

# Deceena

## LGMD “Spotlight Interview”

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



**Country:** USA

**LGMD Sub-Type:** LGMD2A – also known as Calpainopathy

### **At what age were you diagnosed:**

I was diagnosed at the age of 29.

### **What were your first symptoms:**

Muscle weakness in my legs was my very first symptom. I was unable to go up stairs like a normal person, starting in 2008 following the birth of my second child. Doctors chalked it up to just having had a baby and gave me the advice to go exercise. I was only 22 and I knew there was something more going on. I only wish my doctors would have taken me more serious. I went to numerous doctors and specialists, all who said I was “fine”. I ended up finding a holistic based physician who uttered the words “Oh my goodness, why has nobody helped you?” He sent me to PT, and on my last day my PT asked me is anyone in my family had Muscular Dystrophy? (No). He mentioned to me there are forms which are recessive, and he suggested my doctor start finding appropriate testing and referrals for MD. This was the first person to ever mention

the words "Muscular Dystrophy" to me, ever. I then found an amazing group on Facebook that allowed me to post videos of myself. Shortly after this, I was led to genetic research with the Jain Foundation, and was able to see Dr. Jerry Mendel which ended in a definitive diagnosis of LGMD2A. The process from my new provider, to genetic testing, to diagnosis was about 3 MONTHS after many YEARS of being told I was "fine" and to exercise. I received my diagnosis on my youngest daughters 1<sup>st</sup> birthday. A day I will always remember...

**Do you have other family members who have LGMD:**

No one else in my family has LGMD.

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

Currently, my greatest challenge is explaining to my children that I am unable to do certain activities, or run and play with them, or even list them up; and explaining why. It is very difficult sometimes to answer their questions. The second greatest challenge is having people make rude comments about how I should save the handicap parking for those with handicaps. I may look like a "normal" person, however, I DO have difficulty walking long distances and I can no longer go up stairs or a curb without the assistance of my husband.

**What is your greatest accomplishment:**

I would say that my greatest accomplishment would be learning love and compassion for all. I never realized the emotional challenges those with a disability are faced with. Most would think it's just physical, but it's not. I have found a partner who chose to stand beside me and still marry me 9 days later. We had a very frank and difficult (for me) conversation about if we should continue on knowing the difficulties physically, emotionally, mentally we would be facing this awful disease. He could have walked away, knowing I had a progressive

neurological disease, but he loves unconditionally and has taught me the true meaning of unconditional love and acceptance. He has taught me to love deeper and always, in every situation-even situations which we think are terrible. We have built a beautiful family which is my greatest accomplishment. I hope we can continue to lead by example with love and compassion, for our children to see and hopefully live. This world would be such a better place if people treated people like people, and not like their disability.

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

Having LGMD has taught me how to advocate and speak up. I have had to advocate for myself for many years, telling physicians they were WRONG. Who does that?? This girl right here! This has inspired me to now become the voice for others. I advocate wholeheartedly for those who are unable to, or those who may need some assistance. I look at having a disability as a gift. I am given opportunities that help define and shape the beliefs I have today. I will always speak up, even when it is uncomfortable and when nobody else wants to. I will always question my physicians, and I won't stop. Having LGMD has turned me into this fierce person with the drive and determination I have today.

**What do you want the world to know about LGMD:**

I don't even know where I would start on this question. Mainly, those with LGMD are NO different than anyone without it. I still breathe and I still have feelings. I still love the same, and I still hurt the same. I want to be happy and have the same opportunities as those without MD. I am no different, except maybe a little more aware of how people treat people.

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

The absolute first thing I would do would be running to my children, then wrestling with them on the floor, and jumping up with them and tossing them in the air. I miss this more than I can express in words. I was able to do this with my older children who are almost 12 and 9, but haven't been able to do it with the younger two who are 6 and almost 3. After that, I would jump into my husband's arms and just stay there for a moment. Then I would need to go for a run, a long run. Running was my activity of choice, which I haven't been able to do for many years.

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