

Hattie Ewert



Hattie Ewert, 4, after receiving a thymectomy in March 2015 to help alleviate the symptoms of MG.

Hattie Ewert, 4, was diagnosed with myasthenia gravis (MG) when she was just two and a half years old.

“We were very surprised to learn that Hattie had MG,” said Hattie’s mother, Kelli Ewert. “We first noticed facial symptoms, and it was actually a pediatric eye doctor who suspected that she might have MG.”

Although lab tests confirmed the doctor’s suspicions, Kelli says that Hattie’s disease has impacted the lives of her family members in mostly positive ways.

“We have been able to spread awareness through our community, to the point where this entire side of South Dakota knows what MG is, and that it doesn’t just impact adults.”

Despite the challenges that come with having a child who struggles with MG, the Ewerts don’t allow the disease to define Hattie or their family. They still find time to camp, fish, travel, boat and bike ride as a family, simply altering the time of day they do things as to make sure Hattie doesn’t get too hot or too cold.

“When you have a child with MG, you may have to come up with a ‘new normal’ in response to symptoms, and you have to be very flexible,” Kelli said. “One day, everything might be great, but the next day, symptoms can be pretty bad. We celebrate each day, remembering that Hattie is still just a typical 4-year-old! We just want to allow her to live a full and happy life, knowing that we cannot protect her from the world, germs or injury, in most cases.”

Living in rural South Dakota, however, the Ewerts have a hard time when it comes to getting Hattie’s treatments and seeing her neurologist. Their family has to travel seven hours to Denver just for Hattie’s doctor visits, as there are no pediatric neurologists anywhere close to where they live. As parents, Kelli and her husband cope with these struggles by keeping the people in their community aware. She says they tell anyone who asks—even those who just ask how their family is doing—about MG, and all about their journey. Kelli and her husband also travel to schools to educate teachers and school nurses about the disease, and have ensured that the emergency and general physicians in their city know what MG is and that it doesn’t just happen to adults. In 2014, the Ewerts organized the first-ever MG Walk in South Dakota, raising over \$15,000 for the cause.

To learn more about how you can help create a world without MG, visit <http://www.myasthenia.org/HowcanIhelp.aspx>.