

116TH CONGRESS
1ST SESSION

H. R. 594

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

IN THE HOUSE OF REPRESENTATIVES

JANUARY 16, 2019

Ms. CLARKE of New York (for herself and Mr. KING 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 (1) An estimated 6 million people in the United
2 States, or 1 in 50 people, have an unruptured brain
3 aneurysm.

4 (2) Each year, an estimated 30,000 people in
5 the United States suffer a brain aneurysm rupture.
6 Ruptured brain aneurysms are fatal in about 40 per-
7 cent of cases. Of those who survive, about 66 per-
8 cent suffer some permanent neurological deficit.

9 (3) Brain aneurysms are more likely to occur in
10 women than in men by a 3 to 2 ratio. People who
11 experienced a brain aneurysm rupture include the
12 following:

13 (A) Ellie Helton. On July 16, 2014, Ellie
14 Helton, a vibrant, loving 14-year-old from Apex,
15 North Carolina, passed away as a result of a
16 ruptured aneurysm, stunning her parents, two
17 sisters, and many, many loved ones. A day ear-
18 lier, on her second day of high school, she woke
19 up with a terrible headache after a plum-sized
20 aneurysm on her brain stem ruptured. While
21 she suffered headaches throughout her life, she
22 was never diagnosed. Ellie was an avid reader
23 and excellent student, loved the arts, and was
24 incredibly creative. She had an unwavering,

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

3 (B) Lisa Colagrossi. On March 20, 2015,
4 Lisa Colagrossi—WABC Eyewitness News re-
5 porter, wife of 17 years, and mother of two
6 sons—unexpectedly passed away at the age of
7 49 years after suffering a massive ruptured
8 brain aneurysm. Despite experiencing one of
9 the classic warning signs of a brain aneurysm
10 (the “worst headache of my life”), Lisa’s pass-
11 ing came as a tremendous shock to her family
12 and friends, who did not know what a brain an-
13 eurysm was, let alone its signs and symptoms.
14 She is remembered for being a loving wife, a
15 mother, and a successful reporter, and for her
16 love of the New York Rangers.

17 (C) Teresa Anne Lawrence, devoted moth-
18 er of three, beloved wife, and staple of her com-
19 munity, collapsed while visiting her son’s school
20 on December 8, 1983. She had been struggling
21 with and taking medication for hypertension for
22 several years. At age 34, after being uncon-
23 scious for four days, she passed away as a re-
24 sult of a brain aneurysm. Her loving husband

1 and extended family were left to raise their chil-
2 dren, whom Teresa cherished so much.

3 (D) Jennifer Sedney. On December 25,
4 2013, Jennifer Sedney, a beautiful, accom-
5 plished young woman, passed away suddenly at
6 the age of 27 from a ruptured brain aneurysm.
7 Her only symptom was the “worst headache of
8 her life”, which none of her friends or family
9 realized was a symptom of a potentially fatal
10 condition. Jenny was a jogger, a disciplined ex-
11 erciser, and a successful health care consultant
12 and had recently launched a health blog found-
13 ed on three principles—“bee curious, bee radi-
14 ant, bee well”. Her brother, mother, father, and
15 a large devoted network of friends and relatives
16 remember her every day.

17 (4) The combined lost wages of survivors of
18 brain aneurysm ruptures and their caretakers are
19 approximately \$138,000,000 per year.

20 (5) Despite the widespread prevalence of this
21 condition and the high societal cost it imposes on the
22 Nation, the Federal Government only spends ap-
23 proximately \$0.83 per year on brain aneurysm re-
24 search for each person afflicted with a brain aneu-
25 rysm.

1 (6) The first three iterations of the Inter-
2 national Study on Unruptured Intracranial Aneu-
3 rysms (ISUIA) have advanced researchers' and clini-
4 cians' understanding of how to most effectively man-
5 age and treat unruptured intracranial aneurysms.

6 **SEC. 3. FUNDING.**

7 (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 is authorized to be appropriated to the National Institute
12 of Neurological Disorders and Stroke \$5,000,000 for each
13 of fiscal years 2020 through 2024, to remain available
14 through September 30, 2027.

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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