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# H. CON. RES. 314

Expressing the sense of Congress regarding women with bleeding disorders.

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IN THE HOUSE OF REPRESENTATIVES

OCTOBER 29, 2003

Mrs. MCCARTHY of New York (for herself, Ms. NORTON, Ms. CARSON of Indiana, Ms. MILLENDER-MCDONALD, Ms. MCCARTHY of Missouri, Ms. LEE, and Mrs. CHRISTENSEN) submitted the following concurrent resolution; which was referred to the Committee on Energy and Commerce

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# CONCURRENT RESOLUTION

Expressing the sense of Congress regarding women with bleeding disorders.

Whereas the lives of women are impacted by both congenital and inherited bleeding disorders as patients, asymptomatic carriers, and caregivers;

Whereas von Willebrand's disease is the most common inherited bleeding disorder;

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

Whereas studies estimate that 1 to 2 percent of women and girls in the United States suffer from von Willebrand's disease;

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

Whereas the majority of women in the United States who suffer from von Willebrand's disease are undiagnosed;

Whereas an accurate diagnosis of von Willebrand's disease is sometimes difficult to obtain given current standard laboratory testing techniques;

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

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 some women suffer from rare bleeding disorders, such as hemophilia C;

Whereas the study of these rare bleeding disorders often leads to breakthroughs in the understanding of more common disorders;

Whereas women are the carriers of the gene responsible for hemophilia;

Whereas individuals who are asymptomatic carriers of the gene for hemophilia fall into one of three categories—the daughter of a man with hemophilia, the sister of one or more boys with hemophilia, and the mother of a son with hemophilia; and

Whereas women are the primary caregivers and purchasers of health care in the United States: 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—

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

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

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

(2) the Director of the National Institutes of Health should take a leadership role in the fight against bleeding disorders in women by acting through appropriate offices within the National Institutes of Health to provide Congress with a 5-year research plan for women 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, treat-

ment, and prevention of the complications of women's bleeding disorders;

(4) physicians should screen all adolescent females presenting with severe menorrhagia for von Willebrand's disease before the initiation of hormone therapy in order to ensure that the treatment does not mask the diagnosis;

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

(6) hysterectomies for excessive menstrual bleeding should not be performed without first considering whether the patient may have a bleeding disorder;

(7) referral of a woman with a bleeding disorder to a federally sponsored hemophilia treatment center is critical to comprehensive treatment of women with bleeding disorders;

(8) physicians should conduct clotting factor analyses for carrier diagnosis and to facilitate genotyping of the disorder, and patients should be referred for genetic counseling when appropriate; and

(9) patient advocate organizations and medical specialty societies should continue to collaborate on

public education campaigns to educate women about bleeding disorders.

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