

ABOUT HEMOPHILIA AND VWD

Hemophilia is an inherited bleeding disorder predominantly affecting males, and may result in prolonged bleeding primarily into muscles and joints. Hemophilia affects approximately one in every 7,500 males in the U.S.A. The two main forms are hemophilia A (factor VIII deficiency) and Hemophilia B (factor IX deficiency).

It is a rare bleeding disorder where blood clotting is deficient, and a condition where light bumps and bruises can result in serious internal hemorrhaging. Today, persons with severe, moderate and mild hemophilia can be treated by infusion of either plasma derived or recombinant factor products to function as the natural blood-clotting elements they lack.

While these proven therapies are vital to the support of life and relatively normal living for those affected, these treatments are expensive and sometimes painful. A comprehensive treatment program goes well beyond the regular infusion of factor products. Exercise, diet, and preventive activities are also very important elements within a prescribed therapy program.

Von Willebrand Disease (VWD) is the most common of inherited disorders, and may affect both males and females. People with VWD lack a certain protein called the "von Willebrand factor", which helps the platelets to stick to the blood vessel for normal clotting. The disease is estimated to occur in 1% to 2% of the population. von Willebrand Disease (like hemophilia) may be mild, moderate, or severe, and may be treated with medication or factor products.

MEMBERSHIP

Membership opportunities are available for persons with bleeding disorders, families, friends of persons with a bleeding disorder, health care professionals, industry and corporate sponsors. Please visit our website at www.hemophiliaofiowa.com for a membership application and information.

OPPORTUNITIES TO SERVE

Hemophilia of Iowa has a Board of Directors and various committees that give individuals or family members a chance to use their skills, talents and interests toward improving the quality of life in the bleeding disorders community.

COMMITTEES

- Newsletter
- Advocacy
- Membership
- Annual Meeting
- Education
- Scholarship
- Camp Superfly
- Fundraising
- Support Group
- Golf
- Public Relations / Information
- By-laws / Policies
- Medical Advisory
- Website / Technical



HEMOPHILIA OF IOWA

Hemophilia of Iowa, Inc. is an independent, non-profit, tax-exempt 501(c)(3) organization.

Our goal is to assist anyone in Iowa affected with a blood coagulation disorder to become healthier and more self-sufficient.

Visit our website:

www.hemophiliaofiowa.com

HOI Toll-Free Phone:

1-866-464-8061



*Serving persons
and families with
hemophilia and other
inherited bleeding
disorders . . .*

**HEMOPHILIA
OF IOWA, INC.**



Mission
"To provide education and support for persons with bleeding disorders and their families and friends."



PROGRAMS & SERVICES

Information, advocacy and support for the bleeding disorders community are our main focus through partnering with the staff of the U of Iowa Hemophilia Treatment Center, industry, government and other resources.

Among our many valuable services are:

Annual Meeting & Exhibits – A weekend of education and fun for persons with bleeding disorders, their families and friends, featuring quality programs on a broad range of related topics by key persons in the bleeding disorders field.

Newsletter - The "Bloodline" is published quarterly to report on the latest organizational news, programs, and events, as well as the latest technical, research, and related financial news on the local, national and world bleeding disorders scene.

Emergency Assistance – Limited financial assistance is available for persons or families experiencing financial hardship due to bleeding disorder related expenses.

Summer Camp – A unique summer experience for kids ages 6 to 17 with bleeding disorders and their siblings. An opportunity to bond with peers as they learn to manage their conditions under medical supervision. An opportunity to share experiences, challenges and stories of hope.

Scholarships – A number of post-secondary scholarships are presented each year to eligible students with hemophilia, related bleeding disorders, and certain family members.

Adult Retreat – An adults only retreat for a little quality time away from some of the stresses that can occur when a child or other family member has a bleeding disorder.

First Steps – A support group offering educational programs, information and "just being there" for families with newborn and younger children diagnosed with a bleeding disorder.

Golf – The Dude Cremer Memorial Golf Tournament is held each year on one of Iowa's nicest courses, to help raise funds to support all HOI programs throughout the year.

Family Camp – A unique summer experience for kids ages 3-5 and their families. Families experience a weekend of camping activities that create camaraderie among families and valuable knowledge of hemophilia camp before children experience Summer Camp at age 6.

Educational Programs– At various times throughout the year, the Education Committee selects educational programs, based on requests and identified needs, to be offered around the state of Iowa.

COMPREHENSIVE CARE

Clinic visits at a Hemophilia Treatment Center (HTC) are encouraged on a regular basis, usually once a year, to review and evaluate the status of a person with bleeding disorders.

Annual comprehensive evaluation includes:

- Assessment of Bleeding Episodes and Treatment
- Physical Examination
- Nursing Assessment with Teaching
- Diagnosis, Evaluation & Treatment of Affected Individual
- Physical Therapy Assessment
- Home Therapy Instructions
- Coagulation Testing
- Psychosocial Counseling
- Recommendations for Care & Treatment
- Genetic Testing & Counseling
- HIV Antibody Testing and Counseling as needed
- Financial Counseling
- Referral to Local and National Resources as needed



Hemophilia of Iowa is a strong, united and effective voice advocating for the bleeding disorders community at the state and national levels.



Hemophilia of Iowa events give persons of all ages the chance to have fun and associate with others their age who also have bleeding disorders.



Hemophilia of Iowa is proud to award several thousand dollars in post-secondary scholarships

IOWA HEMOPHILIA TREATMENT CENTER

University of Iowa Hospitals and Clinics
Hemophilia Treatment Center
Department of Pediatrics
200 Hawkins Drive
Iowa City, Iowa 52242

Toll Free in Iowa: 1-800-272-3547

Outside Iowa: 1-319-356-4277

See link on HOI website:

www.hemophiliaofiowa.com



Under the watchful eye of trained nursing and medical personnel, children can learn at an appropriate age to gradually take control of their own care.