

# Sabrina

08/27/2015

**Name:** Sabrina      **AGE:** 32



**COUNTRY:** Bangladesh

**LGMD Sub-Type:** LGMD 2D

**At what age were you diagnosed :**

At the age of 9 years old, I was diagnosed.

**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:**

Yeah! My younger sister also has LGMD.

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

Living with LGMD the first challenges for me were social and infrastructure barriers. Like because of

Inaccessibility in our country I could not finish my studies. I could not go to weddings, family reunions, birthdays or

anything of that sort. So I cut down socializing with others from childhood. I mostly grew up within the four walls of my house.

Furthermore, the physical challenges for me are that I can't do anything on my own. I'm unable to move any part of my body, except my fingers, toes & head. I need help with practically everything so have to rely on someone else fully. Days passed and now my physical condition has become more critical. The biggest challenge for me physically at present is my breathing problem in spite of which I want to go ahead in my life with full passion.

**What is your greatest accomplishment :**

My life had changed overnight when one day I came to know that my loving youngest sister has the same disease. I could visualize the same agonizing future for her that I was experiencing- this made me revolt. The rest of the world doesn't show the same picture- why this situation of discrimination in our country? Why do they have to hear 'no' in the very beginning of life for everything? Even after being a part of this society they became to get distanced. With all these questions running over my head I became frustrated. Then a little change in mental frame work and I wrote a letter to the Prime Minister of my country in February'2008.

In April'2009 I got an opportunity to get in touch with the world through internet and Facebook which is an easy way to get people together. With the inspiration from a Facebook friend I tried to reach the letter to as many different people as possible and make them aware about the rights of Persons with Disabilities through advocacy. Thus started the journey of Bangladesh Society for the Change and Advocacy Nexus (B-SCAN), a voluntary organization on 17th July, 2009 in order to give the Persons with Disabilities a better life by creating network through advocacy for the system change in Bangladesh. I also started to write on blogs for raising awareness. I was

nominated in the international blogging competition of German news broadcaster Deutsche Welle in 2011 and achieved World's second best position.

B-SCAN as a whole got tremendous response, many showed their concern. Our life inside the wall got changed. We started dreaming of campaigns for Rights & Awareness for the persons with disabilities throughout the country that will someday make people aware and concerned and thus will help the people with disabilities to get their rights.

Every morning when I get up, the first sight which captures my eyes is the open blue sky. I feel this earth is really beautiful, life is beautiful. I wish to touch the sky. I wish to stand up under the open sky and take a deep breath. I never thought that I would ever be able to do so, I only dreamt and wished. This wish, this will power used to give me strength, to inspire me to live a good life. And this will power only has made me dream of B-SCAN which I think is the greatest success of my life. B-SCAN is the motivation which has brought me out under the open sky.

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

When I was diagnosed with LGMD I never took it as a problem or anything of that sort. My life took a change when the same happened with my sister. When I saw her going through the same it was like a whole new picture, whole new perspective for me. It got me thinking about all the "Sabrinas" in this country, about their survival, their pain and misery. All these thoughts gave birth to a new Sabrina in me. As a person I became stronger.

I wish to change the perspectives of people and make it a suitable place for the Persons with Disabilities establishing their rights.

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

Living with LGMD is not the end of life. Everyone should learn more and more about it. It can be done through studying every related website. Everyone should continue living freely and happily as ever before or even more. Try to enjoy every living moment there is to it. Doesn't matter if still there's no treatment. Frustration only makes your life a burden to yourself. Life is truly beautiful. If there is a problem, there must be a solution. We just have to look for it. Always stay positive.

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

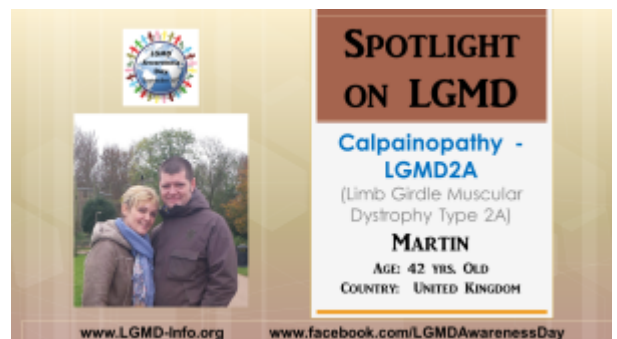
My happiness will know no bounds because for the first time in forever I'll be able to run out of the doors at the first drop of rain. Moreover, if I get cured then I'll let everyone know about the treatment so that they can be cured the same way as me.

---

# Martin

**08/18/2015**

**Name:** Martin **AGE:** 42 yrs. old



**Country:** United Kingdom

**LGMD Sub-Type:** LGMD2A / Calpainopathy

**At what age were you diagnosed:**

I was diagnosed when I was 23 years old.

**What were your first symptoms:**

I had a fall in a garage, dislocated my knee and that wouldn't repair itself in the time expected.

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

Yes, my older brother also has LGMD.

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

My greatest challenges are climbing stairs and trying to get people to understand how hard it is to be an ambulant disabled person that is determined to stay on my feet as long as possible. (and wobbles a bit)

**What is your greatest accomplishment:**

Realizing that I could write about Muscular Dystrophy and people listened too! I've gone on to raise awareness and vital funds for research, attending the houses of Parliament, making sports and TV personalities aware of these conditions via social media, being recognized and rewarded by MDUK for all my efforts to raise awareness and funds for research, changing my career to be in a position of helping others, being a dad to three great girls, trying to be a good role model and to stay positive all of the time.

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

Quite ironically I think that LGMD has made me stronger than what I ever thought I would be, I am extremely determined to let everyone know all about these conditions and make life

easier for many others in the future.

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

That it exists would be a good start! It was not until my diagnosis and years later when I started to talk about the condition that it occurred to me that my family, friends and society in general had not heard of ANY type or strain of Muscular Dystrophy and that has to change; it's imperative that people know about these conditions.

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

To run on a beach as fast as I possibly could (think of the film 'Chariots of fire' and to the Vangelis soundtrack too!) and then have the biggest hug with all my girls and my wife.

To read more "LGMD Spotlight Interviews" or to volunteer to be featured in an upcoming interview, please visit our website at: <http://lgmd-info.org/spotlight-interviews>

---

# Samantha

08/07/2015:

**Name:** Samantha **AGE:** 7 yrs. old



**COUNTRY:** USA

LGMD Sub-Type: LGMD2i

**At what age were you diagnosed:**

I was diagnosed at the age of 2.

**What were your first symptoms:**

My mom and dad saw me fall a lot and I had trouble keeping up with my friends.

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

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

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

I don't like not being able to run as fast as my friends at school. It's hard to do gymnastics but I still have fun trying. My mom and dad make me take a vitamin called "CoQ10" and I don't like the way it tastes. I also don't like wearing my stretching boots at night. I don't really like people knowing that I have LGMD because it's kind of embarrassing.

**What is your greatest accomplishment:**

I'm proud that I can read chapter books now and that I am able to ride horses. I am also excited that I can go off the diving board and swim in the deep end in the pool. I hit the ball well when I play softball and I get excited when I make it on base.

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

I get to do lemonade stands and sell bracelets with my cousins to raise money for LGMD. I'm lucky that I met other people who have LGMD when I went to a conference in Iowa. They are

my friends now.

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

It's hard to have LGMD but sometimes I meet other people who have disabilities that are worse than mine and I realize that LGMD isn't really that bad.

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

I would throw my stretching boots out the window and go to Hershey Park to celebrate!