

# 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.



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 the 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).

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.

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I believe Muscles for Muscles generated a significant amount of conversations and awareness of

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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.

