



# REVERSING A DIRE DISORDER: LORINDA MCKINLEY

**ADVANCED TESTING AT MAYO CLINIC LABORATORIES THAT CONFIRMED A DIAGNOSIS OF MYASTHENIA GRAVIS PUT LORINDA MCKINLEY ON THE ROAD TO RENEWED HEALTH AFTER SHE NEARLY LOST IT ALL TO THE RARE AUTOIMMUNE DISEASE.**

When Lorinda McKinley arrived at Mayo Clinic's Spine Center in February seeking a second opinion for neck surgery, her eyelids were droopy, her jaw routinely fell open, and she couldn't lift her arms above her head.

Based on the results of an MRI she received at a health care facility near her home in Indiana, Lorinda had been told that a pinched nerve was the source of her symptoms, which first appeared in August 2020. But that diagnosis didn't seem to explain the range of issues she had.

"I couldn't eat without moving my jaw with my hand. I couldn't walk a long distance. My speech was slurred; I almost sounded like I had been drinking. My right eye was drooping, and I couldn't see out of it," Lorinda says. "I couldn't believe that a pinched nerve would affect my eyesight. Maybe my arms, but the walking and the speech and the jaw? I didn't think of it all as connected."

The reason Lorinda couldn't fathom how a pinched nerve could trigger such diffuse symptoms was because a pinched nerve was not at fault. The autoimmune disorder myasthenia gravis was the true source of Lorinda's symptoms. A rare condition, the disease is diagnosed in only about 1 in 500,000 people each year.

Even though it's uncommon, myasthenia gravis was among the first diagnoses Mayo Clinic neurologist Karen Truitt, D.O., suspected at Lorinda's initial consultation.

**"WHEN I WALKED IN THE DOOR AND SAW HER EYELIDS DROOPING, DIFFICULTY HOLDING HER HEAD UP, AND HEARD HER SOFT SPEECH, I IMMEDIATELY SUSPECTED THE DIAGNOSIS," DR. TRUITT SAYS. "I STILL REMEMBER LORINDA CRYING AFTER I TOLD HER THAT WE WERE GOING TO HELP HER."**

#### **Streamlined testing**

To pinpoint whether Lorinda's condition was in fact myasthenia gravis, Dr. Truitt sent Lorinda for advanced testing with Christopher Klein, M.D. Dr. Klein works in Mayo Clinic Laboratories' Neuroimmunology Laboratory and Neurophysiology Laboratory, and under his care, Lorinda had electromyography (EMG). The test recorded the electrical activity of her muscles to determine the decrease in her muscles' ability to contract.

In addition, Lorinda's blood was evaluated through complex serological testing developed by Mayo Clinic Laboratories. The two-step assay (Test ID: MGMR) is used to confirm a myasthenia gravis diagnosis. First, it checks for the presence of acetylcholine receptor binding antibodies. Those antibodies interfere with way nerve impulses are transmitted between nerves and muscles, preventing muscular contraction. If the test detects the binding antibodies, it automatically performs confirmatory testing that checks for acetylcholine receptor modulating antibodies. That automatic, second-line testing vastly improves the

test specificity, resulting in 45% fewer false positives for myasthenia gravis. In Lorinda's case, the serological evaluation left no question that she had the disorder.

"In a center of excellence for neuromuscular disease, this testing is very helpful and supportive," Dr. Klein says. "Occasionally the phenotype can be so bizarre that I don't even trust the EMG, and there are other diseases in the differential, like ALS, that can mimic it. Diagnosis can get challenging for those who are atypical or unusual, and I think Lorinda fit into that category."

By detecting both types of antibodies, the test significantly reduces false positives that could potentially lead to unnecessary treatment, such as a thymectomy. In people with myasthenia gravis, the thymus gland, which controls immune function, is believed to give improper direction to immune cells, causing the immune system to produce the harmful antibodies that impair neuromuscular transmission. Studies show that in some people who have myasthenia gravis, removing the thymus can relieve symptoms.

**"IF YOU HAVE A FALSE POSITIVE AND GO THROUGH THAT PROCEDURE, IT IS NOT WITHOUT RISK. IMMUNOTHERAPY IS NOT WITHOUT RISK," DR. KLEIN SAYS. "WE REALLY WANT TO BE CERTAIN THAT THE DIAGNOSIS IS RIGHT. SO THAT'S A VERY STRONG COMPONENT OF OUR ALGORITHM — HOW WELL IT DOES FOR SPECIFICITY."**

#### **Fast track to treatment**

For Lorinda, a positive result meant that she could receive immunotherapies to counteract her debilitating symptoms. The day she received her test results, she was admitted to Mayo Clinic Hospital — Rochester for a seven-day course of intravenous immunotherapy.

The treatment came just in time for Lorinda, whose disease trajectory was on course to seriously impede her breathing in the immediate future. "I've seen these patients go down quickly, and she was definitely close to that," Dr. Truitt says.

Shortly after beginning infusion therapy, Lorinda noticed a difference. "Things changed, oh my gosh, in a couple of days," she says. "My eye started to open up more. By the third day, my speech started getting better, and by the fifth day, I was so happy because I could chew and was eating cottage cheese!"

Although there's no cure for myasthenia gravis, the combination of high-dose immunosuppression and thymectomy, which Lorinda underwent in June, have allowed for a return to normalcy.

**"I'VE THANKED MY MAYO DOCTORS SO MANY TIMES. THEY GAVE ME MY LIFE BACK. IT MAY BE A SLOW START, BUT I AM GOING TO GET THERE," LORINDA SAYS.**

Lorinda's outcome, which was made possible through the nexus of Mayo Clinic Laboratories and Mayo Clinic practice, underscore the value of teamwork to meet patient's needs.

"The ability to easily collaborate with colleagues, the willingness of a world expert such as Dr. Klein to conduct an EMG study on short notice, and collaboration with my neurology hospital colleagues to get a patient admitted for expedited care is an example of the magic of Mayo Clinic," Dr. Truitt says. "This does not happen in a lot of places. Superior quality laboratory testing coupled with diagnostic testing is all part of that. These are the patients that make me look forward to going to work each day. Patients with a life-threatening neurological disease such as myasthenia gravis are the ones where a quick diagnosis, expedited testing, and initiation of treatment really saves their lives."