111TH CONGRESS
1ST SESSION

H. CON. RES. 147

Expressing the sense of Congress regarding people in the United States with bleeding disorders.

IN THE HOUSE OF REPRESENTATIVES

JUNE 11, 2009

Mrs. MCCARTHY of New York (for herself, Mr. BISHOP of Georgia, Ms. KILPATRICK of Michigan, Mr. LOBIONDO, Mr. CUMMINGS, Ms. BALDWIN, and Ms. BORDALLO) submitted the following concurrent resolution; which was referred to the Committee on Energy and Commerce

---

CONCURRENT RESOLUTION

Expressing the sense of Congress regarding people in the United States with bleeding disorders.

Whereas the lives of millions of people in the United States are impacted by both congenital and inherited bleeding disorders as patients, asymptomatic carriers, and caregivers;

Whereas studies estimate that as many as 1 in 50 people in the United States suffer from von Willebrand's disease, making it the most common inherited bleeding disorder in the United States;

Whereas von Willebrand's disease is characterized by frequent nosebleeds, recurrent bleeding from the mouth and gums often resulting in periodontal disease, swollen and painful joints, gastrointestinal bleeding, excessive bruising, postoperative bleeding, prolonged bleeding following minor injury, and menorrhagia (excessive menstrual bleeding);

Whereas studies estimate that 13 to 20 percent of women in the United States diagnosed with menorrhagia suffer from von Willebrand's disease;

Whereas an accurate diagnosis of von Willebrand's disease is sometimes difficult to obtain given current standard laboratory testing techniques, and, as a result, the majority of people in the United States who suffer from von Willebrand's disease remain undiagnosed;

Whereas failure to correctly diagnose von Willebrand's disease in women may lead to unnecessary hysterectomies resulting in increased risk from bleeding at the time of surgery;

Whereas effective medical treatments are available for von Willebrand's disease when it is diagnosed properly;

Whereas the onset of von Willebrand's disease symptoms usually occurs during adolescence and the symptoms can remain undiagnosed for several years;

Whereas programs designed to increase screening for von Willebrand's disease in adolescents could greatly improve diagnosis;

Whereas the Current Population Study estimates that 67 percent of high school graduates enroll in institutions of higher education;

Whereas prior to entering institutions of higher education, students have to receive a physical examination and meet immunization requirements; and

Whereas including a verbal screening tool for von Willebrand's disease as part of the medical requirement for entrance into institutions of higher education would increase early diagnosis, improve treatment, and lead to better health outcomes: Now, therefore, be it

Resolved by the House of Representatives (the Senate concurring), That it is the sense of Congress that—

(1) the Federal Government has a responsibility to—

(A) further the research that is needed to identify a more accurate laboratory test for von Willebrand's disease;

(B) increase funding for biomedical and psychosocial research on von Willebrand's disease, rare blood disorders, and hemophilia;

(C) continue to improve access to treatment centers for all individuals with bleeding disorders;

(D) improve public education and awareness of bleeding disorders; and

(E) support screening for von Willebrand's Disease as an aspect of the health requirements of all institutions of higher education;

(2) the Director of the National Institutes of Health should take a leadership role in the fight against bleeding disorders by acting through appro-

priate offices within the National Institutes of Health to provide Congress with a 5-year research plan for people with bleeding disorders;

(3) the Director of the Centers for Disease Control and Prevention should continue the critical role of the Centers in improving outreach about, treatment for, and prevention of the complications of people with bleeding disorders by facilitating an educational relationship between treatment centers, university health clinics, and undergraduate student populations;

(4) referral of a person with a bleeding disorder to a federally sponsored hemophilia treatment center is critical to comprehensive treatment of people with bleeding disorders;

(5) physicians should screen all women presenting with menorrhagia, especially severe menorrhagia, for von Willebrand's disease;

(6) patient advocate organizations and medical specialty societies should continue to collaborate on public education campaigns to educate people about bleeding disorders; and

(7) physicians should screen all adolescents attending institutions of higher education for von Willebrand's disease.

○