

Michal

12/10/2015

NAME: Michal AGE: 35 yrs. old



COUNTRY: Poland

LGMD Sub-Type: Unknown

At what age were you diagnosed:

I was diagnosed when I was 25 years old.

What were your first symptoms:

When I was a baby, my neck muscles were too weak and I had difficulty holding my head up. I was delayed and didn't start to walk until I was 4 year old. I stopped walking at the age of 14.

Do you have other family members who have LGMD:

NO , I'm the only person in my family who has this disease.

What do you find to be the greatest challenges in living with LGMD: For me the greatest challenge is that I cannot do some things such as walking, running. stand without help, get dressed, etc. I tried to control my activities so that I have enough energy to do the activities that I want to do.

What is your greatest accomplishment:

One of the biggest achievement in my life is that I have real great parents, friends, and colleagues who encourage me to live a fairly optimistic life and let me forget about my disability.

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

I have become more insensitive to pain and I'm not fearful of any challenges

What do you want the world to know about LGMD:

I want the world to know that people with LGMD may need more help to live independently – such as a personal care attendant, improved access to adaptive and assistive equipment as well as medicines. A cure and treatment is needed to treat all the LGMD patients.

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

I think if I were cure tomorrow, I would run and do everything I never could do!

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Robert

12/4/2015:

NAME: Robert **Age:** 71 yrs. old



COUNTRY: Canada

LGMD Sub-Type: Unknown

At what age were you diagnosed:

I was diagnosed when I was 42 yrs. old.

What were your first symptoms:

I did not walk until I was 24 months old. As a child I could not run like others but it was believed at the time to be caused by asthma. I have never been physically strong.

Do you have other family members who have LGMD:

Thankfully, no. I am the only person in my family diagnosed with LGMD.

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

One of the greatest challenges is the high cost of aids to keep one going with a reasonably good quality of life.

What is your greatest accomplishment:

My greatest accomplishment is the friendships I have developed.

How has LGMD influenced you into becoming the person you are

today:

I believe living with LGMD has taught me patience, organization, empathy for others, and humor.

What do you want the world to know about LGMD:

As my disability has progressed and more help is required to keep me active, I have realized that you cannot be poor and have a good quality of life when you are afflicted with a debilitating condition like LGMD, without a lot of assistance, both financial and physical. Not everyone is as fortunate as I to work a full career and be able to plan for retirement. Please help to find a treatment or cure.

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

I want to go for a walk along the roads and in the fields and forest around my home community. I have not done that in over 50 years and I miss it. Also, I would like to take my wife dancing; we have not been able to do that since the year we met (1986) and I think she misses it.

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