



EPILEPSY FOUNDATION OF
VIRGINIA
PROMOTE AWARENESS
PROVIDE ASSISTANCE
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NEWSLETTER

April 2017



On Sunday, March 26th, **Spreading Epilepsy Awareness (SEA)**, a new student-run organization at the University of Virginia, hosted their first annual **Purple Day** event! Purple Day is an international grassroots effort to raise awareness of epilepsy, where people around the world are encouraged to host events and wear purple to promote awareness. SEA collaborated with another organization at UVA, Phi Sigma Pi National Honor Fraternity, to provide a variety of activities at UVA's amphitheater. UVA students volunteered to run several crafts tables, face painting, henna, and outdoor games for families to participate in. Purple Day attendees enjoyed free catering from Cane's Chicken and a performance by The Blenders. The Epilepsy Foundation of Virginia also had an information table that provided resources for epilepsy patients and those looking to learn more about epilepsy. The purple Purple Day event was a wonderful success, as they had over 60 attendees! NBC-29 also attended the event and interviewed SEA president and EFVA program associate Meheret Kinfe about the importance of events like Purple Day.

Spreading Epilepsy Awareness hopes to make this fun and engaging event an annual gathering where people of all ages can come together and raise epilepsy awareness!



Purple Day Celebrations at Winchester Medical Center

Northern VA regional director Gina Washington and the Neurology team at Winchester Medical Center held Purple Day Celebrations on Monday, March 27th. The team served purple ketogenic cupcakes to 65 people to raise awareness about epilepsy.



Fireball Splash & Dash on Saturday, July 1st

Join the Northern VA regional EFVA for the Fireball Splash & Dash! The race starts off with a 1-mile DASH (or walk) from 4th street (near Elkton Car Wash) to Riverside Park (Merck Shelter), where you pick up your tube and SPLASH 1-mile down the Shenandoah River to the Finish Line at the Town of Elkton Boat Launch. In the evening from 6pm-10pm, come to the grassy area behind the Elkton Area Community Center for our finale and enjoy live music by Woody Cambell, Morgan Dean, and Ethan Morris Band, food vendors, KnochBall, Combat Archery, an obstacle course, and more! Proceeds will be donated to EFVA and HFC, The race fee is \$25, and participation is limited to 100 participants, so register early at <https://www.raceentry.com/races/fireball-dash-and-splash/2017/register> <https://www.raceentry.com/races/>



Epilepsy Hero Spotlight: Mark Starnes

Mark Starnes is a 46 year old man who currently lives in Fairfax, Virginia with his wife and two young children. In the August of 1990, he was involved in a serious car accident which led to a traumatic brain injury. This injury, unfortunately, eventually led him to start having surgeries during his senior year at Duke University in January 1993. He had seizures approximately once a month, took many different combinations of medications, and he was forced to center his life around his epilepsy. Finally, in September of 2000, he decided to have a brain surgery which alleviated his seizures tremendously, and in that same year he received his degree from John Hopkins School of Public Health. His surgery was successful, and though he must still take his medication, he has only had five seizures since the surgery! Mark is a very optimistic individual and though he recognizes the challenges he has faced, he still believes there is so much in his life to be happy about! Mark can be reached at 571-278-6524

EFVA TOUR DE MIDNIGHT 2017

The Atkins family wants you to join their effort to make EFVA's new program-- **Grants for Seizure Dogs**—a reality. Many epilepsy heroes, like their daughter Anna Grace, could benefit from a service dog. Unfortunately, the cost is often prohibitive. That's why the Atkins are telling everyone they know about EFVA's Tour de Midnight—a bike ride supporting the Epilepsy Foundation of Virginia with a focus this year of raising enough to start EFVA's Grants for Seizure Dogs.

Anna Grace was diagnosed with generalized absence seizures at age five. She also has photosensitive epilepsy triggered by sunlight. This rare disorder, called sunflower syndrome, requires that Anna Grace's time in the sun be closely monitored. Medication has controlled the absence seizures but so far, despite travel to major medical centers, doctors have been unable to find a cure for her sunflower syndrome.

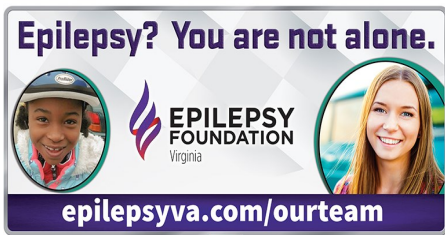
Beth Ann and Jeremy Atkins would like a service dog for their daughter. Since Anna Grace is extremely photosensitive, travel outdoors without a parent or teacher, can be dangerous. The Atkins worry about Anna Grace crossing the street alone. A service dog could be her guide enabling independence as she explores the world around her.

We need your help to make EFVA's Tour de Midnight bike ride a big success.

To register as a rider or virtual rider: www.bikereg.com/Contact/tourdemidnight

To form a team, join a team, donate to a team or individual or to donate directly to the event itself, go to: <https://www.epilepsyva.com/donate/> or to www.pledgereg.com/event/2394





Healthcare Updates



Epilepsy Foundation visit with Capitol Hill

The Epilepsy Foundation is an organization that believes epilepsy should be a federal public health priority, and supports investments in public health programs that help build safer communities, end stigma associated with epilepsy, educate community leaders, and build awareness that benefits everyone with epilepsy and other chronic health conditions and disabilities. The Epilepsy Foundation conveyed these messages with legislative assistants in a visit to Capitol Hill and was met with confirmed support of the initiatives the Foundation advocates for. The following are some of these initiatives. The EFVA supports these efforts and has a Virginia delegation every year.

Funding a Cute & Better Treatments: Federal Funding for Epilepsy Research

The Epilepsy Foundation supports \$175 million in funding for epilepsy research at the National Institutes of Health (NIH) and \$34 billion in overall funding for the NIH.

Building Safer Communities: Supporting Epilepsy Programs at the CDC

The Epilepsy Foundation urges Congress to continue to invest in critical epilepsy public health programs at the Centers for Disease Control and Prevention (CDC) by supporting a funding level of \$9.5 million to ensure the safety and health of people with epilepsy.

Protecting Coverage & Access to Healthcare

The Epilepsy Foundation supports access to quality health care that is affordable and comprehensive, and that meets the needs of individuals with serious and chronic health conditions.

Lifting Barriers to Cannabis: Increasing Research & Improving Safe, Legal Access for Intractable Epilepsy

The Epilepsy Foundation is committed to supporting physician-directed care and to exploring and advocating for all potential treatment options, including medical cannabis and cannabidiol (CBD). The Foundation also supports lifting federal barriers to research on cannabis and CBD and supports access to these potential therapies, through state-regulated programs for individuals when other treatment options have failed.



From left to right, Regional Director Fernando Cordero, Arlyne Foy (Legislative Assistant to Senator Mark Warner), and Natalie Skigen (Virginia TSU Ambassador)



From left to right, Natalie Skigen (Virginia TSU Ambassador), Portia Boone (Senator Kaine's Legislative Assistant), Heather Skigen (Natalie's mother) and Fernando Cordero.