

Five days after my sister was born in 2013, I was diagnosed with epilepsy. It started with a single focal-aware seizure when my right arm lifted above my head and froze for about 30 seconds. The seizures increased to 5–10 a day, plus more than 10 nocturnal seizures, often in clusters, over the course of a few weeks. It got to the point where I hallucinated, my right arm was paralyzed, and I started doing everything with my left hand. For months, my dad stayed up all night monitoring me while my mom barely slept, taking care of my newborn sister and us.

Most of my memories from when my epilepsy was at its worst involve the countless EEGs and MRIs I had to go through. I'll never forget the weird, cold gel they used to stick electrodes to my head, as well as being stuck in a tube for hours. Since then, I've been through several neurologists in different states and tried multiple medications. From time to time I feel that my hand locks up or shakes for a few seconds. I'm lucky that, miraculously, the severity of my condition has been controlled, and I'm now able to live my life normally in a way that once seemed unlikely, playing competitive sports and starting to drive despite once thinking my arm would be paralyzed forever. I'm extremely grateful, and I hope to contribute to allowing others to head in the same direction.

As the Teens Speak Up! Advocate for Delaware, meeting other young people across the country and learning about advocacy has helped me realize why it is so important; it brings attention to a condition that affects millions, but is still widely misunderstood. We often face hidden challenges that others don't understand. Seizures can affect all parts of patients' lives - interactions, activities, feelings, and emotions. By speaking up, we can educate others about the realities of epilepsy and encourage greater acceptance and support. Raising awareness also means pushing for more research, better treatments, and policies. Advocacy is the first step to empowering individuals with epilepsy to live independently and openly in a more inclusive society.