



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



NEWSLETTER December 2015

Thanks to those of you for being present and helping with the strolls. We had good financial results. The number of strolls allowed us to ask for substantial sponsorships.

Statewide donations:

Lundbeck \$5500
 Cyberonics \$5000
 Eisai \$ 5000
 Sunovion \$5000
 Upsher-Smith \$5000
 UCB \$5000

Statewide pledges (not yet materialized)

Bon Secours Neuroscience Institute \$9000

Supernus \$5000

Different walks and volunteers. Many stroll directors got local sponsorships and extra thanks goes to East Virginia Regional Director Patty Hood and Central Virginia Regional Director Fernando Cordero for getting the Supernus and Eisai pledges.

Charlottesville results thanks to UVA, Morgan Stanley, P. Woodie, S. Bischoff. **\$10,002**

Lynchburg and Roanoke results thanks to Titan America, Carilion and WalMart) **\$8270.**

Winchester, Elkton, Fauquier results, thanks to Valley Health and Winchester Health, members of INOVA **\$5075.50**

Fredericksburg results thanks in large part to Sieht and Keenan family: **\$4496**

Williamsburg and Virginia Beach results thanks to L. Bright, and many others. **\$2810**

Richmond results thanks to K. Smith and W. Parker. **\$2661**
 (Radford and NoVa were canceled by event directors).

TOTALS WITH ALL PLEDGES MATERIALIZING: 77814.50 -1035 = \$76,779.50

SKIP ONE GIFT PER FAMILY MEMBER AND DONATE TO OUR CAUSE .

If you donate to EFVA , 99% goes to public and professional education and consumer services. \$ 150.00 is one time medication assistance, \$ 300 .00 buys a bicycle and helmet so epilepsy heroes can stay at work. WWW.EFVA.ORG

JANUARY 16 AT 10.30 am:

MORNING REFRESHMENTS IN NEW EFVA OFFICE BUILDING 560 RAY C. HUNT DRIVE, CHARLOTTESVILLE. (not in clinic building)

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

2. Presentation and questions for Lea H. Becker, Sr. Clinical Research Coordinator, Dept. Emergency Medicine

Regional directors will answer questions. More info call 434 924-8669

ESETT Established Status Epilepticus Treatment Trial Study Summary. For more detailed info see www.esett.org, click on "fast facts" or "emergency research." You may e-mail questions and comments to seizure@virginia.edu .

Patients will be enrolled in UVA emergency department if: Actively seizing with generalized convulsions; Optimal doses of first line medications have not stopped the seizures.

Everyone in this study will be treated with one dose of a medication commonly used for generalized status epilepticus. At the beginning of the study 1/3 of patients will randomly get fosphenytoin, 1/3 levetiracetam and 1/3 valproic acid. Following safety analysis, if one drug appears to be more effective than the others, it will be given more frequently. **These drugs were selected because they are commonly used to treat status epilepticus after benzodiazepine.** After the study medicine is given, blood samples may be taken to measure the amount of study drug in the blood. If the seizure continues doctors will give additional medication to make it stop and prevent more seizures.

How is ESETT different from other studies?

Generally, researchers identify someone who might be eligible to participate then have a detailed discussion to obtain informed consent. No study procedures may be started before consent.

A person having a seizure is unable to give consent. Since a seizure that is not stopping must be treated quickly, time does not allow researchers to locate and talk to the person's legal representative before the study. All patients will be enrolled in the study without consent. This is called "Exception from Informed Consent" (EFIC). Once the representative is located or the participant wakes up, they will be told about the study and asked to consent for study continuation.

Per FDA rules EFIC applies in certain emergency situations only when:

The person's life is at risk, and

The best treatment is not known, and the study might help the person and it is not possible to get permission from the person because of his or her medical problem or from the person's legally authorized representative because the medical problem must be treated very quickly...

Before researchers may do a study using EFIC, they must provide information about the study to the community and get their feedback. This is known as public disclosure and community consultation.

Updated booklets on employment and memory will soon appear on our webpage at www.efva.org/booklets

Youngest EFVA Board member wishes to help. At 17 years of age Alaina Hudson became EFVA's youngest Board Member.

She wishes to help persons with epilepsy. Says Alaina:

I'm interested in becoming a doctor and finding new medical and surgical cures for epilepsy and other methods to help manage the emotional effects of seizures. My grandfather and my mom had severe seizures all of their lives. My grandfather missed my dad's wedding, even though he loves him, because he was afraid of having a seizure. During my mom's high-risk pregnancy with me, she was heavily medicated and suffered a severe grand mal seizure that threatened her life and mine. Doctors, including my father, helped save us. I want to help others too and make other people my age aware of what epilepsy is and how they can help too.



ARTICLE ABOUT COSTS OF EPILEPSY.

Neurology July 2015: Janelle L. Wagner, PhD and Anne T. Berg, PhD

Young people with epilepsy and their families experience considerable burdens, including behavioral health symptoms, social isolation, learning problems, difficulties adjusting to their illness, and daily management of epilepsy. Rising health care costs and policy changes at the national and state level have necessitated a closer look at another source of burden—health care costs associated with epilepsy. For example, Yoon et al. examined medical expenditures from 1996 to 2004 and revealed that annual expenditures for youth with epilepsy (n = 770) were \$6,379, compared to \$1,032 for youth without epilepsy. Cramer et al. examined a 2007–2009 claims database of 2,127 children <12 years old with epilepsy and found that youth with uncontrolled epilepsy (those prescribed additional antiepileptic drugs [AEDs] in the past year) encountered more hospitalizations (30.1% vs 12.0%) and greater overall (\$30,343 vs \$18,206) and epilepsy-related (\$16,894 vs \$7,979) costs than youth with stable epilepsy (same AEDs for the past year). Epilepsy charges per se accounted for a little less than half of the overall costs, suggesting that other factors add considerably to the cost of providing care for youth with epilepsy.



Sudden unexpected death in epilepsy (SUDEP) is the leading cause of death in young adults who have epilepsy and cannot control their seizures. Each year, more than 1 out of 1,000 people with epilepsy die from SUDEP, and, if seizures are uncontrolled, the risk increases to more than 1 out of 150.

A widespread lack of awareness and ongoing fear and discrimination lead too many individuals to hide their epilepsy and to accept ongoing seizures instead of seeking out more effective treatments. This increases their risk of SUDEP. Please speak up and out. EFVA will lead you to the place that might be able to help you.



As you are aware, there are presently several studies in Virginia pertaining to CBD oil. In the first results from nation-wide studies, CBD therapy was associated with a greater than 50% reduction in seizure frequency in more than one-third of patients at 3-months. This was maintained by 40% of patients for the 12-month duration, suggesting that "CBD can be effective in controlling seizures." Anecdotal evidence suggests better cognitive results. EFVA contacted the Virginia Organization of Hemp growers and legislators to clear up the confusion in the laws. Our goal is to have CBD plants grown in Virginia and have at least one reputable Laboratory test those. Until that happens, clients have to trust the Colorado growers. EFVA is working with Dr. Paul Lyons in Winchester



Attorney Generals when they say they will not prosecute and can contact for compassionate use of CBD oil. For more information contact Mindy Dawson at 540-450-2349.

Judy Spasser jspasser@gmail.com

Webpage theroc.us: heather@theroc.us Charlottes Web: CW Retail is 719-373-1276

Gran Fondo bike ride now online <https://www.communityuse.com/default.asp?acctnum=461785057>

