

Victor Mendevil



When Victor Mendevil was diagnosed with myasthenia gravis (MG) at age 8 after suffering from symptoms for three years, he says his entire world was turned upside-down.

“I was forced to withdraw from playing the violin because it was too strenuous on my arm,” said Victor, now 16 years old. “I couldn’t hold it up without feeling fatigued. I also had to give up soccer, fencing, physical education, and all sports in general due to my weakened muscles and difficulty breathing.”

Victor had a hard time adapting to MG, specifically when his symptoms were at their worst. He was given braces and a Herbst brace to address his slurred speech, and required several doctor’s visits, tests, medications, treatments, surgeries and physical therapy sessions. Making things more difficult was the fact that Victor was bullied at school because he couldn’t do simple tasks like his classmates, such as opening a water bottle or throwing a football.

However, Victor says he’s earned more from his disease than he has lost.

“Because of my disease, I am able to educate the public about this condition. I have become a resource for young people, children, parents, caregivers and adults living with MG, and have made some lifelong friends from across the nation throughout this journey.”

In 2013, Victor was named “Local Seattle MG WALK Hero.” In 2014, he received both the “[National MG WALK Hero](#)” title and the title of “Young Person of the Year.”

“I’ve had amazing opportunities, like being invited to the 2014 National MG Conference in Philadelphia,” Victor said. “However, my biggest triumph is that I’ve found my love for motivational speaking, and I now love to tell my story to others to help inspire them.”

While Victor hasn’t necessarily been able to regain any of the activities he enjoyed before his diagnosis, he’s been able to find alternatives. When he could no longer play the violin, he swapped it out for a cello, which causes him much less fatigue since he can play the instrument while sitting. Although he no longer partakes in rigorous physical activities, he enjoys swimming and walking. He notes that he is still able to do regular things, like camping and going to school, just as long as he paces himself and doesn’t overdo anything.

“I still retain my spirit, and plan to live life to the fullest. Though my body may have changed physically, I’m still the same person I was before my diagnosis and before MG became a big factor in my life. I have

been able to find new passions that I probably wouldn't have if I had continued sports, like writing, language arts, poetry, reading, playing video games and so much more."

Although it may not seem like much, Victor says whenever he feels fatigued, he simply lays down for a few minutes to reenergize. For Victor, just a few moments of rest can help alleviate his symptoms.

"The one thing I want people to know about MG is that YOU aren't MG. I also was able to accept MG more into my life when I talked about it, and didn't ignore it. Speaking with my mom, my family and my close friends really helps me relieve my stress and makes me feel more at peace with my condition. Accept MG into your life, but don't let it define you. MG is just a bump on the road."

However, Victor says his greatest coping method has been checking items off of his huge bucket list, one thing at a time.

"It could be anything, even crazy things like skydiving," he said. "When I put these crazy goals down, it's like I'm challenging MG; seeing how far I can go, and how much I can get out of life."

The one thing Victor wants people to know about his condition is that even though MG weakens the body, it may not always be noticeable. Often times, he says, people can mistake an MG patient for simply being tired or lazy, because there is so little awareness about the disease.

"I think it's important that people realize MG should not be taken lightly, and that it should be treated like any other major disease," Victor said. "I want people to know that patients may look or act fine, but they are likely suffering, even if they don't seem like it."

To learn more about how you can help create a world without MG, visit <http://www.myasthenia.org/HowcanIhelp.aspx>.