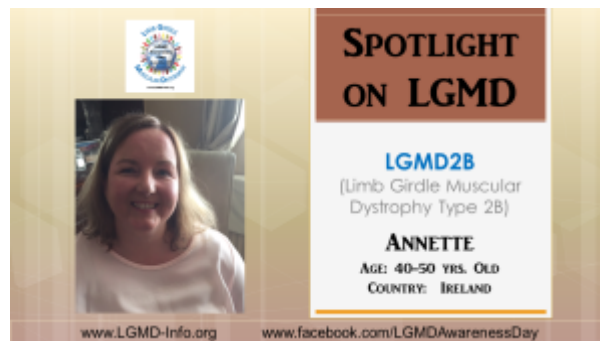


# Annette

10/16/2016

**NAME:** Annette

**AGE:** 40-50 yrs old



**COUNTRY:** Ireland

**LGMD Sub-Type:** LGMD2B

**At what age were you diagnosed:**

I was diagnosed at the age of 38 yrs. old

**What were your first symptoms:**

I was stumbling and falling. I also had problems rising from a seated position and climbing stairs.

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

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

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

Lack of awareness is prevalent. In addition, many facilities in Dublin (transport, restaurants, some theaters) are not anywhere near wheelchair accessible.

LGMD has impacted my professional life as I am no longer able to work full time and there have been financial consequences

of this.

**What is your greatest accomplishment:**

I try to remain positive and optimistic. I am fortunate that I am able to maintain an almost independent life. I am delighted to be taking part in a clinical outcome study in Newcastle, UK (the people there are wonderful).

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

I appreciate what I can do and try not to get downhearted regarding the things that are no longer possible.

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

I am blessed with a wonderful family and core group of friends who never let me down.

LGMD is a challenge but with a good support system in place, life can be good. Greater funding allocations are imperative in order for LGMD to be treated and not be a life altering condition.

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

I would play with my beloved niece Emily, bring her to the park and do all the things a good auntie should do.

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# Mark

10/02/2015

**Name:** Mark **Age:** 54



**Country:** United States

**LGMD Sub-Type** (if known): Unknown

**At what age were you diagnosed:**

Age 41. The day was January 28, 2002

**What were your first symptoms:**

Difficulty climbing ladders and stairs. Also difficulty rising from the floor or a low chair or sofa. But I was always slow as a child. I could not quite keep up with my friends or schoolmates.

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

My father had an unknown sub-type of LGMD. He was the first, and only other, patient in our family. His parents and grandparents seemed to be unaffected. My symptoms parallel his almost exactly. I was his caregiver from the age of 14 to about 25.

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

Having to constantly ask for help. Watching my wife and daughters do the chores that I would enjoy doing, and that the man of the house usually does; yard work, repairs, etc. Watching my wife give up outings, restaurants, vacations, and so on. I can live without, but it's not fair to her. I encourage her to do those things, but she misses going out as a couple as well. We do go out, but it's not spontaneous and the outings are few and far between.

**What is your greatest accomplishment:**

Before the MD? The home and family I've established. And I've many close friends.

In spite of the MD? I've always had a "Bucket List" in my head of life goals. I have seen most of these materialize and come to pass. A few examples: Hire an architect and build our dream home (accessible as well). Read *Les Miserables*. Learn to solve a Rubik's Cube. Take a train across the United States. See the Grand Canyon. There are dozens more, none of which were prevented because of my LGMD.

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

I am determined to identify my sub-type. I believe a genetic diagnosis will be critical in future treatments. I have created a Facebook group, "Muscular Dystrophy Subtype Unknown", for MD patients who have been unable to achieve a genetic diagnosis. The group is far more than venting and support. We share valuable resources and information with the goal that if one gets diagnosed, many others may benefit. This is my mission, my goal and my passion right now; to help as many of my fellow LGMD friends as possible and get myself and every one of them a diagnosis. I won't give up on them even if I identify my own sub-type tomorrow.

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

People with LGMD have the same hopes, dreams and fears as you. In our minds we run on the beach, walk barefoot in the grass, hike along a mountain stream. It takes a great strength of heart to not succumb to the imprisonment in our own bodies. Never take your body and legs for granted! Never take for granted getting up from a toilet, running an errand, hugging a loved one or holding a baby. Those abilities are a distant memory for me. But at the same time, our lives are SO MUCH MORE than healthy legs! Enjoy your family, a sunset, a good book, a thunderstorm, a bird in your backyard. Don't be unhappy because your boss was crabby, you were stuck in traffic or your dinner got cold.

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

I would thank God and the team of doctors and researchers that made it happen. Then I would hug everybody I love...hard and long. Then I would do a few of the things my wife and I love to do; dine out, travel, and walk in the sand holding hands.

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