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(Original Signature of Member)

119TH CONGRESS
2D SESSION

H. R.

To provide for increased research and initiatives related to bleeding disorders in underserved populations, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

Ms. JOHNSON of Texas introduced the following bill; which was referred to the Committee on _____

A BILL

To provide for increased research and initiatives related to bleeding disorders in underserved populations, 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 “Fostering Effective
5 Diagnosis and Treatment for Underserved Populations
6 with Bleeding Disorders Act of 2026” or the “FED UP
7 with Bleeding Disorders Act of 2026”.

1 **SEC. 2. FINDINGS.**

2 Congress finds the following:

3 (1) Current data estimates that as many as 1
4 percent of women in the United States may have a
5 bleeding disorder, and many are unaware of their
6 condition.

7 (2) Women have reported delays in diagnosis of
8 16 years or more.

9 (3) Increasing timely diagnosis for women with
10 von Willebrand disease aligns with public health
11 goals outlined in Healthy People 2030 supported by
12 the Department of Health and Human Services Of-
13 fice of Disease Prevention and Health Promotion.

14 (4) Without diagnosis, women cannot receive
15 proper care and treatment from a provider with the
16 requisite expertise, such as a hemophilia treatment
17 center, which provides specialized care for people
18 with bleeding disorders. Mortality rates and hos-
19 pitalization rates for bleeding complications from he-
20 mophilia are 40 percent lower among all people who
21 receive care in hemophilia treatment centers than
22 among those who did not receive this care.

23 (5) Women with bleeding disorders are at high-
24 er risk of adverse pregnancy outcomes.

25 (6) As many as 50 percent of girls and women
26 who are carriers for hemophilia A or B have factor

1 VIII or IX levels below 50 percent and are at risk
2 for bleeding symptoms or heavy bleeding related to
3 menstruation or pregnancy. In severe cases, a
4 hysterectomy is a recommended treatment option for
5 heavy menstrual bleeding. More research into women
6 and bleeding disorders could help to avoid unneces-
7 sary hysterectomies and preserve fertility.

8 (7) The annual direct economic cost of heavy
9 menstrual bleeding is \$1,000,000,000. The annual
10 indirect cost is \$12,000,000,000.

11 (8) Research into bleeding disorders and clot-
12 ting factors is beneficial for the United States mili-
13 tary and its blood research program as well as ef-
14 forts to prevent or treat bleeding that results from
15 severe injury or trauma.

16 **SEC. 3. INTERAGENCY REVIEW RELATED TO BLEEDING DIS-**
17 **ORDERS IN CERTAIN POPULATIONS.**

18 (a) IN GENERAL.—The Secretary of Health and
19 Human Services (in this Act referred to as the “Sec-
20 retary”) shall conduct a review of, and serve as the lead
21 agency head responsible for reviewing, and as necessary
22 and appropriate, updating Federal programs, activities,
23 and strategic plans related to—

24 (1) the state of the science on bleeding dis-
25 orders in women and girls;

1 (2) training and education of providers on
2 issues specific to women and girls and bleeding dis-
3 orders;

4 (3) access to treatment and services for women
5 and girls with bleeding disorders, including—

6 (A) care delivered at hemophilia treatment
7 centers;

8 (B) care delivered in other clinical settings;
9 and

10 (C) access barriers specific to women and
11 girls living in rural and underserved areas; and

12 (4) inclusion of women and girls in clinical re-
13 search related to bleeding disorders.

14 (b) REPORT.—Not later than two years after the date
15 of the enactment of this Act, the Secretary shall submit
16 to the Committee on Energy and Commerce and the Com-
17 mittee on Appropriations of the House of Representatives
18 and the Committee on Health, Education, Labor, and
19 Pensions and the Committee on Appropriations of the
20 Senate, and make available on the public website of the
21 Department of Health and Human Services, a comprehen-
22 sive report on the review under subsection (a), which shall
23 include—

24 (1) a summary of the review, including a de-
25 tailed assessment of previous and ongoing research

1 and activities related to each area specified in sub-
2 section (a); and

3 (2) a description of recommendations on how to
4 improve on each of the areas specified in subsection
5 (a), related to Federal programs, activities, or stra-
6 tegic plans based on the findings of such review; and

7 (3) the Secretary's recommendations on areas
8 for improved coordination between relevant Federal
9 agencies and programs, including Federal agencies
10 that focus on scientific and clinical research, includ-
11 ing—

12 (A) the Department of Health and Human
13 Services;

14 (B) the Centers for Medicare & Medicaid
15 Services;

16 (C) the Health Resources and Services Ad-
17 ministration;

18 (D) the Centers for Disease Control and
19 Prevention;

20 (E) the National Institutes of Health;

21 (F) the Department of Veterans Affairs;

22 (G) the Defense Health Agency; and

23 (H) the Food and Drug Administration.

24 (c) PUBLIC COMMENT PERIOD.—During the period
25 of the review under subsection (a) and during the period

1 of preparing of the report under subsection (b), the Sec-
2 retary shall provide for a public comment period. The Sec-
3 retary shall consider comments received during each such
4 public comment period in conducting such review and pre-
5 paring such report, especially comments received from—

- 6 (1) individuals living with bleeding disorders;
- 7 (2) national bleeding disorders patient and pro-
8 vider advocacy organizations; and
- 9 (3) entities receiving Federal funds under a
10 Federal program providing for research on bleeding
11 disorders.

12 (d) BLEEDING DISORDER DEFINED.—In this sec-
13 tion, the term “bleeding disorder” means an inheritable
14 disorder which—

- 15 (1) involves an impairment in the blood’s ability
16 to form a proper clot, including hemophilia, von
17 Willebrand disease, and rare factor deficiencies; and
- 18 (2) can cause extended bleeding (internal as
19 well as external), spontaneously or in response to in-
20 jury, surgery, trauma, menstruation, or childbirth.

21 **SEC. 4. NATIONAL PUBLIC EDUCATION AND AWARENESS**
22 **CAMPAIGN WITH RESPECT TO WOMEN AND**
23 **GIRLS AND BLEEDING DISORDERS.**

24 (a) IN GENERAL.—Not later than one year after the
25 date on which the report under section 3 is published, the

1 Secretary, utilizing the information from such report and
2 in coordination with other Federal offices and agencies,
3 as appropriate, shall award competitive grants or con-
4 tracts to one or more public or private entities to carry
5 out a national, evidence-based education and awareness
6 campaign with the aim of improving awareness of, and
7 diagnosis and treatment of, women and girls with bleeding
8 disorder

9 (b) CONSULTATION.—In carrying out the campaign
10 under this section, the Secretary shall consult with appro-
11 priate stakeholders, including national bleeding disorders
12 organizations, national provider organizations, and the re-
13 cipients of Federal grants relating to hemophilia.

14 (c) REQUIREMENTS.—The campaign under this sec-
15 tion shall—

16 (1) be a nationwide, evidence-based campaign
17 related to bleeding disorders in women and girls that
18 is aimed at women and girls and at providers, in-
19 cluding school nurses, pediatricians, primary care
20 physicians, family medicine physicians, obstetricians
21 and gynecologists, and hematologists;

22 (2) utilize strategies to ensure individuals living
23 in rural and underserved areas are reached;

24 (3) include culturally and linguistically appro-
25 priate resources, as applicable; and

1 (4) include the dissemination of information
2 and communication resources related to women and
3 girls with bleeding disorders to public health depart-
4 ments, health care providers, schools, medical
5 schools and health care facilities, including such pro-
6 viders and facilities that provide prenatal and pedi-
7 atric care.

8 (d) EVALUATION.—The Secretary shall—

9 (1) establish benchmarks and conduct quali-
10 tative assessments regarding the awareness cam-
11 paign under this section; and

12 (2) before the end of the last fiscal year for
13 which funding under subsection (e) is available, pre-
14 pare and submit to the Committee on Health, Edu-
15 cation, Labor, and Pensions of the Senate and Com-
16 mittee on Energy and Commerce of the House of
17 Representatives an evaluation of the awareness cam-
18 paign under this section.

19 (e) AUTHORIZATION OF APPROPRIATIONS.—To carry
20 out this section, there is authorized to be appropriated
21 \$10,000,000 for each of fiscal years 2027 through 2031.