

Global Focus on Women with Bleeding Disorders

When it comes to inherited bleeding disorders, it's not just about men; women bleed too. As the World Federation of Hemophilia (WFH) president Mark Skinner stated during his plenary at the World Hemophilia 2010 Congress: "No matter where these women live or their cultural background, the keys to providing psychosocial and therapeutic support to them are the same: education and outreach." This extends beyond the women themselves to their families, medical practitioners, and communities. Although a lot of progress has been made in diagnosis and care, women with bleeding disorders often have no idea that their symptoms are not normal and lack of awareness among healthcare professionals often delays proper diagnosis and treatment.

According to the WFH's 2008 Global Survey, due to the bleeding challenges of menstruation and childbirth, von Willebrand disease (VWD) affects more women than men. It has been estimated that up to 1.3% of the population may have an abnormality in the blood protein that causes VWD, but the percentage of those with bleeding symptoms is much less. There has been an increase in diagnosis among females in developed countries, with the number of female patients treated at U.S. hemophilia treatment centers growing by nearly 300% between 1991 and 2007. However, the U.S. Centers for Disease Control and Prevention found that women with VWD wait an average of 16 years from onset of symptoms to diagnosis. This means 16 years of significantly reduced quality of life that could include unnecessary surgical intervention, such as hysterectomy, due to lack of diagnosis or misdiagnosis. The situation is more serious in developing countries where proper testing is hard to come by and cultural norms can sometimes prevent women talking about their symptoms.

While VWD is the most common bleeding disorder affecting women, they are just as likely as men to inherit rare clotting factor deficiencies and platelet disorders. Even hemophilia can affect women: carriers of the disease can have low levels of factor VIII or factor IX, meaning that they experience similar symptoms as men with hemophilia. These symptoms can manifest themselves in carriers especially during menstruation, childbirth, and surgery. According to the World Health Organization, bleeding after childbirth (postpartum hemorrhage) is an important cause of maternal mortality, accounting for nearly one quarter of all maternal deaths worldwide. Given that women with bleeding disorders are at increased risk of postpartum hemorrhage, the need to identify these women and ensure they are properly managed is imperative.

The WFH's mission is to improve and sustain care for all people with inherited bleeding disorders. The organization has identified women as a keystone of its strategic plan, and is building a development program to identify women with VWD, rare factor deficiencies, and inherited platelet disorders throughout the world. Pilot outreach projects are underway in Lebanon, Egypt, and Peru, and the WFH has partnered with the World Health Organization to raise awareness of the risks of post-partum hemorrhage and maternal death.

An important goal of the WFH's global programs for women with bleeding disorders is awareness-raising among frontline medical practitioners. Hematologists are experts in bleeding disorders, but women usually go to their family physician or gynecologist when first faced with symptoms. As Dr. Paula Bolton-Maggs, chair of the WFH's VWD and Rare Bleeding Disorders Committee said, "We need to educate those who are giving first-hand care to women with symptoms suggesting a bleeding disorder, and stress the importance of collaboration between the members of the healthcare team to ensure proper management of these disorders through various life stages".

Content for this article was adapted from:

www.wfh.org

WFH president Mark Skinner's Hemophilia 2010 Congress plenary:

<http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2516.2010.02285.x/abstract>

http://www.wfh.org/index.asp?lang=EN&url=2/1/1_2_von_Willebrand_disease.htm

http://www.wfh.org/2/docs/Publications/VWD_WomenBleedingDisorders/VWD-brochure.pdf

To request materials about women with bleeding disorders, contact jlaliberte@wfh.org

For more information about WFH activities, visit www.wfh.org.

If you would like to request a photo to use with this article, contact WFH communications manager Liane Cerminara at lcerminara@wfh.org.

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