H. R. 4846

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

March 15, 2010

Mrs. McCarthy of New York (for herself, Mr. Grijalva, Mr. Bishop of Georgia, Ms. Richardson, and Ms. Bordallo) 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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Bleeding Disorder Screening, Awareness, and Further Education (SAFE) Act of 2010”.

SEC. 2. FINDINGS.

The Congress finds as follows:
(1) Millions of men and women in the United States may have an inherited bleeding disorder and not know it.

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

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

(4) The current combination of laboratory tests, clinical observations, and family history to diagnose blood disorders like Von Willebrand Disease is antiquated and unreliable.

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

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

(7) It is believed that many of the 30,000 women who have hysterectomies performed each year to treat severe bleeding may actually have a bleeding disorder, and that these women could avoid
those unnecessary hysterectomies if properly diagnosed.

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

SEC. 3. ADOLESCENT SCREENING PROGRAMS.

(a) In General.—The Secretary of Health and Human Services (in this Act referred to as the “Secretary”), directly or through the award of grants or contracts to States, political subdivisions of States or Indian tribes, or other public or nonprofit private entities, shall carry out the following activities:

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

(2) As widely as possible in adolescent populations—

(A) dissemination and implementation of the screening questionnaire developed or identified under paragraph (1) and other screening tools relevant to the diagnosis of bleeding disorders in adolescents;
(B) if screening suggests the possibility of a bleeding disorder, ensuring the referral for further laboratory-based diagnostic testing; and

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

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

(c) TECHNICAL ASSISTANCE.—The Secretary, directly or through grants or contracts, may provide recipients of grants or contracts under subsection (a) with technical assistance regarding the planning, development, and implementation of activities under such subsection.

(d) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there are authorized to be appropriated such sums as may be necessary for fiscal years 2011 through 2015.

SEC. 4. INCREASING AWARENESS AMONG HEALTH PROFESSIONALS.

(a) IN GENERAL.—The Secretary, directly or through the award of grants or contracts to States, political subdivisions of States or Indian tribes, or other public or non-profit private entities, shall conduct an education cam-
campaign to increase awareness about bleeding disorders among health professionals.

(b) PRIORITY.—In awarding any grant or contract under section (a), the Secretary shall give priority to applicants proposing to increase awareness about bleeding disorders among—

(1) health professionals who commonly provide medical care for the adolescent population, such as primary care physicians, school nurses, physical fitness education teachers in secondary schools, and health professionals providing services to students through an institution of higher education’s health center; or

(2) obstetricians and gynecologists.

(c) TECHNICAL ASSISTANCE.—The Secretary, directly or through the award of grants or contracts, may provide recipients of grants or contracts under subsection (a) with technical assistance regarding the planning, development, and implementation of activities under such subsection.

(d) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there are authorized to be appropriated such sums as may be necessary for fiscal years 2011 through 2015.
SEC. 5. RESEARCH AND SURVEILLANCE.

(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall award grants or contracts to public or nonprofit private entities to—

(1) augment existing research efforts to evaluate, improve, and standardize methods for diagnosing bleeding disorders; and

(2) expand ongoing efforts to—

(A) determine the prevalence of bleeding disorders in the general population, including prevalence of bleeding disorders among adolescent women;

(B) identify symptoms, risk factors, and co-morbidities associated with bleeding disorders; and

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

(b) TECHNICAL ASSISTANCE.—The Secretary, directly or through the award of grants or contracts, may provide recipients of grants or contracts under subsection (a) with technical assistance regarding the planning, de-
development, and implementation of activities under such subsection.

(c) Authorization of Appropriations.—To carry out this section there are authorized to be appropriated such sums as may be necessary for fiscal years 2011 through 2015.

SEC. 6. REPORT.

(a) In General.—Not later than 5 years after the date of the enactment of this Act, the Secretary shall submit to the Congress a report on the results of activities under this Act.

(b) Contents.—At a minimum, the report under subsection (a) shall—

(1) catalog, with respect to bleeding disorder screening, health professional education, and surveillance—

(A) the activities of the Federal Government, including an assessment of the progress achieved under this Act;

(B) the portion of students in United States high schools and institutions of higher education who have received some form of screening for bleeding disorders as a result of programs under this Act;
(C) the number of health professionals who have received some form of bleeding disorder education as a result of programs under this Act; and

(D) the prevalence and incidence of bleeding disorders among the general population and among women; and

(2) make recommendations for the future direction of bleeding disorder activities, including—

(A) a description of how the Federal Government, as well as recipients of grants and contracts under this Act, may improve their screening and education programs to increase bleeding disorder diagnostic rates, including the identification of steps that may be taken to reduce—

(i) the prevalence of undiagnosed bleeding disorders; and

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

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

(C) an identification of programs and procedures that have most effectively and effi-
ciently increased bleeding disorder screening rates, and steps that may be taken to expand such programs and policies to benefit larger populations;

(D) a description of the services provided by hemophilia treatment centers, including information regarding any increase in utilization of such centers and any subsequent increase in resources necessary to ensure sufficient treatment for all those utilizing such centers; and

(E) recommendations for future research and interventions.

SEC. 7. DEFINITION.

In this Act, the term “State” includes the District of Columbia and any commonwealth, territory, or possession of the United States.