

117TH CONGRESS
1ST SESSION

S. 852

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 18, 2021

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, 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 6,500,000 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 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. Ellie's Law
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, 2 sis-
19 ters, and many, many loved ones. A day earlier,
20 on her second day of high school, she woke up
21 with a terrible headache after a plum-sized an-
22 eurysm on her brain stem ruptured. While she
23 suffered headaches throughout her life, she was
24 never diagnosed. Ellie was an avid reader and
25 excellent student, loved the arts, and was in-

1 credibly creative. She had an unwavering, con-
2 stant love for the family and friends in her 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 2
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) Kristen Shafer Englert. On November
18 24, 2013, Kristen Shafer Englert, a devoted
19 wife, mother, daughter, sister, aunt, and friend
20 passed away from a ruptured brain aneurysm
21 at the age of 25, just weeks after giving birth
22 to her son. Prior to her passing, she went to the
23 emergency room with symptoms of a brain an-
24 eurysm and was sent home without a scan.
25 Kristen was a dedicated teacher who loved chil-

1 dren. She was thrilled to become a mother.
2 Sadly, she got to experience motherhood only
3 for a few short days. Kristen's family members
4 have been dedicated advocates for brain aneu-
5 rysm awareness and research since her passing.

6 (D) Teresa Anne Lawrence. On December
7 8, 1983, Teresa Anne Lawrence, devoted moth-
8 er of 3, beloved wife, and staple of her commu-
9 nity, collapsed while visiting her son's school.
10 She had been struggling with and taking medi-
11 cation for hypertension for several years. At age
12 34, after being unconscious for 4 days, she
13 passed away as a result of a brain aneurysm.
14 Her loving husband and extended family were
15 left to raise their children, whom Teresa cher-
16 ished 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 3 principles—“bee curious, bee radiant,
 3 bee well”. Her brother, mother, father, and a
 4 large devoted network of friends and relatives
 5 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 pa-
 10 tients in the United States is approximately
 11 \$1,400,000,000, and the estimated direct cost to
 12 hospitals each year is approximately
 13 \$2,700,000,000. The intensive care unit length of
 14 stay is the largest driver of cost for brain aneurysm
 15 ruptures, and estimates do not reflect indirect costs,
 16 which include travel, food, childcare, and wage losses
 17 for patient and caretakers.

18 (5) Despite the widespread prevalence of this
 19 condition and the high societal cost it imposes on the
 20 Nation, the Federal Government only spends ap-
 21 proximately \$2.08 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 \$10,000,000 for
11 each of fiscal years 2022 through 2026, to remain avail-
12 able through September 30, 2029.

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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