



**EPILEPSY FOUNDATION OF  
VIRGINIA**  
*NOT ANOTHER MOMENT  
LOST TO SEIZURES*



# **EPILEPSY FOUNDATION**

Virginia

## **NEWSLETTER**

### **September 2016**

Adults and children completed the annual art therapy. This time the sessions were held in Northern Virginia and Newport News. Anna, one of the young epilepsy heroes, who participated in the therapy said she sometimes feels trapped in her self expression. **" I try to express myself to other people but when I do, I feel I do not make the point. "**

After such a statement all our epilepsy team feel we have to work even more to make the world epilepsy friendly. Without that, how are our young epilepsy heroes grow up to healthy and lead productive lives? Thanks to Lundbeck and the national office for another year of support. Thanks also to regional directors Gina Washington and Patty Hood for organizing and Denbigh house and Inova for making space available.



## Remarkable mother with a mission: PROMOTE AWARENESS ABOUT EPILEPSY.

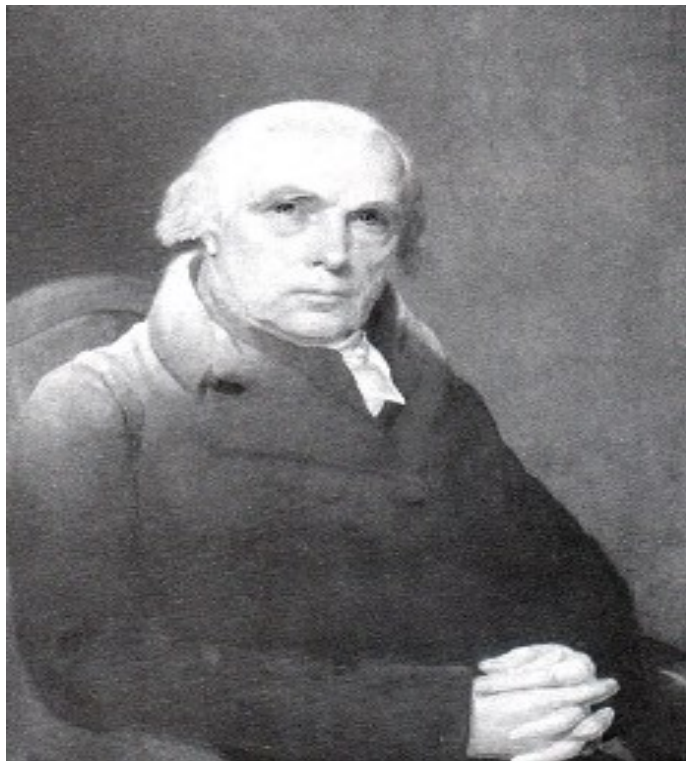
It started when Kay's beautiful daughter Susan had problems at night and amnesia on what happened the evening before. Susan was tested for meningitis and returned to her work as a nurse in the operating room. Susan's second seizure was even scarier: Kay heard her daughter in the bathroom and thought she had had a stroke. Susan was lying behind the bathroom door and Kay could not open the door. After consulting with her husband James, Kay called the rescue squad. Between that June and November Susan, James and Kay lived through the all too common nightmare: Many seizures, emergency room visits, tests, different diagnoses. Sleeping in the same bedroom so James and Kay would wake up during seizures. Susan had forgotten everything she had learned, but being the disciplined young woman she is, she relearned ...step by



step. Kay started to go online to get knowledge she needed. She found the Epilepsy Foundation of Virginia and parent network member Laurie Kelly and regional director Melissa Tuck provided great support. They advised going to an epileptologist instead of a general neurologist. Susan was seen by Dr. Nathan Fountain, Professor and Director of the UVA Neurology Comprehensive Epilepsy Program and President of the EFVA Professional Advisory Board. After a few months under Dr. Fountain's care Susan became seizure free. Susan (29) has been seizure free for five years now,

she is a RN navigator at Central Virginia Family physicians. She also educates on obesity and diabetes and is getting her certificate in diabetic education. So Susan is joining the more than 70% of persons with epilepsy who are seizure free and lead productive lives. When Melissa left her job, Kay became the regional director. She and her entire family are determined to help people with epilepsy and to make the world more epilepsy friendly. She also tries to get the epilepsy families out of the shadows and into the open about their epilepsy. James has forged a mutually beneficial relation between his employer Wal Mart and the EFVA. EFVA thanks the entire Hornby family for being such assets for the organization. "Most people call for our help," Kay and James called and said "how can we help EFVA, it is one of the moments I shall never forget" says Executive Director Suzanne Bischoff. Kay is organizing a picnic on September 17 at RIVER'S EDGE PARK 302 Wiley Drive Southwest Roanoke, VA and a Lynchburg walk On November 6 at the BROOKVILLE HIGH School 100 Laxton Road Lynchburg, VA, 24502. Call Kay at 434-386--7725 (Lynchburg) 540-314-8688 (Roanoke) or e-mail: [kayzie03@verizon.net](mailto:kayzie03@verizon.net).

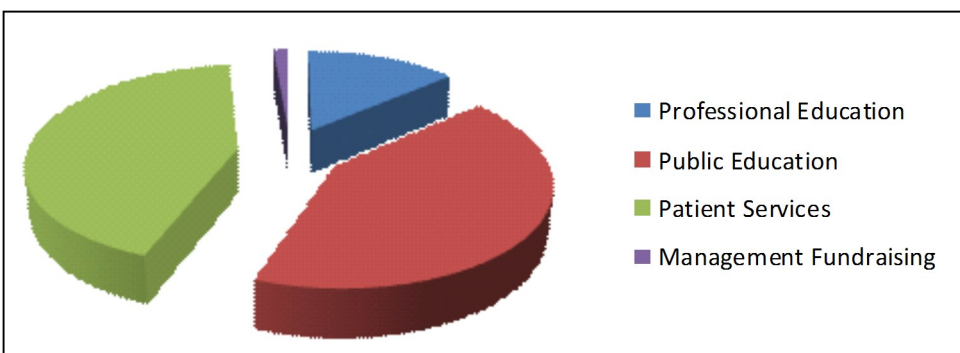




Above: The founding fathers from Virginia all knew about Madison's epilepsy. Both Washington and life long friend Jefferson invited James to their Virginia estates for rest and recuperation. When he became president his rivals wanted to talk about his disease but it got no traction at all. The Virginians never mentioned it.



These pictures of the modified Atkins diet for epilepsy were printed compliments of dietician Ielyzaveta "Lisa" Shkoda, RDN, CNSC. Her e-mail is [ls7ju@virginia.edu](mailto:ls7ju@virginia.edu)



If you like our programs and our low fundraising and management costs, please donate and send a check to EFVA P.O. Box 800754, Charlottesville, VA 22908 or donate via [www.epilepsyva.com](http://www.epilepsyva.com)

I am a faculty member at Harvard Medical School and Brigham and Women's Hospital, and am currently leading a study on Risk Evaluation and Mitigation Strategies (REMS), a safety program that the Food and Drug Administration (FDA) requires the manufacturers of certain medications to implement so that the benefits of drug use outweigh the risks. My project team and I are seeking to better understand the burdens and benefits of REMS on patient care. Our work is being funded by the Greenwall Foundation, a non-profit bioethics organization, and does not involve any pharmaceutical companies.

We are requesting the help of the Epilepsy Foundation Virginia to invite patients who have recently taken, and to identify physicians who have recently prescribed Sabril—a REMS-covered drug—to participate in a phone interview about their experiences. They will receive an honorarium for their time. If you are happy to assist, we ask that you please contact me for the enrollment form to your patient membership list and provide us with the names of physicians known to the Chapter who specialize in treating seizures (for which Sabril is indicated).

If you have any questions or would like to discuss the study in more depth, please contact me at [asarpatwari@partners.org](mailto:asarpatwari@partners.org). Thank you very much for your help on this important investigation.

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The federal Center for Medicare and Medicaid Services (CMS) has approved Virginia's Waiver redesign for implementation. This affects the ID, DD, and Day Support Waivers. Those waivers will now be called the Community Living (CL), the Family and Individual Support (FIS), and the Building Independence (BI) Waivers, respectively. The approved implementation date is September 1. There will be much more information coming from DBHDS and DMAS regarding the schedule and implementation steps over the next few weeks.

If you have questions regarding the redesign of the intellectual, developmental or day support waivers and the changes associated with waiver redesign, please contact the DBHDS hotline at **1-844-603-9248**.

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Lil Wayne forgot his epilepsy medication in June this year.

The rap world was in for a major scare earlier this week, as it was reported that [Lil Wayne](#) suffered two seizures on board his private jet, forcing his pilot to make two separate emergency landings. Luckily, Wayne's folks soon confirmed that he was in stable condition, but a worrisome report claimed that the [Young Money](#) boss had been downing copious amounts of lean (Codeine-Promethazine Cough Syrup) on the night before his seizures. All in all, though, the situation didn't seem to dire, as Weezy performed a show two nights ago (June 15), just a day after getting released from the hospital. While he should probably still control his codeine intake, one of his reps has now told [TMZ](#) that Wayne's seizures were a result of him not taking the medicine he's prescribed for his epilepsy. Wayne apparently forgot his meds while on the road, and he couldn't get his hands on an Rx in Milwaukee, where he was set to perform. He thought he could make it through the trip regardless, but clearly, he was mistaken. Fortunately, he had a pilot who's trained in the art of an emergency descent.

Wayne has suffered with epilepsy for years, and it's unclear if his latest seizures were more threatening than those he's had in the past. Regardless, he's hopefully learned to keep his meds on him at all times, especially when he's on an airplane.