CSL Behring

ROSWELL WOMAN PARTICIPATING
IN NATIONAL CAMPAIGN TO FOCUS ATTENTION
ON UNDER-DIAGNOSED BLEEDING DISORDER

von Willebrand Disease Can Lead to Serious Health Complications

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November 19, 2007 – Von Willebrand disease (VWD) is the most common hereditary bleeding disorder in the United States, yet many people may not realize they have it. While VWD occurs in both males and females, women may suffer severe health consequences if their condition is not correctly diagnosed.

Women with VWD are at greater risk for miscarriage, for life-threatening bleeding following surgery or childbirth and for undergoing unnecessary hysterectomies. Studies conducted by the Centers for Disease Control and Prevention (CDC) show that every year 30,000 women undergo hysterectomy for the diagnosis of abnormal uterine bleeding. Many of these women have an undiagnosed bleeding disorder and their condition could be managed medically. According to the CDC it takes a woman, on average, 16 years to get a diagnosis for VWD.

Karen Giblin of Roswell, a recognized women's healthcare advocate and founder of the Red Hot Mamas, the largest menopause education program in the U.S., is able to successfully manage her VWD. She is hoping she can focus attention on this often under-diagnosed disorder by sharing her story. Karen, along with Hemophilia of Georgia, is participating in the National Hemophilia Foundation's Project Red Flag campaign, *Real Talk About Women's Bleeding Disorders,* that educates women about the signs and symptoms of VWD.

"My story is very typical of the millions of women who have VWD and don't realize it," said Karen. "I hope that by sharing my own experience I can raise awareness of the symptoms of

VWD or 'red flags' that should prompt women to see their physicians for diagnosis and treatment."

Karen was only diagnosed with VWD last year, despite the fact that she had displayed many of the classic symptoms of the disorder since childhood and had her first severe bleeding episode after a tonsillectomy at age 12. Throughout her life, Karen had excessive and prolonged bleeding episodes with her menstrual cycles. At age 40, she underwent an oophorectomy (a hysterectomy with removal of the ovaries) and required platelet transfusions. After experiencing severe bruising from a slight bump while on a sailing trip, Karen's friend, a physician, suggested she consult with a hematologist. After consulting with a hematologist who is part of the Comprehensive Hemostasis Program at Emory University and Children's Healthcare of Atlanta, Karen was finally diagnosed with VWD and has minimized the impact of VWD despite her very busy schedule.

According to currently available statistics from the CDC, von Willebrand disease may affect up to 1 to 2 percent of Americans, although more realistic estimates place the figure of VWD patients who bleed at 0.1 – 0.2%. Either way, anywhere from 500,000 to 2.8 million people may have VWD - about half of whom are women. As in Karen's case, VWD frequently manifests in women as a gynecological problem, such as heavy or prolonged menstruation. This leads the patient and her doctor to believe the problem is gynecologic. It is, in fact, hematologic.

"Von Willebrand disease can be diagnosed by taking a careful patient history of bleeding and confirming the disorder by the results of blood tests," said Tom Abshire, M.D., Professor and Director of the Comprehensive Hemostasis Program at Emory University and physician at the Aflac Cancer Center and Blood Disorders Service of Children's Healthcare of Atlanta.

"While there is no cure for VWD, treatment is readily available and can help prevent complications. But the disorder must be *properly* diagnosed," said Christine Kempton, M.D., Assistant Professor in the Aflac Cancer Center and Blood Disorders Service of Children's Healthcare of Atlanta and member of the Comprehensive Hemostasis Program.

Project Red Flag is NHF's national public awareness campaign created to educate women and their doctors about diagnosing and treating bleeding disorders and is supported by an educational grant from CSL Behring.

"Von Willebrand disease is a serious health issue for women," said Howard A. Balsam, interim chief executive officer of the National Hemophilia Foundation. "We encourage all women to increase their knowledge of bleeding disorders and to see their doctor immediately if they suspect they have symptoms."

Hemophilia of Georgia provides services and support for people in Georgia who have inherited bleeding disorders, including von Willebrand Disease. Founded in 1973 by a group of Georgia families, Hemophilia of Georgia exists so that people in Georgia affected by bleeding disorders live as normally and productively as possible.

The Hemophilia of Georgia full-time VWD Community Outreach Nurse is an expert in VWD treatment and diagnosis. In addition to visiting patients in their homes, she frequently makes presentations to medical professionals, community organizations, and women's groups to build awareness of the disease and its treatment options. Hemophilia of Georgia's social workers provide many services such as counseling and community resource planning to help people with VWD or other bleeding disorders. And, Hemophilia of Georgia's non-profit pharmacy provides convenient home delivery of VWD medications at competitive prices.

Additional resources are available from Hemophilia of Georgia. Contact the von Willebrand Community Outreach Nurse at (770) 518-8272 phone or (770) 518-3310 fax or visit www.hog.org to learn more.

For more information on VWD visit the Project Red Flag web site at www.projectredflag.org or call the National Hemophilia Foundation's Information Resource Center at 1-800-42-HANDI (email to handi@hemophilia.org). Trained staff members are available Monday through Friday, 9 a.m. to 5:00 p.m. EST to answer your requests.

About von Willebrand Disease

Von Willebrand disease is caused by a deficiency or abnormality of the von Willebrand factor, a protein in the blood that is necessary for normal blood clotting. Men and women are equally likely to be affected by VWD. VWD is classified by 3 types, ranging from type 1 (the most common (75-80%) and mild), type 2 (15 – 20%) to type 3 (the most severe and least common (<5%).

Women with VWD are more likely to experience heavy, prolonged menstruation. Other common symptoms of VWD include frequent nosebleeds, gum and mouth-related bleeding, easy bruising and bleeding with lacerations and surgery. Bleeding can be mild or serious (usually with surgery) and can occur as a result of injury, or without any obvious cause. More serious symptoms are related to bleeding with trauma or surgery and can sometimes include bleeding into joints or internal organs. The VWD patient may require special care during dental procedures, surgery and childbirth.

Treatments for VWD may include desmopressin acetate to release stored von Willebrand factor; von Willebrand factor replacement therapies, aminocaproic acid to help keep the blood clot intact (especially useful for mouth and nose bleeding) and oral contraceptives to reduce menstrual bleeding and raise von Willebrand factor in the bloodstream.

About the National Hemophilia Foundation and Project Red Flag

The National Hemophilia Foundation is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing the complications of these disorders through education, advocacy and research.

Established in 1948, the National Hemophilia Foundation is a non profit 501(c)3 organization with chapters throughout the country. Its programs and initiatives are made possible through the

generosity of individuals, corporations and foundations as well as through a cooperative agreement with the Centers for Disease Control and Prevention (CDC).

For more information about the National Hemophilia Foundation visit www.hemophilia.org..

About CSL Behring
CSL Behring is a global leader in the plasma protein biotherapeutics industry. Passionate about improving the quality of patients' lives, CSL Behring manufactures and markets a range of safe and effective plasma-derived and recombinant products and related services. The company's therapies are used in the treatment of immune deficiency disorders, hemophilia, von Willebrand disease, other bleeding disorders and inherited emphysema. Products include Humate P® Antihemophilic Factor/von Willebrand Factor Complex (Human) Dried, Pasteurized, for the treatment of von Willebrand Disease, and Helixate® FS a recombinant factor VIII treatment for hemophilia A. Other products are used for the prevention of hemolytic diseases in the newborn, in cardiac surgery, organ transplantation and in the treatment of burns. The company also operates one of the world's largest plasma collection networks, ZLB Plasma. CSL Behring is a subsidiary of CSL Limited, a biopharmaceutical company with headquarters in Melbourne, Australia. For more information, visit www.cslbehring.com.

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