

Sarah M.

I volunteer for EFDE because I am an epilepsy mom and family doctor. My son AJ had his first seizure at 5 months old and was diagnosed with Dravet Syndrome, a severe, drug-resistant form of epilepsy with many other challenges. AJ was admitted to the ICU monthly as an infant and struggled with warm temperatures and bright sunlight. After many trials of medicine, he began the ketogenic diet at 3 years old and we enjoyed 5 years without an ER visit or hospital stay. He loved school, his physical, occupational and speech therapists and aids, who helped him run, learn to type and read. Our family was able to enjoy the beach and playing outside with this good seizure control. When he was 8 years old, he had an unexpected prolonged seizure and died. I serve with hope for all families to enjoy a good quality of life and the best possible outcomes living with epilepsy.