

I am the Hemophilia Nurse Coordinator for the University of Miami and I work with over 350 children with different bleeding disorders. With support from the CDC, the University of Miami Comprehensive HTC has been in existence since 1987. Over the last 19 years, we have noticed a marked increase in the number of patients who have been identified with a disorder known as von Willebrand's Disease (vWD). This is the most common bleeding disorder, and, unlike Hemophilia, affects both men and women.

We are struck by the number of women with vWD who suffer from unusually heavy menstrual periods and hemorrhage after delivery. We realize that many young ladies experience menorrhagia so severe that it affects their activities of daily living. School nurses are in a special position to make a positive impact in these young girls' lives if they have the necessary education to help them recognize the symptoms as abnormal, and eventually refer them to local hematologist.

You would be astonished to learn how many of these women will undergo early hysterectomies - while in their late 20's and early 30's - as a means to control their menstrual bleeding because all other conventional therapies are ineffective. Many practitioners are not aware of this disorder, and, consequently, will miss the diagnosis when confronted with a woman with menorrhagia, inadvertently recommending what could turn out to be unnecessary medications or surgery.

While the expected (textbook) incidence of an underlying bleeding disorder is only about 3%, in reality, almost 10 % of women with unusual uterine bleeding turn out to have a bleeding disorder - most of these women had von Willebrand's Disease. Once diagnosed, the management relies on a nasal spray medication - Stimate - to control periods, and also a variety of oral medications, in many cases avoiding an unnecessary hysterectomy.

We at the University of Miami have made a commitment to reaching out to both the medical and lay communities to raise awareness of this disorder. We have been very well-received by physicians and nurses alike. The information about von Willebrand's has helped many families recognize symptoms, and therefore seek appropriate medical care. Women have become empowered by the information to insist upon evaluations to help establish their diagnosis and treatment.

The best place to go for information about bleeding disorders is the National Hemophilia Foundation website @ www.hemophilia.org for information on bleeding disorders in women try <http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=192&contentid=20&rptname=bleeding>

I believe that exposure of this problem in your community will provide much-needed health education to nurses, and as a result to adolescent girls who might be living with this condition. If you would like to discuss this idea in more detail, you can reach me or Dr Joanna Davis, M.D., our medical director, to the number provided.

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