IV

107TH CONGRESS
2D SESSION

H. CON. RES. 380

Expressing the sense of the Congress regarding women with bleeding disorders.

IN THE HOUSE OF REPRESENTATIVES

APRIL 17, 2002

Ms. MCKINNEY 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 the Congress regarding women with bleeding disorders.

Whereas the lives of women are impacted by congenital bleeding disorders as patients, 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, post-operative bleeding, and prolonged bleeding following minor injury;

Whereas population prevalence studies have suggested a prevalence in the United States of approximately 1 to 2 percent of all women and girls and 13 to 20 percent of women diagnosed with menorrhagia;

Whereas the majority of women who suffer with 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 if it is diagnosed properly;

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

Whereas some women suffer from rare bleeding disorders such as fibrinogen (factor I) deficiency, prothrombin (factor II) deficiency, parahemophilia (factor V deficiency), proconvertin or serum prothrombin conversion accelerator deficiency (factor VII), Stuart-Prower factor deficiency (factor X), Hemophilia C (factor XI deficiency), Hageman factor deficiency (factor XII), and fibrin stabilizing factor (factor XIII);

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

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

Whereas obligate carriers of hemophilia may 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 hemophiliac son;

Whereas some obligate carriers of hemophilia may also be symptomatic for the disease;

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

Whereas a diagnosis of hemophilia raises both physical and psychosocial ramifications for carriers as well as caregivers: Now, therefore, be it

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

(1) physicians should screen all adolescents 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;

(2) physicians should screen all adult women presenting with menorrhagia for von Willebrand's disease, as objectively documented cases have determined that 13 to 20 percent of these women meet the criteria for diagnosis of mild von Willebrand's disease;

(3) hysterectomy for excessive menstrual bleeding should not be performed without the consideration of a bleeding disorder;

(4) 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;

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

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

(7) 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 basic biomedical research and psychosocial research in von Willebrand's disease, rare factor deficiencies, and hemophilia; and

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

(8) the Director of the National Institutes of Health should take a leadership role in the fight

against bleeding disorders in women by acting with appropriate offices within the National Institutes of Health to provide the Congress with a 5-year research plan for women with bleeding disorders; and

(9) the Director of the Centers for Disease Control and Prevention should continue the critical role of the Centers in improving outreach, treatment, and prevention of the complications of women's bleeding disorders.

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