A volunteer spotlight on:
Marilyn Gray

We have amazing volunteers within our Foundation community. We recently interviewed Marilyn Gray 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 connected with the Epilepsy Foundation of Michigan’s predecessor, the Epilepsy Center of Michigan in 1994. My five-year-old son, Justin, had been diagnosed with epilepsy a few months earlier and I was desperately looking for resources to better understand how my husband and I could care for him. It was also important for us to learn everything we could about the disorder to support his social and emotional well-being. The Epilepsy Center of Michigan served as a beacon of light—we were looking for stories of hope. Justin’s seizures were not controlled with medicine, which was frightening. We felt helpless. Fortunately, with the information we received from the Epilepsy Center and the encouragement of Justin’s pediatric neurologist, we chose to try the Ketogenic Diet as an alternative therapy in 1996, which helped to subside Justin’s daily absence seizures.

In what way have you volunteered for the Foundation, and for how many years?
My volunteerism has been accomplished through fundraising. In 1996, the Epilepsy Foundation of Michigan sponsored “The Great Mother’s Day Tea for Epilepsy,” and I participated in the fundraiser by inviting some of my friends to join me for High Tea on a Sunday afternoon in May. When the Foundation discontinued sponsoring the Great Mother’s Day Tea for Epilepsy in 1998, my friends encouraged me to continue hosting the High Tea fundraiser, which we titled the “Royal Tea.” The Royal Tea was held for 23 consecutive years, and the number of guests increased three-fold to approximately 35.

Do you have a specific passion area that you would like to focus your efforts on to help the epilepsy community?
I am extremely passionate about social justice issues—one of which is health equity relative to marginalized communities. Last year, the incidence of COVID-19 unmasked the prevalence of health disparities in communities of color. I believe equal access to quality health care and resources is a human rights issue. Epilepsy does not discriminate—gender, ethnicity, age, religious beliefs, race, nationality, socio-economics, sexual orientation, education attainment—none of these are exempt. However, those who live with epilepsy can be subjected to ableism—discrimination and social prejudice against people with disabilities. Ableism is akin to the aforementioned, which all classify entire groups of people as “less than.” Justin is now 32 years old. He exists at the intersection of his African American heritage, gender, and his disability—all of which he embraces with pride and dignity. While social inequities are most often associated with class and race—society often marginalizes people with epilepsy. Issues of mobility are real for adults with epilepsy. Mobility is a key to accessing employment, education, and health care—all impact the quality of life. Opportunity quells for those who face prejudices, especially when compounded by those triggered by epilepsy. We must connect with another’s humanity by asking “How are we similar?” and “What can I do to help?”.

What would you tell others to encourage them to become volunteers?
Align your volunteerism with your passion—look for volunteer opportunities that speak to your heart. Everyone has gifts to share; your skills, talents, and time are valued gifts. For example, I will soon be joining the Foundation’s Diversity Council to contribute to the organization’s focus on diversity, equity, and inclusion.

What does the Epilepsy Foundation of Michigan mean to you?
The Epilepsy Foundation of Michigan provided resources for my family during the most difficult time of our lives. The services and programs that we benefited from sustained us. I often share our story because just as we searched when Justin was first diagnosed with epilepsy, someone is looking for a story of hope. The Foundation remains a valued resource and because of this, I always refer people.