

From the Western Kentucky Education Coordinator – David Pettit, MEd

This is not the article I had planned to write, and it is certainly not the story I wanted to tell. I was supposed to write an article celebrating my milestone of being seizure-free for ten years. It was January 25th, 2009, the night of the ice storm. We were without electricity, trying to ride it out with a fire in the fireplace. Suddenly, I started tasting aluminum foil, which had always been my warning sign. That progressed to a creepy-crawly feeling up the back of my neck and I felt the familiar pounding of my heart in my chest and in my head. My arms started convulsing, which was a new twist for me, and I went into what I call the “Twilight Zone.” After several minutes, just as I thought things were calming down, it started all over again. I ended up having two complex partial seizures back to back and they just would not stop. We both knew the danger of prolonged seizure activity, so my wife called 911 and I took a slow, icy ambulance ride to the emergency room.

Since that night I had not had another seizure. Not for over ten years. Then, one night a few weeks ago, my wife and I were having dinner with her family. I made what now seems like a reckless statement. “I haven’t had a seizure in over ten years!” A few minutes later, as I was talking to my mother-in-law, I suddenly realized I didn’t understand what she was saying. It’s nearly impossible to describe the aura I felt, but it wasn’t the weird metallic taste that I was used to. I felt like someone had a squirt gun filled with confusion and they were squirting it at my head. Swish! Swish! Swish! I’ve always felt lucky that I have at least two or three minutes of warning before I start to lose awareness, and it was the same this time. I stood up, got my wife’s attention and let her know what was going on. We went into the living room and sat on the couch until the seizure passed. A seizure is a terrifying experience. It’s knowing that you’re giving up control of your body and your brain. It’s a pervading fear that – despite knowing it’s unlikely – you might die.

Over the next couple of weeks, I had what can best be described as “aftershocks” – simple partial seizures that didn’t develop into anything more serious. A friend of mine has described them as “twingy” feelings, and that seems like an apt description. I was able to get in to see a neurologist right away and he ordered a sleep-deprived EEG and an MRI – tests that I had long assumed I would never need again. My brain seems to have calmed down now and I am feeling back to normal. But a lot of the old fears and feelings have returned.

The experience has left me confused about how and why the seizure happened after so long a time. Is it a normal part of the aging process for someone with epilepsy? I wasn’t under any stress at the time. No flashing lights or other common triggers. I have a follow-up appointment scheduled with my neurologist and hopefully, I will get some answers. In my training sessions, I always make the comment that there’s an awful lot that people don’t understand about seizures and those of us who have them. As it turns out, I guess there’s a lot we don’t understand ourselves.

I share this information with you because I want our readers to know that I understand what it is like to have a seizure. I understand the fear that many of you live with daily. While this experience has been scary, I want to let you know that it has only strengthened my resolve to educate individuals in western Kentucky about seizures and epilepsy. Beth is also working

diligently to educate those throughout the rest of the state, and we have the same goal, to ensure that those living with epilepsy in Kentucky and southern Indiana are safe and understood in their communities, wherever they are.