Myasthenia Gravis – A Personal Experience

Art Gentry

Not many have heard of this potentially fatal disease that only affects a small percentage of the population or about 1 in 5000. It is an autoimmune disease where the immune system turns on the body and attacks the muscle receptors at the neuromuscular junction resulting in weakness. The range of symptoms can be very little or very extreme.

Nine years ago I was experiencing symptoms of double vision (diplopia) and drooping eyelid (ptosis) and thought it was just an eye problem. After a visit to an ophthalmologist in Wichita, the doctor suspected Myasthenia Gravis, and said I should see a neurologist. So next stop was a primary care doctor at the local VA medical center. That doctor assigned me to a neurologist who read the letter I received from the ophthalmologist. She sent me to the lab for a blood workup including an acetylcholine receptor antibody test. I scored a high 30 on a scale beginning at point 5 (.5). So next the CAT scan was ordered and a 2.6-centimeter tumor was found on the Thymus gland which is situated just behind the sternum. About half of these tumors turn into cancer and gave another reason for removal.

Next came the surgery called a medium sternotomy and thymectomy. This was my first major surgery of life and I was very nervous about it being age 62 at the time. The VA doctors and staff helped me through the preparation both physically and emotionally with all the pre-op tests, Xrays and instructions. I was Admitted on Monday, surgery Tuesday, dismissal Friday. It was a 4-hour surgery and I remember waking up in recovery intubated but alive. My son-in-law who was an EMT looked in on me and noticed my struggles with the ventilator. He called the nurse who then called the doctor into ICU. He then removed the ventilator tube and the first thing I said was, “now that's a whole lot better”. It was a relief because the surgeon said I was expected to be intubated for up to 24 hrs post-op to make sure I was breathing on my own and remain 7 days in the hospital.

The morning after surgery in ICU, my wife was sitting there, and a nurse was standing nearby when the neurologist entered the room and took one quick look at me and said, “well Art, I see you finally got something off your chest”. Not to be outdone by that one, I replied, “yeah doc, they finally looked to see if I was all that I was cracked up to be” surprising everyone in the room. Dismissal came Friday, and I was both amazed and deeply grateful for the great care I received at the VA in Wichita. (Robert J Dole Medical Center in Wichita)

Now roll the clock 8 years forward. In May 2018, I began experiencing the return of symptoms which I was well informed would one day return. In a very short time, I was having severe symptoms beginning with a drooping eyelid and double vision. A few days later I had weakness over the neck and arm muscles which fluctuated from slight to severe throughout the day. Back to the doctor and subsequently then the

neurologist. New blood workup followed with the diagnosis, it has returned and with a vengeance. I am now on three medications to try to control the symptoms of this weakness. The immunosuppressant medications reduce the anti-bodies that attack the muscular receptors at the neuromuscular junction. Right now, just writing this is a struggle because I can barely move or control my fingers or hold up my arms. Some patients who have even more extreme symptoms have to have plasmapheresis every few days to screen out the attacking antibodies. One of my medications enhances the acetylcholine which crosses the junction and attaches to the muscle receptors which in turn cause the muscle to contract, all this takes place at instantaneous speed. With the medication and rest, I can do things for a few minutes and then I have to stop again and rest. This has no cure but the medications can help with near-normal functionality unless myasthenia gets much worse and becomes debilitating to where even breathing, chewing and swallowing becomes more than just a simple challenge. When A respiratory arrest occurs, this is called a myasthenic crisis and is life-threatening.

In all this, I must say to everyone, be thankful to God for the talent on this Earth that has advanced the medical profession and continues to do so. Much more research needs to be done regarding all auto-immune neuromuscular diseases and to reach possible cures one day.

About the author: Art Gentry lives in Clearwater Kansas and has served on the city council, planning commission and in 2017 served on the Wichita-Sedgwick County Metropolitan Area Planning Commission for part of an unexpired term. He is a WSU graduate and served in the Navy during the Viet-Nam era as a Journalist. He is a member of St. John the Evangelist Catholic Church near Clearwater.

Postscript: The neurologist admitted me to the VA hospital on July 17 through July 22, 2018. Five of those six days I underwent IVIG immune globulin infusions to try to replace the attacking anti-bodies with new anti-bodies. I was also placed on prednisone, mycophenolate mofetil also known as Cellcept which is an anti-rejection drug used for transplant patients and in my case as an immunosuppressant medication. I am also on pyridostigmine-bromide to enhance the acetylcholine level at the neuromuscular junction. My strength has returned to about 70% but the neurologist said I may have to repeat the infusions every 3 months. My endurance or fatigue stamina time is about 30 minutes with exertion and requires rest to restore strength. Pyridostigmine is taken 5 times a day every 3 hours.