

# ELLIE'S LAW



**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.**

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*“Ellie’s Law”* is a bipartisan bill introduced by Reps. Brian Fitzpatrick (R-PA), Yvette Clarke (D-NY), Mary Gay Scanlon (D-PA), John Rutherford (R-FL), former Sen. Markwayne Mullin (R-OK), and Sen. Richard Blumenthal (D-CT), 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 6.8 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 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 more likely to rupture in African-Americans (2.1 to 1 ratio) and Hispanics (1.67 to 1 ratio) than Caucasians.

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## **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 \$3.02 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-\$20 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; WABC Eyewitness News reporter Lisa Colagrossi; 25-year old Kristen Shafer Englert, a devoted wife and mother; Teresa Anne Lawrence, devoted mother of three, and 27-year-old and 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 fund critical research on what causes aneurysms and 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 aneurysms and family genetics, and socioeconomic research on aneurysm treatments, costs, and systems of care.

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***This legislation will save lives, and we urge your support of Ellie's Law and increased federal funding for brain aneurysm research.***

For more information or to sign on as a cosponsor of Ellie's Law, please contact:  
Clare Dentner (Rep. Fitzpatrick) at [Clare.Dentner@mail.house.gov](mailto:Clare.Dentner@mail.house.gov)  
Yania Campbell (Rep. Clarke) at [Yania.Campbell2@mail.house.gov](mailto:Yania.Campbell2@mail.house.gov)  
Kasandra Navarro (Sen. Blumenthal) at [Kasandra\\_Navarro@blumenthal.senate.gov](mailto:Kasandra_Navarro@blumenthal.senate.gov)