

Epilepsy feels personal



Your Turn

Andria Keil Bilan
Guest columnist

November, designated as Epilepsy Awareness Month, is a time when organizations like JoshProvides Epilepsy Assistance Foundation share statistics – such as the facts that 1 in 26 people will have a seizure during their lifetime and epilepsy is the fourth-most-common neurological disorder.

Awareness means education and that can be very personal. Today, I want to make this personal by putting a face to epilepsy and highlighting the story of Brooke, a daughter, wife, mother, friend and employee. Brooke also has epilepsy and that has turned her life upside down.

Diagnosed at age 22, Brooke experiences multiple convulsive epileptic seizures that incapacitate her. Her memory is impaired. She cannot drive until she is six months seizure-free. She forgets more than she remembers about her daughter's first steps and first words. Surgery was supposed to help control her seizures. Today, she still takes 12 different medications daily.

JoshProvides Epilepsy Assistance Foundation was founded in 2008 to improve the quality of life for individuals diagnosed with epilepsy or other seizure disorders. Last year, JoshProvides awarded 161 direct assistance grants to children, families, and individuals. Frequent grant awards are assistance with seizure alert and detection devices;

trained service dogs; transportation and medical services.

During COVID-19, the families who turn to JoshProvides have suffered from increased isolation, job furloughs and loss of employment. Several have contracted the coronavirus, and financial resources are limited. Thanks to the support of local businesses, foundations and individual donors, JoshProvides has been able to help fill the gap to ensure no one is without their anti-seizure medication, transportation and basic groceries.

Broad-based community awareness has been possible through A Community Thrives online campaign sponsored by USA TODAY, Gannett Foundation and locally through the Herald-Tribune. ACT provided a national platform for JoshProvides to educate the public about epilepsy and raise more than \$7,500 to support families who turn to us for help and hope.

Brooke has found a support network through JoshProvides: people who understand and know what she experiences and how she feels. And she has access to resources that help her manage her seizures.

"I can be myself," she says. "People listen and they understand. I am not alone."

Yes, 1 in 26 people will have a seizure during their lifetime and Brooke is one. For information visit our website, JoshProvides.org.

Andria Keil Bilan is CEO of the JoshProvides Epilepsy Assistance Foundation in Sarasota.