Brain Aneurysm Foundation and US Food and Drug Administration Partner to Improve Patient Experiences and Outcomes

(Hanover, MA—January 19, 2017) The Brain Aneurysm Foundation, the national voice of those living with or impacted by brain aneurysms, has joined with the US Food and Drug Administration (FDA) to hold a meeting to “get a better understanding of patients’ experiences with the different treatment options, technologies, and clinical research opportunities, as it relates to medical devices development,” according to the FDA.

Brain aneurysms, which affect 1 in 50 people leading to an estimated 30,000 ruptures annually, are a silent killer, providing little or no warning. 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. The Brain Aneurysm Foundation was founded in 1994 at Massachusetts General Hospital and is now based in Hanover, MA.

The FDA approached the Brain Aneurysm Foundation to organize the panel discussions, which will be held today, at the Center for Devices and Radiological Health (CDRH) at the FDA’s headquarters in Silver Spring, MD, as part of the federal agency’s efforts to enhance its approaches to achieve its mission and vision to serve patients by further engaging with patients, clinicians, caretakers, patient organizations.

“From the first discussion with the FDA it was clear that we had a lot we could collaborate on—all to better serve those who suffer from a brain aneurysm,” said Christine Buckley, executive director of the Foundation, who will participate the discussions.

The day’s agenda includes: Dr. Robert Rosenwasser, professor of Radiology and Neurosurgery at Thomas Jefferson University Hospital in Philadelphia, who will give a presentation titled “Aneurysm Current State of Science”; and Foundation board member Scott Campbell and his wife, Cheryl, who survived a brain aneurysm rupture, and Kristine Svagdis, a survivor of an unruptured brain aneurysm, who will discuss the patient’s perspective of the disease and its effects.

Brain aneurysms are weakened arterial walls that can rupture; causing bleeding that damages the brain. Each year, brain aneurysms cause nearly 500,000 deaths worldwide. Researchers estimate six million Americans have an unruptured brain aneurysm. The condition strikes:

- Women at three times the rate of men (a 3:2 ratio)
- African-Americans at twice the rate of whites (a ratio of 2.1:1)
- Hispanics at nearly twice the rate of whites (a ratio of 1.67:1)

“The only way we will ever reduce the health disparities those statistics reveal and one day eradicate the devastation of brain aneurysm disease is to make real, long term investment in research,” said Buckley, which is why the Brain Aneurysm Foundation is also supporting an important legislative initiative, “Ellie’s
Named in honor of Ellie Helton, a 14-year-old Cary, NC girl, who died on July 16, 2014 as a result of a brain aneurysm, the proposed legislation would authorize $25 million in federal funding for brain aneurysm research. Increased funding for brain aneurysm research is the key to finding effective treatments, interventions, and ways to prevent aneurysms from developing.

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