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# GNE Myopathy: Why It Is A Bad Dream

Shilpi Bhattacharya says people with GNE Myopathy face multiple challenges -- finding a job, completing education and getting married. And there is no treatment available!

SHILPI BHATTACHARYA | 13 JUNE 2019

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GNE myopathy, New Delhi

PHOTOGRAPH BY JITENDER GUPTA

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When a rope is continuously rubbed against a stone, the friction wears away the fibres until the rope finally breaks. Think of the rope as muscle and the rubbing as life. As life goes on, my muscles are slowly dying, until one day there will be no muscles left. I have GNE myopathy, a progressive disease that starts in early adulthood and causes loss of skeletal muscle leading to total disability, typically within 10 to 20 years of diagnosis. At present, there is no treatment for it.

Ever since I was diagnosed 10 years ago, I have not known a moment that was carefree, when I did not have some aspect of my disease on my mind. The relentless progression is the most challenging part of GNE myopathy. It has taken much effort for me to accept each of the changing bodily avatars brought by this disease. For the most part, I felt ashamed as if the disease made me lesser than others; I found it difficult to discuss or disclose my disease to anyone, including close friends and colleagues who were almost like my family. For a long time, I thought of GNE myopathy as a bad dream.

The most difficult change to accept was when I needed a walking stick. It had become exhausting to walk even a small distance, and a cane would have helped me greatly and made me more stable, but I couldn't get myself to use it. So I started using a big umbrella as a walking stick—until it broke. All the while I was tormented by questions about what people would think of me. Would they stare at me when they saw me with a cane? When I finally started using a cane I felt humbled because my disease had brought down to size my exaggerated sense of self-worth, about my ability to be independent. Over the years I have been in countless situations where I could not have managed on my own—whether it was a sudden slippery surface that I could not negotiate, a fall from which I could not get up, or progression creeping up on me that left me stranded and unable to walk without help. Through all of these situations, I have witnessed humanity, kindness and generosity of strangers and friends alike. In a world where existence is largely individualistic, my vulnerability helped me build connections, without judgement.

When I was diagnosed, I did not know of any other person with GNE myopathy. It is a genetic disease, but people with this disease have no previous family history of it. This is because one copy of the defective gene comes from each parent and the disease manifests only when the child inherits both copies of the gene. Like many other genetic diseases, GNE myopathy is an extremely rare disease and affects approximately one in six million people. This means that for many, there is complete isolation—no one to talk to who can understand what you are going through, no one to give you advice on what to expect in the future or to explain to you that the changes in your body are the norm for the disease. Even doctors can't provide accurate prognosis.

A few years later I met another person with GNE myopathy. Rushabh was

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already involved in raising awareness and introduced me to an entire community of international patients on a Facebook support group. Years later, my parents and a few others, including Rushabh and I, started our own organisation, World Without GNE Myopathy (WWGM), to fight for a treatment. As we started raising awareness about GNE myopathy in India, talking to doctors and organising conferences, we came into contact with more Indian patients. Now we have a WhatsApp group of more than 60 people with GNE myopathy in India. We organised a patient day last year, and another this year where more than 20 patients will gather. People are able to share their struggles with others and get advice. Our challenge at WWGM is to mobilise people towards actively participating in efforts to find a treatment for GNE myopathy. For many, it is hard to understand why they must play a role in the path towards a treatment. The ordinary citizen conceptualises medicine as something that is bought at a pharmacy. I am fortunate to have scientist-parents who understand the role that science plays in the development of new medicines. People with GNE myopathy face multiple challenges—finding a job, completing education, getting married et al. They often simply do not have time or energy to spend on efforts towards treatments. This is why we need the larger society's involvement to help us. I sincerely hope that a treatment will be available to us soon.

*The writer is an associate professor at Jindal Global Law School. She can be reached at [wwgm.india@gmail.com](mailto:wwgm.india@gmail.com).*

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