



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



**EPILEPSY  
FOUNDATION**  
Virginia

## Staunton purple day walk and walk through the city.

Staunton has one architectural advantage over other small towns in the Shenandoah Valley of Virginia: It escaped the Civil War unscathed. Many of its 18th and 19 century homes still stand and are well preserved. Scottish Irish Immigrant John Lewis and his family built the area's first homestead in 1732 and most of the early settlers were Scots-Irish. It is 25 minutes walk from Gypsy Hill park to the old town or one can take the tree trolley (every thirty minutes) Museums, shops and most restaurants are open on Saturday The visitors center is open Saturdays. <http://www.visitstaunton.com/stauntonontap.htm>

Picture on the right from left to right Organizer Joanne Harris, spouse Jessie, Katherine Jacobson and Tiffany Eimers, below Tiffany and son Parker. A nice article about the organizers was published in [http://www.dailyprogress.com/newsvirginian/news/local/teacher-doesn-t-walk-alone/article\\_7b07410e-c933-11e4-bb6e-bf00242f1caa.html](http://www.dailyprogress.com/newsvirginian/news/local/teacher-doesn-t-walk-alone/article_7b07410e-c933-11e4-bb6e-bf00242f1caa.html)



Please join Staunton support members Joanne, Jessie, Katherine and Tiffany and plan to walk and run in our first **Purple Day Awareness Stroll and Run. Registration a 9.30 AM in 3/28/2015, Gypsy Hill Park in Staunton. Come in via Thornrose Avenue and park your car. The Art Deco Band stand in the south east corner of the park will be right in front of you. If you use the GPS type in GPS address 504 Thornrose Avenue.**

**Sponsor: Lundbeck.**



# Advocacy in the Virginia General Assembly and new action Federally:

Despite support from the national Epilepsy Foundation and EFVA Bill 1339 was tabled. House Bill 1339 introduced by Delegate Ware, would make prescription drug coverage and formularies easier to understand by creating a consumer-friendly way for individuals to search for the drugs they need when comparing marketplace plans. For persons living with complex chronic conditions, like epilepsy, making sure that the health insurance plan they choose covers the prescription drugs they need is incredibly important because they rely on meaningful access to lifesaving medications to maintain their quality of life.

We hope to help revive the bill during the next General Assembly.

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Thanks to parent **Lisa Oelman Smith** and others the Virginia General Assembly has expanded the use of medical marijuana to epilepsy on the recommendation of physicians. EFVA will work very hard to make the synthetic and natural substances available via the pharmacies, where quality can be guaranteed. For this to happen we need studies, change of the federal DEA scheduling and many more steps.

Likelihood of persecution when having CBD oil or THC products and a recommendation from your physician, is extremely small.

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Congress has reintroduced the *Improving Regulatory Transparency for New Medical Therapies Act* in both the House of Representatives (H.R. 639) and the Senate (S. 481) which would improve the transparency and consistency of the Drug Enforcement Agency (DEA) review of new Food and Drug Administration (FDA) approved medications and bring these medications to patients faster. Please contact your members of Congress and urge them to support H.R. 639 and S. 481 to speed up access to new therapies and help those living with uncontrolled or intractable seizures and other medical conditions.

### Background

Currently when a new therapy with abuse potential is approved by the FDA, it is not available for patients until it has been scheduled by DEA in accordance with Controlled Substances Act. Without an obvious cause or justification, the time period between initial drug approval by FDA and final scheduling by DEA has increased over the years.

Between 1997-1999 and 2009-2013, the average time between FDA approval and **DEA's final scheduling increased from an average of 49.3 days to an average of 237.6 days**, an almost five-fold increase. The delay between FDA approval and DEA scheduling has an unknown range of time, and there is no formal deadline or requirement that a timeline for agency action be provided to patients or physicians. During this time, patients may not access these new therapies, despite FDA approval.

**Access to new therapies is particularly important for the one third of people living with epilepsy who experience intractable or uncontrolled seizures, and the many more who experience significant adverse effects from medication.** H.R. 639 and S. 481 would improve the DEA scheduling process for new FDA-approved drugs subject to the Controlled Substances Act and the registration process for the use of controlled substances in clinical trials. These bills would allow safe and innovative treatments to get to patients in a more timely and predictable manner.

<http://capwiz.com/efa/issues/alert/?alertid=64268626>

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Epilepsy Hero Elizabeth Musick wishes to introduce a Virginia Standard license plate saying: Storming ahead of epilepsy. Virginia Delegate Plum will introduce legislation if we can get 450 of such license plates before November 1. If you are interested e-mail us or Gina Washington at [ginal216@comcast.net](mailto:ginal216@comcast.net) to receive the papers.



“Storming ahead of epilepsy”





Thanks to grants from the CDC, Genan and Walmart the senior trainings are still continuing. Patty Hood made the posters below and left of this text. Thank you Patty.



Laila Ragland received a helmet from the EFVA. She and her mother will be spokespersons for EFVA in the future. Laila is a very bright young lady who understand her own epilepsy very well. Thanks to Mary Thompson for introducing us.

