

# What is Hemophilia?

You may have heard hemophilia referred to as the “Bleeders Disease.” Adults and children with this condition experience both internal and external bleeding due to the lack of a clotting factor in their blood.

People with hemophilia can face persistent challenges. They must be very careful about minor injuries the rest of us would hardly notice. Treatment involves regularly infusing the missing clotting factor into the bloodstream.

Bleeding disorders—like hemophilia—are lifelong conditions that can affect anyone. Treatments, which can cost \$10,000 a month or more, can never be stopped. There is no cure.

## Hope

Many advances have been made in the treatment of hemophilia. The development of laboratory-made clotting factor has led to the virtual elimination of infusion-related infection with HIV or other viruses.

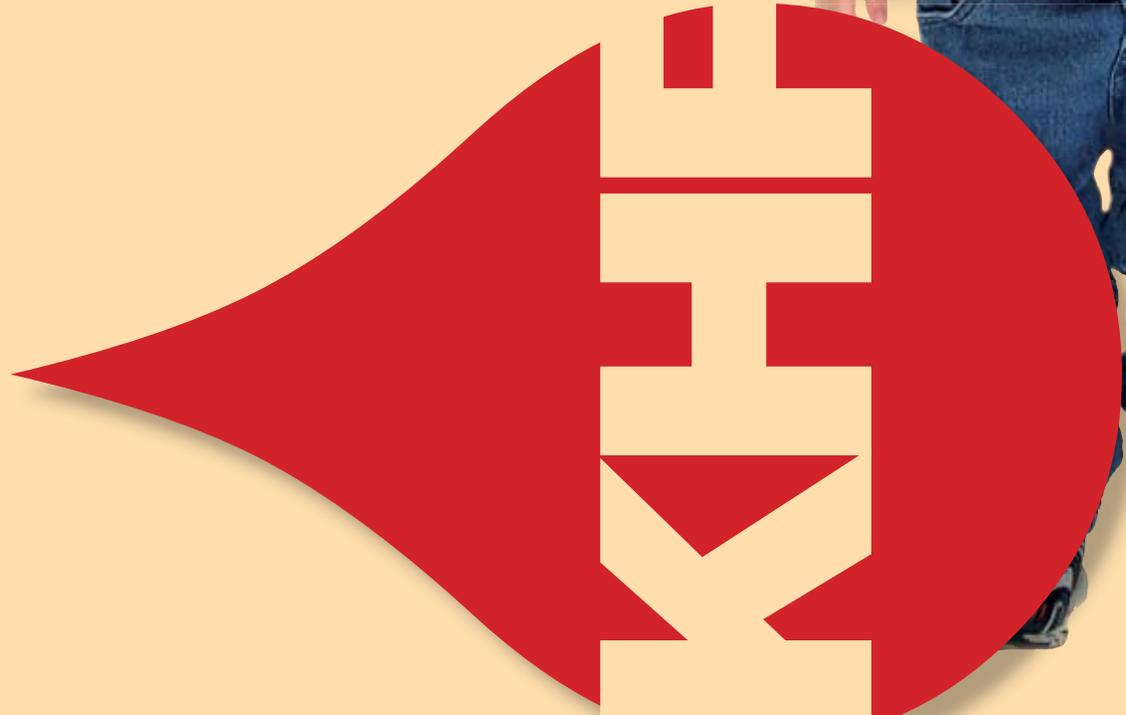
Thanks to changes like these, people with hemophilia, von Willebrand disease, or a similar bleeding disorder can now participate in a healthier, more active life.



**KHF is  
there when  
it counts.**



**Kentucky Hemophilia Foundation, Inc.**  
1850 Taylor Avenue, Suite #2  
Louisville, KY 40213-1594



# Kentucky Hemophilia Foundation



## **About KHF**

The Kentucky Hemophilia Foundation (KHF) is a statewide health agency serving all those affected by hemophilia, von Willebrand disease and similar bleeding disorders. One of the most important things we do is to help the newly diagnosed and their families cope with the many life changes that these disorders can cause.

We help hundreds of families across Kentucky whose lives revolve around incurable bleeding disorders and related health complications. By providing a safety net of education, advocacy, and support services, we help them through the daily challenges of living with a chronic illness.

## **Education & Advocacy**

Through seminars, health fairs, and educational meetings, we strive to keep families up-to-date on the latest research news, treatment advances, and legislative actions concerning bleeding disorders. We also make presentations to schools and community groups and provide regular mailings of education materials. Our advocacy includes cooperative linkages with community services providers and other essential services professionals.

## **We also provide the following:**

- Educational Literature and Video Resource Library
- Annual education meeting with nationally known speakers
- A scholarship for post-secondary educational pursuits is awarded twice per year
- The C.A.R.E.S (cultural and recreational enrichment scholarship) program – for children with hemophilia or von Willebrand disease, up to age 15
- Speaker's Bureau
- *Hemosphere* newsletter with updates on advocacy, education, and KHF events and activities
- Toll-free "800 Answers" Line

## **Support & Outreach**

The changes brought about by learning a child has a bleeding disorder are life altering. The support of KHF helps affected families through a lifetime of transitions. Our *First Step Outreach* works with the families of the newly diagnosed, and the phone support network gives them a much needed source of information and encouragement. We also have many social and recreational gatherings throughout the year, and our on-line blog allows families to communicate regularly.

## **Other support services we offer:**

- Bicycle Helmets, Child Safety Items
- Clinic, Home, and Hospital Visits
- Emergency Financial Assistance
- Sponsorships to Educational and Support Meetings
- Birthday Card and Gift Program
- KWOP (Women w. Bleeding Disorders Outreach Project)
- "On the Road" Outreach to Rural Areas
- Peer Outreach

## **Healthy Living & Independence**

Our summer camp is a recreational and educational five-day residential program for children who have a bleeding disorder and their unaffected siblings, ages 7-15; and youths, ages 16-18, who have a bleeding disorder and aspire to become camp counselors. Eligible participants must be residents of Kentucky and/or receive treatment in Kentucky. Summer camp combines life skills education and leadership development with outdoor adventure. Summer camp empowers children and youths living with bleeding disorders to be as healthy and active as possible "just like any other young person" while learning to manage their lifelong condition.

If you or someone you know is affected by a bleeding disease, we can help. Call or visit our web site for more information.

## **Contact us at:**

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