Ninth grader, Mackenzie Hopfaufer was chosen to go to Washington, D.C. in March for the teen program, Kids Speak Up 2014, by the Rockford Epilepsy Foundation.

Mackenzie personally petitioned with Congressional Leaders for aid in assuring better access to care, improved public education, the importance of research towards a cure, and she brought awareness of what it is like to live with epilepsy. Mackenzie will serve as an active advocate for The Rockford Epilepsy Foundation in the Rockford area for one year helping kids and families to understand epilepsy and work for policies that support people with epilepsy. While in Washington D.C., Mackenzie was able to participate in the National Walk for Epilepsy, raising more than $2,000.

“Participating in Kids Speak Up program was a life changing experience! I got to meet teens from all over the United States and make friends with people going through similar experiences in dealing with epilepsy. We learned how to become an advocate. The epilepsy walk gave me the feeling of hope and support. I really enjoyed seeing the many sites of Washington D. C. as well.”

Mackenzie’s epilepsy reoccurred right before seventh grade after being seizure and medication free for about five years. Mackenzie says, “Having epilepsy can slow you down at times, you have to take extra precautions for some activities such as swimming, and it can take away some of your independence. Having a seizure can prevent me from getting my homework done and it usually wipes me out for the next day. Getting rest, watching stress levels, staying hydrated and eating right is important. Patience is needed in finding the right combination of medications that work and in dealing with medication side effects. Gaining seizure control has been difficult this year, but it makes me more determined to charge forward and do what I love. I am working towards transforming this challenge and the obstacles it presents into a positive contribution to society. Advocating for those with epilepsy, gives me that opportunity.”

“I don’t allow epilepsy to affect my life too much or let it slow me down for long. I love to be active! I am in ballet, tap and on a dance team. I enjoy photography and love filmmaking. I entered a film in the Beloit Film Festival Student Showcase this year. I am involved in the Drama Club. I was in the fall play, Charles Dickens’ Ghost Stories and helped with costumes and props in the Footloose musical. Mostly I love hanging out with friends.”

Epilepsy is not a disease or a mental disorder; it is a neurological disorder of the central nervous system. A seizure is an electrical storm in the brain where excessive discharge of electrical activity changes behavior. There are more than 30 different types of seizures. This condition is more prevalent than Autism Spectrum Disorder, Cerebral Palsy, Multiple Sclerosis and Parkinson’s disease combined. Over 2 million people in the United States have epilepsy. 1 in 26 people in the United States will develop epilepsy at some point in their lifetime. The cause is unknown for 7 out of 10 diagnosed with epilepsy. Epilepsy can be very debilitating and can affect a person’s quality of life. Epilepsy is not contagious. Treatments can include drug therapy, diet or surgery.

If a person is having a seizure; * Turn them gently on their side to keep the airway open. * Cushion head and note how long the seizure lasts, * Do not put anything in their mouth or hold them down, * Call 911 If a seizure lasts longer than three minutes, a second seizure starts, the person is injured, if it is a person’s first seizure, a person has difficulty breathing or consciousness does not return.

“I want to thank all my teachers for being so supportive this year! I especially want to thank my Theater Arts Teacher, Mr. Mazur for providing me with this great opportunity of going to Washington D.C. Mr. Mazur taught me that it is ok to inform and educate others about epilepsy. Mr. Mazur took it upon himself to learn more about epilepsy and taught the cast from the fall play about epilepsy. He also set up a booth to raise money for the Epilepsy Foundation of Rockford. This prompted the director at the Rockford Epilepsy Foundation to pick me to go to Washington. As Mr. Mazur says, “If you know someone with epilepsy then you also have epilepsy.” This is true because having epilepsy affects the lives of everyone around you. Mr. Mazur was an advocate for me and now I get to be an advocate for others living with epilepsy.

“As a friend of mine once said, “This is just a small part of who you are. It is not all of you.” Whatever obstacles you face, think about how you can use that obstacle to positively move you forward in life. Use it as a stepping stone to become stronger and transform it into helping others.”

To learn more, visit epilepsyfoundation.org