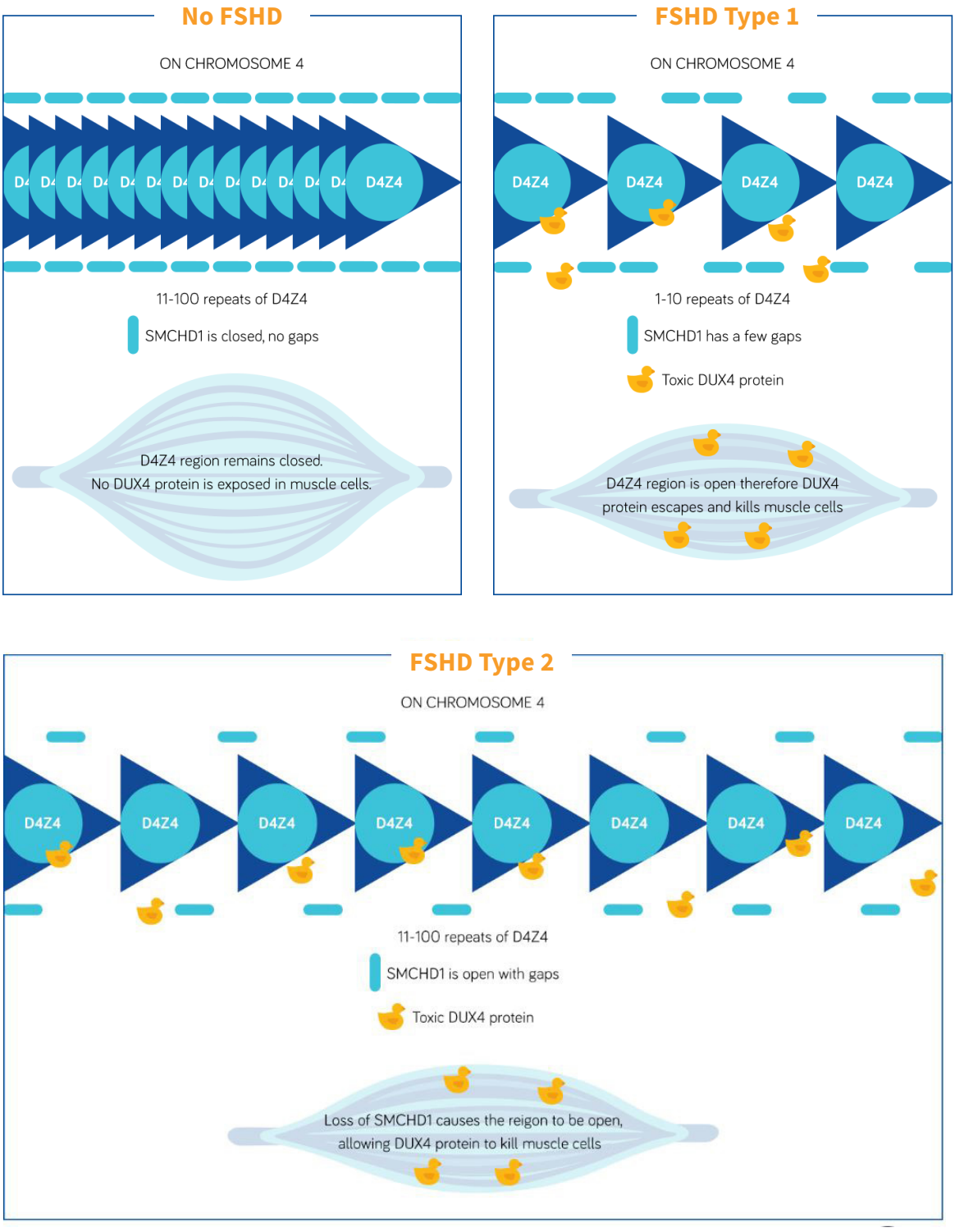
The Global footprint of this disease is enormous, with an estimated 1 million people living with FSHD.

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.



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.

Since 2007, the Foundation has committed over $10 million to fund 42 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.

We allocate 100% of cash tax deductible donations we receive to current and future medical research grants, investments and education.

Our Progress, Our Future

FSHD Global has one simple quest – find a cure for FSHD. We don't have a 20 year strategy, in fact, we don't want this Foundation to exist in 10 years time. We just want a cure as quickly as possible.

Prior to the establishment of the Foundation in 2007, little was known about the disease and its genetic cause. During the past decade, the Foundation has dramatically advanced global research and awareness towards FSHD, having funded 42 medical research grants across 10 countries.

As one of the world's largest funders of FSHD medical research, FSHD Global has funded multiple world first medical breakthroughs; successfully generating the first embryonic stem cell line with FSHD mutations, investigated biomarkers to help with diagnosis, paved the way towards drug development and most recently invested in innovative FSHD biotech, a stepping stone towards clinical trials.

The power of the biotech industry is to fast-track research processing ideas in to the clinic and ultimately to treatments in a fraction of the time traditional medical research takes. The Foundation is excited to be part of the FSHD biotech research revolution. This is a game changer for the disease, as we believe treatments are in sight.

We have achieved significant milestones over our 10 year journey, and believe in the near future we can overcome FSHD together. We welcome you to take part on this life changing journey, as we execute our vision and mission with continued drive and passion, to find a cure for FSHD.

2018

Outstanding Achievement

The Australian Charity Awards

2017

Winner

Australian Charity of the Year

2016

Outstanding Achievement

The Australian Charity Awards

2014

Winner

Australian Service Innovation Awards

Our Patrons, Ambassadors and State Branch Presidents

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

Patrons

Jamie Durie OAM

Justin Reid

Luke Mangan

Prof. John Rasko
Patron of Science

Ambassadors

Ben Schultz

Tania Spagnolini

Charlotte Caslick

Emma Weatherley

Julie Wood

Kerry-Anne Johnston

Lewis Holland

Paul Gallen

Rochelle Collis

Rohan Hardcastle

State Branches

Carol Major

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

James Wakim
Deputy Chair

Natalie Moss
Managing Director

Alan Watts
Head of Science

Andrew Rigney
Secretary / Director

Andrew Frost
Director

Barry Robinson
Director

Bechara Shamieh
Director

David Mackay
Director

Glenn Willis
Director

Malcolm Beville
Director

Nigel Virgo
Director

Pradnya Dugal
Director

Bev Baker
Alternate Director

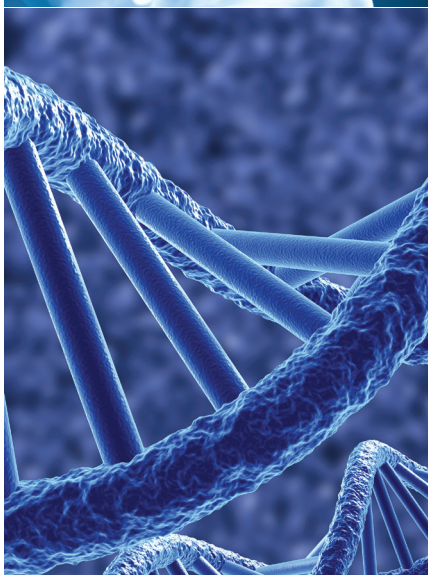
James Harvey
Alternate Director

At the Edge of Research

In a short period of time the Foundation has successfully generated 42 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.

Our research is divided into four key areas;



1 Basic Research

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

DUX4 is the main toxic protein that promotes skeletal muscle wasting, but relatively little is known about its interactions with other proteins. We must learn more about these interactions and determine inhibitors for rational design of future FSHD therapies. The Foundation has funded over 24 basic research grants, each bringing more knowledge to better understand the complex mechanisms underlying FSHD.

2 Diagnostic Research

Diagnostics are the tools used to tell if someone has a certain condition. FSHD Global is exploring ways to improve diagnostics for FSHD in Australia to help ensure people who suspect they have the condition have timely access to a definitive diagnosis.

The Foundation is proud to fund a joint project between the Concord Hospital and the Garvan Institute of Medical Research, which looks to improve the diagnostic pathway for Australian patients. The genetics of FSHD are complex. Instead of looking at one region of the genome, this project looks at the entire genome, allowing us to investigate other genetic causes for FSHD and may explain why some people have very mild symptoms while others have very severe symptoms. Moreover, allowing us to further understand clinical measures of disease progression.

Biotech Investment »

The main difference between traditional medical research and biotech is the ability to approach the challenges of developing treatments for FSHD through the lens of a business model. These two approaches are complementary, this synergy helps to fast-track our goal of overcoming FSHD. The Foundation is excited to be part of this research revolution supporting an innovative and socially responsible biotech aimed at translating basic research into a therapy that will stop the progressive muscle wasting caused by FSHD. Facio Therapies have established the first-ever screening platform that enables reliable quantification of the naturally occurring toxic DUX4 protein, in cultured FSHD-affected muscle cells, and furthermore have begun to characterise and develop FSHD viable drug candidates.

In addition the Foundation is currently investigating opportunities to provide seed capital towards the establishment of an early stage biotech company which would be directed at the development of 3D Muscle Printing technology. This project would look to build new muscle tissue suitable for transplants into FSHD sufferers specifically, but also with broader applications for other muscle diseases/ repair of injuries.

Therapeutic Research »

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

For example, people with FSHD experience progressive muscle weakness which, at some point, will involve the muscles of the neck and chest wall. Consequently, breathing function during sleep as well as in wakefulness may be affected. The frequency and type of breathing problems that can occur in people with FSHD have not been widely addressed. Therapeutics often leads to clinical trial readiness, of which we are thrilled to have established Australia's first clinical trial for Infantile FSHD. This study aims to assess the effects of dietary supplementation on muscle strength, function and body composition of children living with FSHD. The study will use Magnetic Resonance Imaging (MRI) as a biomarker to identify disease progression and look to assess the activities of daily living, mood and general wellbeing of children with FSHD. This is an exciting trial that hopes to give further insight into this complex disease.

Through the Foundation's 'FSHD - Find the Cure' APP, you can actively monitor your involvement in all of our Grants, tracking 100% of your donation and further understanding the full impact you have had on a project as it progresses.

If any of these projects or areas of research excite you, and you wish to support our quest for a cure, please show your support by donating, and change the lives of the one million people living with FSHD.

Grants Snapshot

BASIC

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

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

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

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

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

Grant 5:
Defining the mechanism controlling musclespecific gene expression in FSHD

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

Grant 7:
Molecular Genetic Basis of Facio Scapulo Humeral Dystrophy

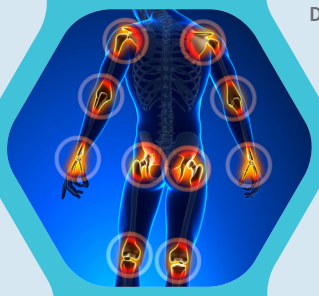
Grant 8:
Title: Dysregulated Pathways in FSHD: Recreating the FSHD Phenotype

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

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

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

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



Grant 13:
Bill Moss AO Fellowship for Dr Leslie Caron

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

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

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

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

Grant 35:
The Consensus

Grant 25:
Enhancing BMP signaling to treat FSHD

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

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

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

Grant 31:
Development and synthesis of AO transporter

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

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

<<<<<

BIOTECH INVESTMENT

The main difference between traditional medical research and biotech is the ability to approach the challenges of developing treatments for FSHD through the lens of a business model.

Grant 33:
Facio Therapies Biotech

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

Grant 29:
Training Agreement to The Netherlands

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

DIAGNOSTICS

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

Grant 15:
DUX4 inhibition as a therapeutic strategy for FSHD

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

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

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

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

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

Grant 42:
Respiratory restriction and sleep disordered breathing in FSHD

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

Grant 27:
Increasing SMCHD1 Levels as a Therapy for FSHD1 & FSHD2

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

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

Grant 38:
Small molecule inhibitors of DUX4 as FSHD therapeutics

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

THERAPEUTICS

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

Active Grant Update

Grant 20

Research Institution:
San Raffaele Scientific Institute, Italy

Principal Investigator:
Dr Davide Gabellini

Type:
Collaboration

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

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

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

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

OSPEDALE SAN RAFFAELE

Grant 25

Research Institution:
Baker IDI Heart and Diabetes Institute

Principal Investigator:
Dr Paul Gregorevic

Type: Australian

Project Title:
Enhancing BMP signalling to treat FSHD

The Team's first objective was to develop a new mouse model in which to study 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.

Baker HEART & DIABETES INSTITUTE

Grant 26

Research Institution:
University of Massachusetts Medical School

Principal Investigator:
Professor Rossella Tupler

Type: International

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

FSHD is considered an autosomal dominant disease associated with changes of DNA or chromatin of a region located at the very end of the long arm of chromosome 4. Studying FSHD for over 25 years we understood that FSHD does not always present as an autosomal dominant trait with affected people in all generations of a family tree. Instead we found families in which two sibs have FSHD with healthy parents and healthy children.

This type of setting is suggestive of an autosomal recessive mode of inheritance. In this case genetic counselling is different because parent and children are carriers of only

one mutated gene and have no risk of developing disease. Moreover, the study of these families can bring more knowledge to understand FSHD.

With these considerations in mind we studied a family in which FSHD seemed to be transmitted as autosomal recessive disease. The two sisters with FSHD presented a rapid progression and very severe outcome. Both sisters presented severe reduction of muscle mass and respiratory difficulties. We found they carry homozygous mutations in one gene encoding a protein that might play a role in chromatin conformation.

We demonstrated that the two identical mutations present on both copies of this gene causes the lack of one of the two forms of the protein that the cell can produce. We think that the absence of this specific form can trigger a cascade effect and interfere on the function of several genes with severe consequences for the muscle.

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

University of Massachusetts Medical School
UMASS

Grant 32

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

Principal Investigator:
Dr Jean Mah in collaboration with Professor Monique Ryan

Type: Collaboration

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

Supported by Grant 32 from the FSHD Global Research Foundation and the aTyr Pharma, we analyzed clinical data collected by the Cooperative International Neuromuscular Research Group (CINRG) and published a research paper in the Neurology journal earlier this year (Mah et al, 2018).

In the article titled "A Multinational Study on Motor Function in Early Onset FSHD", we reported that shoulder and abdominal muscles were most affected among the 52 participants enrolled in the study. As expected, older enrollment age was associated with greater disease severity. After taking age, sex, and D4Z4 repeats into consideration, we found that greater disease severity was

significantly associated with earlier age at onset of facial weakness.

We are currently analyzing data from eye examinations and will prepare a manuscript to report the findings.

In addition to clinical characterization, we have been studying blood samples collected from the participants to search for circulating biomarker candidates that can potentially be used as surrogate biomarkers for treatment efficacy.

In addition to the originally proposed studies, we used various omics approaches to identify RNA and protein molecules that are good candidates. One of the protein biomarker candidates identified was glutathione peroxidase 3 (GPX3). We found that GPX3 was significantly lower in the FSHD patients' blood samples in comparison to blood samples from healthy individuals and patients with Duchenne muscular dystrophy.

We further confirmed the findings using an enzymatic functional assay. We showed that the GPX activity correlated with disease severity, suggesting that GPX3/GPX activity may be a good biomarker for FSHD.

In the same study, we identified additional protein biomarker candidates that have been shown to be biomarkers in other muscle disorders. We are preparing a manuscript to report the GPX findings and conducting more proteomic assays to validate the other candidates.

In addition to the protein study, we have identified RNA biomarker candidates in the blood samples collected from the individuals with FSHD. Both microarrays and RNA-seq were used to identify the differences.

We will validate these findings once we obtain funding to support the study. We thank the FSHD Global Research Foundation for supporting this work.

aberrant protein production by the FSHD locus for the treatment of the disease.

UNIVERSITY OF CALGARY

The Royal Children's Hospital Melbourne

Grant 34

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

Principal Investigator:
Dr Yi-Wen Chen

Type: International

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

Gene-silencing oligonucleotides (GSOs) produced by Idera Pharmaceutical are designed to reduce the expression of the pathogenic DUX4 expression in FSHD. The goal of this study is to determine their efficacy using both human cell and mouse models of FSHD. In the first part of the study, we have tested five GSOs using FSHD muscle cells and showed that the GSOs reduced DUX4 levels in the cells. In addition, the FSHD cells behaved more similar to the healthy cells after the treatments.

In this report period, we started animal studies to determine whether we can successfully deliver GSOs to muscles and whether the GSOs reduce expression of DUX4 and genes regulated by DUX4. To allow us visualize the GSOs, we added a florescent tag to the GSO compounds before we injected them into the mice.

Our results showed that GSOs were able to enter muscle cells after intramuscular injection (direct injection into muscle), as well as after the subcutaneous injection (injection under the skin which allows systemic delivery).

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

Major finding: Six-week GSO treatment restored muscle strength in a FSHD mouse model During the past 6 months, we conducted a six week drug trial to determine in vivo efficacy of the antisense oligonucleotides developed by the Idera Pharmaceutical.

We selected one GSO from the original five GSOs based on our in vitro assays and short-term in vivo studies. Six male and six female FLExDUX4 mice received subcutaneous injections of the GSO for total 13 injections (two injections per week). Same numbers of male and female FLExDUX4 mice only received saline injections as controls. We conducted grip strength testing to evaluate the muscle function and to determine whether the muscle weakness was improved by the treatment.

We conducted the first testing before the first injection to determine the baseline. We then measured the muscle strength of the mice at two time points, 3 weeks and 6 weeks after the 1st injection. Our data showed that the grip strength of the FLExDUX4 mice improved significantly ($p<0.05$) three weeks after the first injection, in comparison to the untreated mice. The treatment improved the muscle strength to a level similar to the healthy wildtype mice. Muscle strength of both formlimbs and hindlumbs in both genders was significantly improved.

We repeated the grip strength measurements at week 6 after the initial injection (end of the treatment). The improvement was more significant ($p<0.001$) and the muscle strength reached the same level as the healthy wildtype littermates. The results suggested that the GSO treatment quickly improved muscle function and was able to restore the muscle strength after six weeks of treatment.

Twenty-four hours after the last injection, we collected muscles and other organs (livers and kidneys) for pathological studies. We are processing the muscle samples to determine the DUX4 changes as well as pathological changes. Serum samples will be analyzed for toxicity. Although no significant body weight changes were observed in the mice, we observed a trend of weight reduction in the treated mice. Toxicology data will help us determine the cause of the change of weight.

We are also looking into the possibilities of off target effect. While the findings are promising, Idera Pharmaceutical is closing their research facility therefore we will no longer receive the GSO compounds from the company. By communicating with the lead scientist at the Idera, we have identified companies that can potentially help synthesize the compound.

For the near future, our work will focus on analyzing the samples that have been collected; and to submit NIH grant applications to obtain funding to move the GSO forward for drug development. We thank the FSHD Global Research Foundation for the critical support.

Children's National Health System

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 of 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 already identified 40 hits, that potentially activate SMCHD1. We are now keenly working on these molecules to validate their effect on SMCHD1, then study their interaction with SMCHD1.

Alongside this preliminary work on the hits from our pilot screen, we will now screen the full library of around 113,000 chemicals, to find more such hits for future validation, with the clear aim of identifying, characterising and developing drug- like molecules that activate SMCHD1 as potential treatment for FSHD.

Walter+Eliza Hall Institute of Medical Research
DISCOVERIES FOR HUMANITY

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 localized 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 localize 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 tissues, thus demonstrating their clinical relevance.

THE HEBREW UNIVERSITY OF JERUSALEM

FSHD
Find the Cure
APP

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

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

Service Science Society AUSTRALIA

2014 AUSTRALIAN SERVICE INNOVATION AWARDS

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.

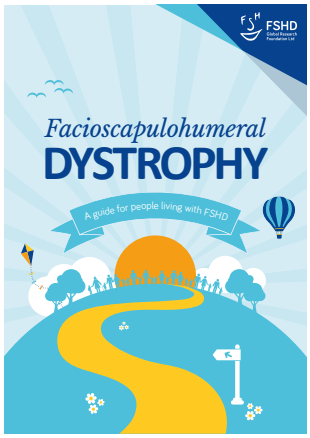
FSHD Global convened a workshop of 13 leading International and Australian clinicians to develop a clinical practice guideline on FSHD. The guideline covers diagnosis and management of FSHD and sets out the standard of care that people with FSHD in Australia should expect from their care team.

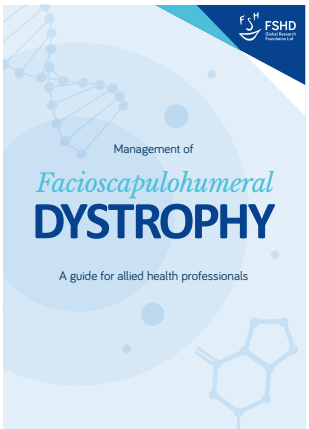
From this, the Foundation created a set of free and accessible Educational Toolkits for people living with FSHD and health care providers. The "Living with FSHD" booklet covers the care that you should expect from your healthcare team, steps for diagnosis, understanding test results, guidance on communicating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

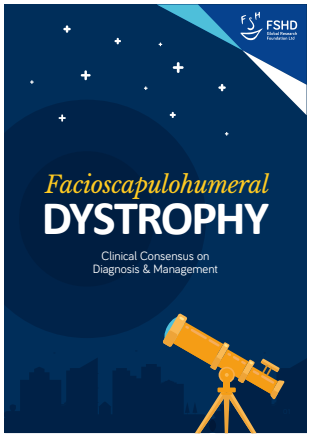
These global resources are available to download and share at www.fshdglobal.org/news/fshd-educational-toolkits/

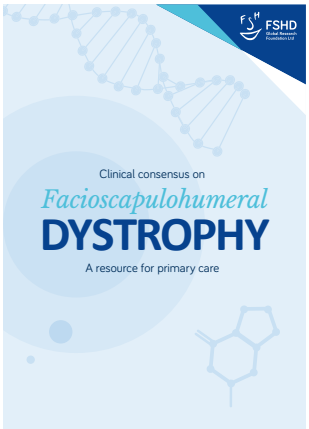
Contact the Foundation to receive your hard copy or learn more on how these resources can benefit you!

admin@fshdglobal.org
(02) 8007 7037









Save the date

FSHD Global Research Foundation Ltd

The 10th annual 2019 Sydney Chocolate Ball

Saturday 15 June 2019
The Star Event Centre, Sydney

Join us for a fabulous evening of fine food, exquisite champagne and world class entertainment. To secure your place, contact the FSHD Global Research Foundation.

02 8007 7037
events@fshdglobal.org
www.fshdglobal.org

WORLD FSHD DAY

Unite to find a cure

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.

Our Events

FSHD Global Golf Tournament

Held on Friday 13 October 2017 at St Michaels Golf Club, we saw over 90 people come together to support FSHD Global and enjoy 18 holes of golf on this spectacular course. Our guests enjoyed a day of golfing with plenty of antics on the course, followed by lunch and presentations at the Clubhouse. Thank you to our sponsors, volunteers, special guests and players for participating in yet another successful golf tournament. Congratulations to the winning team Wyndham.

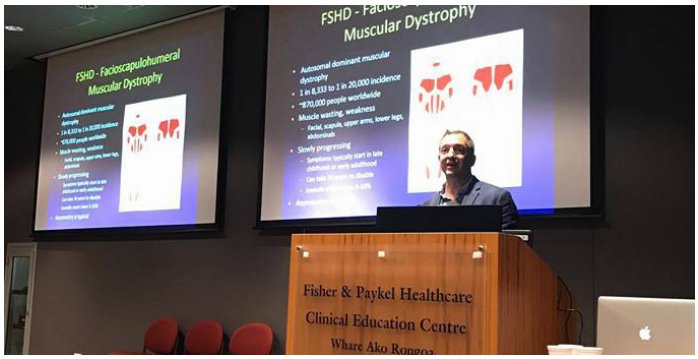
Thank you to our sponsors, volunteers, special guests and players for participating in yet another successful golf tournament.

9th Annual Sydney Chocolate Ball

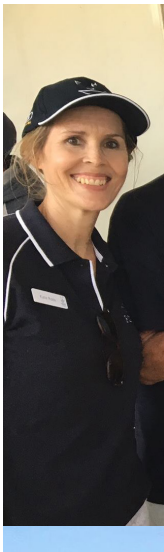
On 16 June 2018, FSHD Global held its annual Sydney Chocolate Ball! With over 630 guests attending a divine Masquerade Ball, this amazing event was held at The Star's Event Centre, Sydney. Raising over $1.2 million, guests were treated to a decadent Lindt chocolate menu, exclusively designed by celebrity chef and FSHD Global Patron – Luke Mangan, whilst delighting in free flowing Möet Hennessy champagnes. Hosted by FSHD Global Patron – Jamie Durie OAM and headlined by our own Founder and Chairman Bill Moss AO, whose personal, inspirational and emotional speech was the highlight of a truly spectacular evening.

FSHD Global Annual Science Week

In September 2017, FSHD Global invited some of our leading scientists to travel around Australia and New Zealand to update, educate and create further awareness on the progress in medical research into FSHD. We were delighted to have Dr Scott Harper, who joined us from the US and Dr Paul Gregorevic, who is one of our leading Australian scientists, meet with our communities and share their insights on the most recent scientific breakthroughs for FSHD. This is an important event on the FSHD Global calendar, which is inspiring and provides hope for those patients, families and friends living with FSHD.



FSHD Global is proud to have an active and engaged community of supporters and friends. Thank you to our 2018 event champions!



Wyndham Destinations Corporate Surf Challenge

Wyndham Destinations has been a long and loyal supporter of FSHD Global for over 8 years. The 2017 Corporate Surf Challenge was the 4th event hosted by Wyndham which raised money specifically for FSHD Global. Proudly supported by Wyndham Destinations Ambassador Layne Beachley AO and attended by a fantastic group of corporates who came together to not only surf but raise much needed donations 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 $1,300 for FSHD Global.

Blackmores Sydney Marathon

Congratulations to Dane Knight! Not only did Dane reach his personal target of finishing this years Blackmore Marathon by under 4 hours, he successfully raised over $1,400 for FSHD Global.

International Day of People with a Disability

Proud supporter of FSHD Global, Tracey Jackson raised $750 at a community fundraiser on International Day of People with a Disability. Tracey spoke about living with FSHD and creating further awareness of the disease and the work of FSHD Global.

World FSHD Day

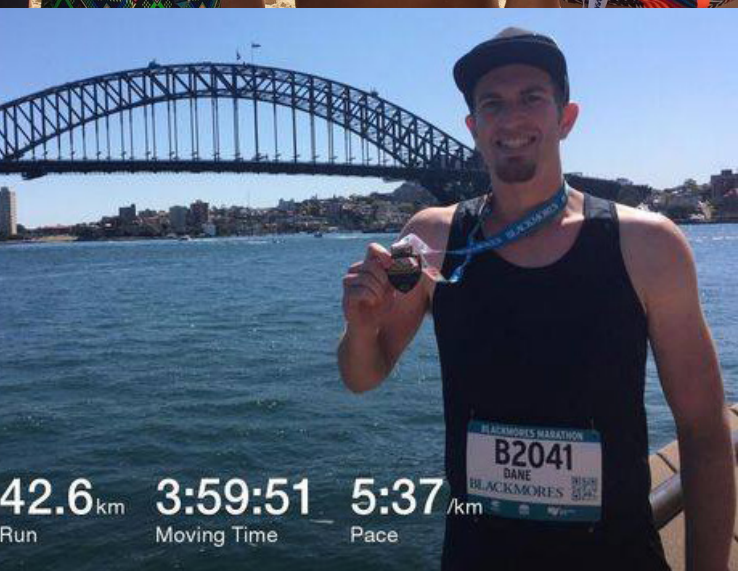
FSHD Global initiated World FSHD Day – a day uniting all FSHD organisations around the world to bridge the gap of education across government, families and media on the effects of the disease and raising greater awareness and funding opportunities worldwide. This initiative continues to grow each year with our communities hosting their own events to raise awareness and funding for FSHD Global. Thank you to Mary Garratt who raised over $3,000, Madi who cut her hair in support of her friend Mitch who has FSHD and raised over $2,800, Les Jones who raised over $350 and Mach2 who donated $150. No matter how big or small your event is, every dollar counts and is invested directly into medical research for FSHD.

WORLD FSHD DAY

Unite to find a cure

June 20th 2018

OUR COMMUNITY



ASX Thomson Reuters Charity Foundation

FSHD Global was once again a benefiting charity in the ASX Thomson Reuters Charity Foundation. By selling raffle tickets and partaking in their charitable events, the Foundation received an amazing $36,000. We thank ASX Thomson Reuters for their continued support of FSHD Global.

Cole Classic Ocean Swim

Team FSHD Global participated in the Cole Classic Ocean Swim in February 2018. Congratulations to Kate Ross, FSHD Global Ambassador Kerry Johnston, FSHD Global Director Bechara Shamieh and to the wonderful Preston family who travelled from Canberra to take part in the event and for raising $5,330.

Roger Muller and Jeff Williams Fundraiser

Congratulations to Roger Muller and Jeff Williams on the success of their fundraiser held in May. They hosted an evening at the cinema and were able to promote their event and awareness of FSHD through 91.1 ABC Central Victoria. A raffle was held on the night, raising over $1,000, with first prize being a painting by Jeff Williams himself.

Sutherland to Surf

Thank you to the Albert family for participating in the Sutherland to Surf fun run and continuing to support and raise funds for FSHD Global. The Albert family has been a long time supporter and friend of FSHD Global and through this event, raised over $2,500 for the Foundation.

Emma's Story

A family's perspective

Many people in the FSHD community may remember the story of my life that I shared at the 2015 Sydney Chocolate Ball. At that time, I was transitioning to a motorised wheelchair because I was about to have a shoulder reconstruction that would limit the use of my arm. In my talk, I mentioned that the transition to the chair would mean changes were required to our home and car. After my speech, a very generous and kind hearted man donated a fully converted brand new car to me - an act which changed my life and for which I will be forever grateful.

Since that speech, a lot has changed in my little family's lives. I had my shoulder surgery which was successful and my shoulder now does not dislocate which is a big plus! About six months later, my husband was diagnosed with Hodgkin's Lymphoma and that turned our whole life upside down. Shortly after Rob's diagnosis, my motorised wheelchair arrived and then my car arrived. Talk about life changing!! For the duration of Rob's treatment I was able to independently get to and from the hospital and be the supportive wife that I wanted to be – it was my turn to be the strong one. Thankfully, he came through chemo and radiation very well, even attended the 2016 Sydney Chocolate Ball mid chemo cycle! He is now showing no signs of lymphoma and just had his 2 year cancer free milestone.

Another very important point I raised during my speech was how I always look for signs of FSHD in our daughters. We

had decided not to have them tested unless they developed symptoms. During 2016, we started to notice signs of FSHD in our youngest daughter, Hannah. She got a bike for Christmas in 2015, and while she was very excited to get it, when she would ride it, she would complain her arms got very sore from holding them up on the handle bars. She has always been a bit clumsy and falls over easily, but many kids go through these stages so we had not worried too much.

However, when she started complaining of not being able to hold her arms up, and whenever we went anywhere and she had to walk longer distances, her legs would ache. We saw she slept with her eyes a little bit open. Slowly, we came to terms with the idea that these were likely FSHD symptoms we were seeing in our little girl. Hannah was then clinically diagnosed with FSHD in 2017. The genetic testing performed did not confirm this diagnosis so we are still awaiting clarity on what type of FSHD she has.

Functionally though, her limitations remain the same so we just take each day at a time and help Hannah live her best life. Since her diagnosis, Hannah has continued her passions of dancing and horse riding. She dances three afternoons a week, studying ballet, jazz, tap, contemporary and hip hop. There are some moves and poses she struggles with, so we are extremely grateful to her inclusive and understanding teacher who ensures the choreography and dancing assessments are within Hannah's physical abilities. Hannah was even awarded a dance scholarship this year due to her enthusiasm and effort. She is often sore after dance class but loves it so much she perseveres. I think Hannah's determination and grit will see her live life to the fullest.

She was lucky enough to be given her first horse in early 2018 by some beautiful friends of ours. His name is Bailey and he is the most beautiful, calm, patient boy. Hannah loves riding him and also loves to decorate him beautifully with chalk. They have a very special bond already with many more years ahead to enjoy. Hannah has registered for an upcoming clinical trial for infantile FSHD and we are excited to see what that may bring.

The last few years have also seen my condition progress somewhat. I am still able to walk inside the house and for short distances with a walking stick outside, but I get sore and tired very quickly. Rob is now my full time carer, and after all that has happened for us in the last few years, we have really changed our life priorities.

We live a lot more in the moment and focus on memories, moments and fun, not material things. As soon as Rob was given the all clear from his cancer journey, we booked a holiday. We took both our girls to Disneyworld and Universal in Florida and to New York, Niagara Falls and LA and made some amazing memories. We also got a puppy, and our little Maltese cross, Mitsy, has brought our family lots of laughs and happiness (and many missing socks and chewed items!).

We are realising more and more that life is about moments that really matter. We plan to be at the Sydney Chocolate Ball again in 2019, because for us, that is a moment that really matters. The Ball is a night that fills us with hope. It is very powerful to be surrounded by a room full of people who are there to help fund research into a treatment and cure for this dreadful disease.

I could cope with the idea of a lifetime of progression when I was thinking just of my condition. Now that it is also impacting on my daughter, I can't stand the thought of what her future may hold. I struggle to watch her in pain and I am often in tears when I watch her dance because I can see her struggling with moves that I know she could do only months ago. That's when FSHD really becomes real for me, when I see the progression in her with my own eyes.

A cure for FSHD would mean Hannah and I can run on a beach together. She could dance and twirl till her heart is content. I hope that one day, she can. Thank you for being part of our FSHD journey, and for supporting the Foundation, because they are the driving force towards progress in science and the ultimate goal, a cure.

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.

THE AUSTRALIAN CHARITY AWARDS®

CHARITY OF THE YEAR WINNER 2017

Thank You

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

Tania's Story

I was diagnosed with FSHD when I was 12, but I've had the symptoms for as long as I can remember. As a child I was always slower at sports and it was an effort to catch up to the other kids. I was tired, slow and I couldn't smile. It was very frustrating. I had terrible balance but loads of determination - it took me a while but I finally managed to ride a bike after all the bumps and bruises but that was a great day.

The symptoms got worse as I grew older –making raising my arms difficult and painful. At 23 I had an operation to fuse my shoulders straight. I was very excited as I would have straight shoulders and be able to move with no pain. The operations were successful and my determination was evident here too – even when I was in an upper body cast I'd still go dancing with my friends at our local disco! I just wore a big jumper to cover it and got out on the dance floor with my friends.

But jokes aside, life with FSHD is really tough. As the weeks and years go by life gets harder as I keep losing piece by piece of my physical self. Every month I realise that I can't do something that I could do last month. It's really heartbreaking. I've also had to watch my mum and family go through it – They have the FSHD gene too. I've spent the last ten years as my mum's carer, and this has been so hard watching her waste away before my eyes. Mum sadly passed away on 30th April 2018 because of FSHD. It wasted away her muscles and she was unable to swallow or breathe. This insidious disease took her life away. Mum was a fighter until the end. Mum had no energy left and was finding it difficult to breathe. She had her eyes closed when I asked my daughter to come and say good-bye to her Nonna. Francesca gave Mum a kiss on the head and said "I love you Nonna so much!" My mum using all the energy she had left opened her eyes looked up at her granddaughter and said "I love you too amore so much!" They were Mum's last words.

I gave birth to a healthy daughter in 2004. By then scientists had identified the faulty gene for FSHD, and through IVF we were able to block the gene so my beautiful 13-year-old daughter is FSHD free and doesn't have to go through what I have gone through. I am the proudest mum. My daughter brings light and love to my family and I'm so happy she's bright, happy, healthy and FSHD free.

I've been involved with FSHD Global for about 8 years now. Three of those have been as a volunteer and the last 10 months as an office assistant.

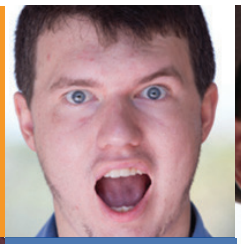
Working on the team at FSHD has given me such a sense of purpose. I'm desperate for a cure and through this role I feel like I'm helping everyone else across the world who is also living with FSHD. I really love my job!

The fact that the Foundation exists and has done so much in its short life also gives me so much hope that a cure will be found. As a sufferer you can feel so helpless and I know that the Foundation will find a cure, it's just a matter of time. When I meet other people with FSHD through my contact with the Foundation I realise that like me, they are relying so much on the Foundation for a cure. Hope is something that we all share and we'll never stop hoping.

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.

FSHD Global established Australia's first clinical trial for Infantile FSHD

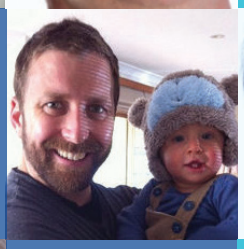


100%

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

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

Within 10 years we have funded 42 successful medical research grants across 10 countries



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

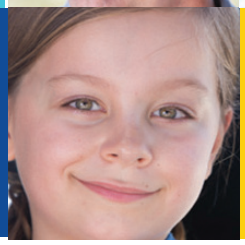
The Foundation remains committed to fund every grant to full term

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

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

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
Facebook: /FSHDGlobal
Twitter: @FSHD
Instagram: @fshdglobal

FSHD
Global Research Foundation Ltd

Shane's Story

My name is Shane and this is my story. I have just turned 51 years old and I have FSHD.

I was first diagnosed when I was 8 years old with a painful muscle biopsy at the old Royal Newcastle Hospital, I didn't know what was happening and no one told me what I had, my parents had taken me because I have a long family history of this terrible condition and they wanted me to be tested.

As an eight year old I was a lot skinnier than the other kids and my shoulder blade wings had started to stick out, at that early stage my legs still worked. I was able to have a normal childhood, running, playing sports and even started boxing. It wasn't until puberty kicked in that things really started to happen, shoulder aches, muscle weakness and the winging of my shoulder blades became more prominent. As a young teenager I became more and more self-conscious about my appearance and tried to hide it away, I would never wear just a t-shirt or no shirt at all. Imagine the embarrassment of being made to participate in the school swimming carnival, standing on the blocks with the other teens pointing and laughing at your appearance.

During my late teens I went through the "I hate the world" stage because I didn't look like anyone else, I rebelled against everything due to anger at this horrible condition, there was no internet to look up information, there were no doctors to talk to, there was nowhere to turn, it was at this time that the girl who would become my wife entered my world, she didn't care how I looked she loved me for me. We have been together now for 34 years and married for 27. We have 2 beautiful girls who have grown into amazing young ladies, they have not been tested but we hope they not been affected.

My mother and grandmother explained to me that I had FSHD but no one really knew what was going to happen in the future. I knew my aunty was in a wheelchair by age 40 and my grandmother was in one by age 60. Both of my parents passed away when I was aged 25, my aunty shortly after, so there was no one except my grandmother who I could speak to about what was happening and even then she did not know much about FSHD just that she had it and it was in the family.

I still work fulltime at a small family company that knows what I am facing and helps where they can with compassion and understanding. Over the last 5 years there has been a rapid decline in my health and mobility. I am now in constant excruciating pain for which I take very high doses of prescription only medication. I can only walk short distances and this is achieved by using a stick, anything more than 20 metres I require a wheelchair to get around. When I do walk I am in constant fear of falling over, because if this happens I cannot get back up unaided. I can no longer bend down to pick things up from the ground, I can no longer lift anything, I can't even help lift the groceries from the boot of the car or help with chores around the house.

I do not know how much longer I will be able to work as the pain is getting too much, what happens then? I will be stuck at home no longer able to help provide for my family, I can't get income protection insurance because I have a pre-existing condition. I will be totally dependent on my family for everything, this is not something that sits very well with me. I worry every day how we will pay the mortgage and still be able to live but that's life I guess, sometimes you get oranges sometimes you get lemons.

We live in an exciting time in regards to finding a cure and providing people who are only now being diagnosed with the information they need to give them an understanding of what is happening to them. My one wish is that a cure can be find so my grandchildren never have to go through this insidious disease so please donate to FSHD Global so a cure can be found in the next few years.

Our Finances

Where the money comes from

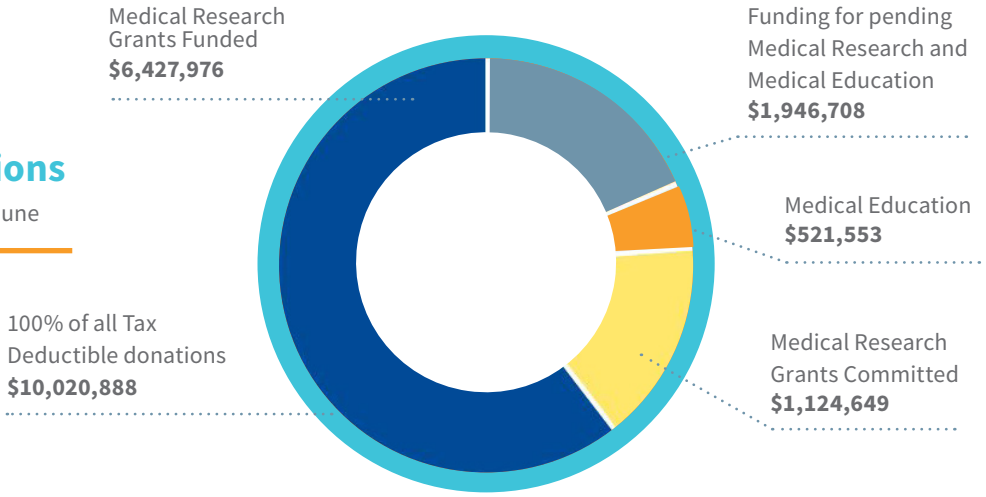
As at June 30 2018, the Foundation has successfully raised over $10 million in tax deductible donations and over $2.6 million in net non-tax deductible income. This has been achievable because of the support of our community and the hard work of our lean, dedicated team.

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.

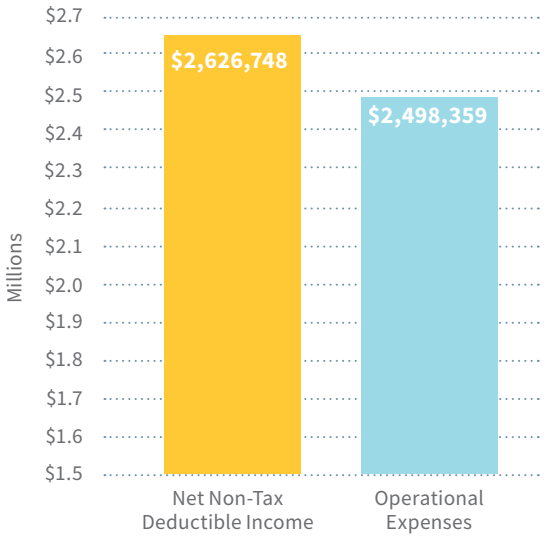
Allocation of Tax Deductible Donations

Inception - 2018 FY: As at 30th June



Net Non-Tax- Deductible Income vs Operation Expenses

2007 - 2018 FY: As of 30th June



100%

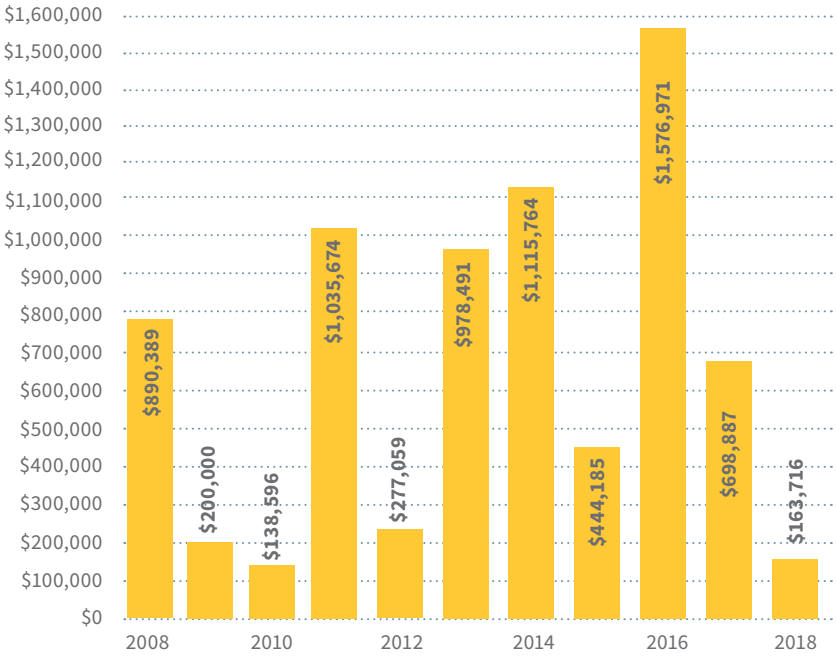
100% of all cash tax deductible donations are allocated to current or future medical research investment, grants and education.

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.

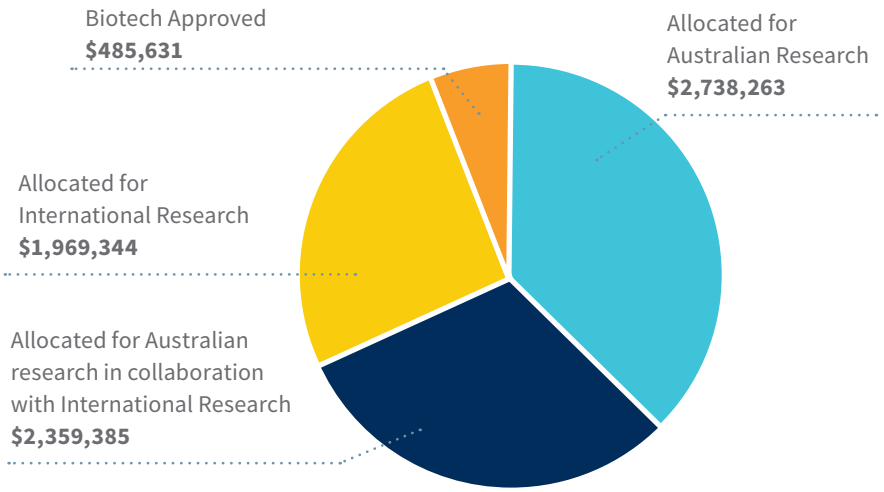
Medical Research Contracted

2007 - 2018: As at 30th June



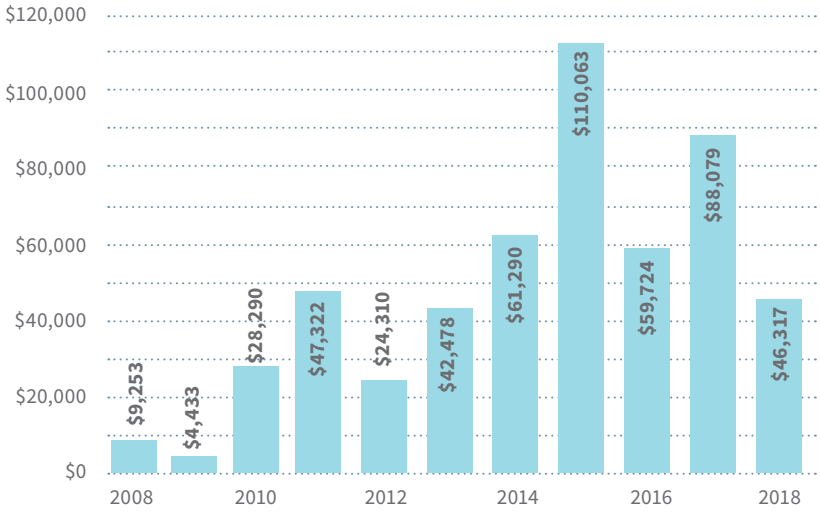
Medical Research Allocated

2007 - 2018: As at 30th June



Medical Education Funded

2007 - 2018: As at 30th June



Statement of Profit or (Loss) and Other Comprehensive Income For the year ended 30 June 2018

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

	Notes	2018 $	2017 $
Donations	3	$813,013	$901,757
Other Fundraising Income	3	$748,435	$773,602
Other income	3	$56,434	$70,540
		$1,617,882	$1,745,999
Grants made	4	(833,505)	(987,982)
Fundraising expense		(486,768)	(503,389)
Education programs		(46,312)	(88,079)
Sponsorship		–	–
Employee expense		(261,528)	(271,243)
Other expenses		(26,653)	(52,727)
(Loss)/Surplus for the year		**(36,884)**	**(157,421)**
Other comprehensive income:		–	–
Other comprehensive (loss)/income for the year, net of income tax		–	–
Total comprehensive (loss)/income for the year		(36,884)	(157,421)

Statement of Financial Position As at 30 June 2018

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

ASSETS	Notes	2018 $	2017 $
CURRENT			
Cash and cash equivalents	5	1,667,530	2,226,011
Trade and other receivables	6	101,829	73,535
Financial assets	7	1,523,170	984,733
Other assets	8	9,954	43,306
Total Current assets		3,302,483	3,327,585
NON-CURRENT			
Investments		485,632	485,632
Property, plant and equipment		6,675	10,312
Total Non-current assets		492,307	495,944
Total assets		3,794,790	3,823,529
LIABILITIES			
CURRENT			
Trade and other payables	11	30,794	22,649
Provisions	12	4,105	4,105
Total Current liabilities		34,899	26,754
Total liabilities		34,899	26,754
Net assets		3,759,891	3,796,775
EQUITY			
Retained earnings		3,759,891	3,796,775
TOTAL EQUITY		3,759,891	3,796,775

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.

Our Sponsors and Supporters

Anthony Hartman

Arab Bank Australia

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Third Generation Australian Pearl Divers Gem Jewellers

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ASX THOMSON REUTERS CHARITY FOUNDATION
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PCL CORP

PHERRUS Tax Strategy | Asset Protection | Wealth Creation

PRECIPICE FILMS

QUALITAS health

ROBERT OATLEY

rubicor

SCRUFFY MURPHY'S

sentia

SYDNEY CITY PRESTIGE

SKYCORP

Synergy radiology

STRATEGIC CORP INVESTMENTS

TOP KNOT Carpentry & Joinery

THE DOSS HOUSE

THE STAR SYDNEY

The Tender Team

WILLIAM ROBERTS LAWYERS SYDNEY | MELBOURNE | BRISBANE | SINGAPORE

WIN TELEVISION SALES

WYNDHAM VACATION RESORTS ASIA PACIFIC

YOUNG HENRYS

Thank you

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