Rare Disease Day
Fundraising Toolkit

Support FSHD Global Research Foundation on February 28th for Rare Disease Day and help raise awareness and funds for diseases like FSHD.
Rare Disease Day has and continues to collaborate with organisations globally in order to put on events, create media coverage, and ultimately raise awareness amongst the general public and policymakers about rare diseases and their impact on patients’ lives.

On 28 February 2017, the tenth year of Rare Disease Day will see thousands of people from all over the world come together to advocate for more research on rare diseases.

Over the last few decades, funds dedicated to rare disease research have increased. But it can’t stop there. Rare Disease Day 2017 is therefore an opportunity to call upon researchers, universities, students, companies, policy makers and clinicians to do more research and to make them aware of the importance of research for the rare disease community.

Facioscapulohumeral muscular Dystrophy

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

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

FSHD is the most common form of muscular dystrophy affecting both adults and children. It is estimated to affect 1 in every 7,500 Australians, however, this number is probably higher as FSHD is commonly misdiagnosed or undiagnosed.
The FSHD Global Research Foundation focuses on finding treatments and a cure for the debilitating disease Facioscapulohumeral Muscular Dystrophy (FSHD) and are 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 has FSHD. Since then, we have been addressing the chronic lack of medical funding and awareness of FSHD, both in Australia and globally. Over the past 9 years, the Foundation has committed $8.3 million to fund 40 ongoing medical research grants in 9 countries.

The FSHD Global Research Foundation does not operate like an average not for profit.

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

We are also transparent in doing so, offering all donors via the ‘FSHD – Find the Cure’ mobile app the opportunity to track exactly which research programs their money has been allocated and the latest milestones of those programs.

Connect with us!
Events@fshdglobal.org
(02) 8007 7037
www.fshdglobal.org
One in three people have no family history

FSHD is hereditary

It affects all the skeletal muscles in the body

There are no treatments

There is no cure

It affects one in every 7,500 Australians

100% of all tax deductible donations fund research

The symptoms are highly variable

FSHD Global is a multi award winning charity

The age of onset can range from infancy to adulthood

No government funding in Australia

Is a common form of Muscular Dystrophy
Get Creative!

Every dollar counts, so no matter how big or small your event is – we’d love your support. Here are some ideas and inspiration to get you started:

**Morning or Afternoon Tea**
Morning or afternoon teas are a great idea to get everyone involved. Host it at your home or work and ask your friends or colleagues to bring a plate and charge an entry fee to attend.

**Casual Day or Dress Up Day**
Hold a casual or dress up day at your work and ask your colleagues to donate a set amount for being involved.

**School Mufti Day**
Get involved with your local school community by organising a school mufti or orange dress up day for a gold coin donation.

**BBQ/Sausage Sizzle**
Everyone loves a sanga! Think about putting on a BBQ at your local Bunnings store, school fete, Saturday sports or shopping centre/ Woolworths/Coles.

**Dinner Party**
Get together with your friends and family and host a dinner party. Seek donations of goods or local vouchers from your community to hold a raffle on the night.

**Trivia Night**
Create a trivia night with your friends or colleagues. Each guest could pay an entry fee to attend with the winner taking home some donated prizes from your community.
REGISTER YOUR EVENT
It is important you let us know about your fundraiser and become an official FSHD Global fundraiser. This way we can help promote your event and help you out in any way we can. Let us know all about your event by completing an ‘Authority to Fundraise’ form. Simply call our office on 02 8007 7037 or email events@fshdglobal.org.

FOCUS ON FUNDRAISING
Although Rare Disease Day’s main goal is raising awareness for the disease, we still aim to raise funds for medical research and education to ultimately find a cure for FSHD. Put a fundraising strategy in place – how much do you want to raise from your event? How will you achieve this?? Raffles, gold coin donations, entry fees, guessing competitions and sales are all great ways to raise funds.

CONSIDER CREATING A PAGE
Consider using a fundraising platform to assist in your fundraising. Everydayhero.com.au is a fantastic website to help you promote your event, receive and track donations. For more details on using Everyday Hero, please contact admin@fshdglobal.org
PROMOTE YOUR EVENT
Make sure everyone knows about your event by posters, email reminders and social media! We encourage you use all social media platforms including Facebook, Twitter and Instagram to promote your event. Send us your official poster, announcement, images and we’ll help promote your event on our official social media sites. If you haven’t already – follow us:
Facebook: /FSHDGlobal
Twitter: @FSHD
Instagram: @fshdglobal
Hashtag: #FSHDGlobal, #RareDiseaseDay

POST EVENT
Ensure that you take lots of photos of your event and let us know how you went. Don’t forget to bank your funds! Ensure you deposit cash donations to your everyday hero page or directly to the Foundation through our website www.fshdglobal.org. We look forward to announcing your achievements and celebrating your success!!

If you have any questions or would like some more information about how to get involved in Rare Disease Day, please contact us at admin@fshdglobal.org or visit our website www.fshdglobal.org

Unite to raise awareness!