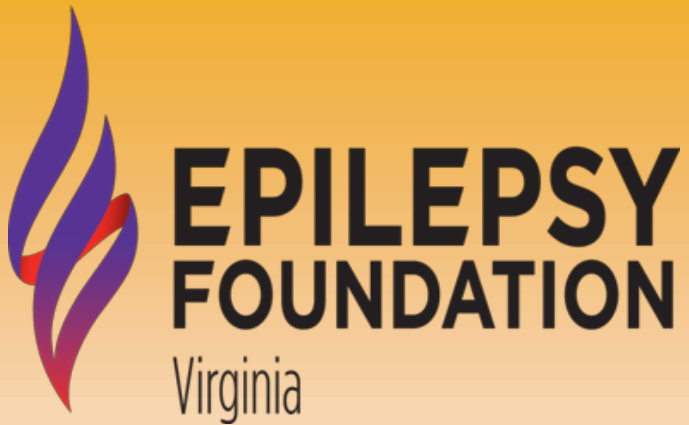




EPILEPSY FOUNDATION OF VIRGINIA
NOT ANOTHER MOMENT LOST TO SEIZURES
WWW.EFVA.ORG



Ruchelle Buenaventura is our newest team member working with the Epilepsy Foundation of Virginia, Charlottesville area. She will be in the office assisting, communicating with patients, and helping create exciting ideas regarding outreach to the community, including memory improvement. She is looking at more efficient ways to connect with patients through enhanced communication through videos, social media, and more. Ruchelle comes to us from Virginia Beach, VA, though she attends American University in

Washington, D.C. majoring in Neuroscience, minoring in Communications, while also in the AU College of Arts and Sciences Leadership & Ethical Development program. She is vastly interested in the field of neuroscience and hopes to become a physician involved with clinical research.

This past spring, she received her third concussion from cheerleading and missed over a month of college. Due to athlete protocol, she took a baseline concussion test in the fall of 2015 that measured her brain efficiency at norm. She took the same test again a month after the initial incident hoping to be cleared for practice, being symptom-free. As a result, her verbal memory and reaction time was below average, which did not clear her for any physical activity. This influenced Ruchelle to work on improving her memory capabilities through online memory games and memory apps, which successfully allowed her to pass those areas in the concussion test she took again only 48 hours after failure. Though her memory is back to full speed, her memory frustrations during the concussion is part of what continuously drives her to explore new solutions for memory pathways in neuroscience. She will also be helping with our trial on memory improvement for epilepsy patients and spreading awareness. If anyone is interested in participating or contacting Ruchelle, please email at rb6740a@american.edu.

NEWSLETTER JULY 2016



Missy and Dennis Terry and the Williamsburg epilepsy support group have had a successful baseball fundraiser on June 5. Thank you Dennis and Missy.

COMING EVENTS GO TO EFVA.ORG FOR MORE DETAILS.

Summer camps for young epilepsy heroes.

Splash and dash Elkton July 2 Gina1216@comcast.net

Refreshments art therapy sessions Newport News July 9 contact srb3m@virginia.edu
 Refreshments art therapy sessions NOVA Fairfax hospital August 20 contact srb3m@virginia.edu

Gran Fondo bike Ride October 15, 9 AM 2016 craft brewery I 64 W. Richmond. Speakers Drs. Towne and Epps.
 Contact lcworth@comcast.net; efva.fc@gmail.com

Winchester: October 1 2016, at 1:00 P.M.
 Old Town + 5k run
 Speakers: Drs. Lyons and Selznick
 Contact: Gina1216@comcast.net
 (540) 908-3400

Virginia Beach: October 23, at 2 P.M.
 Mount Trashmore, Shelter 1
 Speaker Dr. Firas Beitinjaneh
 Contact: Patty Hood, efva.hr@gmail.com

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Richmond :November 13, at 1:00 PM (tentative)
 Bon Secours Redskins Training Camp
 2401 W. Leigh Street
 Richmond
 Speaker: Dr. Stacey Epps
 Contact: (804) 549-9875 or efva.fc@gmail.com

Roanoke November 5 at 11 A.M.
 Patrick Henry High School
kayzie03@verizon.net

Williamsburg: October 29 at 1 P.M.
 Matthew Whaley Elementary School
 301 Scotland Street
 Contact: Patty Hood, efva.hr@gmail.com

Fredericksburg: November 12, at 3:00 P.M.
 Old Mill Park Shelter D
 Speaker: Elaine Hudson
 Contact: Lori Hudson Compasol@hotmail.com or srb3m@virginia.edu

Northern Virginia, November 5 1-3 P.M. Hyatt Hotel
 Rosslyn VA, 1 P.M.
 Speaker: Dr. Jack Cochran
 Contact: gina1216@comcast.net or (703) 349-2790

October 22 5k Walk and 10k Run Elk Run Trails
 Elkton, VA, Dr/ Lyons speaking
Gina1216@comcast.net

Lynchburg event: November 6, 2 P.M.
 Brookeville High School
 Mr. and Mrs. Hornsby
kayzie03@verizon.net

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Charlottesville: November 5 at 2:00 P.M.
 Down Town Pavilion
 Speaker: Dr. Fountain and Brandi R Underwood
 Contact: srb3m@virginia.edu; patty.woodie@ms.com

Falls Church support group with Dr. Kurukumbi Falls Church 540-908-3400

July 13 Reston support group elmsnick@gmail.com

August 8 7-8 PM support group Richmond Brigit 76@gmail.com

July 13 Winchester conference with Dr. Paul Lyons speaking on CBD oil srb3m@virginia.edu

Latest PAME conference was very well organized. Parents of young epilepsy heroes who passed, scientists and clinicians worked together to understand better the risks of epilepsy. Generalized tonic clonic seizures, not taking one's medication all contribute to the risks. Then, there are also the unexplained deaths. Approximately 3,500 infants die suddenly and unexpectedly each year in the United States (1). Less is known about the incidence in children because epidemiologic studies of these deaths in children are rare (2). The increased mortality risk in children with undetected heart conditions or epilepsy highlights the need for expanded surveillance to identify sudden unexpected death associated with these conditions (3,4).

<http://www.nhlbi.nih.gov/news/spotlight/fact-sheet/frequently-asked-questions-about-sudden-death-young-case-registry>.



Below: Heroes at very exciting Dash and Splash organized by NOVANW regional director Gina Washington and the city of Elkton. When 80 people participated the remaining crowd had to wait as there were no more tires and safety personnel .

Thanks Gina for this initiative.



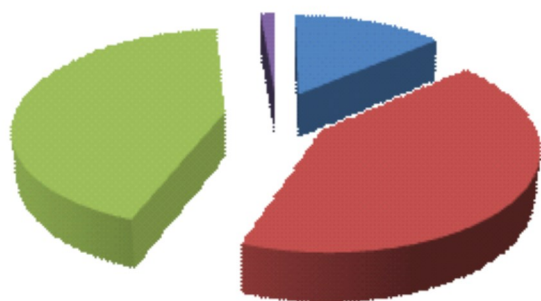
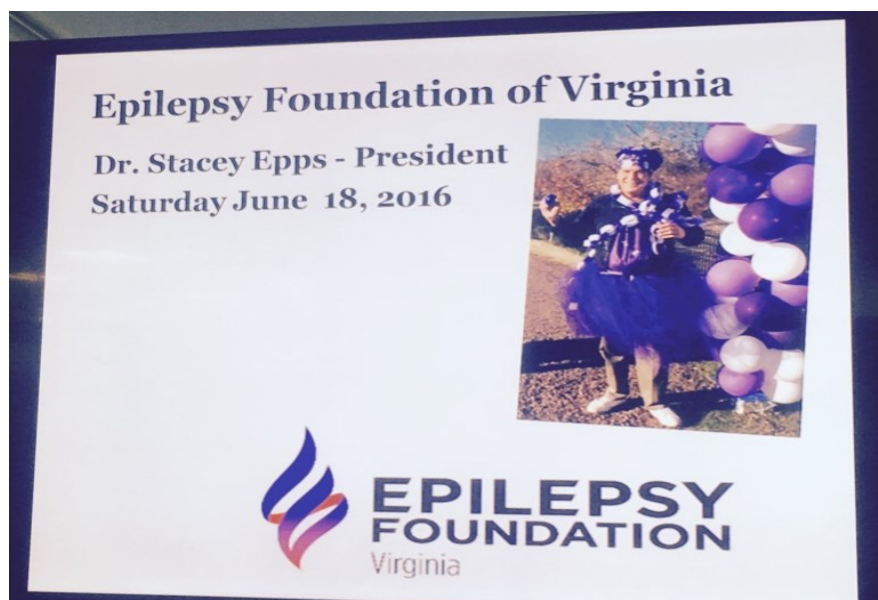
Patsy Custis, George Washington's step-daughter, died suddenly during a brief seizure in 1773. Accounts of Patsy's illness and unexpected death were abstracted from George Washington's papers available via the Library of Congress. Patsy's epilepsy, the treatments she received, and his descriptions of her death were studied. Sudden unexplained death in epilepsy (SUDEP) criteria are applied and discussed. From George Washington's description of Patsy's epilepsy and subsequent death meet criteria for SUDEP. When George Washington married widow Martha Custis, he accepted her little boy, Jack, and her daughter, Patsy, as his own. At age 12, Patsy had her first seizure. Physicians could do little at the time. Martha took her daughter to the most skilled medical specialists of the day: One charged \$5 for an iron ring to ward off seizures. Another specialist prescribed ineffective "fit drops." In spite of her illness, Patsy was encouraged to live the same kind of life as other young girls of her day. She was fortunate that those who loved her felt no need to hide her condition.



Board June 2016

Board June 16 is unified to organize a large bike ride.

Great enthusiasm was generated by President Epps show of purple (see below) and Pat Lane, Carolyn Gray's Tina Worth and special volunteer Erik Conrad's introductions. The Board presented relevant reports and made great plans for itself to make the bike



- Professional Education
- Public Education
- Patient Services
- Management Fundraising

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 do-

July 5, 2016

Dear Friends,

I trust you and your families had an enjoyable Independence Day weekend. As a supporter of the Epilepsy Foundation of Virginia, I thank you for your past contributions of time and resources to help us raise awareness of epilepsy and to provide assistance to those affected by epilepsy. Without you, the mission of EFVA cannot be fulfilled and the Board of Directors and the Professional Advisory Board acknowledge your efforts and have directed me to relay their appreciation for all you do to help us fulfill our mission.

I am excited to inform you of a new event to take place October 15, 2016 which will not only raise epilepsy awareness across the Commonwealth, but will also promote our “Wear a Helmet, Prevent Epilepsy” campaign. This inaugural event, The Tour de Midnight to Support EFVA, is a 100km bike ride starting at the Midnight Brewery in Goochland with riders travelling to Lake Anna and then returning to Goochland. We are planning a huge event with a post-race party including live music, food, various activities, etc.

In order to make this event a success, we need to have as much participation as possible from across the Commonwealth. I ask you to share the news of the event with your family, friends, and co-workers, and invite them to attend. If you know people who cycle, please encourage them to sign up for the ride. If you own a business or know someone who owns a business, please ask them to support our event with a sponsorship.

There is a website for the event www.bikereg.com/tourdemidnight to facilitate registration for both the 100k ride as well as a 50k ride. For those who are not cyclers or for those who are unable to participate in the actual ride, a virtual ride option is also available. There is also a Facebook page and I ask you to share this information especially via social media.

Attached is an information/sponsorship form as well which you can also share with others.

Volunteers to help with the continuing event planning as well as volunteers for the day of the event are also needed.

Any assistance is welcomed, and to volunteer, drop me an email at Stacey_epps@bshsi.org, and I will have the planning team reach out to you.

This is an exciting time for EFVA and I look forward to everyone's participation.

Sincerely,

Stacey L. Epps, MD
President, Epilepsy Foundation of Virginia

Bronze Level: \$250

- ★ Sponsor Company may display sponsor- provided banner and booth at event location the day of the event
- ★ Sponsor Company logo to be included on local event signs

Friends of EFVA: \$50 - \$249

- ★ Donations of services, gift certificates, and merchandise to use for prizes and registration packets for riders in Gran Fondo gratefully accepted in lieu of cash donations.
- ★ Sponsor name to be included on local event signs

For more info on sponsoring please contact srb3m@virginia.edu