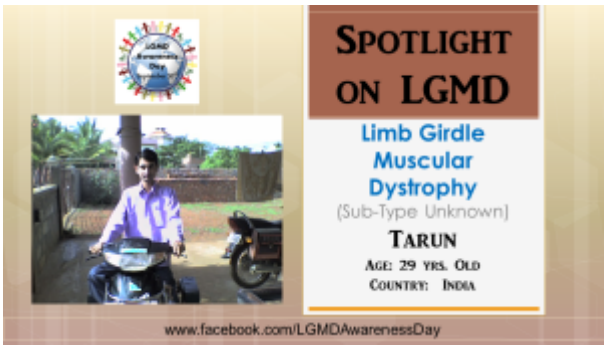
Tarun

5-28/2015:

Name: Tarun Age: 29 yrs. old



COUNTY: India

LGMD Sub-Type: Unknown

AT WHAT ARE WERE YOU DIAGNOSED:

I diagnosed at the age 13.

WHAT WERE YOUR FIRST SYMPTOMS:

I first noticed muscle weakness at age 13. As a child, I had a tendency to walk on my toes. I would fall over when trying to run & also struggled standing up from a chair or the ground,

DO YOU HAVE OTHER FAMILY MEMBERS WHO HAVE:

Yes, My elder sister too has LGMD

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

The greatest challenge is finding the energy to do everything I want to do. I want to be an independent person and I would resist taking help as much as I can but I have to rely on family for simple daily things. Sometimes it is like having an

itch that I can’t scratch.

WHAT IS YOUR GREATEST ACCOMPLISHMENT:

My greatest accomplishment is living a productive and active lifestyle despite the challenges that I encounter on a daily basis due to my LGMD diagnosis. I stay happy and keep smiling no matter what. I used to go to the office on my 3 wheel scooter, so many times I fell down from my scooter and had stitches on my face. People around me told don’t stop driving if you fell we are here to pick you.

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

LGMD has helped me in a lot of ways; despite causing me to be physically weaker. It taught me how to keep a smile on my lips without caring about ups and downs of life. It showed how great parents could be. How loving, caring and dedicated a mother could be. How sacrificing and loving a father could be. How supportive siblings could be. It has also taught me a lot about myself. I have made life-long friendships with so many special people who have disabilities.

WHAT DO YOU WANT THE WORLD TO KNOW ABOUT LGMD:

I want people to know that the disease of LGMD exists. You may not even be able to tell that someone has LGMD. You may see another person and think they just walk differently or slower. Though my country is developing quickly but it lacks disable friendly zones in public places such as banks, ATMs, post office etc. Generally people think we are useless and sympathize but I would want this type of attitude to change. We have disability in our body not in our mind. Most importantly, I want the world to know that LGMD is not a reason to believe that someone’s life is any less valuable. God can and does use difficult experiences, trials, and suffering.

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

First thing I would probably just drive car till the road ends J and run, sit down and then stand up and then sit down and stand up over and over because I could.

Andrea

05/21/2015:

Name: Andrea **Age:** 17 yrs. old

Country: Norway

LGMD Sub-Type: LGMD 1B / Laminopathy

At what age were you diagnosed:

I was about 6 months old when they discovered that something was wrong, but it wasn't until I was about 2 years old that they decided it was muscle dystrophy. I have probably had the disease my whole life. I was 7 years old when I got the diagnosis LGMD 1B.

What were your first symptoms:

I couldn’t hold my head up when I started sitting on my own.

Do you have other family members who have LGMD:

No, I am the only one with LGMD in my family. Both my parents have been tested and the results showed that I didn’t inherit it, it was from a mutation.

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

The greatest challenges are that I can’t do anything on my own. I need help with practically everything, like getting dressed, getting in and out of bed, and picking up stuff.

What is your greatest accomplishment:

My greatest accomplishment is my mind. How I have a positive look on everything.

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

It has made me appreciate the small pleasures and made me a very positive person.

What do you want the world to know about LGMD:

I want the world to know that I am not chained to my wheelchair, the wheelchair is the most helpful aid I have. Without it I would be chained, it is my freedom. When some people see me they only see the wheelchair, the noise around me, and not me. The disease only affects my muscles and not my brain, I am a normal 17-year-old girl.

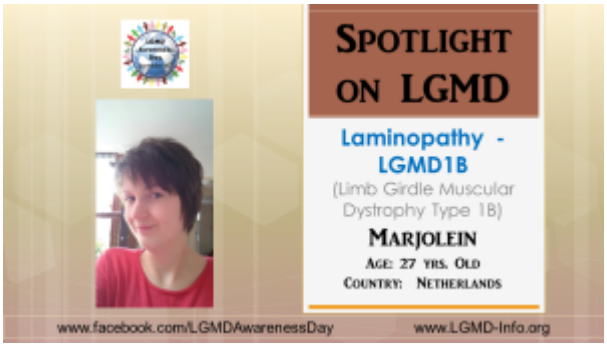
If your LGMD could be “cured” tomorrow, what would be the first thing that you would want to do:

I would jump, run up and down the stairs, pick up things, do all the normal things I never have been able to do!

Marjolein

05/15/2015

Name: Marjolein



Age: 27 yrs. old

Country: The Netherlands

LGMD Sub-Type: LGMD1B / Laminopathy

At what age were you diagnosed:

I was diagnosed at the age of 4 with LGMD but the sub-type was unknown. At the age of 23 I had a DNA test done which was relatively new in Holland, and that is when they found out that I had LGMD type 1B.

What were your first symptoms:

My mother noticed that I had trouble climbing the stairs. My sister is 1 year and 9 months younger and she could already climb stairs but I still had to use my arms to help me climb the stairs. I was also born with heterochromia iridum (two colored eyes (with one blind eye)) and a palato cisis (an opening in the palate) so my parents figured I had something more.

Do you have other family members who have LGMD:

No, I am the only one so far. We looked in to our history but couldn't find anything that said that others in the family had LGMD.

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

The greatest challenge is having to accept all of the losses regarding the physical things that I cannot do anymore. Sometimes it goes so that my head can't keep up.

What is your greatest accomplishment:

My greatest accomplishments are finishing college, finding my soulmate and buying a house together.

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

I don't really know because I don't know how it is to not have LGMD. I do have a lot of patience. Maybe that is because of all the waiting we have to do to get the things we need to function in our lives….you know, things like wheelchairs and other stuff.

What do you want the world to know about LGMD:

LGMD is a very frustrating disease. People living with LGMD deal with losses day in and day out.

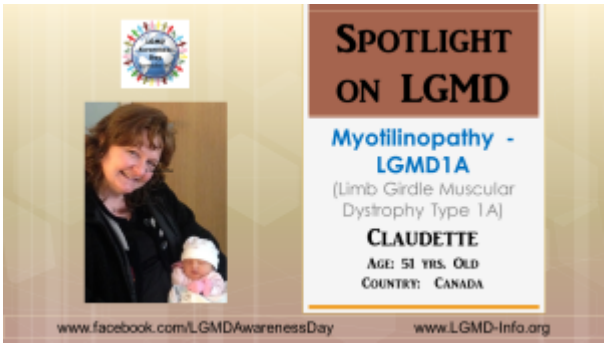
If your LGMD could be "cured" tomorrow, what would be the first thing that you would want to do:

If I could be cured tomorrow, I would dance with my boyfriend in a club all night! And, I would go on a hiking vacation.

Claudette

05/7/2015

Name: Claudette
Age: 51 yrs. old
Country: Canada
LGMD Sub-Type: LGMD1A / Myotilinopathy



AT WHAT AGE WERE YOU DIAGNOSED:

I was diagnosed at the age of 39.

WHAT WERE YOUR FIRST SYMPTOMS:

My first symptoms included: difficulty with stairs, shoulder pain, shuffling or dragging my feet

DO YOU HAVE OTHER FAMILY MEMBERS WHO HAVE LGMD:

Yes, my father, my brother and my sister also have LGMD.

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

The challenges I face are minimal due to tremendous support from my family. I am hard pressed to find any one main challenge for me. I think my main difficulty though is watching my husband trying to do it all! There are so many household chores I used to do and can’t anymore, laundry, cleaning, meal prep, outside chores like cleaning vehicles or mowing the lawn! We used to be a great team but of course now he has taken over these tasks. He is my primary caregiver. He

also holds a full-time and very demanding job. I am so grateful for his amazing love and support!

I know this is a very common issue for many people, not only for those of us living with LGMD. I think my disease is often harder for my family than it is for me.

WHAT IS YOUR GREATEST ACCOMPLISHMENT:

My marriage, soon to be 29 years, and raising two fine boys to become strong, independent and hard working adults. Our eldest and his wife just became parents, so now I am proud to say I'm a grandmother to a beautiful baby girl!

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

My father was in a wheelchair for most of my childhood. We lived in a rural area where LGMD was rare and unfamiliar to medical people in the 1970's. As a result, his condition was defined as a "rare neurological disorder". He died in 1985. In the early 90's his muscle biopsy from the 1970's was matched to my brother's, confirming LGMD. Throughout his illness, my father demonstrated a very off-beat sense of humor and a positive attitude. His influence has made me a rather positive person. My dad and my brother have inspired in me the courage to tackle anything LGMD will hand me. I live by the words "it could always be worse!"

WHAT DO YOU WANT THE WORLD TO KNOW ABOUT LGMD:

Sometimes we don't fit into a box. A hundred people could be diagnosed with LGMD at the same time, and most likely all of us will progress at different rates.

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

If I were to be cured tomorrow, I would do something spontaneous. Something I wouldn't have to plan or anticipate

due to barriers, my own or otherwise.