

119TH CONGRESS
1ST SESSION

S. 1609

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

MAY 6, 2025

Mr. BLUMENTHAL (for himself and Mr. MULLIN) 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 6,800,000 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, and are nearly twice as likely to rupture in
11 African American and Hispanic individuals. Ellie's
12 Law represents all those who have been affected and
13 died due to a ruptured brain aneurysm, and their
14 loved ones. The personal stories of individuals who
15 have recently experienced a brain aneurysm rupture
16 include the following:

17 (A) Ellie Helton. On July 16, 2014, Ellie
18 Helton, a vibrant, loving 14-year-old from Apex,
19 North Carolina, passed away as a result of a
20 ruptured aneurysm, stunning her parents, 2 sis-
21 ters, and many, many loved ones. A day earlier,
22 on her second day of high school, she woke up
23 with a terrible headache after a plum-sized an-
24 eurysm on her brain stem ruptured. While she
25 suffered headaches throughout her life, she was

1 never diagnosed. Ellie was an avid reader and
2 excellent student, loved the arts, and was in-
3 credibly creative. She had an unwavering, con-
4 stant love for the family and friends in her life.

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

19 (C) Kristen Shafer Englert. On November
20 24, 2013, Kristen Shafer Englert, a devoted
21 wife, mother, daughter, sister, aunt, and friend
22 passed away from a ruptured brain aneurysm
23 at the age of 25, just weeks after giving birth
24 to her son. Prior to her passing, she went to the
25 emergency room with symptoms of a brain an-

1 eurysm and was sent home without a scan.
2 Kristen was a dedicated teacher who loved chil-
3 dren. She was thrilled to become a mother.
4 Sadly, she got to experience motherhood only
5 for a few short days. Kristen’s family members
6 have been dedicated advocates for brain aneu-
7 rysm awareness and research since her passing.

8 (D) Teresa Anne Lawrence. On December
9 8, 1983, Teresa Anne Lawrence, a devoted
10 mother of 3, beloved wife, and staple of her
11 community, collapsed while visiting her son’s
12 school. She had been struggling with and taking
13 medication for hypertension for several years.
14 At age 34, after being unconscious for 4 days,
15 she passed away as a result of a brain aneu-
16 rysm. Her loving husband and extended family
17 were left to raise their children, whom Teresa
18 cherished so much.

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

1 condition. Jenny was a jogger, a disciplined ex-
2 erciser, and a successful health care consultant
3 and had recently launched a health blog found-
4 ed on 3 principles—“bee curious, bee radiant,
5 bee well”. Her brother, mother, father, and a
6 large devoted network of friends and relatives
7 remember her every day.

8 (4) Brain aneurysm ruptures have a significant
9 fiscal impact on survivors, caretakers, and the health
10 care community. The annual estimated pre-insur-
11 ance direct cost of brain aneurysm ruptures to pa-
12 tients is approximately \$2,000,000,000, and the me-
13 dian expected patient payment is \$144,000. The
14 length of stay in an intensive care unit is the largest
15 driver of cost for brain aneurysm ruptures, and esti-
16 mates do not reflect indirect costs, including travel,
17 food, childcare, and wage losses for the patient and
18 caretakers.

19 (5) Despite the widespread prevalence of this
20 condition and the high societal cost it imposes on the
21 Nation, the Federal Government only spends ap-
22 proximately \$2.94 per year on brain aneurysm re-
23 search for each person afflicted with a brain aneu-
24 rysm.

1 (6) The first 3 iterations of the International
2 Study on Unruptured Intracranial Aneurysms
3 (ISUIA) have advanced researchers' and clinicians'
4 understanding of how to most effectively manage
5 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 \$10,000,000 for
13 each of fiscal years 2026 through 2030, to remain avail-
14 able through September 30, 2033.

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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