

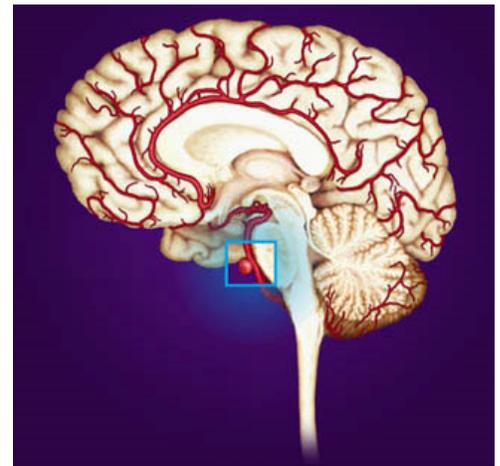


The Bee Foundation (TBF)

The Bee Foundation (TBF) was founded in 2014 after the cousin of its co-founders passed away from a ruptured brain aneurysm at the age of 27. TBF's mission is to raise awareness of brain aneurysms and increase funding for preventive research that saves lives. After just six years, TBF has built a dynamic Scientific Advisory Board, funded five rounds of research grants and a dedicated research fellow, and continues to focus on growing a robust donor and research community to advance meaningful brain aneurysm awareness and research.

Brain Aneurysm Basics

A brain aneurysm, also referred to as a cerebral aneurysm or intracranial aneurysm (IA), is a weak bulging spot on the wall of a brain artery very much like a thin balloon or weak spot on an inner tube. Over time, the blood flow within the artery pounds against the thinned portion of the wall and aneurysms form silently from wear and tear on the arteries. As the artery wall becomes gradually thinner from the dilation, the blood flow causes the weakened wall to swell outward. This pressure may cause the aneurysm to rupture and allow blood to escape into the space around the brain. A ruptured brain aneurysm commonly requires advanced surgical treatment.



Americans Affected by Brain Aneurysms

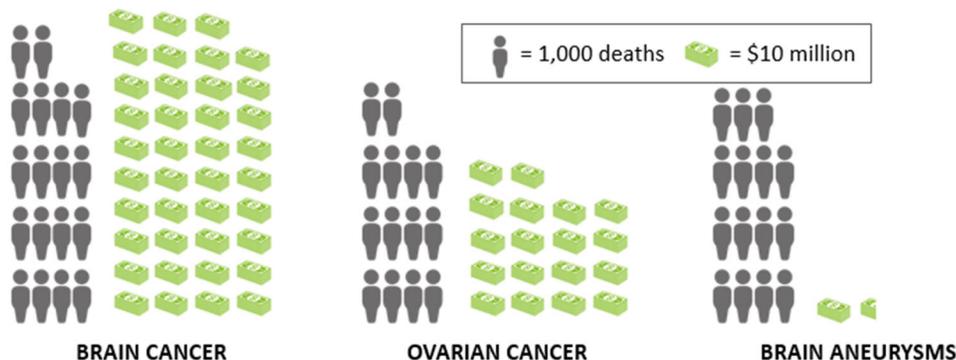
- An estimated **6.5 million people** in the United States, or **1 in 50 people**, have an unruptured brain aneurysm.
- The incidence rate of 1 in 50 people means that, on average, **14,000 constituents in each congressional district** are afflicted with this disease.
- Each year, an estimated **30,000 people** in the U.S. suffer a brain aneurysm rupture, **50 percent** of which are fatal.
- Brain aneurysms are **more likely to occur in women** than in men (by a 3 to 2 ratio) and more likely to rupture in **African-Americans** (2.1 to 1 ratio) and **Hispanics** (1.67 to 1 ratio) than Caucasians.
- Of those who survive, about **66 percent** suffer some permanent neurological deficit.
- The combined lost wages of survivors of brain aneurysm ruptures and their caretakers are approximately **\$150 million per year**.
- Of the nearly 500,000 deaths worldwide each year caused by brain aneurysms, half of the victims are **younger than 50-years-old**.
- The annual estimated pre-insurance direct cost of brain aneurysm ruptures to U.S. patients is approximately **\$1.4 billion** and the estimated direct cost to hospitals is approximately **\$2.7 billion** per year.
- The Intensive Care Unit length of stay is the largest driver of cost for brain aneurysm ruptures, and estimates do not reflect indirect costs such as travel, food, childcare, and wage losses for patients and caretakers.



The Need for Research Funding

Despite the widespread prevalence of this condition, the federal government only spends \$2.08 per year on brain aneurysm research for each person affected by the disease. The federal government spends far more on many medical conditions with similar numbers of deaths each year.

Number of Deaths, Federal Funding in 2020
Brain Aneurysms, Brain Cancer, and Ovarian Cancer



Sources:

National Institutes of Health: "Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC)," FY2020
American Cancer Society. *Cancer Facts & Figures 2020*.

Ellie's Law

Representatives Yvette Clarke (D-NY) and Brian Fitzpatrick (R-PA) and Senator Richard Blumenthal (D-CT) introduced *Ellie's Law* (H.R. 1553/S.____), which would authorize an additional \$10 million each fiscal year, for five years, for the National Institute of Neurological Disorders and Stroke (NINDS) to conduct or support further comprehensive research on unruptured intracranial aneurysms, studying a broader patient population diversified by age, sex, and race. *Ellie's Law* honors five women who passed away as a result of a brain aneurysm: 14-year-old Ellie Helton; 49-year-old WABC Eyewitness News reporter Lisa Colagrossi; 25-year-old Kristen Shafer Englert, who passed away just weeks after giving birth to her son; 34-year-old Teresa Anne Lawrence, devoted mother of three; and, 27-year-old Jennifer Sedney who passed away on Christmas Day in 2013.

- ***Please support H.R. 1553 to authorize an increase in federal funding for brain aneurysm research.***
- ***Please support the Senate companion bill, when introduced, to authorize an increase in federal funding for brain aneurysm research.***

Support for Brain Aneurysm Research in Recent Appropriations Bills

Congress expressed support for brain aneurysm research and education in recent appropriations bills. In the FY 2018 appropriations bill, Congress requested a report from NINDS regarding its annual funding level for brain aneurysm research over the past five years, including the types of grants supported. In FY 2019, appropriators included language encouraging the Secretary of Health and Human Services (HHS) to facilitate the development of best practices for brain aneurysm detection and diagnosis for medical personnel. In FY 2021, appropriators included language stating the Appropriations Committees' concern that not enough research is focused on prevention of brain aneurysm ruptures. For FY 2022, there is support for the inclusion of appropriations report language directing the Secretary of HHS to develop and enact a strategy for disseminating information about the best practices. The brain aneurysm community appreciates these recent steps and looks forward to seeing the results of these efforts.