

No known cure, but there are effective treatments, for MG

by *Diana Rossetti*

Now, when he reflects on it, John Ness, 64, of Massillon, Ohio, knows his body was sending a message when he was in the service 43 years ago.

"We went on a 20-mile hike and afterward I almost couldn't move," Ness recalled. "I was very weak so I went to the doctor. But after I sat in the waiting room for an hour, I felt pretty good when I got in his office. Because of that, the service would never list it. But I feel that was the beginning."

MYASTHENIA PATIENT - In recent years, Myasthenia gravis, a chronic autoimmune neuromuscular disease, contributed to John Ness' decision to retire and move. By monitoring his medication as well as physical activity, he's improved. 'At this point in my life, I'm probably more normal now than I have been any time from 1972 on.' CNS Photo. The beginning he referred to was Ness' relationship with a disease he had never heard of, myasthenia gravis.

For many people, the only picture of myasthenia gravis is the face of the late Greek shipping magnate and husband of Jacqueline Kennedy, Aristotle Onassis. His eyelids drooped involuntarily, a response to the disease.

Experts at the National Institutes of Health call the disease a chronic autoimmune neuromuscular disease characterized by varying degrees of weakness of the voluntary muscles of the body.

It is maddeningly elusive. Coming and going but never going away. Draining the strength from a variety of muscles. Introducing itself insistently but differently in all its victims.

For Ness, there was that hour after the hike and then ... nothing. For awhile.

Then, working afternoons at Superior Meats in the early '70s, the Lincoln High School graduate enjoying running with a friend following their shift. He trained with weights then, too.

"We would get back to the plant and my legs were so weak that they were actually shaking and wobbly," Ness remembered. "Then I started getting double vision."

An optometrist saw nothing wrong with his eyes and Ness' next stop was a neurologist.

TESTS AND MORE TESTS

After a three-month period when he was in and out of hospitals where doctors attempted to diagnose his

symptoms, it was determined that the young husband and father had myasthenia gravis. But it was a young neurology intern at the Cleveland veterans' administration hospital who closely monitored him to develop an effective medication treatment regimen.

"I'll never forget him, Dr. Greenham. He had me, every 15 minutes at this point, writing down what I was doing, when I took my medication, how much, everything. By that time, I would be able to talk maybe a minute and then my voice was so slurred nobody could understand. Your vocal cords and muscles, they're affected. So every week, he would come and take everything I had written and evaluate it and come back. He'd say, 'Here, you're a little bit weaker, so take a little more (medication) here.' Then, when he sent me home, he took away my wheelchair telling me if he let me take it, I'd become dependent on it and not try," Ness said. "He was probably right."

Glad to be home with his wife, Judy, Ness still vividly remembers the depths of his muscle weakness. Judy had to bathe him. He could chew and swallow only a few bites of food before becoming exhausted. But he was vigilant in tracking his physical peaks and valleys and doled out his 10 daily pills to help level them.

AMAZON INDIANS CONTRIBUTED

Interestingly, the medication Ness took then and still does today had its origins in curare, a lethal paralyzing brew concocted from a jungle vine by Amazon Basin natives. They then tipped their arrows with the substance after it had been boiled down into a sticky sap. In 1935, an English doctor refined the mix and called it Mestinon. Soon, physicians found it had a positive effect on victims of myasthenia gravis, explained pharmacist Steve Fettman of Davies Drugs of Canton, Ohio.

In recent years, the disease contributed to Ness' decision to retire from a job in Cleveland and he and his wife moved to Massillon. By monitoring his medication as well as physical activity, Ness commented, "At this point in my life, I'm probably more normal now than I have been any time from 1972 on."

Before moving to Cleveland, he was active in the Ohio chapter of the National Myasthenia Gravis Association. Today, he, with co-chairman Canton attorney Sandra Merrill, is working toward making the state headquarters in Perry Township as community and education oriented as possible.

"When I first got it, people died. But with medications today, patients don't die. Sure, there are complications, maybe pneumonia and your immune system is affected to a certain degree, but you can go on," he said. "And that's our goal. To get the word out."

FOR MORE INFORMATION

The Myasthenia Gravis Foundation national office in St. Paul, Minn., can be reached by calling 800-541-5454.

MYAS ... WHAT?

Pronounced my-us-thee-nee-uh-grah'viss, myasthenia gravis generally is referred to by its acronym, MG. Its name, Latin and Greek in origin, literally means grave muscle weakness. It occurs when communication between nerves and muscles break down. Currently, there is no prevention and no cure for a disease known as an equal opportunity attacker. An estimated 20 people per 100,000 are affected, regardless of age, sex or race. It is not hereditary, nor is it contagious.

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