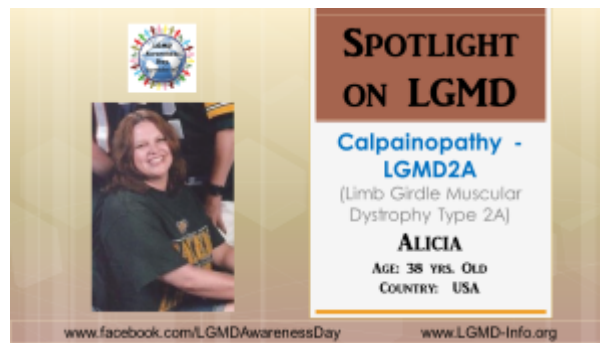


Alicia

04/29/2015

Name: Alicia

Age: 38 yrs. old



Country: United States

LGMD Sub-Type: LGMD2A / Calpainopathy

At what age were you diagnosed:

I was diagnosed at age 35 after years & years of being misdiagnosed.

What were your first symptoms:

Walking & running on my toes and climbing stairs were the first symptoms.

Do you have other family members who have LGMD: No

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

One of the biggest challenges for me has been finding physicians who are educated when it comes to LGMD and the challenges & symptoms that come along with the disease. Many doctors didn't take my issues seriously (muscle pains, loss in strength, problems walking/stairs) or thought I had an

autoimmune disease before I found a doctor that finally sent me to the Mayo Clinic. After an EMG, blood tests & a muscle biopsy I was finally diagnosed but it took many years and many doctors to get where I am at.

What is your greatest accomplishment:

Raising two amazing daughters with my husband of 14years has been an accomplishment and a blessing. Teaching them kindness and to be more empathetic towards people since we never really know the struggles of those around us.

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

It has taught me to be kinder, listen more and laugh every day. Sometimes all you can do is laugh.

What do you want the world to know about LGMD:

That there are currently no treatments or cure for LGMD and if you have a family member or even a friend who has been diagnosed please educate yourself about the disease. It could mean the world to someone.

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

Dance all night!

Audrey

04/25/2015

NAME: Audrey



AGE: 42 Yrs. Old

COUNTRY: United States

LGMD Sub-Type: LGMD2i

AT WHAT AGE WERE YOU DIAGNOSED:

I was diagnosed with LGMD when I was 37. I had never heard of it before my diagnosis.

WHAT WERE YOUR FIRST SYMPTOMS:

I noticed in my twenties I began having trouble climbing stairs, raising from the floor, and lifting my legs. Unfortunately, I didn't know how abnormally weak I was becoming. I thought I was just out of shape or uncoordinated. When I needed physical therapy for shoulder pain, the PT sent me back to my doctor because she recognized something was seriously wrong.

DO YOU HAVE OTHER FAMILY MEMBERS WHO HAVE LGMD:

My older sister also has LGMD2i, but her progression is slower.

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

My greatest challenge has been to accept help without feeling like a burden on others. I'm still able to walk, but I need a lot of help from my family with everyday life. I am so fortunate to have such a great family support system.

Sometimes I can't believe how lucky I am!

WHAT IS YOUR GREATEST ACCOMPLISHMENT:

I've spent the last 23 years being a mother to my 3 daughters. Motherhood is certainly my greatest accomplishment.

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

LGMD has allowed me to simply accept what life offers. When faced with this diagnosis and an uncertain future, I've found out I'm still okay... I can do this, and I'm going to be okay!

WHAT DO YOU WANT THE WORLD TO KNOW ABOUT LGMD:

I think it would be great to put LGMD on more people's radar. Most doctors I've seen haven't heard of it.

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

If I were cured tomorrow, I'd run. I'd run as far as I could, then I would climb the stairs. I'd help every person who dropped something pick it up. I would plant and tend a beautiful garden. I would never take these legs for granted!

Jane

04/20/2015:

Name: Jane

Age: 18 yrs. old



Country: United States

LGMD Sub-Type: LGMD2i

At what age were you diagnosed:

I was diagnosed when I was 5 years old.

What were your first symptoms:

I was experiencing difficult climbing stairs and keeping up with my peers on the playground.

Do you have other family members who have LGMD:

No, I am the only person in my family with limb girdle muscular dystrophy.

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

I find that it is difficult searching for accessible paths when in an unfamiliar setting. It can also be challenging to have to pace myself – more than my friend.

What is your greatest accomplishment:

I suffered a major accident in October, 2014. My greatest accomplishment is working so hard to walk independently again. I was told no weight bearing on my legs while in the hospital for a month. But, after several consultations with

multiple doctors, they reversed the orders. I worked hard every day to be able to walk out of the hospital on my own, one month later!

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

It has taught me to think outside the box – to be creative and original.

What do you want the world to know about LGMD:

Just because one is physically disabled doesn't mean you are mentally disabled.

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

I would run a race and jump for joy!

Freddy

04/14/2015

NAME: Freddy **AGE:** 49 Yrs. Old



COUNTRY: Denmark

LGMD Sub-Type: LGMD2A – Calpainopathy

AT WHAT AGE WERE YOU DIAGNOSED:

I was initially diagnosed with LGMD at the age of 29 years old. Around my 34th birthday I received confirmation of my LGMD2A diagnosis.

WHAT WERE YOUR FIRST SYMPTOMS:

I had a stiff neck when walking and was having problems lifting objects up from the ground. My right arm could not bend. I was also experiencing fatigue.

DO YOU HAVE OTHER FAMILY MEMBERS WHO HAVE LGMD:

No, I am the only person in my family with this diagnosis.

WHAT DO YOU FIND TO BE THE GREATEST CHALLENGE IN LIVING WITH LGMD:

I struggle to have enough energy to do the things that I want and need to do during the day. I try to plan my day in advance so I know what and how to use my energy during the day. Unexpected things or chores are sometimes a problem.

The long winters are also a challenge. In the winter I stay indoors as much as possible. I only go out when I really have to. My son understands this, but is it not always nice for him that we cannot play outside or spend more time outdoors in the winter. When there is frost or snow I stay indoor even more because I'm afraid to fall.

Because of the LGMD sometimes I seem to have a short temper...?

WHAT IS YOUR GREATEST ACCOMPLISHMENT:

One of my greatest accomplishments is that I moved from Holland to Denmark 15 years ago. I have a nice wife and son who is 7 years old (almost 8). I also have a job where I am

able to work 20 hours a week. (Denmark is trying to help the disabled where they can.)

HOW HAS LGMD INFLUENCE YOU INTO BECOMING THE PERSON YOU ARE TODAY:

I am still able to walk, and my doctor told me that I will be able to do that forever J, but sometimes I'm a bit unstable and walking "strange".

I have to plan my days, to plan my energy , if there is something different like an appointment I have to know it days in advance. Otherwise I take it as it comes, one day at the time.

WHAT DO YOU WANT THE WORLD TO KNOW ABOUT LGMD:

I want the world to know that the disease Limb Girdle Muscular Dystrophy (LGMD) exists and that it is a rare disease. The form of LGMD that I have – LGMD type 2A – is quite rare! In Denmark it is estimated that only 6% of LGMD patients are diagnosed with LGMD2A.

IF YOUR LGMD COULD BE "CURED" TOMORROW, WHAT YOU'LD BE THE FIRST THNG THAT YOU WOULD WANT TO DO:

Running! It has been many years ago since I have been able to run or since I was stable in my walking.

Melissa

04/08/2015

NAME: Melissa **AGE:** 47 Yrs. Old



COUNTRY: United States

LGMD Sub-Type: LGMD2i

AT WHAT AGE WERE YOU DIAGNOSED:

I was diagnosed at the age of 18

WHAT WERE YOUR FIRST SYMPTOMS:

As a child, I was clumsy.

DO YOU HAVE OTHER FAMILY MEMBERS WHO HAVE LGMD:

No, I am the only member in my family diagnosed with limb girdle muscular dystrophy.

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

The greatest challenge for me is not being able to get up from a chair.

WHAT IS YOUR GREATEST ACCOMPLISHMENT:

My greatest accomplishment is growing my non-profit, Legacy Counseling Center, into a one and a half million dollar organization that helps thousands of people annually.

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

I changed my career choice to something that would be wheelchair friendly, in case I would ever be in that position.

WHAT DO YOU WANT THE WORLD TO KNOW ABOUT LGMD:

At the moment there is no treatment or cure.

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

I would travel without boundaries like I used to.

Lacey

04/03/2015

NAME: Lacey **AGE:** 42



COUNTRY: United States

LGMD Sub-Type: LGMD2i

AT WHAT AGE WERE YOU DIAGNOSED:

I was diagnosed with Muscular Dystrophy at 16 and LGMD2i at 34. Both diagnosis' came over the phone. In hindsight, I wish the doctors would have told me in person, I had so many questions and was scared.

WHAT WERE YOUR FIRST SYMPTOMS:

The first symptoms I noticed were painful leg cramps when

running and not being able to keep up with the other kids. I was told I was lazy and to try harder in PE and in softball. I remember thinking, "I am trying as hard as I can, how do I make myself go faster like the other kids?"

DO YOU HAVE OTHER FAMILY MEMBERS WHO HAVE LGMD:

No, I don't have any other family members with LGMD.

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

The constant changes and trying to find ways to adapt to my new normal.

WHAT IS YOUR GREATEST ACCOMPLISHMENT:

My greatest accomplishment is living each day as it comes with compassion and courage, being a wife to my supportive husband, and a mom to our loving girls.

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

LGMD has forced me to slow down, to become present and aware. I am a stronger, more empathetic person because of this disease. I have learned to cry and laugh at the same time.

WHAT DO YOU WANT THE WORLD TO KNOW ABOUT LGMD:

I would want the world to have more awareness of LGMD, especially doctors. I know for many of us, the road to getting a diagnosis is a long one and it doesn't have to be. Some LGMD's have cardiac and pulmonary issues and I think it's essential to have knowledgeable doctors monitoring and providing support.

IF YOUR LGMD COULD BE "CURED" TOMORROW, WHAT WOULD BE THE FIRST THING THAT YOU WOULD WANT TO DO: The first thing I would want to do, is run-I wish I could remember what it feels

like. Sometimes when I'm driving in my scooter, I close my eyes and pretend I'm running-it gets a bit dangerous ☐