



***Ellie's Law* (H.R. 902/S. 895)**

Brain aneurysms are one of the most underfunded disease research projects in the U.S. relative to the number of Americans affected and the tremendous loss of life, diminution of quality of life for survivors, and the long-term medical costs for impacted families. *Ellie's Law* ([H.R. 902](#) / [S. 895](#)), a bipartisan bill drafted in consultation with members of the brain aneurysm medical and research communities, would provide the first ongoing dedicated research funding stream for breakthroughs in preventing potentially fatal brain aneurysms from rupturing and improving the long-term medical consequences and quality of life issues for aneurysm survivors. *Ellie's Law* is led by Reps. Yvette Clarke (D-NY) and Brian Fitzpatrick (R-PA) in the House and Sens. Richard Blumenthal (D-CT) and Markwayne Mullin (R-OK) in the Senate.

Now is the time to address this issue by passing *Ellie's Law* to increase funding for brain aneurysm research.

Brain Aneurysms Impact Millions of Americans Every Day

An estimated **6.6 million people** in the U.S., or **1 in 50 people**, have an unruptured brain aneurysm. Each year, an estimated **30,000 people** in the U.S. suffer a brain aneurysm rupture, of which **50 percent** are fatal and **15 percent** lead to death before reaching a hospital or provider.

A recent study, funded by The Bee Foundation (TBF), found the annual estimated pre-insurance direct cost of brain aneurysm ruptures to patients is approximately **\$2 billion**, and the median expected patient payment is \$114,000. The Intensive Care Unit length of stay is the largest driver of cost for brain aneurysm ruptures, and other costs such as travel, food, child care, and wage losses for patients and caretakers also were taken into consideration.

Preventive medical care is much more cost-effective than waiting until after a rupture occurs. However, **25 percent** of patients who seek initial medical attention experience misdiagnosis or delays in brain aneurysm diagnosis. Of those who survive, approximately **66 percent** suffer some permanent neurological deficit. The combined lost wages of survivors of brain aneurysm ruptures and their caretakers are more than **\$150 million** per year.

Brain Aneurysms Disproportionately Affect Women and People of Color

Brain aneurysms are more likely to occur in women than in men (by a 3 to 2 ratio) and nearly twice as likely to rupture in African Americans (2.1 to 1 ratio) and Hispanics (1.67 to 1 ratio) than Caucasians.

Federal Funding for Brain Aneurysm Research is Disproportionately Low

Despite the widespread prevalence of this disease and the high societal cost it imposes on the nation, the federal government only spends approximately **\$2.08** per year on brain aneurysm research for each person afflicted with a brain aneurysm.

***Ellie's Law* Provides Critical 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. *Ellie's Law* 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.



This legislation would allow NINDS to conduct critical research on what causes brain aneurysms, what causes them to rupture, the efficacy of intervention on smaller unruptured aneurysms, development of drugs or treatments, development of neuroprotection or regeneration for brain injury from ruptures, detection of unstable brain aneurysms using imaging, prevention of brain aneurysm recurrence, and development of a biomarker for brain aneurysms and family genetics.

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 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.

Their loving families, like so many others, have now dedicated themselves to advocating for more research funding for brain aneurysms to prevent these tragedies from occurring.

Proposed Appropriations Committee Requests

Proposed requests for the House & Senate FY 2024 Labor, Health and Human Services, Education, and Related Agencies Bills

REPORT LANGUAGE:

Brain Aneurysm Research. - The Committee remains concerned that an estimated 1 out of every 50 individuals in the United States has a brain aneurysm and an estimated 30,000 Americans suffer a brain aneurysm rupture each year, with little or no warning. Ruptured brain aneurysms are fatal in about 50 percent of cases. Despite the widespread prevalence of this disease and the high societal cost it imposes on our Nation, the federal government only spends approximately \$2.08 per year on brain aneurysm research for each person afflicted with a brain aneurysm. The Committee continues to be concerned about the lack of research focused on prevention and early detection of brain aneurysms.

Brain Aneurysm Best Practices. - The Committee urges the Secretary to, within 12 months, develop best practices on brain aneurysm detection and rupture for first responders, emergency room physicians, primary care physicians, nurses, and advanced practice providers. The agreement further directs the agency to submit a report to the Committees on Appropriations, no later than 180 days after the enactment of this Act, to outline the agency's action plan to develop these best practices.

BILL TEXT:

Ellie's Law Programmatic Funding. - To conduct or support further comprehensive research on unruptured intracranial aneurysms, studying a broader patient population diversified by age, sex, and race, there is authorized to be appropriated to the National Institute of Neurological Disorders and Stroke \$10,000,000 for each of fiscal years 2024 through 2028, to remain available through September 30, 2031.

For more information or to sign on as a cosponsor of *Ellie's Law* (H.R. 902 / S. 895), please contact:

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