Scottsdale Family Raises Money in Annual MG Walk

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Cameron (left) and Peyton (right).

Cameron and Peyton Emens are just like all girls entering fourth grade. They like to dance and play basketball, collect items like stuffed animals, particularly pigs, and their favorite class is “when school ends,” which their mother quickly reminds them is actually not a class at all.

By their personalities alone, one would never know the adversity the two have faced in their short 9 years of living, but with a look into their eyes it is clear the girls are, in fact, different than others.

Cameron and Peyton’s weak eyelids droop downward and cover about 50 percent of their eyes when not treated with their Mestinon tablets, which Cameron takes thrice daily and Peyton as needed.

The Emens sisters were diagnosed at 2-years-old with ocular Myasthenia Gravis. MG is a rare “chronic autoimmune neuromuscular disorder characterized by fluctuating weakness of the voluntary muscle groups,” according to the Myasthenia Gravis Foundation of America, Inc (MGFA).

MG affects approximately 20,000 out of every 100,000 people in the United States today. Its symptoms include droopy eyelids, blurred vision, chronic muscle fatigue and more.

The disease can be treated, but there is no known cure. Each year, the Emens family raises money and spreads awareness of the disease by walking in the annual “MG Walk” at Chaparral Park in November, organized by the MGFA.

In 2014, Team Emens was the top fundraising team in Arizona, raising more than $25,000 for MG research. Jamee says she estimates she has risen close to $100,000 total since her daughters’ diagnosis.

From 5 to 7 years old, Cameron’s eye condition grew so intense she had difficulty keeping her eyes open at all and was at risk of going blind. She underwent surgery to reattach her eyelids to her eyebrows, a necessary fix with minor setbacks.

Because Cameron cannot blink without consciously furrowing her eyebrows in a vertical downward then upward motion, she blinks less often than most and her eyes dry out often.

Jamee Emens, the girls’ mother, says eye drops are essential.

Her attitude toward her girls’ disorder could be described as unperturbed and tranquil, but the fear and heaviness of potentially losing her daughters shows through her shaky lips and trembling voice when she explains the disease’s fatal consequence if it were to attacks the lungs.

The verbal declaration of this unimaginable but possible outcome leaves the girls distraught.

When Cameron leans into Jamee covering her mouth, she whispers in her mom’s ear, “Could I die?” to which her mom nods her head, lips squeezed tightly shut.

The girls and Jamee both agree they don’t think about their MG daily, as Cameron and Peyton have grown used to the disease and Jamee says she couldn’t cope if she worried each day.

“They still need to lead a normal life,” she says.

Cameron and Peyton’s primary complaint of growing up with MG is the constant questioning by peers, teachers and adults if they are tired or not paying attention, a side effect of having droopy eyes.

The girls’ school friends and teachers are more aware now of the disease, but before Peyton says, “(The questions) would drive us crazy!”

Jamee says she hopes in the future people have more of an understanding of MG, so her daughters don’t have to explain their tired-looking eyes all the time, and they can go about their lives as anyone else would.

“It’s important to think of them as individuals,” Jamee says. “Yes they have Myasthenia Gravis, but it doesn’t define who they are.”

While the MG Walk in Arizona is growing in support each year, it is still relatively new. To help the Emens sisters and all others with MG, visit mgwalk.org and donate or register for the walk at Chaparral Park November 15, 2015. Proceeds go to MG research.