

# Rebecca

04/30/2016 LGMD "Spotlight Interview"

**NAME:** Rebecca      **AGE:** 29 years old



**COUNTRY:** Australia

**LGMD Sub-Type:** LGMD2A / Calpainopathy

**At what age were you diagnosed:**

I was diagnosed with LGMD2A when I was 26 years old.

**What were your first symptoms:**

My first symptoms included: difficult climbing stairs and inclines as well as not being able to rise without using my hands to me up.

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

I am the only one out of 4.

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

The greatest challenge for me is battling fatigue. It can become really hard to find a balance between doing too much and not doing enough. I have found that I'm adapting to

change basically every year. It is also a challenge to not be so hard on myself when I see others doing activities which I can't do. It can be challenging to ask for help when I cannot fulfill a task on my own. Pain – I can't remember the last time that I woke up and felt no pain, discomfort and feeling fragile.

**What is your greatest accomplishment:**

My daughter is 10 years old and she is my greatest accomplishment. I might not be good at some things in life but I can honestly say I'm the best Mum! She is my life. And, as she is growing up, she is starting to look after me in more ways than one.

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

I might be becoming physically weaker in my body but I have become stronger mentally.

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

That is strips away everything that you know.

I also want them to know about Coalition to Cure Calpain 3 – the organization focused on finding a cure and treatment for LGMD2A.

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

If I was “cured” tomorrow, I would go out with my family with not limits. I would run around with my daughter and climb 100 stairs.

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# Mary

04/08/2016 – LGMD “Spotlight Interview”

**NAME:** Mary    **Age:** 46



**COUNTRY:** United States

**LGMD Sub-Type:** LGMD2A / Calpainopathy

**At what age were you diagnosed:**

I was diagnosed with LGMD when I was 25 years old.

**What were your first symptoms:**

My first symptoms were being unable to rise from a seated position without placing weight on my arms for support and difficulty in climbing stairs.

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

No, I am the only family member to ever be diagnosed with LGMD.

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

The greatest challenges for me are trying to remain

independent with daily activities. The disease progression is slow but not being able to do what you once were able to do is hard to adjust to.

**What is your greatest accomplishment:**

My greatest accomplishment was marrying my husband. I became a widow in 2014. He was one of my greatest supporters. He inspired me to be the best person I could be. My family and friends are encouraging and a great support.

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

I take nothing for granted. Each day is a gift – some better than others. I became more outgoing once my mobility became limited as I still want to experience and be active in life despite my diagnosis.

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

LGMD is a muscle wasting disease.

Help those you can, become educated and treat everyone respectfully.

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

If a cure was found tomorrow, I would run, dance and jump! All the things that I can no longer physically do would be top priorities!

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