A volunteer spotlight on: Carolyn Riley

We have amazing volunteers within our Foundation community. We recently interviewed Carolyn Riley about her connection to the Foundation and what being part of our community means to her.

How did you first become connected with the Foundation?
I first heard of the Foundation from my neurologist in 2003 after being diagnosed with epilepsy in October 1997, when I was in my late twenties. I was asking for resources to help me understand my epilepsy and to meet others who were also looking for support. My first event with the Foundation was the Summer Stroll in 2003. In 2004, I started volunteering at the office by helping with data entry, among other things, because I wanted to learn about and be around others who also had epilepsy. I was the only one out of my family & friends with it.

I also have greatly appreciated the Foundation getting me involved with advocacy by taking me to Washington DC in 2010 to the National Epilepsy Conference, during which I was able to meet with/and talk to our senators and legislative supporters about needing to spread awareness everywhere.

What is your main volunteer role with the Epilepsy Foundation of Michigan?
I have helped out in multiple ways; I’ve volunteered at many events—including the Stroll for Epilepsy™, Camp Discovery, and the Toasting Hope Tasting Event—along with helping out in the office in any way that I can. I have volunteered with the Foundation for the past 17 years.

Tell us one of your most memorable moments in your volunteer role.
There are many wonderful memories I have from over the years, but one of the best was when I was a Counselor at Camp Discovery in 2014, as it was four girls in my cabin’s last year as campers. I loved seeing them having fun while petting and riding the horses, as well as working on a big art project with the boys. I just really appreciated seeing the remarkable camaraderie those girls built over the years, along with watching them provide support to fellow campers. It was a very rewarding experience to share with them.

What would you tell others to encourage them to become volunteers?
I would like to tell others how rewarding and inspiring all of the opportunities the Foundation has given to me; the opportunities have meant the world to me, and they have provided amazing support over the years. I wouldn’t feel as strong as I do without having met so many people, from those who have epilepsy to those who advocate for and treat us.

Tell us something that would surprise the people you have volunteered with.
My first seizure happened when I was 16 months old, which was called Febrile Idiopathic Seizures. I was on seizure medication until I was seven years old. Many years went by, and I was diagnosed with epilepsy in my late twenties. My seizures were simple and complex partials in my left temporal lobe. For 10 years, they were very difficult to control with medications, which is why I had brain surgery. I have been free of seizures since then—even though I am still on seizure medications—so I am very thankful and grateful to the doctor who performed the operation. My seizure freedom is a key reason why I do all I can to help the Foundation. I want to help others in any way possible to help them understand what’s happening, and I want to be available as a resource. I know I wouldn’t be as strong as I am now without the Foundation.

What does the Foundation mean to you?
The Epilepsy Foundation of Michigan has provided tremendous support to me over the years, from helping me stand up for myself to providing me with coping skills. If it wasn’t for their resources and time spent advocating for us, I wouldn’t be as strong as I am now, which is why I am so involved. The Epilepsy Foundation of Michigan is a very caring and nurturing agency, which is why I wanted to get involved and help them out in any way possible.