

## Maryann's Health Story

My name is Maryann Gonzalez, and I am 55 years old. This health story is for doctors and advocacy. My favorite healthy activities are golf, volleyball and walking. One important fact about my family's health history is that strokes run on my dad's side of the family. My mom also has anxiety, which makes it hard for her to have company. I live in a group home. We play a lot of games and we have fun together. We share chores and we each take turns cooking. Some people have "famous" recipes that everyone loves to eat. My famous recipe in our home is Italian chicken which I make in the croc pot. I work at Special Olympics Florida, and I'm a sports assistant.

When I was little, I had seizures until I was two. They came back when I was in 9<sup>th</sup> grade, and then they went away again before I graduated from high school. Now, I always get headaches, I am legally blind in my left eye, I have asthma, high blood pressure, I am hard of hearing, I have a muscle disorder and mental health issues. My muscle disorder is called myotonia congenital. It makes my muscles tighten up and it takes them a long time to release. I have medicine that I take for this, and I think that this helps me be pretty stable.

Something I am wondering about with my health is when I am in the heat and I stay there for too long, I feel dizzy and dehydrated. I am drinking water, but this still happens and I am wondering why my body doesn't accept the heat that well. I'm going to ask my doctor about this the next time I go in.

Some things I do to keep my body healthy are drink water, take my medications, eat a proper meal and exercise. Some things I do to keep my mind healthy are watching TV, reading and doing puzzles. These activities make me feel relaxed. The other people I live with sometimes help me with puzzles, and we also play Uno Flip. Living with others and playing games together keeps my mind balanced.

I wish that others understood more about my muscle disorder because it is not well known. When I go to explain it, it is hard for the doctor to know what it is unless it's a neurologist. I think that doctors need to be educated more about my condition and that more research should be done. I've done some research and I know it's genetic and that one side of my family

carries this condition. My brother told me that he has similar problems with his legs if he runs up the steps, but he doesn't have it to the degree that I have it. For about a year and a half I was using a walker and a wheelchair before they found a good medicine that I would work for me. I actually learned that one of the medicines I was taking earlier for my seizures also helps with my muscle disorder. When I learned this, I went back to my doctor and asked to be put back on that medicine because it was on the list of medications that would work for my muscle disorder. After four months of taking it, I was back to walking. This is something I am very proud of!

I would like my doctor to know that I can talk for myself and I only need a little help with things if I ask for it. If I don't understand what my doctor is saying, the person who goes with me explains it.

Another thing that I am proud of is that even though I have a disability, I still went to college. I worked with the disability office, and they helped me so that people could take notes for me. I would study my notes and I would take the test and I would get extra time with the test. I graduated with honors and I am a member of the sorority PTK. My associate degree was in computer technology. This shows that just because you have a disability and you have health issues, that doesn't stop you from doing what you want to do in life. It just might take us longer.

What I really want people to know is that just because it seems like people with disabilities may not be able to do anything for themselves, a lot of them really can if you give them a chance. They can easily talk for themselves, even if they use sign language that is still communicating. A lot of us can physically tell the doctor what's wrong with us instead of our guardians. Because it's our body, not our guardian's body. Doctors should work to be inclusive and let us participate in our own care.