

Maram

07/26/2016 – LGMD “Spotlight Interview”

NAME: Maram **AGE:** 26 years old



COUNTRY: Palestine

LGMD Sub-Type: LGMD2E

At what age were you diagnosed:

I was diagnosed with muscular dystrophy at the age of 10. When I was 26 years old, I received genetic confirmation of my LGMD2E diagnosis.

What were your first symptoms:

When I was 3 years old, my parents noticed that my gait was unsteady and it was difficult for me to stand up from the ground.

Do you have other family members who have LGMD:

No, I am the only one in my family.

What do you find to be the greatest challenges in living with LGMD:

There are so many challenges. Simple things for many people are my greatest challenges but going to the bathroom and

changing my position from side to side while sleeping make me feel so weak.

What is your greatest accomplishment:

Well, in my country people know nothing about LGMD. I am trying every day to increase the awareness of the disease by social media. I have helped many patients in my country and in the Arab world to the genetic test to confirm their diagnosis and to get the equipment that we need to make life a little easier for us. I have also contacted my patients from around the world and we have become close friends. They are my greatest accomplishments.

How has LGMD influenced you into becoming the person you are today:

I think it has made me stronger in one way or another. I have become more caring for the people around me. I appreciate every little blessing in my life including my great family. I have become closer to God. I think it changed me in a good way and I like who I am today.

What do you want the world to know about LGMD:

I want them to know that we are not so different from normal people. What happened that a simple genetic error or mutation has caused me difficulty in moving while they can. The cause is not so complicated and if we understand that, we can find the treatment.

If your LGMD could be “cured” tomorrow, what would be the first thing that you would want to do:

I would like to hug my parents so tightly and never let them go. I keep thinking how hard life would be without them.

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Jonathan

LGMD "SPOTLIGHT INTERVIEW"

07/10/2016

Name: Jonathan **Age:** 54 yrs. old



Country : England

LGMD Sub-Type : Not known

AT WHAT AGE WERE YOU DIAGNOSED?

Initially when I was 11 (1973), I was diagnosed with Congenital Muscular Myopathy. No further action was taken or attempt made to identify what type of Muscle condition.

Finally, following a mini breakdown in 1988, further tests were done and I was diagnosed with Limb Girdle Dystrophy. Sub Type unknown, and at that time it was not suggested that further investigation would help or be necessary.

As I had always done, I adapted and learned how to deal with it.

WHAT WERE YOUR FIRST SYMPTOMS

When I was a baby, my mother noticed that I could not lift my head up. Whilst I walked at a normal age, she said I found it

hard, fell a lot and seemed a lot weaker than other toddlers of a similar age. Later on, trouble walking, falls and other issues flagged up warning signs.

DO YOU HAVE OTHER FAMILY MEMBERS WHO HAVE LGMD?

No, although it's possible a maternal great Aunt had a Muscle condition ...but that is historical.

WHAT DO YOU FIND TO BE THE GREATEST CHALLENGES IN LIVING WITH LGMD?

- The mental acceptance of being subject to a muscle wasting condition.
- The frustration of being unable to undertake simple tasks such as getting out of chairs.
- The exclusion of certain activities.
- Being unable to control muscle strength.
- Breathing – two near death experiences –living with a ventilator.
- Heart – curtailng improving fitness.
- Becoming exhausted all the time.

WHAT IS YOUR GREATEST ACCOMPLISHMENT?

My children, neither of whom have any indication of muscle weakness. Both are fit and healthy.

Being a nice guy, with many friends and a great family. I worked for 35 years full time.

HOW HAS LGMD INFLUENCED YOU INTO BECOMING THE PERSON YOU ARE TODAY?

I believe LGMD has influenced me, for the worse mainly.

From an early age I was conscious I failed at a lot. Especially at school, but also in the family.

My sister was three years younger than me, but seemed to

overtake me very quickly and achieve success in many areas. She's lovely, my sister, and I didn't begrudge her, but it was hard to take. I got used to losing. I was sent to Public school which specialised in sport, Cross country runs I would come last by such a distance that I would be told to go round again and I tried Rugby, Football, Squash, Cricket, Hockey, Fives...I never used LGMD to avoid having a go. But I was hopeless and hated it. This inadequacy crept in all areas, I lost all confidence in academic work... I panicked in exams and failed most of them. True friends were few and far between...and I couldn't get a girlfriend for anything...they just laughed at my attempts. I am sure this lack of self-confidence was a result of my physical condition impinging of emotional and spiritual feelings. Whilst I still feel this , I have developed ways to overcome most areas of life, and have made it through 54 years.

WHAT DO YOU WANT THE WORLD TO KNOW ABOUT LGMD?

That it is as much to do with internal emotions, as practical difficulties.

IF YOUR LGMD COULD BE CURED TOMORROW WHAT WOULD BE THE FIRST THING THAT YOU WOULD WANT TO DO?

I'm not sure I'd change much. I love walking and perhaps I'd go back to Cornwall to enjoy the Coastal cliff walks. It would be nice also to do a bit of travelling without the worry of exhaustion, breathing and logistical practicalities.

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