

SARATOGA SPRINGS, N.Y. >> Jaina Davis is like any other second-grade student. She loves playing in the snow, reading “Ready, Freddy!” books and catching Pokémon with her brother.

Last October, however, things changed for Jaina.

The day started as a normal one. Jaina’s mom, Michele, and her sister, Jasmine, went to an appointment. Meanwhile, Jaina and her father, Ulysses, watched her brother, Justin, play in a basketball game.

The plan that night was to get pizza. Ulysses, Jaina and Justin picked up the pizza after the game — but Jaina wouldn’t speak. She walked in a different direction. Ulysses knew something was wrong and called Michele to have her meet them at the hospital.

“[Jaina] was slumped over in a wheelchair,” said Michele. “I was trying to get her to respond to me, but she wasn’t responding to me, so naturally that was terrifying because she had been fine all day.”

The hospital thought maybe she had an infection, so Jaina was prescribed an antibiotic.

Two days later, the children had time off from school for Yom Kippur when it happened again.

“She was eating. Her mouth was all foamed,” said Michele. “She was staring off to the side, but since her mouth was foaming I thought she was choking on her pasta.”

Michele tried the Heimlich maneuver while Ulysses called 9-1-1.

Jaina ended up at Albany Medical Center.

“They were wonderful. A whole team of people came in. She ended up with a neurologist [Dr. Viswanauth,]” said Michele. “Thank God for him because he took everything very seriously. He suspected she was having seizures. He wanted to prove it with EEGs and whatnot. We did all these tests.”

The doctors said Jaina had complex partial seizures, which happen in the left side of her brain.

“It was just scary for us because she’s been a completely healthy kid up until now,” said Michele. “It was horrible. I hate thinking about it.”

Every year, the Epilepsy Foundation of Northeastern New York recognizes two winning kids. Jaina, who attends Dorothy Nolan Elementary School in Saratoga Springs, was one winner for 2017.

“She’s so inspiring, watching the way she’s facing it,” said Gwennan Booth of the Epilepsy Foundation of Northeastern New York. “It’s a difficult diagnosis and it’s hard to get your head around how that would feel for a little kid. She’s very open about it and very willing to talk about it. She’s been really strong.”

Jaina experienced what they call a breakthrough seizure right before Thanksgiving and has been on a controlled dosage ever since.

One in 26 people will be diagnosed with epilepsy throughout a lifetime. Over 25,000 people in the Northeastern New York region have epilepsy.

“Epilepsy is so individualized. Some people, like Jaina, there’s no warning,” said Booth. “Some people have things called auras and before a seizure comes on they’ll have a feeling, some people actually smell something or hear something or almost see color. In an aura they

manifest into something different, too. So, some people have an idea that it's coming on and they know to get themselves in a safe place."

Epilepsy has changed the Davis family.

"My husband and I don't get comfortable anymore because you just never know when it's going to happen again," said Michele.

World Purple Day, a worldwide initiative started by the Anita Kaufmann Foundation to raise awareness about epilepsy, is Sunday, March 26.

Michele wants to become an advocate for people suffering from seizures.

"I think more people need to hear about it. I do think it tends to be stereotypical because when you think of epilepsy you think of people dropping to the floor and spoons in the mouth and all that type of stuff," said Michele. "I said I want to do whatever I can and help this cause now. It's definitely a part of our family and it always will be. And my husband feels the same way."

And Jaina still has the same mindset.

"It has not impacted her attitude about things. She's still silly, fun and sweet," said Michele. "It doesn't seem to phase her."

Jaina's teacher, Natalie Noll, has gone above and beyond to make things work for Jaina.

"Jaina is a sweet, easy-going little girl with a very curious nature," said Noll.

Erica DeNicola, a health educator from the Epilepsy Foundation, visited the classroom.

"Jaina was very excited to share her history with the Foundation with her classmates, and they were proud of her. Erica explained epilepsy openly to the children, and gave them clear instructions if anyone was to have a seizure," said Noll. "The students were intrigued."

Earlier this month, the Epilepsy Foundation of Northeastern New York honored Jaina and the other winning kid at an annual fundraising Gala.

Jaina said the event was fun and it was an honor to be a winning kid.

In 2017, Jaina and Jacob — the other winner, who is from Rotterdam — will appear at different events to raise awareness for epilepsy.

Moving forward, Jaina cannot swim alone. Michele has to be in the room whenever Jaina takes a bath. Jaina might not be able to drive if she continues to have seizures; to be able to drive, you have to be seizure-free for at least one year.

It's unclear how Jaina's life will be impacted further by epilepsy.

"It's hard to tell because they're new in this journey and it's just happened and she's still little, so it's hard to know how it'll evolve and what medications she'll remain on if she'll have to remain on medications," said Booth. "There are kids who grow out of it."

Jaina remains positive about her new situation, which is all a parent can ask.

"She's a great kid. She doesn't seem to let this diagnoses get her down. She goes about her life as if she's just like any other kid," said Michele. "I'm glad that she's able to function and be happy and not let it impact her too much."

To find out more about the Epilepsy Foundation of Northeastern New York, visit <http://www.epilepsy.com/northeastern-new-york>