

Rod

06/25/2015:

Name: Rod **Age:** 65 Yrs. Old



Country: United States

LGMD Sub-Type: LGMD2L / Anoctaminopathy

At what age were you diagnosed:

I was diagnosed at the age of 49.

What were your first symptoms:

My first symptoms included difficulty going up stairs and calf weakness.

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:

The greatest challenges that my LGMD2L presents are: 1) reduced mobility and 2) not being able to participate in sports that I love such as surfing, snow skiing and water-skiing.

What is your greatest accomplishment:

My greatest accomplishment are my two wonderful, mature and beautiful daughters!

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

Living with LGMD has shown me the way to strength, patience and empathy.

What do you want the world to know about LGMD:

I want the world to know that LGMD exists and what it is. Most people have never heard of it.

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

The first thing that I would do if my LGMD were cured tomorrow would be to go to Slick Rock country in Utah and go for a long hike...with some river fly fishing thrown in at the end!

Rinku

06/15/2015:

Name: Rinku **Age:** 23



Country: INDIA

LGMD Sub-Type: Unknown

At what age were you diagnosed:

I was diagnosed at the age of 8 yrs. old.

What were your first symptoms:

I was falling frequently and had difficulty with climbing stairs and running.

Do you have other family members who have LGMD:

No, I am the only family member

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

The greatest challenge for me is that LGMD is a progressive disease. My muscles are getting weaker day by day and keeps getting worse. My mind is not accepting it. It is very difficult for me to lose my independence.

What is your greatest accomplishment:

My friends and my family are my greatest and I never lose hope in any condition...that is my greatest accomplishment.

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

Having LGMD has changed everything in my life. My dreams, my future, my hopes... everything! Other people think about their careers and I am only thinking about that how much longer I will be able to run, walk or even stand at all. LGMD is not all bad. I have learned many things from LGMD – 'learn ground mode of disabled'. If any treatment is discovered, I want to become normal.

What do you want the world to know about LGMD:

The world?? First of all I personally do not know about the LGMD. My doctors don't know all about LGMD and about the different LGMD sub-types.

Unfortunately, every association or organization In India uses only the English language. Where on other hand, people with any type of muscular dystrophy are not good in education or skilled in English so there is a very big problem in communication.

And I want that first government to help make doctors aware of muscular dystrophy and all the different types. They need to open special research institutes for muscular dystrophy. If the doctors can treat the LGMD, they may also become able to treat the old aged body the experiences weakness...

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

If my LGMD was "cured" tomorrow...First, I would cry so much and then dance like a crazy person ...

Rona

06/04/2015

NAME: Rona **AGE:** 35 Yrs Old



COUNTRY: Philippines

LGMD Sub-Type: Unknown

AT WHAT AGE WERE YOU DIAGNOSED:

I was diagnosed when I was 21 years old.

WHAT WERE YOUR FIRST SYMPTOMS:

First I noticed I began to walk with a "waddling" *gait* because of *weakness* of the hip and leg muscles. I had trouble getting out of chairs, rising from a toilet seat and climbing stairs. I was losing my balance to when standing.

Do you have other family members who have LGMD: No.

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

The greatest challenge for me is having a hard time walking on my own. Occasional falls that sometimes cause me injuries. Sometimes my physical limitations keeps hindering of things that I can do but it motivates me also to try my best to stay stronger and better.

What is your greatest accomplishment:

After being diagnosed with LGMD, I have always wanted to be positive in life. I had the most challenging job and that is being a sales assistant as standing for eight hours was hard. But with a lot of patience I made it.

I love swimming and going to places that even I find it difficult to go. I dare to live out the closet of limitations. Because I always believe that I am never a failure unless I haven't tried it.

As a mother of two children and a wife I believe that I tried my very best to support the family and to stay strong for them. I choose to be productive and efficient in all the things that I do. That is why I want to be a blessing to others by doing some community work as a volunteer teacher in our community helping children to enhance their skill and knowledge in school by giving them after school service program. All things work together for good if we just see things in a positive way. I stay strong and determined because there a lot of things that I can do and be thankful of.

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

I know that I have gained respect and trust for others and for myself who have gone through tough, times and triumphed, by placing myself in their shoes, whether they have disabilities or not. I was more hopeful in spite of the sickness that I have there is still a PURPOSE to succeed. I open my arms to LOVE and HEALING...My legs carry me forward in life...My disability sometimes indicates a fear of moving forward or a reluctance to step through...but...Life is beautiful...nothing is perfect in the world I live in...My physical limitations is not a hindrance...All it takes to live in peace with your age is a positive outlook on life...a happy personality...a lot of smiles...Know that inner beauty and inner strength are the mark of a winner in life, not the age or outer physical appearance. WE are all a WINNER...

What do you want the world to know about LGMD:

We are strong to Live a life of LGMD!

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

I want to run and drive.