

Lacey mom fights battle against daughter's epilepsy

Posted by the [Ocean County Observer](#) on 07/12/06

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In March, during a special presentation in Washington, D.C., for kids with special needs, Harlem Wizard Mike "Mighty Mike" Simmel spun a basketball on one finger for the crowd. After the "ooh's" and "ah's" subsided, Simmel turned to the crowd and said: "I bet you can't believe I have epilepsy!"

Simmel has joined forces with Kathy Rapsas, who lives in the Lanoka Harbor section of Lacey, to begin the process of organizing a local benefit to promote epilepsy awareness.

Rapsas' daughter Mary had her first epileptic seizure at 16 months old. Now 6 years old, Mary has experienced seizures so severe as to be life-threatening, and requiring resuscitation.

"I breathed life into my daughter on Christmas Day," Rapsas said. "The ambulance would show up at our door regularly — about every two weeks — and we got into a routine of spending about eight hours in the local emergency room before she would be transported to Hackensack (University Medical Center) for more specialized tests."

Rapsas, a former pharmaceutical technician, was told that her daughter is one of the 30 percent of epilepsy patients whose seizures are not controllable. In fact, Mary suffered from seizures of such frequency and variety that it was feared that she might have Lennox-Gastaut syndrome, which causes a person to abruptly fall from the loss of muscle tone and consciousness.

In her short life, Mary has experienced many weeklong stays in Hackensack University Medical Center — always accompanied by her mother — and has been prescribed an arm's-length list of medications to control her seizures.

Hope finally arrived in the form of neurologist Michael Katz, who suggested vagus nerve stimulation — an FDA-approved pacemaker-like electrical pulse generator that delivers mild pulses of electrical stimulation to the brain via the vagus nerve in the neck — along with the drugs Keppra and Neurontin.

The results have proved to be dramatic in Mary's case, offering her better cognition, a greater capacity for social interaction, improved motor and developmental skills — and fewer seizures.

Researchers and physicians are hopeful that VNS therapy will help improve more outcomes for patients like Mary, who have drug-resistant epilepsy.

A deeper look at the disorder

Epilepsy comes from the Greek word "pilambabein," meaning to seize or to attack. Such notable figures as Julius Caesar, Joan of Arc, Alexander the Great, Napoleon, Beethoven, Vincent Van Gogh, Charles Dickens, Agatha Christie and Richard Burton had epilepsy.

Statistics provided by the Epilepsy Research Foundation reveal that more than 2.7 million Americans have epilepsy, making it the second leading neurological brain disorder. And it's

important to remember that epilepsy is a disorder, not a disease. Every year, an estimated 181,000 Americans will experience an initial epileptic seizures, according to Foundation reports.

A major roadblock in treating epilepsy is the time required to see a specialist; it is not unusual for patients to wait literally months to schedule an appointment with a neurologist with a specialty in epilepsy. Another concern for adults with epilepsy is the fact that many states stipulate that once a physician diagnoses a patient with epilepsy, driving is prohibited for a certain period of time — often a year or more — and only if the patient remains seizure free within that time. Add to this that it often requires months, if not years, of trial and error to establish an effective drug treatment program that will treat an individual's epilepsy symptoms.

The toll on a family

For children with epilepsy and their families, the toll can be enormous: Because of Mary's epilepsy, her parents and three siblings lived in a state of heightened vigilance, afraid to leave the house for fear Mary would experience another seizure away from where she could be treated in an emergency.

"I knew every parkway exit that had a hospital," Rapsas said. "When we would travel home from Hackensack, we would always be prepared in case Mary had seizures during the trip.

"What was normal for us wouldn't be considered normal for other people," Rapsas said. "In the beginning, I tried to reason things out. When Mary had a seizure, we would try to think about what may have caused it — was it light stimulation, heat, cold, a certain smell? But we didn't find any particular trigger.

"It's been difficult for the family. (Her daughter) Allison was only 10 when this started, and we saw her self-esteem fall as she became more introverted. My older son Kenneth became more aggressive; fortunately, the teachers at school recognized this as something that was a result of all that we were dealing with. And my youngest son, William, was only a toddler at the time, and I think he regressed a little bit. But we all got through it."

Taking action in an imperfect world

Instead of withdrawing completely from the tremendous responsibilities she carried, Rapsas decided to step forward to try to raise awareness about epilepsy. She has worked tirelessly to educate the public about the truths and fallacies of the seizure disorder, becoming a N.J. representative for the National Initiative for Children's Healthcare Quality and traveling to Washington, D.C., in March to raise awareness for the disorder.

It was on this trip that Rapsas met Simmel.

"I was so impressed with Mike," she said. "Here was someone with real visibility who wanted to remove the stigma associated with epilepsy, and help kids find hope. He's such a great role model and inspiration."

As for the future of epilepsy treatment, Rapsas speaks from the heart and from experience when she said she hopes to join in the fight to improve the lives of persons with epilepsy and their families.

"In a perfect world, all seizures would be under control," Rapsas said. "There would be access to a specialist within one week of diagnosis.

"Doctors would call patients or their families back right away to answer questions, and they would refrain from 'playing down' (the severity of) episodes. Primary care physicians and specialists would all be on the same page and work together to help the patient.

"We were fortunate to have finally found a doctor who said: 'I'll never tell you there are no more options.' There have been a lot of strides made in the treatment of epilepsy, but much more needs to be done."