



**BUILDING MUSCLES FOR
THOSE WHO CAN'T!**

MAY 2021

PROUDLY SUPPORTING





THE SQUAT CHALLENGE

Rally up your mates and join in completing the Muscles For Muscles Squat Challenge and help build your muscles for those who can't - in honour of the million people living with FSHD muscular dystrophy worldwide.

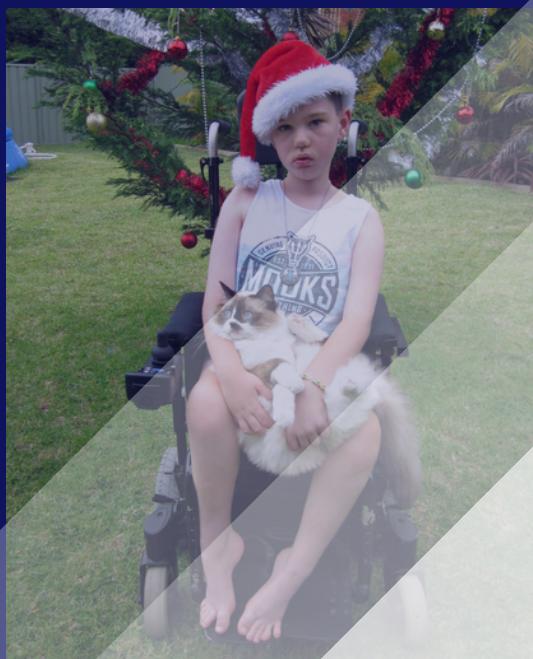


WHY?

The Muscles For Muscles Squat Challenge encourages people of all fitness levels to partake in building their muscles for those who simply can't.

It also gives people living with this debilitating disease an opportunity for their friends and loved ones competing in their team, a sense of empathy to the importance of having functional muscle and movement.

100% of all tax deductible donations generated from the Muscles For Muscles Squat Challenge will help fund medical research and education into muscle wellness, muscle technology and an ultimate cure for FSHD. With your help we can continue to fight for a cure, and fast track treatments for our loved ones in the community.



SQUAT CHALLENGE OVERVIEW

Muscles For Muscles was specifically designed to create empathy of what it is like to live with a muscle wasting disease (FSHD), and highlight the importance of muscles. Hence build muscles for those who can't! We want to achieve 1 million squats representing the number of people living with FSHD worldwide! With your help - we can do this!!

The Squat Challenge is perfect for gyms and personal trainers and can be achieved in many ways:

- Register your Squat Squad - recruit as many members as possible
- Each participant is required to register as part of your team
- We invite each participant to contribute \$20 as part of their registration and help kickstart your teams fundraising efforts
- Choose how you would like to run your own campaign. Some ideas are:
 - Set a daily squat target to achieve throughout the month of May
 - Decide to do a 24 hour challenge
 - Dedicate 1 day per week to achieve a set amount of squats
 - Participate in our Super Saturday Squat Challenge on Saturday 15 May 2021
 - Dedicate Tuesdays throughout the month of May to be Turbo Tuesday and run a challenge on each of these days

You will receive a toolkit including social media content, fundraising link to drive donations, tips and tricks and how to get involved.

Why do the squat challenge?

- Drive awareness for FSHD
- Help drive donations which will go towards medical research into FSHD
- Easy to get involved
- Helps build a positive working environment
- Build better connections with your employees
- Brings fun into the workplace. Helps keep your staff fit and healthy.
- Allows people to learn and raise awareness about FSHD and raise donations to ultimately find a cure for this debilitating disease.

WAYS TO PARTICIPATE

You can participate in the Squat Challenge at any time throughout the month of May. Here are some ideas on how you might like to play.



MONTHLY CHALLENGE

Set a daily team squat target for the month of May!

24 HOUR CHALLENGE

Short on time? Join Super Saturday (15 May) or dedicate another day

CHALLENGE YOUR MEMBERS

Encourage your members to participate by asking all them to join your gym team.



COMPETE

Will you top the leaderboard for most squats and/or donations raised?



HELP US RAISE AWARENESS

Share a post on social media to help get the word out to fundraise and raise awareness.



DONATE

Support an individual or team, or make a tax deductible donation to support the cause.

HOW IT WORKS?



REGISTER

Register as a team or individual



SET A FUNDRAISING TARGET

How many donations do you think you or your team can achieve?



TELL YOUR MEMBERS

Share your link with your network and invite your members to join your team or support your fundraising target by donating.



SET YOUR TARGET

How many squats can you or your team achieve in 30 days?



GET SQUATTING

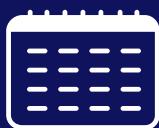
Time to get ass to grass. Anytime, anywhere, any squat style!



GET SOCIAL

Use our weekly social post to share with your network to help generate awareness and raise funds

KEY DATES



Muscles For Muscles Squat Challenge will be run during the month of May 2021. Here are key dates for your calendar in preparation for the challenge:

- Thursday 1 April 2021 – Muscles For Muscles launch: Register your participation as an individual or team
- Saturday 1 May 2021 – Challenge commences
- Saturday 15 May 2021 - Super Squat Saturday
- Monday 31 May 2021 – Challenge concludes



MUSCLES FOR MUSCLES AMBASSADORS

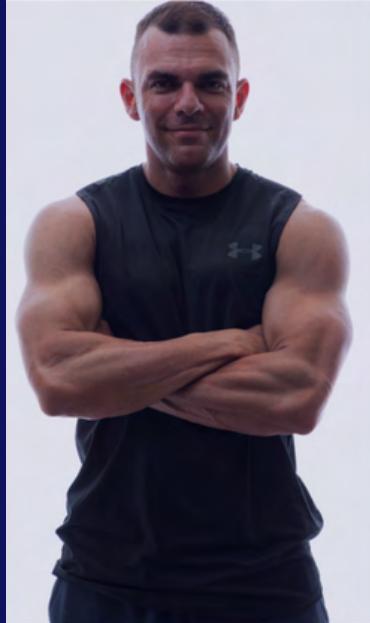


MEET DREW!

Media / TV Personality

Why are you completing The Squat Challenge?

Having attended last years Sydney Chocolate Ball, I was incredibly moved and left with the feeling of wanting to help however I can. Being a part of this campaign is a great way for myself and others to do something as a community whilst raising much needed funds and awareness for a very good cause.



MEET PHIL!

Personal Trainer

Why are you completing The Squat Challenge?

I have a personal connection to FSHD as it affects several members of my family.



MEET JESS!

The Women's Strength Coach

Why are you completing The Squat Challenge?

To help create a community to raise awareness for FSHD so that ultimately it can give relief to those who suffer from this disease.



MEET JOE!

Personal Trainer - Strength

Why are you completing The Squat Challenge?

Strength is never a weakness. If I ever have an opportunity to help others with my knowledge and experience then I am game for the challenge.



SOCIAL MEDIA

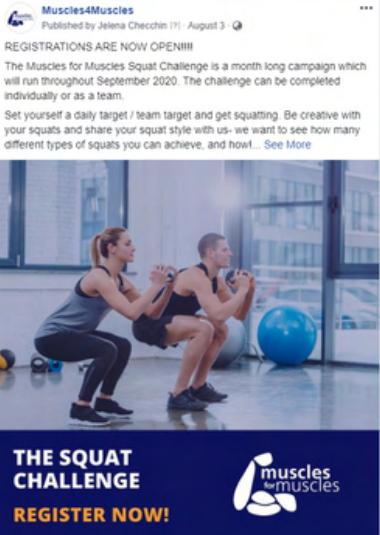
Get creative and share your journey via your social media platforms. Be sure to follow the Muscles and Muscles social media channels and the FSHD Global social media platforms for constant updates, tips and tricks. Don't forget to hashtag: #musclesformuscles and #fshdglobal



Muscles4Muscles...

Published by Jelena Checchin (1) · August 3 · 

Team What The Squat Thorney showing their creativity again but this time with their outfits!! 🎉💃 Team What The Squat Thorney are completing the challenge on behalf of our FSHD-Global Research Foundation Ambassador Jodie Thorne. They have already...



Muscles4Muscles

Published by Jelena Checchin (1) · August 3 · 

REGISTRATIONS ARE NOW OPEN!!!!

The Muscles for Muscles Squat Challenge is a month long campaign which will run throughout September 2020. The challenge can be completed individually or as a team.

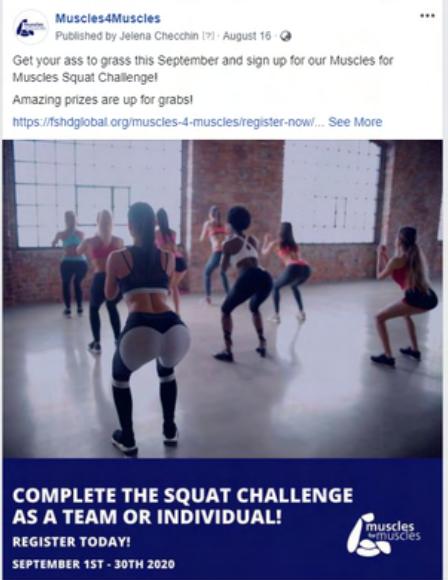
Set yourself a daily target / team target and get squatting. Be creative with your squats and share your squat style with us- we want to see how many different types of squats you can achieve, and how!... See More

THE SQUAT CHALLENGE
REGISTER NOW!

muscles4muscles

Nonprofit Organization

7,222 People Reached 1,004 Engagements Boost Again



Muscles4Muscles

Published by Jelena Checchin (1) · August 16 · 

Get your ass to grass this September and sign up for our Muscles for Muscles Squat Challenge!

Amazing prizes are up for grabs!

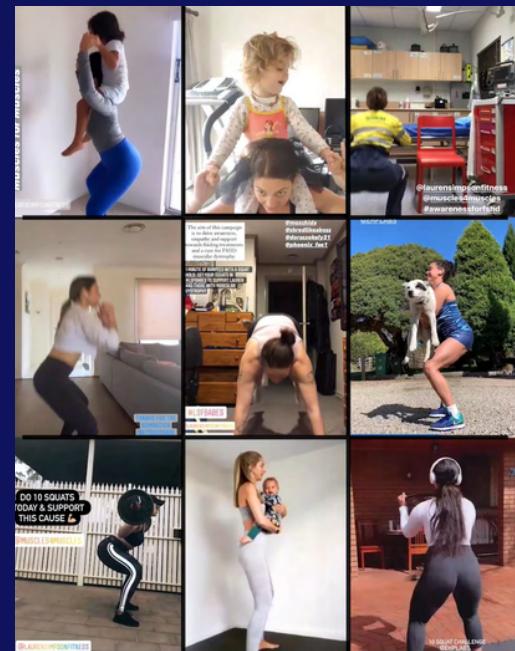
<https://fshdglobal.org/muscles-4-muscles/register-now/>... See More

COMPLETE THE SQUAT CHALLENGE AS A TEAM OR INDIVIDUAL!

REGISTER TODAY!

SEPTEMBER 1ST - 30TH 2020

1,993 People Reached 187 Engagements Boost Unavailable





WHAT IS FSHD?

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.

People with FSHD live with no known cure and few treatments currently available. As a genetic disease, FSHD affects people of all ages, religion, sex and body type. It does not discriminate, and neither does this campaign!



FSHD GLOBAL RESEARCH FOUNDATION

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), 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

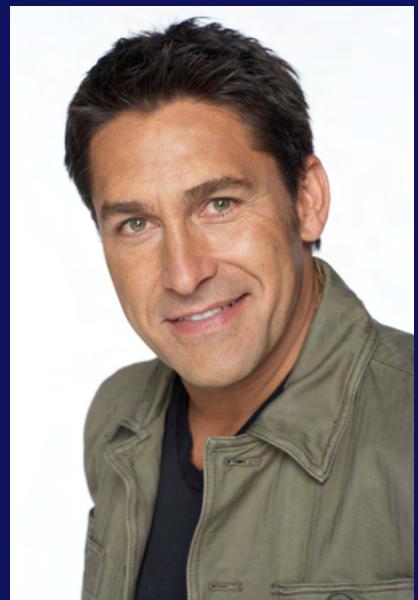


FSHD GLOBAL HIGHLIGHTS

- **Multi-award winning Charity:** Winner of Outstanding Achievement in the Australian Charity Awards 2020, 2019 and 2018. Winner of the Charity of the Year in 2017
- **Medical Research and Education Grants:** Since establishment the Foundation has funded 51 medical research grants across 10 countries in the areas of basic science, diagnostic and therapeutics leading the way towards clinical trial readiness programs for FSHD
- **Raised over \$18 million in 12 years:** FSHD Global remains one of the largest funders of global research, proudly allocating 100% of all tax deductible donations toward current and future medical research and education grants
- **\$0 Remuneration:** Our Board of Directors, Science Advisory Boards, Patrons and Ambassadors receive \$0 remuneration
- **FSHD Education Toolkits:** FSHD Global launched Australia's first FSHD Education Toolkits for patients, GP's and allied health groups to better understand the impact of living with FSHD
- **FSHD Medical Education Portal:** This Portal centres on establishing a FSHD Registry, collating information on disease evolution and connecting our community with clinical trial readiness programs. Furthermore participants can now order a complimentary FSHD Saliva Research Test sent to their home to better understand their own DNA



FSHD GLOBAL PATRONS



BILL MOSS AO

LUKE MANGAN OAM

JAMIE DURIE OAM

BRAD'S STORY

Our September Muscles for Muscles campaign saw participants from all walks of life - those living with FSHD, family and friends participating on behalf of someone living with FSHD, fitness gurus, corporates, athletes, ambassadors and our loyal and strong community.

Our winning team, Brads Brigade had over 30 family and friends who participated in support of Brad, who lives with FSHD.

This team raised over \$3,300 and completed over 19,000 squats during the challenge.

Brad has kindly shared his story with us, highlighting his journey living with FSHD and how the Muscles for Muscles campaign helped him create awareness and support in his fight to help find a cure or treatments for FSHD.



BRAD'S STORY

Throughout my childhood into my teenage years I had always been extremely active, participating in many sports. Around 17 years of age, I started to notice a small gap in one of my pectoral muscles. I didn't think much of it at the time but as time went on the gap became bigger. It wasn't until I had lost half my pectoral muscle that I knew something was wrong. I went to see a doctor who forwarded me onto a specialist. I think I had seen about three different specialists and participated in different types of testing, when one advised he thought I may have a genetic disorder named Fascioscapular Humeral Muscular Dystrophy (FSHD). I had never heard of this condition. After a blood test it was confirmed that I had FSHD. The doctor advised this disorder is usually passed down by mum or dad, so I told my family and as a result it turns out my mother, Aunty and two cousins have FSHD also.

I met my wife who is the most supportive and caring person in the world. She knew I had FSHD when I met her. FSHD has impacted her significantly as well. Along with looking after me, she makes sure I go and see my doctor yearly, she asks all the right questions and even holds me accountable when I see the physio to make sure I am doing my exercises. The biggest hurdle though was when we wanted to have children. We went to a genetic counsellor as we knew that if we had children there was a 50 percent chance that our child could get FSHD if we conceived naturally. We looked into IVF where the embryo is tested and we were told we had a low chance of bringing home a healthy baby. We have seen some of the severest cases of FSHD which affects young children restricting them from moving and can cause difficulty breathing. The doctors could not guarantee the severity of the disease if our children had FSHD. We were advised there was testing that could be carried out to see if a baby had FSHD which had to be done at 14 weeks and with significant risk. We decided that this was the best option for us. We are extremely lucky to have two beautiful healthy children without FSHD.

FSHD has impacted my life significantly physically, but mostly mentally. When I got my diagnosis, I only told my family and for over 10 years I kept playing sport and worked as muscles in my chest and back slowly deteriorated away. Many would say I looked weird, I had bad posture and that I needed to keep my shoulders back. I would laugh it off and not tell them about what I had because I didn't want them think I was making excuses or receive sympathy and treat me differently. My wife kept telling me I need to tell people that I have FSHD and to talk about it. It was only recently that I became open about what I have. Everyone has been really supportive and I have felt a big weight lifted off me as a result. Now I just battle my own demons which is having expectations which are too high compared to my capabilities, I am getting better but still have a long way to go (my brain doesn't match my body).

BRAD'S STORY

I am 36 years old now and I suffer from winging which is where I cannot keep my shoulders back because I have lost all scapular strength. This impacts me lifting my arms over my head, I bend over to make it easier to wash my hair, I also find it difficult to do everyday tasks like hanging the clothes on the line or putting my seatbelt on. I take an anti-inflammatory each day because in the past year or so I have been waking up with a sore upper back and shoulders. I have lost some muscles in my face which restricts some of my expressions, I have lost both pectoral major and latissimus dorsal muscles this affects me from trying to keep fit and healthy and also aesthetically. I have just noticed my bottom left abdominal muscle is starting to waste away also. One positive is my leg muscles and arms aren't affected as yet, and my doctor predicts I should not need a walking aide in my lifetime. We are all hoping that this is the case.

My wife saw the Muscles for Muscles campaign and immediately sent it to me asking if we should get a team together. What a great way to raise awareness for FSHD. The support we received from my friends and family was amazing, so much so we decided to create a Facebook group. This would help keep us and others accountable while keeping the momentum going. My local gym got involved and held a raffle donating some awesome prizes, all ticket money was donated to the FSHD foundation.

I believe Muscles for Muscles generated a significant amount of conversations and awareness of FSHD. It acted as a catalyst for conversations with my family and friends around my struggles with the disease and it helped to build some awareness and empathy. It also gave me the opportunity to open up and talk about how it affects me and share some of the burden that this disease brings. One of the things that came up during the campaign was that people had never heard of FSHD or how many people are affected by it.

FURTHER INFORMATION

The FSHD Global Research Foundation looks forward to partnering with you.
Help build muscles for those who can't!

Here is a list of your key contacts:

DANIELLE THOMSON

Chief Executive Officer
danielle@fshdglobal.org



NATALIE COONEY

Chair Person
natalie@fshdglobal.org

For further information on the
FSHD Global Research Foundation, visit www.fshdglobal.org

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