

115TH CONGRESS 1ST SESSION H.R. 1533

To provide for further comprehensive research at the National Institute of Neurological Disorders and Stroke on unruptured intracranial aneurysms.

IN THE HOUSE OF REPRESENTATIVES

March 15, 2017

Ms. Clarke of New York introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To provide for further comprehensive research at the National Institute of Neurological Disorders and Stroke on unruptured intracranial aneurysms.

- 1 Be it enacted by the Senate and House of Representa-
- 2 tives of the United States of America in Congress assembled,
- 3 SECTION 1. SHORT TITLE.
- 4 This Act may be cited as the "Ellie Helton, Lisa
- 5 Colagrossi, Teresa Anne Lawrence, and Jennifer Sedney
- 6 Focused Research Act" or "Ellie's Law".
- 7 SEC. 2. FINDINGS.
- 8 The Congress makes the following findings:

- (1) An estimated 6 million people in the United States, or 1 in 50 people, have an unruptured brain aneurysm.
 - (2) Each year, an estimated 30,000 people in the United States suffer a brain aneurysm rupture. Ruptured brain aneurysms are fatal in about 40 percent of cases. Of those who survive, about 66 percent suffer some permanent neurological deficit.
 - (3) Brain aneurysms are more likely to occur in women than in men by a 3 to 2 ratio. People who experienced a brain aneurysm rupture include the following:
 - (A) Ellie Helton. On July 16, 2014, Ellie Helton, a vibrant, loving 14-year-old from Apex, North Carolina, passed away as a result of a ruptured aneurysm, stunning her parents, two sisters, and many, many loved ones. A day earlier, on her second day of high school, she woke up with a terrible headache after a plum-sized aneurysm on her brain stem ruptured. While she suffered headaches throughout her life, she was never diagnosed. Ellie was an avid reader and excellent student, loved the arts, and was incredibly creative. She had an unwavering,

1 constant love for the family and friends in her 2 life.

(B) Lisa Colagrossi. On March 20, 2015, Lisa Colagrossi—WABC Eyewitness News reporter, wife of 17 years, and mother of two sons—unexpectedly passed away at the age of 49 years after suffering a massive ruptured brain aneurysm. Despite experiencing one of the classic warning signs of a brain aneurysm (the "worst headache of my life"), Lisa's passing came as a tremendous shock to her family and friends, who did not know what a brain aneurysm was, let alone its signs and symptoms. She is remembered for being a loving wife, a mother, and a successful reporter, and for her love of the New York Rangers.

(C) Teresa Anne Lawrence, devoted mother of three, beloved wife, and staple of her community, collapsed while visiting her son's school on December 8, 1983. She had been struggling with and taking medication for hypertension for several years. At age 34, after being unconscious for four days, she passed away as a result of a brain aneurysm. Her loving husband

and extended family were left to raise their children, whom Teresa cherished so much.

- (D) Jennifer Sedney. On December 25, 2013, Jennifer Sedney, a beautiful, accomplished young woman, passed away suddenly at the age of 27 from a ruptured brain aneurysm. Her only symptom was the "worst headache of her life", which none of her friends or family realized was a symptom of a potentially fatal condition. Jenny was a jogger, a disciplined exerciser, and a successful health care consultant and had recently launched a health blog founded on three principles—"bee curious, bee radiant, bee well". Her brother, mother, father, and a large devoted network of friends and relatives remember her every day.
- (4) The combined lost wages of survivors of brain aneurysm ruptures and their caretakers are approximately \$138,000,000 per year.
- (5) 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.

1 (6) The first three iterations of the Inter2 national Study on Unruptured Intracranial Aneu3 rysms (ISUIA) have advanced researchers' and clini4 cians' understanding of how to most effectively man5 age and treat unruptured intracranial aneurysms.

6 SEC. 3. FUNDING.

- (a) Authorization of Appropriations.—To con
 8 duct or support further comprehensive research on

 9 unruptured intracranial aneurysms, studying a broader

 10 patient population diversified by age, sex, and race, there

 11 are authorized to be appropriated to the National Institute

 12 of Neurological Disorders and Stroke \$5,000,000 for each

 13 of fiscal years 2018 through 2022, to remain available

 14 through September 30, 2026.
- 15 (b) SUPPLEMENT, NOT SUPPLANT.—Any funds 16 made available pursuant to this section shall supplement, 17 not supplant, other funding made available for research 18 on brain aneurysms.

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