



A letter carrier tells her story

In past issues of *The Postal Record*, I've written about ordinary people who did extraordinary things when faced with a diagnosis of a serious disease in their family. No one knows what the future holds for any of us except for our Maker. I believe that the true measure of a person is when they face the difficulties of life and somehow keep on going.

I want you to get to know a letter carrier who did just that. Suzanne Johnson does not think she is any different from you or me. In fact, she was surprised by what happened to her son, Zachary. She didn't see it coming and had no history of the disease in her family. At least, it had never been diagnosed.

When her son was in middle school, about 11 or 12 years old, she noticed Zachary had trouble running and at first thought it was growing pains. He was a big kid then and even now is a big man at 20 years old. Zachary is 6 feet 6 inches tall and weighs enough to be a lineman. His childhood goal was to play football for the University of Georgia. The family lives in Athens, the home of the Bulldogs. Because of Charcot-Marie-Tooth disease, he never will.

Charcot-Marie-Tooth disease is a form of muscular dystrophy that attacks nerves and typically weakens the foot and lower leg muscles. Named after the three physicians who first identified it 1886, it is the most common inherited neurological disorder in the United States, affecting about 1 in every 2,500 people.

Zachary began to fall down often and Suzanne was concerned about what was happening to her son. First, she went to her primary physician who said it was normal and he was just getting used to his growing body. But she knew it was more. Kids began to make fun of Zachary because he was falling so much and, as cruel kids can be, started to push him down for laughs. Suzanne decided to go to an orthopedic doctor but received no help. Doctors who don't work with muscular dystrophies often miss the signs. Then it was to a neurologist who referred them to a child neurologist. It was this doctor who suggested a DNA test. A diagnosis of Charcot-Marie-Tooth was the result.

Suzanne was doubly scared now because, as time went by, Zachary was having more difficulty getting up when

he fell. He would have to crawl to a wall to push himself up. She says that the worst part for her as a parent was that she did not know the cause. She had a million questions and no answers. The child neurologist just wasn't aware of the disease and did not know much more than Suzanne after her search of the Internet. She was in a panic mode. It was a referral to the Muscular Dystrophy Association that made all the difference.

Next month I'll continue their story of how MDA brought help and hope to their family. Zachary's growth as a young man in the face of this disease is one of courage and strength. You won't want to miss it. MDA camp became a major influence in his life.

Bowlathon is around the corner: November 7 marks the second annual national NALC bowlathon for the Muscular Dystrophy Association. I'm sure that your branch is planning diligently for this very important event. Last year, we raised more than \$300,000 for MDA on this one-day effort. President Rolando has decided that any branch that holds a bowlathon during the year will be in the running to win each category. The categories will be the same as the annual Honor Roll.

In addition, our MDA reception at the national convention will be next month and some lucky winner will be riding home on a brand new Harley-Davidson motorcycle. Harley is also contributing other prizes for the drawing, including a men's and women's leather jacket, men's and women's packages (with picture frame, mug, etc.), a shoulder bag briefcase, four watermen pens and two Harley-Davidson 100th anniversary books by Willie G. Davidson.

Forms were in the April *Postal Record* and last month's issue as well. Send in your form as soon as possible and a donation to MDA will be credited to your branch, and you don't have to be present to win. We will be selling tickets on Saturday and Sunday at the MDA booth before the reception which will begin at 1 p.m. and end at 3 p.m. The location for the reception is at the Hilton next to the convention center. We'll see you there!

Update: For the 2009 bowlathon, Salt Lake City, Utah Branch 111 raised \$3,409 and Monterey, California Branch 1310 raised \$5,398. ☒