



'There are a lot of misconceptions': Experts weigh in on seizure disorder for epilepsy awareness month

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Shelby Myers, of Washington Township, poses with her family for a portrait. Clayton Myers, 15, (center) was diagnosed with epilepsy in 2006 after getting a virus. The family's work for epilepsy research funds and awareness attracted the attention of state legislators who appointed Shelby Myers to the New Jersey Epilepsy Task Force.

November marks epilepsy awareness month, and local experts agree while people may think they know what epilepsy and seizure disorders entail, they may not know the whole truth.

"There are a lot of misconceptions about epilepsy and seizures" said Dr. Megdad Zaatreh, neurologist and director of epilepsy at Kennedy Hospital in **Washington Township**.

First off, he said many people think of epilepsy as a single condition or disease, when really the word simply means that a patient has had two or more seizures over their lifetime.

What those seizures look like is also a point of confusion for people who aren't familiar with epilepsy, since the obvious tonic-clonic, or grand mal seizures, marked by shaking and loss of consciousness make up just a fraction of all seizures.

"Although it is one of the most recognizable types, it's probably one of the least common," Zaatreh said.

Many patients may seem as if they're just "spacing out" or staring into space, when really they're suffering from what Zaatreh called a "subtle seizure" that's no less damaging.

Epilepsy is most commonly seen in young children and adults older than 40, and affects about one percent of the population. However, one out of every 10 people will suffer from some type of seizure during their lifetime.

"That's a huge number," Zaatreh said.

In adults, they could be caused by secondary issues such as strokes, tumors, trauma or drug and alcohol abuse. In children, however, seizures are often related to genetic diseases or injuries suffered during birth.

For **Washington Township resident Shelby Myer's son Clayton**, who **died last year** after a long battle with epilepsy, it was a virus he came down with when he was in first grade that moved to his brain and caused debilitating seizures.

Despite suffering up to 200 a day and being bound to a wheelchair, Clayton — nicknamed "Clayton the Great" — inspired his family and friends to create the organization Clayton's Hope to raise awareness about epilepsy and funds for in-depth research into treatments.

Myers said they held their seventh **annual fundraising walk Steps for Seizures** on Nov. 3 and raised more than \$24,000 for epilepsy research at Children's Hospital of Philadelphia, bringing their total amount donated over the years to more than \$80,000.

Beyond her work with Clayton's Hope, **Myers was also called on last year to serve on an official state task force on epilepsy**, supported by Sen. Fred Madden (D-4 of Washington Township).

The task force — made up of medical professionals, patients and caregivers of patients appointed by Governor Chris Christie — was charged with making recommendations on issues facing residents affected by epilepsy. They held public hearings, gathered feedback online and talked about the issue they were presented with. They had a range of recommendations that Myers said they can't yet publicly discuss, but the top one was simple — give them more time.

"If anything, we mostly learned how much that needed to be addressed with the state. It was not even the tip of the iceberg," Myers said.

They were granted the extension and will meet again in coming weeks to schedule additional public hearings and arrange for more feedback from those dealing with epilepsy and seizure disorders. During their last public hearings, Myers said they heard concerns from patients about issues ranging from difficulties driving to discrimination.

"[Not being able to drive] not only affects a person's ability to do normal daily activities, it hampers them working ... that was a major concern," Myers said.

That's another misconception, too, Zaatreh said — that epilepsy patients are doomed to live with seizures or be on medication for the rest of their lives.

"They do have some limitations, but very few. A lot of patients who have seizures can lead a normal life," he said. "It is foremost a treatable condition."

The key to finding out the right treatment — whether it be medications, surgery or a specialized diet — is to find the cause of the seizures and tailor the medications specifically to the individual.

"Some patients don't need treatments for life. They find that nobody told them that before," said Zaatreh, who trained in epilepsy treatment at Yale University. "I saw patients who stayed on medication for many, many years, and they actually did not need to be on medication for decades, or twenty or thirty years."

Seizures can cause damage to patients by affecting their speech or memory capabilities, or causing secondary injuries after suffering convulsions, Zaatreh said.

To Myers, however, one of the most damaging things to epilepsy patients isn't just the physical toll seizures can take on a body, it's the discrimination stemming from a lack of clear awareness about what epilepsy is and what it isn't.

"My main goal with Clayton's Hope and the task force is really to bring awareness to epilepsy itself and make people aware it's not uncommon," she said.

That means getting the word out, especially to individuals who work with children on a daily basis, Myers said, and children themselves.

"[The Epilepsy Foundation] has a fifth-grade program where they go to schools and perform," she said. They demonstrate symptoms of seizure and first-aid techniques that can help, something that can help dissolve some of the mystery and misconceptions surrounding seizure disorders.

"The less scary you make something, it just makes it normal, and you go on," Myers said. "Hopefully the awareness helps."

For more information about Clayton's Hope visit www.claytonshope.org. For more information about epilepsy, visit www.epilepsyfoundation.org.

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