

# Vicki

## LGMD "SPOTLIGHT INTERVIEW"

**Name:** Vicki    **Age:** 44 yrs. old



**Country:** Canada

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

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

I was diagnosed at the age of 22.

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

I was having difficulty climbing stairs. The Doctor told me that the tendons in my ankles were short, he then sent me to a neurologist for a second opinion to see if there was an underlying condition as to why they were short. My neurologist sent me to have a muscle biopsy in Montreal.

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

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

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

There are many challenges; to stay independent alone in my home, and to stay active in my community and with friends. It is challenging when planning to go somewhere new. I have to

ensure it is accessible for a wheelchair and I have to ask about the washroom facilities. It is also challenging to stay positive- when you can't perform an ordinary task, go somewhere you want to go, or just see others moving so easily in public.

**What is your greatest accomplishment:**

My family is my first great accomplishment- My husband, Dean, and our son, Tyler. They make my life worth living; they make me feel like I can do anything. I am very blessed. I also take great pride in my MD fundraising. In the past, I have organized a yearly auction, online FB auctions, yard sales, raffles, etc. My latest idea has been making and selling felt ornaments. I started making them January 2016. I design a pattern, cut it out on felt, hand sew them together then market them on Facebook. They have their own FB page: "Vicki's Handmade Ornaments for MD". My husband and I have donated all the supplies to make them, I have even gotten business cards. ALL proceeds from the sale of the ornaments go to MD Canada every year in June for our Walk for Muscular Dystrophy. Since starting I have sold ~\$4000 worth of ornaments. My fundraising goal for the walk for MD has been \$6000 for the past many years. I always find a way to exceed my goal.

My husband and I started a healthy eating regime back in March. We have both gotten lighter, and healthier because of it. I was able to stop taking the 3 medications I was taking for inflammation, pain and high blood pressure. We feel great and I love to spread the word about it!

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

I am learning more and more about myself every day. My challenges and past experiences have made me learn so many things about myself. I have learned to love myself for who I am and not for what I can or cannot do. I have become a

strong, self-confident person. I have realized that I am who I am and the wheelchair does not define me! I also belong to a local disability group. We go into middle schools every Spring and talk about living with a disability, and how you can help people with disabilities. My public speaking has come a long way because of this.

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

It is rare but it is also a common disability. Some of us liked to be offered a helping hand, some like to do it themselves however difficult it may be. Everyone is different. Ask before helping someone and never be turned off by someone with a negative attitude or personality. I always smile because I know what I have in my life and LGMD cannot take my smile away from me!

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

There are probably many things that I would do: travel, swim, run, go shopping on my own, work, exercise, visit my friends' houses with stairs, get in and out of the bathtub, clean the house, I am sure I could come up with a long list... A lot of these things I can do now, but in a modified way. It would be nice to do these things without thinking, in a more carefree way.

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