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Lifestyle
Saturday, February 23, 2008 11:56 PM EST

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BY CARRIE MACMILLAN REPUBLICAN-AMERICAN

For one Cheshire woman, a near-fatal car crash caused her to undergo brain surgery. Her seizures stopped immediately. For a Cheshire boy, it took three brain operations to stop the electrical storms in his head. He, too, has not had a seizure since.

Gina Reynolds of Cheshire had major brain surgery to terminate seizures that are a symptom of her epilepsy. Darlene Douty/Republican-American

Gina Reynolds, 47, and Patrick Kenney, 10, are just two of the 60,000 people in Connecticut living with epilepsy. Nationally, that number is 3 million.

Epilepsy is a neurological condition that affects the nervous system and causes seizures. A person is considered to have epilepsy if he or she has recurrent seizures that are not brought on by a known medical condition like alcohol withdrawal or extremely low blood sugar.

A seizure is a brief, but strong, surge of electrical activity that affects part or all of the brain. It can last a few seconds or a few minutes. Symptoms include loss of consciousness, blank staring, lip smacking and jerking movements of the arms and legs.

Epilepsy may be caused by a brain injury, an infection, gene disposition or a family tendency, but often, the cause is unknown. The goal in treatment is to control the seizures, said Dr. Susan Spencer, a neurologist and director of Yale's Epilepsy Program.

Many epilepsy cases can be managed by medication, but both Kenney and Reynolds had seizures that were intractable, meaning medication could not control them. Surgery can be a

lifesaver for people with epilepsy who have intractable seizures, Spencer said.

"About 0.5 to 1 percent of the population has epilepsy and of those, probably 30 percent or so are intractable," she said. "There are many individuals with intractable epilepsy who are being treated by different kinds of specialists and being helped by medications, but they may be having excessive side effects. I think there is a real deficiency in the frequency with which a person is referred to an epilepsy center because there are surgical approaches that may help." Aside from brain surgery, doctors can implant electrodes in patients to help control seizures.

"We often see people who have had uncontrolled seizures for 25 years and it has impacted their school and employment and their entire life, yet there might have been something they could do," Spencer said.

Epilepsy is frequently misunderstood, said Dr. Dennis Spencer, chairman of the department of neurosurgery at Yale University School of Medicine, and Susan Spencer's husband. "There are people who still think of it as a psychiatric or behavioral problem," he said. "Most seizures are not the motor kind where you jerk an arm or leg. A seizure can last for 30 seconds and be mistaken for something else. We want to let people know that these brief changes in behavior are probably a seizure and that it will probably pass in a minute, but for most, you don't have to call an ambulance."

Patrick's story

Nearly four years after his third brain surgery, 10-year-old Patrick Kenney is seizure free and catching up on lost time.

At five weeks old, Patrick was diagnosed with infantile spasms, or sudden jerks of the body followed by stiffening. Despite medications, the seizures got progressively worse and eventually occurred as often as every 15 minutes.

When Patrick was 30 months old, his parents, Mary and Michael Kenney, brought him to Dr. Dennis Spencer, director of the Yale Epilepsy Surgery program. Spencer diagnosed him with cortical dysplasia, a congenital abnormality in which nerve cells in the brain fail to properly migrate. The condition can cause epilepsy and affect development. Patrick is the Kenney's youngest child.

For Patrick, it manifested in a malformation in his motor cortex, or the left side of the brain that controls voluntary motor functions for the right side of the body. The gene responsible for cortical dysplasia is unknown, but Dennis Spencer expects it will be found in the next few years.

Fortunately, brain scans detected where Patrick's seizures were coming from, which made surgery a viable option. Dennis Spencer recommended a brain resection, or removing pieces of abnormal tissue in hopes of stopping the seizures. The goal was to take out only a tiny bit of diseased tissue to avoid impairing more of Patrick's motor functions.

His medications were severely limiting his development. Going on 3, Patrick could barely walk or crawl, much less say more than a few words. His parents elected for the brain resection. But less than 24 hours later, he had a seizure. The seizures, at least, were less frequent, and he soon started to walk. The milestone proved something Patrick's parents always knew: He was motivated.

"Even when he was 6 months old, you could see he was following you," Michael said. "We knew that if we could find a way to help him, that he has an inner drive to get through."

The decision of whether or not to do another surgery proved more difficult. "We thought, 'We could probably live with this and manage it,'" Michael said.

"But because of his past, doctors were afraid he could get back to where he was," added Mary.

Patrick was almost 4 when he had his second brain resection. This time, the seizures didn't return for a month. He was 6 when he had his final surgery, a functional hemispherectomy. Portions of the nonfunctioning hemisphere are removed and the corpos callusom, a thick band of nerves that connects the two sides of the brain, is split.

By doing so, seizures cannot spread from the "bad" hemisphere to the functional hemisphere, Dennis Spencer said.

"Essentially, you isolate that hemisphere's seizure activity and you have a good chance of stopping the seizures," the surgeon explained. "The younger the child, the better. Because of Patrick's age, he would regain a lot of his motor function because the opposite side of the brain would make up for it."

The same would not happen for an adult brain that has less "plasticity," he added.

Patrick has sine been seizure-free. He remains on a low dose of antiseizure medicine, which he will stay on indefinitely. Developmentally, he blossomed after the surgery, Mary said. Patrick, a thin boy with thick, dark brown hair and chocolate brown eyes, was watching "SpongeBob" cartoons in his family's den the day after Thanksgiving.

"He wouldn't laugh like that before," Mary said, sitting at the kitchen table and eyeing Patrick in

"Seizures destroy a family," Dennis Spencer said. "When you do a surgery like this, you are not just thinking about the patient, but about the whole family."

Patrick wears braces on his lower legs to help with balance and attends regular speech, physical and occupational therapy. He has a full-time aide at school, but is in regular classes. "He brings so much joy and happiness to so many people in this town," Michael said. "You go to the store, and everyone knows him. You find out how many wonderful people are out there. So many people have been so good to us."

Patrick's experiences motivated Mary to become a HOPE mentor with the Epilepsy Foundation of Connecticut. HOPE stands for "helping other people with epilepsy." Mary speaks to groups on common myths and misconceptions about epilepsy.

"It is such a hidden disorder, but I think that is changing," she said.

"We want to help other families know that there is a light at the end of the tunnel," said Michael.

Gina's Story

Gina Reynolds was 4 when she contracted bacterial meningitis. The infection led to seizures — an uncommon, but not unheard of, way to contract epilepsy. No one knew what was wrong.

"My mom would shake me and try to wake me from seizures," Reynolds, 47, recalled.

A few years later, she was diagnosed with epilepsy. The youngster was put on her first round of antiseizure medications by age 7. But for a long time, she would only have one or two seizures a year. They would usually occur during the night when she was sleeping.

"I would wake up tired with a headache and be sore," said Reynolds.

As a result, she rarely spent the night at friends' houses growing up.

"When I was growing up, you just didn't talk about it," she said. "But now, I think more people do."

After high school, she went to school to become an X-ray technician and accepted a job as a technician at St. Raphael's Hospital in New Haven. She worked at the hospital for the next 27 years.

During that time, she married her husband, Bruce, and they had three children: Bruce, now 18;

"It was around the time when everything went digital at work," she said. "It was taking me a really long time to understand the new computers. I thought it was just my age setting in, but it wasn't."

A near-death experience in spring 2005 changed everything. Reynolds was driving her car just a half-mile from her Cheshire home when she suffered a seizure.

"The car flipped twice, but I didn't have a scratch on me," she said.

But she lost her license because her seizures caused her to be a risk. (See box.) The severity of the accident convinced Reynolds to seek more aggressive treatment. She was referred to Dr. Susan Spencer, a neurologist at Yale-New Haven Hospital. A series of scans showed that Reynolds' seizures were originating in her temporal lobe.

The cerebrum, the largest part of the brain, is divided into four paired sections: the frontal, parietal, occipital and temporal lobes. Each controls a specific group of activities. The temporal lobe, which is on either side of the brain just above the ear, plays an important role in hearing, language and memory. Seizures originating from the temporal lobe are the most common type of epilepsy in teens and adults.

"We think that some seizure activity, in the long run, can be damaging to the brain because the neurotransmitters and chemicals that are released during a seizure can be toxic to brain cells over time," Susan Spencer said.

Reynolds had mesial temporal lobe epilepsy, a form caused by an abnormality in the brain's hippocampus, an area that controls memory.

"It is notoriously difficult to manage it with medication, but surgery is quite effective," Susan Spencer said. "Eighty to 90 percent of those who have surgery will stop having seizures."

Reynolds' doctor recommended a temporal lobe resection. She was admitted into Yale-New Haven Hospital in June, 2006 and slowly taken off her mediations. She started to get seizures by the second day.

The surgery, in which brain tissue in the temporal lobe was cut away, took eight hours. Reynolds remained hospitalized for one week. Nearly two years later, she remains seizure-free, but she still takes antiseizure medications. "I'm afraid to go off of them," she said.

She suffers from frequent headaches and always knows when it will snow or rain. Sunlight also bothers her and she hasn't felt comfortable swimming yet.

Her daughter gave her the fish, named after a character from "Finding Nemo" who has memory problems. Reynolds still has short-term memory problems.

She now belongs to epilepsy support groups and works one day every other week with a cardiothoracic group.

"I never realized how many people have epilepsy," she said.

She got her driver's license back in June.