



Ellie's Law (H.R. 1553/ S.____)

Brain aneurysms are one of the most underfunded disease research projects in the U.S. in terms of 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 families affected. *Ellie's Law* is a bipartisan bill introduced by Reps. Yvette Clarke (D-NY) and Brian Fitzpatrick (R-PA) (H.R. 1553) and Sen. Richard Blumenthal (D-CT) (S.____) and was drafted in consultation with members of the brain aneurysm medical and research communities. *Ellie's Law* 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. Now is the time to address this critical issue by adequately funding brain aneurysm research.

Brain Aneurysms Impact Millions of Americans Every Day

An estimated 6.5 million people in the United States, or **1 in 50 people**, have an unruptured brain aneurysm. Each year, an estimated 30,000 people in the United States suffer a brain aneurysm rupture, **50 percent** of which are fatal.

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.

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 more 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 condition 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.

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. 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.

This legislation would allow NINDS to conduct critical research on what causes 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 aneurysms using imaging, prevention of aneurysm recurrence, and development of a biomarker for aneurysms and family genetics.

Proposed Appropriations Committee Report Language

(Proposed report language for the House and Senate FY 2022 Labor, Health and Human Services, Education, and Related Agencies Bills)

Early Detection of Brain Aneurysms. The Committee recognizes that although 1 in 50 Americans have a brain aneurysm, there are typically no warning signs or symptoms unless they rupture. Currently, up to 50% of patients will not survive such a hemorrhage. Even when an aneurysm has ruptured, the symptoms are not widely known among healthcare professionals, such as first responders and emergency room physicians. The Committee reiterates the language provided in Fiscal Year 2019 [H. Rept. 115-862 and S. Rept. 115-289] directing the Secretary, in consultation with appropriate stakeholders — including healthcare providers (e.g., neurosurgeons, neurologists, neuro-interventional surgeons, emergency physicians), brain aneurysm patient advocacy foundations, brain aneurysm survivors, and caregivers — to facilitate the development of best practices on brain aneurysm detection and rupture for first responders, emergency room physicians, primary care physicians, nurses, and advanced practice providers. In doing so, the Committee encourages the Secretary to consider incorporating topics including, but not limited to, the symptoms of brain aneurysms, evidence-based risk factors for brain aneurysms, appropriate utilization of medical testing and diagnostic equipment, and screening recommendations. The Secretary shall, in consultation with appropriate stakeholders, develop a strategy for disseminating information about the best practices and begin implementing this strategy at least one year after the date of enactment of this Act. Every three years thereafter, the Secretary shall review research on brain aneurysm detection and diagnosis, and update the best practices, as appropriate.

The above report language enjoys support from the following physicians:



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