

Emily

03/28/2016

LGMD "SPOTLIGHT INTERVIEW"

Name: Emily Age: 29 yrs. old



Country: United Kingdom

LGMD Sub-Type: LGMD2B

At what age were you diagnosed:

I received confirmation of my LGMD2B diagnosis at the age 28 but at the age of 24 it was already suspected.

What were your first symptoms:

My first symptom was struggling to climb stairs and I also noticed that I couldn't stand on tip toes to reach books on my bookshelf

Do you have other family members who have LGMD:

No, it's just me – all by myself!

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

There are many challenges. Like trying to be accepted as "disabled" when I don't use a wheelchair. I find people don't

want to talk to me about it in general, which can be very isolating! At times I get self-conscious and anxious. Falling over in front of people is the worse and struggling to do things I once could is quite sad. I miss being able to run! Also the need to try and explain yourself. Having the odd wobble and feeling pathetic or weak.

What is your greatest accomplishment:

At the moment, leaving home and living independently in the countryside. I also volunteer for Muscular Dystrophy UK as a peer supporter, which to me is an amazing accomplishment.

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

Having LGMD has definitely given me a different outlook! I've learned to appreciate smaller things in life and become more determined to achieve things on any scale. I feel very positive and want to turn my diagnosis around to focus on the good things not the bad. It's made me more aware and empathetic, I want to help others like myself. It's aided my 'wicked' sense of humor too!

What do you want the world to know about LGMD:

Everything! I just want people to understand the complexities of these conditions and the condition itself.

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

This is a tough question, there are so many!

I'd probably want to run first but also get on a sporty motorbike and learn to ride!

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