

Ellie's Law (H.R. 594/S. 864)

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 Peter King (R-NY) (H.R. 594) and Sen. Richard Blumenthal (D-CT) (S. 864) 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 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, 40 percent of which are fatal. 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.

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 \$0.83 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 \$5 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 four women who passed away as a result of a brain aneurysm: 14-year-old Ellie Helton; WABC Eyewitness News reporter Lisa Colagrossi; 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 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.

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

AMERICAN ASSOCIATION OF
NEUROLOGICAL SURGEONS

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January 30, 2019

The Honorable Yvette Clarke
U.S. House of Representatives
2058 Rayburn House Office Building
Washington, D.C. 20515

SUBJECT: Neurosurgery Support for H.R. 594, Ellie's Law

Dear Representative Clarke,

On behalf of the American Association of Neurological Surgeons (AANS) and the Congress of Neurological Surgeons (CNS), we are pleased to offer our support of your legislation, H.R. 594, Ellie's Law.

An estimated six million people in the United States, or one in 50 people, have an unruptured brain aneurysm. Each year, an estimated 30,000 people in the U.S. suffer a brain aneurysm rupture, 40 percent of which are fatal. Of those who survive, about 66 percent suffer some permanent neurological deficit. Additionally, the economic toll on survivors and their caretakers is significant, with the combined lost wages approximating \$138 million per year. Despite these startling statistics, the federal government spends only about \$5 million per year on brain aneurysm research, or 83 cents per American afflicted with the disease each year. Notwithstanding its widespread prevalence, the federal funding for brain aneurysm research is almost non-existent.

Importantly, Ellie's Law would authorize additional funding for the National Institute of Neurological Disorders and Stroke (NINDS) to specifically further our knowledge and understanding of brain aneurysms and how to effectively manage and treat this condition.

Organized neurosurgery is very concerned about the current lack of federal funding devoted to brain aneurysm research; specifically, those projects focused on prevention, detection, treatment, and rehabilitation. We look forward to assisting in your efforts to pass this crucial legislation.

Sincerely,

Shelly D. Timmons, MD, PhD, President
American Association of Neurological Surgeons

Ganesh Rao, MD, President
Congress of Neurological Surgeons

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March 26, 2019

The Honorable Richard Blumenthal
United States Senate
706 Hart Senate Office Building
Washington, D.C. 20510

SUBJECT: Neurosurgery Support for S. 864, Ellie's Law

Dear Senator Blumenthal,

On behalf of the American Association of Neurological Surgeons (AANS) and Congress of Neurological Surgeons (CNS), we are pleased to offer our support of your legislation, S. 864, Ellie's Law.

An estimated six million people in the United States, or one in 50 people, have an unruptured brain aneurysm. Each year, an estimated 30,000 people in the U.S. suffer a brain aneurysm rupture, 40 percent of which are fatal. Of those who survive, about 66 percent suffer some permanent neurological deficit. Additionally, the economic toll on survivors and their caretakers is significant, with combined lost wages approximating \$138 million per year. Despite these startling statistics, the federal government spends only about \$5 million per year on brain aneurysm research, or 83 cents per American afflicted with the disease each year. Notwithstanding its widespread prevalence, the federal funding for brain aneurysm research is almost non-existent.

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