



EPILEPSY FOUNDATION OF VIRGINIA
NOT ANOTHER MOMENT LOST TO SEIZURES
WWW.EFVA.ORG



EPILEPSY FOUNDATION
 Virginia

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My first encounter with a seizure was the summer before I came to UVA. I was at my aunt's house watching a movie with my sixteen year-old cousin after an active day outdoors. I remember turning to ask him a question and instead of seeing his goofy face, feeling terrified and heartbroken. I jumped out of my seat but then I couldn't move a single step. I had a million thoughts running through my head. Why is he having a seizure? Does he have epilepsy? What should I do right now? Should I touch him and comfort him? Is he even conscious? Unable to answer any of these questions I frantically yelled for his older brother. Unlike me, his brother came into the room in a calm manner and went to his seizing brother's side. Once my cousin stopped seizing and I knew he was okay, I went outside, sat on the patio and cried. I cried because I had never felt so helpless in my life. I watched someone I love undergo a seemingly painful experience, and I couldn't do anything about it.



Eventually, I learned that my dear cousin had epilepsy. I also learned that many people with "invisible disabilities" like epilepsy feel stigmatized and don't feel comfortable sharing their disorder with friends and family. To this day I'm disappointed in the way I reacted to the situation, and to this day I regret that no one told me my cousin had epilepsy. I needed to take a different approach: When I became a student at UVA I got the wonderful opportunity of doing clinical research with and shadowing a neurologist in the UVA Epilepsy Clinic, Dr. Jennifer Langer.

NEWSLETTER March 2016

This experience has allowed me to gain a different perspective on epilepsy, an academic one. However, I didn't stop there. I went even further and created an organization at UVA to raise epilepsy awareness, fundraise, and educate the general public about epilepsy basics and seizure first aid, all with the help of the Epilepsy Foundation of Virginia. My personal epilepsy experience fueled a passion in making a difference for patients with epilepsy, but also for those like me who should never feel helpless at the sight of a seizure.

EPILEPSY HERO CODY HAYDEN ORGANIZES PURPLE DAY EPILEPSY AWARENESS WALK.

Cody wishes to come out of the shadows. Purple day is his first step to create awareness and he organizes a purple epilepsy walk on purple day March 26 at 1 p.m. on the Virginia Beach Board Walk at 17th street at 1 –3 P.M.

Thank you Cody, we shall join you!



Employment Study in Epilepsy Research Participants Wanted!

Dear EFVA Member:

High rates of unemployment and underemployment have been a major challenge facing individuals with epilepsy. We are conducting a research study about employment in epilepsy until **April 30th, 2016**. As a member of the Epilepsy Foundation VIRGINIA, you have been selected to participate in this study to help us collect information about school experience and employment status, and to identify factors affecting employment rates and quality of life of people with epilepsy.

You are eligible to participate in the study if you meet all the following criteria:

- (a) you are an individual with a seizure disorder between the ages of 18 and 35;**
- (b) you live in the community (i.e., you are not living in a residential setting.)**
- (c) you have a diagnosis of epilepsy or seizure disorder at least for one year; and**
- (d) have never had a diagnosis of traumatic brain injury and profound intellectual disabilities.** You can participate by completing a survey comprising several psychosocial and vocational questionnaires, which will **take about 30 minutes**.

Please complete the online survey by clicking on the following link:

<https://goo.gl/FkKdF0>

We would like to thank you in advance for your participation in this important study. In addition, findings from this study will also help rehabilitation and health professionals develop effective vocational rehabilitation services to help people with epilepsy find jobs and to promote career opportunities for those who are underemployed. In recognition of your contributions and participation in this study, you will receive a **\$20 Gift Card** upon completion of the survey. The gift card will be sent to you via mail at the end of **May 31st, 2016**.

For more information, please refer to the attached flyer.

Thank you very much for your participation!

Sincerely, Wei– Mo University of Wisconsin Madison

Dear PAME friends,

In case you have not already heard, the Partners Against Mortality in Epilepsy (PAME) 2016 meeting is just around the corner. We are grateful for your previous meeting attendance and hope you will consider joining us again this year. The meeting will take place June 23-26, in Alexandria, VA, just outside of Washington DC.

The goal of PAME remains the same: to bring together providers, researchers, patients and their families to share information, advance research, facilitate collaborations, and foster action to prevent all epilepsy related mortalities. People living with epilepsy, their families and bereaved family members are critical partners in realizing our shared goals.

We are excited by this year's meeting and believe it will provide for new opportunities to learn and connect with others. A real effort has been made to ask new questions and to create a dynamic meeting format. We will have smaller breakout session that will promote more interaction and dialogue, while covering more topics and engaging a wider audience.

Additionally, this year we have added an advocacy day where families, researchers and providers can visit legislative leaders to increase awareness of epilepsy-related mortality and identify opportunities for prevention.

If you are interested in learning more or in registering for the meeting, please visit:

<http://pame.aesnet.org>

Early bird registration discounts end May 17th



Epilepsy Center of Tidewater: 6161 Kempsville Circle Suite 315, March 25 from 10– 3 P.M.

Dr. Beitinjaneh, EFVA Executive Director Suzanne Bischoff and regional director Patty Hood will participate.

Refreshments

Literature

DVD's

Personal advice

Meeting between epilepsy heroes

EFA and EFVA will not split the revenues for the walk in DC this year April 16.

Those who wish to give to EFA please do, those who give to EFVA can send their walk money via www.efva.org or EFVA P.O. Box 800754 Charlottesville, VA 22908.



Volunteer Anita Mays is thanked for her many contributions to EFVA.



Winning Children Lt. Governor and teacher Tio at EFVA's USE A HELMET PREVENT EPILEPSY.



EFVA president Epps, and Delegates Kirkham and Herring with helmets.



Patty Hood helps children draw more, Glenn Catalano takes pictures and Dr. Epps and Deb Mullins relax.

Grants from the national Epilepsy Foundation handed to Drs. Fountain and Joshi and short discussion on what their research means for epilepsy heroes.

