

Nitesh

LGMD "SPOTLIGHT INTERVIEW"



Name: Nitesh **Age:** 27 years old

Country: India

LGMD Sub-Type: LGMD (sub-type unknown)

At what age were you diagnosed:

I was diagnosed at the age of 10.

What were your first symptoms:

My first symptoms included: calf muscle stiffness and pain and frequent falls along with difficulties in running and jumping.

Do you have other family members who have LGMD:

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

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

The greatest challenge in living with LGMD is that you have to plan and depend on others for things which normal people take for granted in their lives. For example, if you are going to restaurant or movie theatre or checking in a hotel you need to check if the infrastructure is disabled friendly, if you are travelling you need to make sure that the personal care

assistant is available, make provisions for your wheelchair battery etc.

What is your greatest accomplishment:

There are so many accomplishments. The fact that I am still working and is leading a happy and a wonderful life is an accomplishment itself. Despite the challenges I have been able to complete my undergraduate degree in Finance and has also completed all level of Chartered Accountancy (CA) and Chartered Financial Analyst (CFA, US)

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

Living with LGMD is challenging but full of teachings and experience. It is a progressive disease and in the entire journey you face several challenges of different magnitude. It had made me stronger and less worrisome. Most importantly it imparted training unconsciously to become more used to changing environment which has helped me personally adjust in various spheres. I have come a long way from being able to play cricket to a situation where now even standing is little difficult. All such experiences have taught me to stay contented and happy with whatever I am left with.

What do you want the world to know about LGMD:

According to me LGMD is not a disease but a way of life. There are numerous forms of physical disabilities where you see a lot of inspiring people are able to develop a skill such as painting with one hand or leg, finding their own unique way to lead normal life, but what's most unique about LGMD is that it constantly changes the situation and the moment you find yourself in a comfort zone, it throws some another challenge and leaves you at a starting point again. So it's important to treat each individual with LGMD differently and that all the solutions needs to be tailor made.

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

I would like to go on an adventure spree, do all sort of activities such as mountaineering, paragliding, driving car or as simple as taking a long walk.

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