



EPILEPSY FOUNDATION

Virginia

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

NEWSLETTER August 2016

www.epilepsyva.com

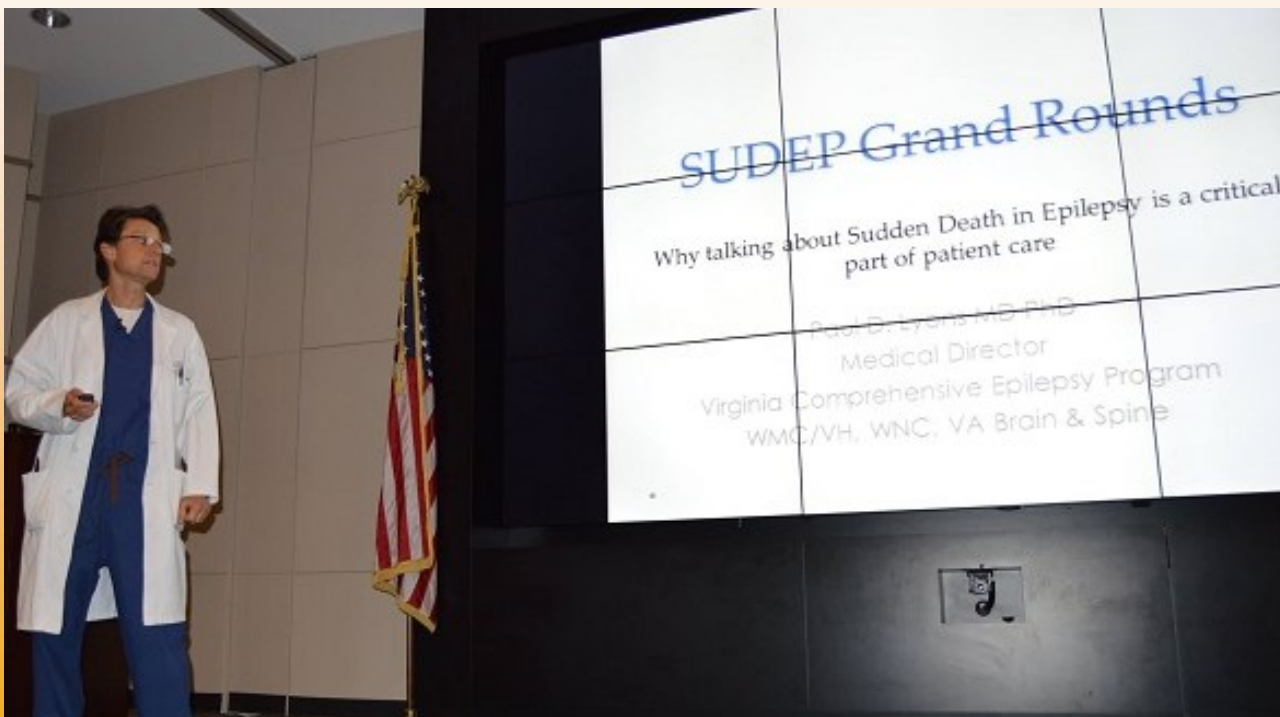
IS OUR NEW WEBPAGE WITH LOTS OF INFORMATION.

For events go to *calendar*, for info about epilepsy go to *learn* for staff and network, go to *about*, to donate online go to *donate* and to give comments go to *comment*.

For our walks go to *calendar*; for our bike ride go to www.bikereg.com/tourdemicnight

Last week Dr. Lyons gave an excellent grand rounds on SUDEP. Regional director, Gina Washington secured a grant from the national Epilepsy Foundation to give the grand rounds. 54 Physicians attended the lecture and discussed the conclusion from Dr. Lyons that SUDEP and dying and epilepsy had to be discussed as aspects of living with epilepsy.

Pictured: Dr. Lyons and Gina Washington.

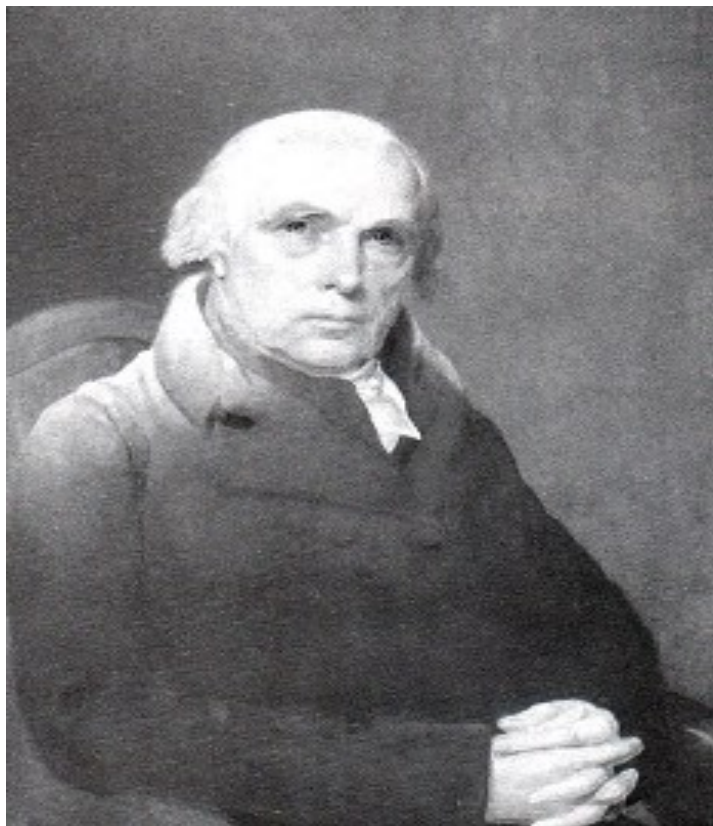




Activities for epilepsy children and their parents in the different camps the EFVA partners with, in addition to our own events.



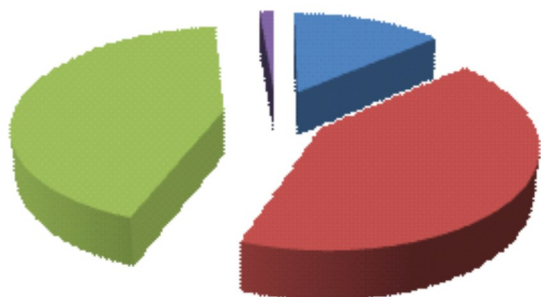
James Madison, shown below at the ripe age of 66 had epilepsy throughout his life. When Jemmy (nick name for James) was two years old, his grandmother Frances ordered herbs which at the



time were believed to help seizures. His first major public seizures he had as a student in Princeton, where he tried to cramp his course in two years. A letter was dispatched to Virginia described "sudden attacks somewhat resembling epilepsy." After returning home he was able to keep epilepsy at bay with a healthy lifestyle and became the force behind the creation and ratification of the Constitution, the first president who led his nation into war. He had attacks throughout his life and his wife Dolly described in a lively way how she felt as she herself had a painful abscess on her knee in 1805: On the way to Philadelphia "he was taken very ill with his old bilious complaint. I thought all was over with me, I could not fly to him and aid him like I used to do." James died in 1836 from what he himself called: "Nothing more than a change of mind." We thank Dr. William Garnett for bringing the biography of Madison by Lynne Cheney with the descriptions of epilepsy to our attention.



We thank neurologist Dr. Zhang and Waynesboro City lawyer Todd Patrick for joining our Professional Advisory Board!



- 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 donate via www.epilepsyva.com

As part of the nationwide effort the Virginia Delegation advocated

1.- FUNDING FOR CDC EPILEPSY PROGRAMS

The Epilepsy Foundation believes epilepsy should be a federal public health priority, and supports investments in public health programs that help build safer communities, end stigma associated with epilepsy, educate community leaders, and build awareness that benefits everyone with epilepsy and other chronic health conditions and disabilities. The Epilepsy Foundation urges Congress to continue to invest in critical epilepsy public health programs at the Centers for Disease Control and Prevention (CDC) by supporting a funding level of \$9.5 million to ensure the safety and health of people with epilepsy.

2.- FUNDING FOR EPILEPSY RESEARCH AT NIH

The Epilepsy Foundation supports \$175 million in funding for epilepsy research at the National Institutes of Health (NIH) and \$32 billion in overall funding for NIH. The Epilepsy Foundation urges Congress to continue to invest in research initiatives that have been partially funded at NIH, and to support funding for a cure and better treatments for epilepsy.

3.- LIFTING BARRIERS TO CANNABIS RESEARCH

The Epilepsy Foundation is committed to supporting physician-directed care and to exploring and advocating for all potential treatment options, including medical cannabis and cannabidiol (CBD). The Epilepsy Foundation supports re-scheduling cannabis to a schedule other than Schedule 1 and lifting federal barriers to research on cannabis and CBD. The Epilepsy Foundation also supports safe, legal access to medical cannabis if a patient and their health care team feel that the potential benefits of medical cannabis for uncontrolled epilepsy outweigh the risks.

4.- ADVANCING RESEARCH FOR NEUROLOGICAL DISEASES

The Epilepsy Foundation supports efforts to track neurological diseases and conditions to provide additional information for researchers. Without basic data concerning the size and makeup of the epilepsy population and the population of other neurological diseases and conditions, researchers are working at a distinct disadvantage. Additional epidemiological data on populations living with epilepsy and other neurological conditions and diseases could lead to new treatment targets, better clinical understanding of these conditions and diseases, and, eventually, new treatments and cures.

5.- STRENGTHENING MEDICARE PART D's SIX PROTECTED CLASSES

The Epilepsy Foundation supports legislative proposals that strengthen the six protected classes policy in Medicare Part D, which by ensuring timely access to lifesaving



medications.

Picture Beth, Senator Kaine and Jennifer.

Mother Beth Collins is very active: first she became involved in medical marijuana advocacy in 2013 while trying to help treat her daughter Jennifer's intractable epilepsy. After trying and failing numerous pharmaceutical medications, Beth and Jennifer left her husband and other daughter in Virginia, and moved to Colorado to access cannabis oil to treat Jennifer's seizures. While in Colorado, Beth began lobbying the Virginia General Assembly for access to medical cannabis. In 2014, Beth and her daughter returned to Virginia and she worked with other parents to pass legislation that allows her daughter to take THCa oil in the state without fear of prosecution. She continues to work with Virginia's lawmakers to expand access and cultivation in the state.

In addition, Beth helped form and lead the Parents Coalition for Rescheduling Medical Cannabis, a national parent group with the mission of removing cannabis from its current schedule 1 status. She has also lobbied Congress in support of the CARERS Act, the most comprehensive piece of federal medical marijuana legislation ever introduced in both the U.S. House and Senate.

In January 2016, Beth joined the staff of Americans for Safe Access as Senior Director of Government Relations and External Affairs where she hopes to help advocates initiate, expand, and improve state medical cannabis laws and programs, and work with Federal decision makers to reschedule cannabis and reduce the conflict between state and federal cannabis laws.