

# KENTUCKY HEMOPHILIA FOUNDATION

*Keeping Healthy Families*



How often do you knick yourself shaving, bang your elbow on a door jam, or stub your toe as you make your way to the bathroom? Chances are, like most of us, these are nearly daily occurrences, and though painful they are not life threatening. For thousands of people across the country and many in the state of Kentucky with hemophilia and similar bleeding disorders, a small bruise or cut can warrant a trip to the emergency room and requires vigilance on a daily basis to ensure good health.

## KHF's Vision

KHF strives to make a positive impact on individuals' lives who have to cope with the daily challenges of living with a chronic condition.

## What is KHF?

The Kentucky Hemophilia Foundation (KHF) is the Kentucky Chapter of the National Hemophilia Foundation (NHF). KHF is a private, non-profit organization established in 1960 as a support system for families affected by hemophilia and similar bleeding disorders. We fill an important role for people impacted by these conditions throughout the Commonwealth. KHF serves individuals and their families through support, education, and advocacy. More than 1000 Kentucky families used our services last year.

## Whom We Serve

Bleeding disorders like hemophilia and von Willebrand disease (vWD) can affect anyone. There are approximately 800 individuals in Kentucky living with hemophilia and many more with vWD, a similar bleeding disorder. These rare bleeding disorders have no cure, require a lifetime of expensive treatment, and prevent people who have them from participating in activities that might lead to bruising or bleeding. Currently available treatment requires clotting factor to help the blood clot to be injected several times a week, every week of their lives. The costs for treatment often exceeds \$250,000 a year.

## What Are Bleeding Disorders?

Hemophilia and von Willebrand disease (vWD) are inheritable, genetic bleeding disorders that cause an individual's blood not to clot properly. The clotting factor in blood normally stops the bleeding when you cut or bruise yourself. Adults and children living with these condition experience frequent, lifelong bleeding episodes due to a lack of clotting factor in their blood. For someone with hemophilia or a similar bleeding disorder, the bleeding cannot be stopped and even minor scrapes and abrasions can become serious. Bleeding into joints, muscles, and organs can occur spontaneously causing chronic pain, arthritis, other health related problems that worsen over time. They can also face secondary health issues, and persistent other challenges to daily living.

## Why We Serve

The changes brought about by learning your child has a chronic condition are life altering. Having a support system that is there for you along a lifelong journey with a bleeding disorder is vitally important. We are here to:

- Provide a Kickstart Health & Fitness Awareness
- Provide a Kind Harbor for Kids and their Families
- Offer Humor, Friendship & Support

Since its incorporation in 1960, KHF has grown into a statewide health agency serving Kentucky's bleeding disorders community.

## How We Serve

This year, we commemorate our 60th service anniversary in the state of Kentucky serving affected families. The key components of our programs and services are:

- Advocacy
- Support
- Education
- Health and Independence

We facilitate support, empowerment, and advocacy activities; supply information and referrals through a toll-free number; offer educational seminars about bleeding disorders and how to best live with them; provide a residential summer camp to allow children to have a shared summer experience others take for granted, and bring families together for activities and to let them know they are not alone.

## Hope

Hemophilia is an invisible condition to most of us. Right now, these bleeding disorders cannot be prevented and treatment lasts a lifetime. Many advances have been made in the treatment of hemophilia and similar bleeding disorders. The development of laboratory-made recombinant clotting factor has led to the elimination of a number of clotting factor-related viral infections, and the more recent development of a product that is injected under the skin and requires fewer "shots" has increased hope for a cure.

Kentucky Hemophilia Foundation never charges for our services. KHF needs your help to continue to make our services possible. Despite our best efforts we continue to struggle to provide the support these families need. Your contribution will make a difference in the lives of families across the state who live with hemophilia. To those suffering, a little assistance goes a long way.