

Melanie

LGMD "Spotlight Interview"

NAME: Melanie **AGE:** 33



COUNTRY: USA

LGMD Sub-Type: LGMD2b (Dysferlinopathy/miyoshi myopathy)

AT WHAT AGE WERE YOU DIAGNOSED:

I was diagnosed one week before my 29th birthday.

WHAT WERE YOU FIRST SYMPTOMS:

I could not rise up on my toes, I had hammer toes (foot deformity) and was in pain and fatigued all the time.

DO YOU HAVE OTHER FAMILY MEMBERS WHO HAVE LGMD:

Nope, not one!

WHAT DO YOU FIND TO BE THE GREATEST CHALLENGE TO LIVING WITH LGMD:

Losing the ability to do everyday tasks and activities has made life quite challenging. You have to plan ahead for every little thing. It also makes it difficult when people do not understand this fact. When you do not look sick, people do not take your needs seriously.

WHAT IS YOUR GREATEST ACCOMPLISHMENT:

Getting my Master's Degree and securing a great job in the Federal Government (while being sick every day).

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

After I was first diagnosed I felt helpless and alone. I knew of not one other person with this form of MD and I was scared.

Instead of sulking or letting this get me down, I thought “why not go out and do something about it?!” So I started looking into the MDA and how to fundraise. I started an MDA Muscle Walk Team and have has one every year since. Then I decided that I will do everything I can while I still can (since I am losing the ability to walk). And so I did. I have traveled all over and to some places alone. I have even gone sky diving. I believe that this diagnosis has made me an even more positive person. It has certainly made me an even stronger person. Many of the experience that I have had in the last 4 years, are a directly result of me sticking it to the LGMD and proving the odds wrong.

WHAT DO YOU WANT THE WORLD TO KNOW ABOUT LGMD:

First, it does not define us. We are who we are, and we only happen to have this awful disease. Second, just because we look okay, does not mean we feel okay. Third, muscular dystrophy is not MS.

IF YOUR LGMD COULD BE “CURED” TOMORROW, WHAT WOULD BE THE FIRST THING THAT YOU WOULD DO.

Dance like I used to! Then hike in all the National Parks and take lots of amazing photographs. Then run a marathon or do an obstacle race.

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