

112TH CONGRESS
1ST SESSION

H. R. 1919

To authorize the Secretary of Health and Human Services to conduct programs to screen adolescents, and educate health professionals, with respect to bleeding disorders.

IN THE HOUSE OF REPRESENTATIVES

MAY 13, 2011

Mrs. MCCARTHY of New York (for herself, Ms. RICHARDSON, Ms. NORTON, Ms. BORDALLO, and Mr. GRIJALVA) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To authorize the Secretary of Health and Human Services to conduct programs to screen adolescents, and educate health professionals, with respect to bleeding disorders.

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 “Bleeding Disorder
5 Screening, Awareness, and Further Education (SAFE)
6 Act of 2011”.

7 **SEC. 2. FINDINGS.**

8 The Congress finds as follows:

1 (1) Millions of men and women in the United
2 States may have an inherited bleeding disorder and
3 not know it.

4 (2) The most common bleeding disorder, Von
5 Willebrand Disease (VWD), affects up to one in fifty
6 Americans, occurring equally amongst men and
7 women.

8 (3) Most of those affected by Von Willebrand
9 Disease remain undiagnosed.

10 (4) The current combination of laboratory tests,
11 clinical observations, and family history to diagnose
12 blood disorders like Von Willebrand Disease is anti-
13 quated and unreliable.

14 (5) During adolescence, men and women may
15 become aware of some of the symptoms of bleeding
16 disorders.

17 (6) Many Americans with bleeding disorders
18 learn to live with the chronic health risks which their
19 bleeding causes, and do not realize that they may
20 have a bleeding disorder.

21 (7) It is believed that many of the 30,000
22 women who have hysterectomies performed each
23 year to treat severe bleeding may actually have a
24 bleeding disorder, and that these women could avoid

1 those unnecessary hysterectomies if properly diag-
2 nosed.

3 (8) Improved diagnosis of bleeding disorders,
4 through expanded screening of adolescents, improved
5 physician awareness, and additional research, could
6 improve the quality of life for millions of Americans.

7 **SEC. 3. ADOLESCENT SCREENING PROGRAMS.**

8 (a) IN GENERAL.—The Secretary of Health and
9 Human Services (in this Act referred to as the “Sec-
10 retary”), directly or through the award of grants or con-
11 tracts to States, political subdivisions of States or Indian
12 tribes, or other public or nonprofit private entities, shall
13 carry out the following activities:

14 (1) Development of a new, or identification of
15 an existing, screening questionnaire that is evidence-
16 based and in accordance with clinical guidelines for
17 use in the diagnosis of bleeding disorders in adoles-
18 cents and young adults.

19 (2) As widely as possible in adolescent popu-
20 lations—

21 (A) dissemination and implementation of
22 the screening questionnaire developed or identi-
23 fied under paragraph (1) and other screening
24 tools relevant to the diagnosis of bleeding dis-
25 orders in adolescents;

1 (B) if screening suggests the possibility of
2 a bleeding disorder, ensuring the referral for
3 further laboratory-based diagnostic testing; and

4 (C) if laboratory testing confirms diagnosis
5 of a bleeding disorder, ensuring the referral for
6 medical management.

7 (b) PRIORITY.—In awarding any grant or contract
8 under subsection (a), the Secretary shall give priority to
9 applicants proposing to provide screening to high school
10 or institution of higher education students.

11 (c) TECHNICAL ASSISTANCE.—The Secretary, di-
12 rectly or through grants or contracts, may provide recipi-
13 ents of grants or contracts under subsection (a) with tech-
14 nical assistance regarding the planning, development, and
15 implementation of activities under such subsection.

16 (d) AUTHORIZATION OF APPROPRIATIONS.—To carry
17 out this section, there are authorized to be appropriated
18 such sums as may be necessary for fiscal years 2012
19 through 2016.

20 **SEC. 4. INCREASING AWARENESS AMONG HEALTH PROFES-**
21 **SIONALS.**

22 (a) IN GENERAL.—The Secretary, directly or through
23 the award of grants or contracts to States, political sub-
24 divisions of States or Indian tribes, or other public or non-
25 profit private entities, shall conduct an education cam-

1 paign to increase awareness about bleeding disorders
2 among health professionals.

3 (b) PRIORITY.—In awarding any grant or contract
4 under section (a), the Secretary shall give priority to appli-
5 cants proposing to increase awareness about bleeding dis-
6 orders among—

7 (1) health professionals who commonly provide
8 medical care for the adolescent population, such as
9 primary care physicians, school nurses, physical fit-
10 ness education teachers in secondary schools, and
11 health professionals providing services to students
12 through an institution of higher education’s health
13 center; or

14 (2) obstetricians and gynecologists.

15 (c) TECHNICAL ASSISTANCE.—The Secretary, di-
16 rectly or through the award of grants or contracts, may
17 provide recipients of grants or contracts under subsection
18 (a) with technical assistance regarding the planning, de-
19 velopment, and implementation of activities under such
20 subsection.

21 (d) AUTHORIZATION OF APPROPRIATIONS.—To carry
22 out this section, there are authorized to be appropriated
23 such sums as may be necessary for fiscal years 2012
24 through 2016.

1 **SEC. 5. RESEARCH AND SURVEILLANCE.**

2 (a) IN GENERAL.—The Secretary, acting through the
3 Director of the Centers for Disease Control and Preven-
4 tion, shall award grants or contracts to public or nonprofit
5 private entities to—

6 (1) augment existing research efforts to evalu-
7 ate, improve, and standardize methods for diag-
8 nosing bleeding disorders; and

9 (2) expand ongoing efforts to—

10 (A) determine the prevalence of bleeding
11 disorders in the general population, including
12 prevalence of bleeding disorders among adoles-
13 cent women;

14 (B) identify symptoms, risk factors, and
15 co-morbidities associated with bleeding dis-
16 orders; and

17 (C) implement female-specific surveillance
18 systems and conduct related research projects
19 to improve bleeding symptoms and quality of
20 life among adolescent and adult women with
21 bleeding disorders.

22 (b) TECHNICAL ASSISTANCE.—The Secretary, di-
23 rectly or through the award of grants or contracts, may
24 provide recipients of grants or contracts under subsection
25 (a) with technical assistance regarding the planning, de-

1 velopment, and implementation of activities under such
2 subsection.

3 (c) AUTHORIZATION OF APPROPRIATIONS.—To carry
4 out this section there are authorized to be appropriated
5 such sums as may be necessary for fiscal years 2012
6 through 2016.

7 **SEC. 6. REPORT.**

8 (a) IN GENERAL.—Not later than 5 years after the
9 date of the enactment of this Act, the Secretary shall sub-
10 mit to the Congress a report on the results of activities
11 under this Act.

12 (b) CONTENTS.—At a minimum, the report under
13 subsection (a) shall—

14 (1) catalog, with respect to bleeding disorder
15 screening, health professional education, and surveil-
16 lance—

17 (A) the activities of the Federal Govern-
18 ment, including an assessment of the progress
19 achieved under this Act;

20 (B) the portion of students in United
21 States high schools and institutions of higher
22 education who have received some form of
23 screening for bleeding disorders as a result of
24 programs under this Act;

1 (C) the number of health professionals who
2 have received some form of bleeding disorder
3 education as a result of programs under this
4 Act; and

5 (D) the prevalence and incidence of bleed-
6 ing disorders among the general population and
7 among women; and

8 (2) make recommendations for the future direc-
9 tion of bleeding disorder activities, including—

10 (A) a description of how the Federal Gov-
11 ernment, as well as recipients of grants and
12 contracts under this Act, may improve their
13 screening and education programs to increase
14 bleeding disorder diagnostic rates, including the
15 identification of steps that may be taken to re-
16 duce—

17 (i) the prevalence of undiagnosed
18 bleeding disorders; and

19 (ii) the burden of bleeding disorders
20 as a chronic condition;

21 (B) an identification of organizations that
22 have most effectively and efficiently increased
23 bleeding disorder screening rates;

24 (C) an identification of programs and pro-
25 cedures that have most effectively and effi-

1 ciently increased bleeding disorder screening
2 rates, and steps that may be taken to expand
3 such programs and policies to benefit larger
4 populations;

5 (D) a description of the services provided
6 by hemophilia treatment centers, including in-
7 formation regarding any increase in utilization
8 of such centers and any subsequent increase in
9 resources necessary to ensure sufficient treat-
10 ment for all those utilizing such centers; and

11 (E) recommendations for future research
12 and interventions.

13 **SEC. 7. DEFINITION.**

14 In this Act, the term “State” includes the District
15 of Columbia and any commonwealth, territory, or posses-
16 sion of the United States.

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