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(Original Signature of Member)

119TH CONGRESS  
1ST SESSION

**H. R.** \_\_\_\_\_

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

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IN THE HOUSE OF REPRESENTATIVES

Mr. FITZPATRICK introduced the following bill; which was referred to the Committee on \_\_\_\_\_

\_\_\_\_\_  
**A BILL**

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

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”.

1 **SEC. 2. FINDINGS.**

2 The Congress makes the following findings:

3 (1) An estimated 6.8 million people in the  
4 United States, or 1 in 50 people, have an  
5 unruptured brain aneurysm.

6 (2) Each year, an estimated 30,000 people in  
7 the United States suffer a brain aneurysm rupture.  
8 Ruptured brain aneurysms are fatal in about 50 per-  
9 cent of cases. Of those who survive, about 66 per-  
10 cent suffer some permanent neurological deficit.

11 (3) Brain aneurysms are more likely to occur in  
12 women than in men by a 3 to 2 ratio and nearly  
13 twice as likely to rupture in African Americans (2.1  
14 to 1 ratio) and Hispanics (1.67 to 1 ratio) than  
15 Caucasians. This Act represents all those who have  
16 been affected and died due to a ruptured brain an-  
17 eurysm, and their loved ones. People who experi-  
18 enced a brain aneurysm rupture include the fol-  
19 lowing:

20 (A) Ellie Helton. On July 16, 2014, Ellie  
21 Helton, a vibrant, loving 14-year-old from Apex,  
22 North Carolina, passed away as a result of a  
23 ruptured aneurysm, stunning her parents, two  
24 sisters, and many, many loved ones. A day ear-  
25 lier, on her second day of high school, she woke  
26 up with a terrible headache after a plum-sized

1           aneurysm on her brain stem ruptured. While  
2           she suffered headaches throughout her life, she  
3           was never diagnosed. Ellie was an avid reader  
4           and excellent student, loved the arts, and was  
5           incredibly creative. She had an unwavering,  
6           constant love for the family and friends in her  
7           life.

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

22                   (C) Kristen Shafer Englert. On November  
23          24, 2013, Kristen Shafer Englert, a devoted  
24          wife, mother, daughter, sister, aunt, and friend,  
25          passed away from a ruptured brain aneurysm

1 at the age of 25, just weeks after giving birth  
2 to her son. Prior to her passing, she went to the  
3 emergency room with symptoms of a brain an-  
4 eurysm and was sent home without a scan.  
5 Kristen was a dedicated teacher who loved chil-  
6 dren. She was thrilled to become a mother.  
7 Sadly, she only experienced motherhood for a  
8 few short days. Kristen's family members have  
9 been dedicated advocates since her passing.

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

21 (E) Jennifer Sedney. On December 25,  
22 2013, Jennifer Sedney, a beautiful, accom-  
23 plished young woman, passed away suddenly at  
24 the age of 27 from a ruptured brain aneurysm.  
25 Her only symptom was the "worst headache of

1 her life”, which none of her friends or family  
2 realized was a symptom of a potentially fatal  
3 condition. Jenny was a jogger, a disciplined ex-  
4 erciser, and a successful health care consultant  
5 and had recently launched a health blog found-  
6 ed on three principles—“bee curious, bee radi-  
7 ant, bee well”. Her brother, mother, and father,  
8 and a large devoted network of friends and rel-  
9 atives, remember her every day.

10 (4) Brain aneurysm ruptures have a significant  
11 fiscal impact on survivors, caretakers, and the health  
12 care community. The annual estimated pre-insur-  
13 ance, direct cost of brain aneurysm ruptures to pa-  
14 tients is approximately \$2,000,000,000, and the me-  
15 dian expected patient payment is \$114,000. The  
16 length of stay in the intensive care unit is the larg-  
17 est driver of cost for brain aneurysm ruptures, and  
18 estimates do not reflect indirect costs including trav-  
19 el, food, child care, and wage losses for patients and  
20 caretakers.

21 (5) Despite the widespread prevalence of this  
22 condition and the high societal cost it imposes on the  
23 Nation, the Federal Government only spends ap-  
24 proximately \$2.94 per year on brain aneurysm re-

1 search for each person afflicted with a brain aneu-  
2 rysm.

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

8 **SEC. 3. FUNDING.**

9 (a) AUTHORIZATION OF APPROPRIATIONS.—To con-  
10 duct or support further comprehensive research on  
11 unruptured intracranial aneurysms, studying a broader  
12 patient population diversified by age, sex, and race, there  
13 is authorized to be appropriated to the National Institute  
14 of Neurological Disorders and Stroke \$20,000,000 for  
15 each of fiscal years 2026 through 2030, to remain avail-  
16 able through September 30, 2033.

17 (b) SUPPLEMENT, NOT SUPPLANT.—Any funds  
18 made available pursuant to this section shall supplement,  
19 not supplant, other funding made available for research  
20 on brain aneurysms.