

Cecilia

LGMD Spotlight Interview

Name: Cecilia **AGE:** 36 years



Country: Argentina

LGMD Sub-Type: LGMD2A/Calpainopathy

At what age were you diagnosed?

I was diagnosed when I was 12 years old.

What were your first symptoms:

I began walking on my toes. Also, from the time I was little, my mother noticed I had delayed reactions, for example in chasing a ball.

Do you have other family members who have LGMD?

No, I am the only one in my family with LGMD.

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

The biggest challenge was getting accustomed to the first changes, the first things that I became unable to do: for example, climb stairs and get up from the floor. At a more advanced stage, coming up with strategies to be able to get up from the bed, from a chair, etc. and then, mourning the loss

of walking ability and beginning to use a wheelchair or scooter part-time or full-time.

Also, it was a challenge to find balance and know the limits of my body. Knowing how far I could go without exhausting myself; deciding what to do myself and when to ask for help.

The good thing is that I learned to accept changes, to be clever and creative, and to think of solutions to do things in other ways, and to look for alternatives.

What is your greatest accomplishment?

My biggest accomplishment is that I've always achieved what I wanted, and I continue to do so. My family deserves a lot of credit for that, they always taught me that the disease isn't a barrier or an excuse, that everything is possible if one can "find a way", that there is an alternative path, which may have obstacles, but which will lead us to our goal.

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

If I didn't have this disease I wouldn't be the person I am. The challenges made me grow and become strong. I don't deny what I can't do and the circumstances that affect me. I developed the ability to confront with a positive attitude the changes that occur. I know that in some way things always work out.

This has influenced my professional career and the field that I chose to work in. I work in non-governmental organizations on behalf of the rights of people with disabilities, especially where physical accessibility is concerned. Also, here in Argentina, I'm part of the Muscular Dystrophy Association, and write articles giving encouragement to others who are experiencing situations which cause disability.

What do you want the world to know about LGMD?

1. That this disease, just like many others, doesn't make people less than others.
2. To shoot down myths, such as that we are weak and fragile.
3. To move past prejudice.
4. For there to be equal rights: that we can study, work, fall in love, and accomplish so many things.

I'm a person determined to live a full life. Isn't that what everyone is looking for?

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

I can imagine so many things! Nothing very special, but just to reconnect myself with my body: run, jump, climb stairs, ride a bicycle, play with my nephew on the floor, go to all the places that I couldn't get in to.

And clearly, I would have more push to keep helping those who are still waiting for a cure! I'm a part of this.

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Keisha

LGMD "Spotlight Interview"

Name: Keisha **Age:** 31 yrs. old



Country: United States

LGMD Sub-Type : Unknown

At what age were you diagnosed:

I was diagnosed about 5 years ago at the age of 25-26.

What were your first symptoms:

I noticed that I was repeatedly falling and that my leg would give out without any warning. I also recall that I was unable to raise my right arm unless I had assistance.

Do you have other family members who have LGMD:

So far, no one in my family has muscular dystrophy but I plan to have my parents tested to see if they are carriers.

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

One of the greatest challenges is always having to plan ahead – if going out with friends or family to make sure the place is handicapped accessible. Every day it also takes me longer to get dressed in the morning.

What is your greatest accomplishment:

Coming to the fact that I have LGMD and still trying to figure out which form of LGMD. And learning to embrace it.

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

I feel LGMD has made me an unique individual helped me to bring awareness of the disease to others that don't know much about it. Having LGMD has helped me to become stronger and more independent. I know that having LGMD is a part of me, I am human and still have my days just like anyone else. I am a strong and proud woman with LGMD.

What do you want the world to know about LGMD:

LGMD is something that currently has no cure. It is something that won't go away. Physical therapy and aquatic therapy help manage the disease. Even with LGMD, we are still strong and can live a normal life just like anyone else.

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

If I could be cured tomorrow, I would want to run a marathon, run up and down the stairs, and take a big vacation somewhere to celebrate!

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