



# FOUNDATION FOR Women & Girls with Blood Disorders

## Recognizing and Identifying the Signs and Symptoms of Bleeding Disorders Among Women and Girls: How Mobile Health Clinics Can Help

You might already be aware that a typical mobile health clinic serves approximately 3,100 visitors each year, and of these, 42% are people under the age of 18 years, and many of these (54%) are women.<sup>1</sup>

But did you know that several of these women visitors might be experiencing heavy menstrual bleeding or possibly prolonged bleeding after a tooth is pulled? And such excessive or prolonged bleeding could be a sign for an undiagnosed bleeding disorder?

When a woman has a bleeding disorder, the symptoms often go unrecognized due to the lack of awareness among providers and patients. Yet, some studies have found that as many as 50 percent of females with heavy menstrual bleeding may have a bleeding disorder. That is where mobile health clinics like yours can help.

Mobile health clinics are an effective tool for screening populations for previously undetected conditions, including HIV/AIDS, hypertension, and diabetes to name a few. And since bleeding disorders in women and girls often go undiagnosed, the Foundation for Women and Girls with Blood Disorders (FWGBD) is working to make mobile health professionals aware of the signs and symptoms of bleeding disorders, as well as providing them with training and risk assessment tools that identify symptoms will ensure that more undiagnosed women get proper diagnosis and treatment.

### The Foundation for Women & Girls with Blood Disorders

In 2010, the Foundation for Women & Girls with Blood Disorders (FWGBD) was launched to serve as a single-site, single-source of information for physicians and healthcare providers. Its goal: correct diagnosis and optimal treatment and management of women and girls with blood disorders.

The mission of FWGBD is **to ensure that all women and girls with blood disorders are correctly diagnosed and optimally treated and managed at every life stage.** In particular, FWGBD has focused on educating providers on the single most common bleeding disorder among women and girls: von Willebrand disease.

### *About von Willebrand Disease*

von Willebrand disease (VWD) is the single most common bleeding disorder, affecting up to 1 to 2 percent of the US population<sup>2</sup> and accounting for 80 to 85 percent of all bleeding disorders.<sup>3</sup> While it affects both men and women, the consequences of VWD are more dire for women because of menstruation, pregnancy and childbirth.<sup>4</sup> Yet the majority of VWD cases are undiagnosed due to the lack of awareness among providers and patients. Often bleeding symptoms manifest in the reproductive tract and the condition is misdiagnosed as a gynecologic problem rather than an underlying bleeding disorder. This is such a significant problem, it prompted the stated objective in Healthy People 2020: increase the proportion of VWD females who are timely and accurately diagnosed.<sup>5</sup>

The “hidden” nature of VWD and women’s bleeding disorders is evidenced by the fact that so few women and girls who are affected have been identified and diagnosed. Even in the US, only slightly more than 10,000 women and girls with bleeding disorders have been diagnosed and connected to the network of 130 federally funded treatment centers across the country.<sup>5</sup> The Centers for Disease Control and Prevention (CDC) studied women already diagnosed and found that the average interval between a woman’s first seeking medical help for VWD symptoms and receiving an accurate diagnosis is 16 years.<sup>6</sup> In addition, the National Hemophilia Foundation-Harris interactive survey on bleeding disorders (2005) showed that 91 percent of women in the general population had never heard of VWD, yet 31 percent documented experiencing “heavy” periods, a major symptom of VWD.

Women and girls with VWD experience excessive bleeding related to menstruation, childbirth or other gynecologic issues.<sup>7</sup> If these issues are ignored, the patient may encounter life-threatening complications such as postpartum hemorrhage, a 5-fold increased risk of transfusion and maternal mortality rates 10 times higher than those for other women.<sup>4</sup>

### **Collaborating with Mobile Healthcare Professionals and Clinics**

Recently, FWGBD began collaborating with mobile health clinics to educate their healthcare professionals on the signs and symptoms of bleeding disorders among women and girls, as well as to increase the referral and access to specialty clinics for women and girls who have heavy menstrual bleeding to local Hemophilia/Thrombosis Treatment Centers (HTCs) for further assessment and if necessary, treatment.

The FWGBD plans to provide education and training presentations and symposia to mobile healthcare providers, and assist with the dissemination of education materials, such as risk assessments and other tools that they will need to assist with screening and referral among them.

FWGBD will also work with professionals to develop licensing exam questions for key specialties (i.e., dental health providers); offer continuing education and resources on its state-of-the-art Web site; and develop live Webinars, which are free of charge and will be archived for continued access.

## How You Can Be Involved

Taking steps to identify women and girls who are at risk for bleeding disorders or who have a bleeding disorder is not limited to healthcare professionals. The entire community can work together to increase the likelihood that females at risk or who demonstrate signs and symptoms of a bleeding disorder will be correctly diagnosed before problems become serious or lead to a crisis. The key is collaboration and follow-up. Here are some ideas that can be helpful:

### Help Spread the Word:

- Include questions about bleeding disorders on medical history intake forms, then follow-up with information about local HTC's or other appropriate places for care
- Assess women and girls, using appropriate screening tool questions, for the symptoms of a bleeding disorder
- Hold events such as a Bleeding Disorder Awareness Day to enable women and girls to find out whether they have symptoms of a bleeding disorder that warrant further testing
- Provide information about bleeding disorders and available services at a local HTC's or other appropriate places for care

FWGBD is an innovative organization that is dedicated to provider education, and will build and disseminate the education resource base in these important areas and would like to work with mobile healthcare clinics nationwide. Educated providers and other healthcare professionals, armed with evidence-based, and/or expert-consensus-based practices, will be able to optimally serve women and girls with blood disorders and enhance their quality of life.

If you would like more information about this project and how to participate, please contact Kerry Funkhouser, EdD, Director of Education at [kfunkhouser@fwgbd.org](mailto:kfunkhouser@fwgbd.org).

### What's at Stake: The situation is concerning

- The consequences of VWD are more dire for women because of menstruation, pregnancy and childbirth<sup>3</sup>
- Bleeding symptoms often manifest in the reproductive tract and the condition is misdiagnosed as a gynecologic problem rather than an underlying bleeding disorder
- Only slightly more than 10,000 women and girls with bleeding disorders have been diagnosed and connected to a Hemophilia/Thrombosis Treatment Center<sup>4</sup> or appropriate care
- The average interval between a woman's first seeking medical help for VWD symptoms and receiving an accurate diagnosis is 16 years<sup>5</sup>
- 91% of women in general population have never heard of VWD, yet 31% documented experiencing "heavy" periods, a major symptom of VWD

## References

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