



**BRAIN ANEURYSM  
FOUNDATION**

**Raising Awareness. Ending Fear.™**

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## **Brain Aneurysm Foundation Hosts Congressional Advocacy Day to Support Passage of “Ellie’s Law” for Brain Aneurysm Research**

**More than six dozen doctors, survivors and family members join BAF on March 29  
in Washington, D.C.**

(Hanover, MA—March 28, 2017) The **Brain Aneurysm Foundation** will lead a delegation made up of 100 brain aneurysm survivors, family members of those affected by the disease, advocates and medical professionals from around the country for a Congressional Advocacy Day on Wednesday, March 29, 2017. The effort set forth is to raise awareness of brain aneurysm disease and to seek support for Ellie’s Law.

Ellie’s Law is a bill that seeks federal funding for brain aneurysm research. It is named in honor of Ellie Helton, a 14-year-old Apex, NC teenager, who died on July 16, 2014 as a result of a brain aneurysm. The bill, HR 1648, provides \$5 million each fiscal year, for five years, to the National Institute of Neurological Disorders and Stroke (NINDS) to conduct or support further comprehensive research on brain aneurysms, studying a broader patient population diversified by age, sex, and race.

This legislation will allow NINDS to conduct critical research on what causes aneurysms, what causes aneurysms to rupture, determining the efficacy of intervention on smaller unruptured aneurysms, development of drugs or treatments, development of neuroprotection or regeneration for brain injury from ruptures, detecting unstable aneurysms using imaging, preventing aneurysm recurrence, finding a biomarker for aneurysm and family genetics, socioeconomic research on aneurysm treatments, costs, and systems of care.

“Increased funding for brain aneurysm research is essential to find effective treatments, interventions, and ways to prevent aneurysms from developing,” said Christine Buckley, Executive Director, Brain Aneurysm Foundation. “The passage of “Ellie’s Law” represents a real, long-term investment in brain aneurysm research, with the goal of eradicating the devastation of brain aneurysm disease.”

Federal funding for brain aneurysm research is disproportionately low. Despite the widespread prevalence of this disease, for which there is no cure, and the high societal cost it imposes on the nation, the federal government only spends approximately \$0.83 per year on brain aneurysm research for each person afflicted with a brain aneurysm.

The BAF delegation is scheduled to meet approximately 200 key legislators including Senator Edward Markey (D-MA).

The Brain Aneurysm Foundation is joined in this advocacy effort by three brain aneurysm survivors. Tonya Robinson of Michigan, Kerri Messinger of New Jersey and Ann Waldo of Washington, D.C., will take part in Advocacy Day activities and speak to legislators and their staffs about their personal stories of suffering from one or more large or giant wide-necked, unruptured aneurysms.

Medtronic, one of the world's largest medical technology, services and solutions companies, will also join the Brain Aneurysm Foundation by providing educational materials, including animation of brain aneurysms, as well as medical devices to help explain possible treatments for the disease.

The Bee Foundation, a non-profit brain aneurysm organization based in Wayne, PA, will also participate.

“This is our sixth year participating in Congressional Advocacy Day and the effort is so important to our mission in helping to reduce the healthcare disparities associated with brain aneurysm statistics,” said Buckley. “Legislators throughout the country have been very supportive of looking at funding for research, as well as for awareness and education initiatives, but they often tell us that we’re the first people to bring this disease to their attention. And to have so many people representing so much of the country on this important day is truly gratifying.”

Brain aneurysms are weakened arterial walls that can rupture; causing bleeding that damages the brain. Researchers estimate six million Americans have an unruptured brain aneurysm. This disease strikes indiscriminately, but communities of color have a higher risk of rupture often causing death or cognitive disability. In general, women are at a greater risk to form a brain aneurysm than men. Brain aneurysms are a silent killer, providing little or no warning and lead to an estimated 30,000 ruptures annually and cause nearly 500,000 deaths worldwide.

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#### **ABOUT THE BRAIN ANEURYSM FOUNDATION**

The Brain Aneurysm Foundation is the globally recognized leader in brain aneurysm awareness, education, support, advocacy and research funding. Now celebrating more than 20 years of service and led by Executive Director Christine Buckley, the Brain Aneurysm Foundation was established in 1994 at Massachusetts General Hospital in Boston, Massachusetts. Its mission is to promote early detection of brain aneurysms by providing knowledge and raising awareness of the signs, symptoms and risk factors; work with the medical communities to provide support networks for patients and families; as well as to further research that will improve patient outcomes and save lives. The Foundation is unique in that it has a Medical Advisory Board of Directors, which is made up of more than three-dozen doctors—neurologists, neurosurgeons, and interventional neuroradiologists—representing the best research hospitals, facilities, and universities throughout the country. Its members provide expertise and support to the Foundation in a variety of ways.

**For more information about the Brain Aneurysm Foundation, visit [www.bafound.org](http://www.bafound.org)**