

# NEWS FROM HEMOPHILIA FEDERATION OF AMERICA



**FOR IMMEDIATE RELEASE**  
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## **Hemophilia Federation of America Observes Rare Disease Day**

*February 29, 2012 Marks the Fifth International Rare Disease Day*

Washington, D.C. – The Hemophilia Federation of America (HFA) will join the National Organization for Rare Disorders (NORD), and others around the world in observing Rare Disease Day on February 29, 2012. The purpose of this day is to focus attention on the needs of patients and families affected by rare diseases.

In the U.S., any disease affecting fewer than 200,000 Americans is considered rare. According to the National Institutes of Health (NIH), there are nearly 7,000 such diseases affecting nearly 30 million Americans -- hemophilia is one of them.

According to the Center for Disease Control and Prevention (CDC), hemophilia is a rare genetic bleeding disorder, which affects only 19,000 people in the United States and results in excessive bleeding. 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.

“The celebration of Rare Disease Day has created a public awareness campaign and international advocacy movement for the millions of people living with a rare disorder,” said Kimberly Haugstad, HFA Executive Director. “I am proud that HFA is participating in this important day to help spread recognition of rare diseases, like hemophilia, as a global health challenge.”

In 2008, Rare Disease Day began in Europe and was launched by EURORDIS (Rare Diseases Europe). Last year, it was observed in more than 60 countries, with a national sponsor in each country -- NORD is the sponsor in the U.S.

HFA is proud to be one of 500 patient organizations, government entities, research institutions, and companies developing treatments to participate and observe, “Rare but Stronger Together, -- the theme for Rare Disease Day 2012.

To recognize Rare Disease Day 2012, HFA created a short video to bring awareness and encourage patients to ask their governor to proclaim Rare Disease Day in their state. Video can be viewed at: <https://vimeo.com/36321215>.

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

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