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MARKET RESEARCH

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## Hereditary Bleeding Disorder – von Willebrand Disease – Seems to be Widely Undiagnosed and Untreated

A Harris Interactive survey conducted for the National Hemophilia Foundation provides new data which strongly suggests that most women with von Willebrand Disease are not diagnosed or treated for it.

Although other research (<http://www.cdc.gov/genomics/info/reports/files/print/menorrhagia.pdf>) has suggested that up to three percent of women have von Willebrand Disease, not one of the 1,083 women surveyed recently in a nationwide sample of women aged 18 to 45 had been diagnosed with this condition.

### What is von Willebrand Disease?

It is thought to be the most common bleeding disorder affecting up to 5% of the population. It is a genetic disease affecting both males and females. It is caused by a deficiency, or a defect, of a blood clotting protein, the von Willebrand factor, crucial to blood clotting.

Symptoms of the von Willebrand Disease include heavy and prolonged menstrual bleeding, prolonged and frequent nosebleeds, easy bruising and bleeding with teeth brushing or after dental surgery.

*Source: National Hemophilia Foundation*

The survey found that many women report symptoms, related to their periods, which are possible indicators of bleeding disorders, of which von Willebrand Disease is the most common.

- 10% of women aged 18 to 45 who have periods reported that their periods last more than seven days.
- 33% of women who have periods described their menstrual flow as heavy.
- 48% of women aged 18 to 45 have at one time bled through a tampon or napkin in an hour or less.

### *What's Ahead in Health Care News?*

In 2004, Harris Interactive and IMS Health will launch a global physician poll that provides insights on the perspectives and experiences of physicians in the U.S., U.K., France, Germany, Italy and Spain. Look for results in upcoming issues of the Harris Interactive *Health Care News*.

These are some of the results of a nationwide survey of 1,083 women aged 18 to 45 surveyed online by Harris Interactive between August 1 and 8, 2003. Copies of the full report can be obtained from the National Hemophilia Foundation (Contact: Anna DeSimone, Education Coordinator of Project Red Flag, a public education program about women and bleeding disorders, 1-800-424-2634, ext. 3705).

Just over half (54%) of the women surveyed reported that they, or someone they knew, had sought treatment from a doctor for a heavy period. However, not one of these women was diagnosed with von Willebrand Disease. The most common diagnoses were fibroids (25%), endometriosis (21%), hormonal imbalance (17%), polyps (8%), and cancer (3%). Fully 17% reported that no diagnosis was made.

Other research quoted by the National Hemophilia Foundation has concluded that:

- An estimated 20% of adolescent girls report problems with excessive menstrual bleeding.
- As many as 20% of women with heavy menstrual bleeding have von Willebrand Disease.

According to the Centers for Disease Control and Prevention (CDC), about five percent of hysterectomies are performed due to excessive uterine bleeding that may be caused by von Willebrand Disease. Other research has shown that up to 23% of women with von Willebrand Disease eventually had a hysterectomy.

## Reasons for misdiagnosis

Earlier this year, at a conference in Philadelphia sponsored by the National Hemophilia Foundation, Jeanne Lusher, M.D., Director, Division of Hematology/Oncology at Children's Hospital of Michigan and a professor at Wayne State University, called the underdiagnosis of von Willebrand Disease "tragic" because treatment is available that is safe and user-friendly. "But, before we can decide on treatment, physicians must first begin considering the possibility of von Willebrand Disease as an underlying cause," said Lusher.

The Harris survey found that only nine percent of women aged 18 to 45 have heard of von Willebrand Disease.

Several other factors have been reported which contribute to the frequent misdiagnosis or dismissal of the disease:

- Many physicians are unfamiliar with von Willebrand Disease.
- Heavy menstrual bleeding is often considered a gynecologic rather than a hematologic problem.
- Many people assuming bleeding disorders, like hemophilia, only affect males.
- Testing can produce false negatives, and the symptoms can be masked by hormonal changes.
- A woman whose female family members have similar bleeding histories may ignore the symptoms and resign herself to "dealing with it."

At the Philadelphia conference, Paul Brenner, M.D., Professor and Vice Chairman of the Department of Obstetrics and Gynecology at the University of Southern California, said, "When patients present with abnormal uterine bleeding, gynecologists must rule out bleeding disorders such as von Willebrand Disease." Dr. Brenner challenged conference attendees to preserve a woman's fertility, stating, "It is up to us."

## Methodology

This survey was conducted online within the United States between August 1 and 8, 2003 among a nationwide cross section of 1,083 women aged 18 to 45. Figures for age, sex, race, education and number of adults in the household were weighted where necessary to bring them into line with their actual proportions in the population. Propensity score weighting was also used to adjust for respondents' propensity to be online.

In theory, with probability samples of this size, one could say with 95 percent certainty that the results have a statistical precision of plus or minus three percentage points of what they would be if the entire adult population had been polled with complete accuracy. Unfortunately, there are several other possible sources of error in all polls or surveys that are probably more serious than theoretical calculations of sampling error. They include refusals to be interviewed (non-response), question wording and question order, and weighting. It is impossible to quantify the errors that may result from these factors. This online sample was not a probability sample.

*These statements conform to the principles of disclosure of the National Council on Public Polls.*

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**Harris Interactive** ([www.harrisinteractive.com](http://www.harrisinteractive.com)) is a worldwide market research and consulting firm best known for *The Harris Poll*®, and for pioneering the Internet method to conduct scientifically accurate market research. Headquartered in Rochester, New York, U.S.A., Harris Interactive combines proprietary methodologies and technology with expertise in predictive, custom and strategic research. The Company conducts international research through wholly owned subsidiaries—London-based **HI Europe** ([www.hieurope.com](http://www.hieurope.com)) and Tokyo-based **Harris Interactive Japan**—as well as through the Harris Interactive Global Network of local market- and opinion-research firms, and various U.S. offices. EOE M/F/D/V

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