

Molly

11/30/2015

NAME: Molly **AGE:** 29 years old



COUNTRY: United States

LGMD Sub-Type: LGMD2B: dysferlinopathy/Miyoshi Myopathy

At what age were you diagnosed:

I started presenting symptoms when I was 17 and at the time I was told I was suffering from Guillain-Barre. When I was 19, my initial symptoms returned and worsened, however, this time I was diagnosed with polymyositis. After 3 years in and out of the hospital I was finally properly diagnosed via DNA testing with Miyoshi Myopathy and the age of 22.

What were your first symptoms:

My first symptoms were difficultly walking up stairs and getting out of chairs. I noticed a significant decrease in athletic activity at around age 15 but chalked it up to teenage laziness. It wasn't until I was a junior in High School and could not complete my P.E. requirement and started falling frequently that I knew there was a problem.

Do you have other family members who have LGMD:

I have no other family members who are affected by LGMD.

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

Some of the greatest challenges are watching friends and family participate in physical activities such as running, hiking, daily exercise, and even dancing. It makes me sad that I cannot participate with them and sometimes I feel like I am missing out on quality time. Another perhaps harder struggle is the daily struggle, it takes much more effort to get ready each morning and also to accomplish daily tasks that many take for granted such as picking up your room, cleaning your house, laundry etc. I have had to learn to set my pride aside and rely on friends and family more, which in and of itself is a challenge.

What is your greatest accomplishment:

I think that my greatest accomplishment to date is that in spite of being in and out of the hospital during my college years, I kept working and finally received a degree. Now, I put that degree to use everyday as a teacher. Teaching was always my dream and I achieved it. My students and colleagues are more that supportive and it makes it worth it every single day.

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

LGMD has made me a more purposeful person. Purposeful with my own life, but also purposeful with who I surround myself with. When you live with a condition that affects your everyday life it is important to surround yourself with people and also activities that have meaning and fulfill your life, and not to waste time on anything petty and insubstantial. I am not sure that I would have realized this as early as I did if not for what I experience every day.

What do you want the world to know about LGMD:

Well, first of all I want everyone to stop thinking I have some strange form of MS. I also want everyone to know that we as a community are valuable and have a lot to offer. Our bodies may not cooperate with us, but we are a very bright and passionate community. Also, I would just like the world to know that LGMD exists, but I think we are making great strides in that area.

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

There is so much that I would like to do and obviously most of them have to do with physical abilities that I don't possess. I would love to hike the Appalachian Trail, or anything else that involves being outside for extended periods of time. Oh, and I would also love to jump again, there is something freeing about that.

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Karen

11/19/2015

Name: Karen **AGE:** 61 yrs. old



Country: United States

LGMD Sub-Type: LGMD1B / Laminopathy

At what age were you diagnosed:

I was diagnosed when I was 54 yrs. old.

What were your first symptoms:

My first symptoms included: falling, inability to climb stairs and difficulty lifting.

Do you have other family members who have LGMD:

My sister, her son and his daughter, her daughter, and a brother all have the same diagnosis. There have been 2 that were also tested and do not have it. LGMD1B has an autosomal dominant inheritance pattern which means that typically this disease appears in every generation without skips.

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

The greatest challenges for me include: getting around, being able to get up when I sit, bathroom problems, lifting, being able to reach items, loading walker in car alone, walking, shopping, and getting dressed.

What is your greatest accomplishment:

For me, my greatest accomplishments include raising my kids and working with school children for 18 years.

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

It makes me more sympathetic to others and their issues. I am feeling blessed to have family members around. I appreciate

what I have left.

What do you want the world to know about LGMD

Not all disabilities are immediately visible. Some of us might not look like anything is wrong and yet people judge us. I get plenty of stares when I park in a handicap parking space. I get the look...until I have to get a cart to even walk. I wish that more people knew how to help us – when we fall, etc.

It is frustrating that a lot of people do not know and understand the difference between MD and MS. I say I have MD and they still say MS.

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

I would want to be able to hold as well as sit down and play with my granddaughter.

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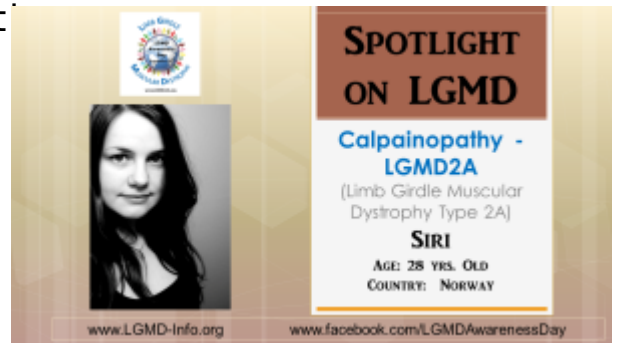
Siri

11/06/2015

NAME: Siri **AGE:** 28 yrs. old

COUNTRY: Norway

LGMD Sub-Type: LGMD2A / Calpainopathy



At what age were you diagnosed:

I was diagnosed when I was 26 yrs. old.

What were your first symptoms:

I started experience unexplained fatigue at age 16. When I was 19, I noticed that I had trouble putting my right arm over my head. In my early 20's my heel cords started to bug me, being super tight. A few years later I started struggling with stairs and low seats and I could no longer run or jump.

Do you have other family members who have LGMD:

No, I am the only family member with LGMD2A.

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

The everyday tasks people take for granted makes me really frustrated some days. Like getting out of a chair, turning in bed or tying my shoes – all these little things make me tired and I don't like wasting energy on it. But the real struggle is all the extra work it is to have a disability. People don't see all the

hours I spend doing paperwork getting the things I need and figuring out my rights, physiotherapy, doctor appointments and so on, or all the time I “waste” resting because I have overdone it one day. It is also a challenge to be dependent on other people.

What is your greatest accomplishment:

I completed 6 years in university and got my degree as a teacher. I have also visited many different

countries and hiked in various mountains despite my struggles.

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

It has taught me not to take anything for granted. It has made me more humble and thankful for all the little things in life. It has taught me to slow down and be more patient and to dare ask for help with small tasks. And to enjoy every day! It has also made me be more creative, because I have to find new ways to do things. And I have made 50 many new friends! I love that.

What do you want the world to know about LGMD:

That it actually exists is a good start! And that it affects people in different ways, but to most of us it is

super frustrating/depressing to lose abilities over time. We are always dealing with this, since it is a

progressive disease. It's an ongoing grief. And that it affects our loved ones too. Be kind, always.

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

I would RUN! And jump all over the place. And I would dance all night long! And I would help my friends move or something,

haha ☐

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