

116TH CONGRESS
1ST SESSION

S. 864

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

IN THE SENATE OF THE UNITED STATES

MARCH 25, 2019

Mr. BLUMENTHAL introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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 Congress makes the following findings:

1 (1) An estimated 6,000,000 people in the
2 United States, or 1 in 50 people, have an
3 unruptured brain 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, 2 sis-
17 ters, and many, many loved ones. A day earlier,
18 on her second day of high school, she woke up
19 with a terrible headache after a plum-sized an-
20 eurysm on her brain stem ruptured. While she
21 suffered headaches throughout her life, she was
22 never diagnosed. Ellie was an avid reader and
23 excellent student, loved the arts, and was in-
24 credibly creative. She had an unwavering, con-
25 stant love for the family and friends in her life.

1 (B) Lisa Colagrossi. On March 20, 2015,
2 Lisa Colagrossi—WABC Eyewitness News re-
3 porter, wife of 17 years, and mother of 2
4 sons—unexpectedly passed away at the age of
5 49 years after suffering a massive ruptured
6 brain aneurysm. Despite experiencing one of
7 the classic warning signs of a brain aneurysm
8 (the “worst headache of my life”), Lisa’s pass-
9 ing came as a tremendous shock to her family
10 and friends, who did not know what a brain an-
11 eurysm was, let alone its signs and symptoms.
12 She is remembered for being a loving wife, a
13 mother, and a successful reporter, and for her
14 love of the New York Rangers.

15 (C) Teresa Anne Lawrence, devoted moth-
16 er of 3, beloved wife, and staple of her commu-
17 nity, collapsed while visiting her son’s school on
18 December 8, 1983. She had been struggling
19 with and taking medication for hypertension for
20 several years. At age 34, after being uncon-
21 conscious for 4 days, she passed away as a result
22 of a brain aneurysm. Her loving husband and
23 extended family were left to raise their children,
24 whom Teresa cherished so much.

1 (D) Jennifer Sedney. On December 25,
 2 2013, Jennifer Sedney, a beautiful, accom-
 3 plished young woman, passed away suddenly at
 4 the age of 27 from a ruptured brain aneurysm.
 5 Her only symptom was the “worst headache of
 6 her life”, which none of her friends or family
 7 realized was a symptom of a potentially fatal
 8 condition. Jenny was a jogger, a disciplined ex-
 9 erciser, and a successful health care consultant
 10 and had recently launched a health blog found-
 11 ed on 3 principles—“bee curious, bee radiant,
 12 bee well”. Her brother, mother, father, and a
 13 large devoted network of friends and relatives
 14 remember her every day.

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

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

24 (6) The first 3 iterations of the International
 25 Study on Unruptured Intracranial Aneurysms

1 (ISUIA) have advanced researchers' and clinicians'
2 understanding of how to most effectively manage
3 and treat unruptured intracranial aneurysms.

4 **SEC. 3. FUNDING.**

5 (a) AUTHORIZATION OF APPROPRIATIONS.—To con-
6 duct or support further comprehensive research on
7 unruptured intracranial aneurysms, studying a broader
8 patient population diversified by age, sex, and race, there
9 is authorized to be appropriated to the National Institute
10 of Neurological Disorders and Stroke \$5,000,000 for each
11 of fiscal years 2020 through 2024, to remain available
12 through September 30, 2027.

13 (b) SUPPLEMENT, NOT SUPPLANT.—Any funds
14 made available pursuant to this section shall supplement,
15 not supplant, other funding made available for research
16 on brain aneurysms.

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