Living with Epilepsy
Kennedy McGurgin

Kennedy McGurgin is a grade 7 student-athlete who loves playing basketball, volleyball and baseball. Since she was five, she has struggled with epilepsy.

McGurgin’s mother, Genny, explained that when her daughter’s first seizure happened, she was confused about what was happening. “We had gone swimming and on our way home Kennedy had fallen asleep,” she said. “So I carried her into the house and told her to go put her pajamas on and she just stood there staring at me. A moment later, she started laughing hysterically, and then all of a sudden she started screaming and crying, saying that her hands, feet and her tongue were swelling.”

Genny realized it was serious after her daughter experienced these symptoms six or seven more times within the next hour.

When McGurgin was seven, doctors diagnosed her with gelastic epilepsy, but her episodes were so infrequent that no prescription was prescribed, explained Genny.

As time passed, the seizures began to happen more regularly, and last year McGurgin experienced her first tonic-clonic seizure.

Tests showed that she although McGurgin had epilepsy, she was also suffering from psychogenic non-epileptic seizures (PNES), so she was prescribed medication to help with her epileptic seizures and other treatments for her PNES.

Genny explained that at school, her daughter was experiencing so many seizures that the bus company no longer allowed her to ride on the bus with the other students. “This forced us to relocate to a town where both the school and hospital were in close enough proximity to drive to,” said Genny.

But, starting at a new school that had never seen a condition like McGurgin’s was a tough transition. ESWO helped to make it a little smoother. “Some of the students were having a very hard time with Kennedy’s seizures,” said Genny. “But ESWO was able to come and help us by
educating the school, so the staff and all the classes could understand that they couldn’t ‘catch’ epilepsy, and the procedure in which to handle during an emergency.”

“Educating the school was really helpful because it gave them the knowledge to know what to do with her and to make her feel like a ‘normal kid,’” she continued. “Kennedy had a seizure in the middle of an assembly and they handled it like pros, and it was only because ESWO was able to come in and train them.”

McGurgin has also attended The YEP! Program, where she had the opportunity to connect with other kids living with epilepsy. “We learned about other people having seizures and we talked about what happens to you in your seizures,” said McGurgin.

Genny feels this program was really beneficial for her daughter, who has had over 400 seizures since March 2018. “There were a couple times where she came home telling stories of different seizures that some of the other kids had, and they could relate to things that had happened so they don’t feel like an outsider.”

She believes that using resources like ESWO has helped the family to tackle the daily challenges they face. “I’m not too sure to be honest what I would have done without ESWO coming to do those things, and being a point of contact for me if there are any questions I have. Participating in The YEP! Program has helped us not feel so alone, because it’s all very new to us. Having an organization like ESWO has been a godsend.”