# Patricia

**07/29/2015:**

**NAME**: Patricia  **AGE**:  26 yrs old


**COUNTRY**: United States

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

**AT WHAT AGE WERE YOU DIAGNOSED**:

I was diagnosed with MD when I was 12 years old.

**WHAT WERE YOUR FIRST SYMPTOMS**:

First symptoms were toe walking, arms not going straight, limping gait, and not gaining weight.

**DO YOU HAVE OTHER FAMILY MEMBERS WHO HAVE LGMD:**

No one in my family has Muscular Dystrophy or LGMD.

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

The greatest challenge is not being able to do certain things such as Walking, Running, Getting out of bed on my own, Bathing on my own, Cooking dinner, Playing with my nephew on the floor. Everything I do is a challenge.

**WHAT IS YOUR GREATEST ACCOMPLISHMENT**:

Greatest accomplishment would be getting married to a wonderful man and hopefully soon starting a family, also when I got my power chair and was able to cook dinner for the first time in 2 years, and being able to go outside with my husband.

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

It has made me realize that even though I am limited on things I can do, with the right tools I can still do some of those things just in a different way.

**WHAT DO YOU WANT THE WORLD TO KNOW ABOUT LGMD:**

Educate yourself on LGMD and some of the struggles people go through. Don't judge someone on how they look. Every form of MD has a different look but that doesn't make the person. their personality makes the person. If you see someone struggling whether in a wheelchair or walking offer to help, I know for me when someone asks if they can help me I am very grateful for it.

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

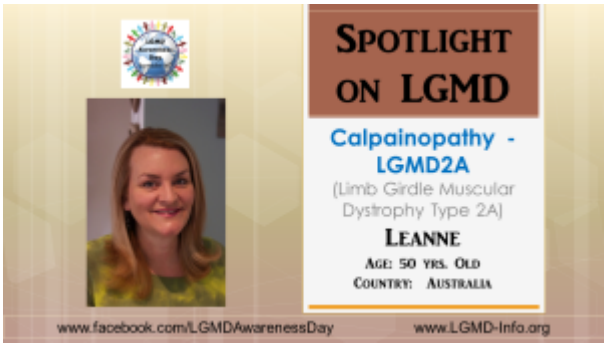
I would run as fast as I can down the road and around the block, I would jump up and down and maybe even do flips. I dream of the day I can do this.

---

# Leanne

07/22/2015:

**NAME**: Leanne **AGE**: 50 yrs. old
**COUNTRY**: Australia
**LGMD Sub-Type**: LGMD2A / Calpainopathy




**AT WHAT AGE WERE YOU DIAGNOSED:**
I was diagnosed at the age of 42 yrs. old through a muscle biopsy.

**WHAT WERE YOUR FIRST SYMPTOMS:**
I was losing weight around hips and glutes. Upon diagnosis other things fell into place i.e. greater difficulty getting up from a squat, not feeling energized after Gym work, and not springing up stairs.

**DO YOU HAVE OTHER FAMILY MEMBERS WHO HAVE LGMD:**
No, I am the only family member diagnosed with LGMD.

**WHAT DO YOU FIND TO BE THE GREATEST CHALLENGES IN LIVING WITH LGMD:**
Lack of spontaneity in activities especially solo trips i.e. camera “playtime”, shopping .

Having to start asking for things to be done when I am always more comfortable being the helper/doer

Having to reassess and redefine my goals and hopes for the future to fit in with the limitations that exist now and will continue to do so without clear guidelines as to how and when the LMGD will progress due to it’s inconsistent nature

**WHAT IS YOUR GREATEST ACCOMPLISHMENT:**
I hope that I am a good, caring person in all my relationships and that I have helped instill in my young adult children good morals and values .

**HOW HAS LGMD INFLUENCED YOU INTO BECOMING THE PERSON YOU ARE TODAY:**
I am definitely more empathetic and in less of a hurry (hahaha) and more accepting that life is not always a "bed of roses"

**WHAT DO YOU WANT THE WORLD TO KNOW ABOUT LGMD:**
I would like to see it as easily identifiable amongst the public as such conditions as ALS (MND); they're still fighting for recognition but have an arguably higher profile than MD, Cancer, MS and many others to help people be understanding and educated about the needs required.

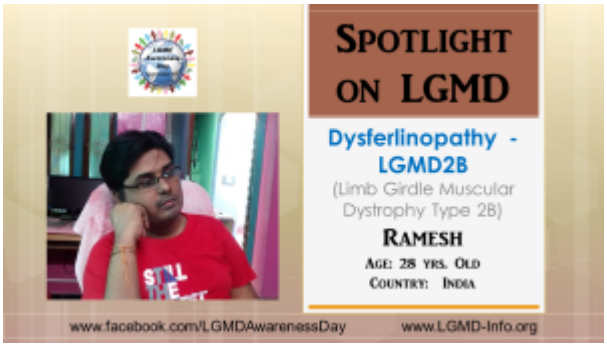
**IF YOUR LGMD COULD BE "CURED" TOMORROW, WHAT WOULD BE THE FIRST THING THAT YOU WOULD WANT TO DO:**
All have equal billing – Go on a big family walk, take my camera to the beach, travel everywhere with no pre-planning, redecorate and garden!!

---

# Ramesh

**07/06/2015:**

**NAME:** Ramesh **AGE:** 28 yrs. old
**COUNTRY:** India
**LGMD Sub-Type:** LGMD2B / Dysferlinopathy




**AT WHAT AGE WERE YOU DIAGNOSED:**
I started having symptoms at the age of 19 but was not

diagnosed until I was about 22 years old.

**WHAT WERE YOUR FIRST SYMPTOMS:**
My first symptom was, when I was going to office suddenly I fell down. I consulted my doctor, he suggested physical therapy but that did not help much. After that, we found it might be best to consult the doctor in Bangalore (India). I had muscle & nerve biopsy and was in a cast for two months on each leg, one at a time. She sent me to a neurologist for further testing.

**DO YOU HAVE OTHER FAMILY MEMBERS WHO HAVE LGMD**: No

**WHAT DO YOU FIND TO BE THE GREATEST CHALLENGES IN LIVING WITH LGMD:**
I find that the greatest challenge in living with LGMD is that people have a hard time understanding it. It is not easy to describe LGMD to someone. Many people think that I am exaggerating or even lying about having this disease. In addition to the condition, I find the lack of accessibility and social attitudes toward disabled people as very limiting. I wish people would be more open to learning about these diseases and understanding how get rid of this disease.

**WHAT IS YOUR GREATEST ACCOMPLISHMENT:**
My greatest accomplishment is, managing to work and keep working in my own way.

**HOW HAS LGMD INFLUENCED YOU INTO BECOMING THE PERSON YOU ARE TODAY:**
I’ve learned to appreciate people helping me, to have patience, to keep being hopeful and avoid feeling depressed, to be thankful for everything, to understand people who aren’t in the same situation as me and who are in a difficult situation, to value what I have and to be a saver, to give more love to my family each day as if it were the last.. I have learned to be patient and accept the fact that everyone needs a helping hand!

**WHAT DO YOU WANT THE WORLD TO KNOW ABOUT LGMD:**
Even most medical professionals are unaware of this condition they have to aware of this and teach the patients how to be safe and challenging towards life.

**IF YOUR LGMD COULD BE "CURED" TOMORROW, WHAT WOULD BE THE FIRST THING THAT YOU WOULD WANT TO DO:**
First of all I would like to congratulate each and every doctor who helped me, in person. The main thing is, I would like to open one blog about this disease and I will guide and support the patients how to overcome through the disease. I know how I am suffering with this disease. I will not give a chance to others suffer again.