

117TH CONGRESS
1ST SESSION

H. R. 1553

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 3, 2021

Ms. CLARKE of New York (for herself, Mr. FITZPATRICK, Ms. SCANLON, and Mr. STIVERS) 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, Kristen Shafer Englert, Teresa Anne Law-
6 rence, and Jennifer Sedney Focused Research Act” or
7 “Ellie’s Law”.

8 **SEC. 2. FINDINGS.**

9 The Congress makes the following findings:

1 (1) An estimated 6.5 million 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 50 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. This Act rep-
11 represents all those who have been affected and died
12 due to a ruptured brain aneurysm, and their loved
13 ones. People who experienced a brain aneurysm rup-
14 ture include the following:

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

1 incredibly creative. She had an unwavering,
2 constant love for the family and friends in her
3 life.

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

18 (C) Kristen Shafer Englert. On November
19 24, 2013, Kristen Shafer Englert, a devoted
20 wife, mother, daughter, sister, aunt, and friend,
21 passed away from a ruptured brain aneurysm
22 at the age of 25, just weeks after giving birth
23 to her son. Prior to her passing, she went to the
24 emergency room with symptoms of a brain an-
25 eurysm and was sent home without a scan.

1 Kristen was a dedicated teacher who loved chil-
2 dren. She was thrilled to become a mother.
3 Sadly, she only experienced motherhood for a
4 few short days. Kristen’s family members have
5 been dedicated advocates since her passing.

6 (D) Teresa Anne Lawrence. On December
7 8, 1983, Teresa Anne Lawrence, a devoted
8 mother of three, beloved wife, and staple of her
9 community, collapsed while visiting her son’s
10 school. She had been struggling with and taking
11 medication for hypertension for several years.
12 At age 34, after being unconscious for four
13 days, she passed away as a result of a brain an-
14 eurysm. Her loving husband and extended fam-
15 ily were left to raise their children, whom Te-
16 resa cherished so much.

17 (E) Jennifer Sedney. On December 25,
18 2013, Jennifer Sedney, a beautiful, accom-
19 plished young woman, passed away suddenly at
20 the age of 27 from a ruptured brain aneurysm.
21 Her only symptom was the “worst headache of
22 her life”, which none of her friends or family
23 realized was a symptom of a potentially fatal
24 condition. Jenny was a jogger, a disciplined ex-
25 erciser, and a successful health care consultant

1 and had recently launched a health blog found-
2 ed on three principles—“bee curious, bee radi-
3 ant, bee well”. Her brother, mother, and father,
4 and a large devoted network of friends and rel-
5 atives, remember her every day.

6 (4) Brain aneurysm ruptures have a significant
7 fiscal impact on survivors, caretakers, and the health
8 care community. The annual estimated pre-insur-
9 ance direct cost of brain aneurysm ruptures to
10 American patients is approximately \$1,400,000,000,
11 and the estimated direct cost to hospitals each year
12 is approximately \$2,700,000,000. The length of stay
13 in the intensive care unit is the largest driver of cost
14 for brain aneurysm ruptures, and estimates do not
15 reflect indirect costs including travel, food, childcare,
16 and wage losses for patients and caretakers.

17 (5) Despite the widespread prevalence of this
18 condition and the high societal cost it imposes on the
19 Nation, the Federal Government only spends ap-
20 proximately \$2.08 per year on brain aneurysm re-
21 search for each person afflicted with a brain aneu-
22 rysm.

23 (6) The first three iterations of the Inter-
24 national Study on Unruptured Intracranial Aneu-
25 rysms (ISUIA) have advanced researchers’ and clini-

1 cians' understanding of how to most effectively man-
2 age and treat unruptured intracranial aneurysms.

3 **SEC. 3. FUNDING.**

4 (a) AUTHORIZATION OF APPROPRIATIONS.—To con-
5 duct or support further comprehensive research on
6 unruptured intracranial aneurysms, studying a broader
7 patient population diversified by age, sex, and race, there
8 is authorized to be appropriated to the National Institute
9 of Neurological Disorders and Stroke \$10,000,000 for
10 each of fiscal years 2022 through 2026, to remain avail-
11 able through September 30, 2029.

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

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