

# NEWS FROM HEMOPHILIA FEDERATION OF AMERICA



**FOR IMMEDIATE RELEASE**  
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## **Families Throughout the U.S. Celebrate World Hemophilia Day** ***April 17 Designated to Create Public Awareness about Bleeding Disorders***

*Washington, DC*– Today, Tuesday, April 17, tens of thousands of families across our nation and around the world are celebrating World Hemophilia Day to raise awareness of bleeding disorders.

“World Hemophilia Day brings public awareness about bleeding disorders and encourages the development of improved treatment,” said Kimberly Haugstad, Executive Director of Hemophilia Federation of America (HFA). “Worldwide, 1 in 1,000 women and men have a bleeding disorder and 75% of them still receive inadequate or no treatment at all. Today is about shining a light on a disorder too few understand, and too many are affected by. HFA stands with thousands of families around the world today in calling for better treatments and quality of life for those affected by bleeding disorders.”

World Hemophilia Day focuses attention on the importance of comprehensive health care. Such care is at the heart of major changes currently happening to our health care system and can positively impact the health of families.

Comprehensive care is particularly important to treating the physical, emotional, psychological, social, and educational needs of people with hemophilia and other bleeding disorders.

An estimated 3 - 5 million Americans have a bleeding disorder, including about 20,000 with hemophilia -- affecting all ethnic and economic groups.

**\*Photos and personal stories available and we can assist in setting up interviews.**

**\*\*World Hemophilia Awareness Video:** <http://hemophiliafed.org/2012/04/10/world-hemophilia-day/>

### About Bleeding Disorders

Bleeding disorders are a group of conditions in which there is a problem with the body's blood clotting process. These disorders can lead to heavy and prolonged bleeding, either spontaneously or after an injury. Individuals with bleeding disorders lead productive lives with regular and ongoing access to needed treatments, therapies and when specialized medical professionals are available.

Hemophilia and von Willebrand Disease (vWD) are two of the most common types of bleeding disorders and are lifelong, genetic illnesses in which one of the proteins needed to form blood clots is missing or reduced.

### About Hemophilia

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Hemophilia is a sex-linked, hereditary blood clotting disorder. The underlying cause is missing or deficient protein -- known as factor --that is needed for blood to clot. The bleeding can occur spontaneously and/or after injury. Bleeding episodes may be external or internal into joints, muscles, the abdominal cavity, the brain, and other organs. Untreated bleeds can lead to crippling deformities of the joints or life threatening bleeds within the body.

Currently, there is no cure, and medication needed to treat the disorder typically costs \$60,000 to \$300,000 annually per person.

## About von Willebrand

Von Willebrand Disease (vWD) is an inherited bleeding disorder with similarities to hemophilia. vWD is caused by a decreased or defective function of a protein called von Willebrand factor, which is necessary for normal blood clotting and affects men and women.

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*Hemophilia Federation of America is a national 501(c) (3) organization consisting of more than 30 member organizations and numerous individual members who offer assistance and grassroots advocacy education on behalf of the bleeding disorders community. Incorporated in 1994, the (delete) HFA provides programs and services to improve the quality of life for persons with hemophilia, von Willebrand disease (VWD) and other rare bleeding disorders.*

*For more information, visit our website at [www.hemophiliafed.org](http://www.hemophiliafed.org) or call 1-800-230-9797.*