



# NEBRASKA CHAPTER NATIONAL HEMOPHILIA FOUNDATION

The National Hemophilia Foundation, Nebraska Chapter (NENHF) is dedicated to finding cures for inheritable blood disorders and to addressing and preventing the complications of these disorders through research, education, and advocacy enabling people and families to thrive.

## Education

Year-round education and learning opportunities for all ages on living with and navigating all the challenges that come with a bleeding disorder. Education is offered both in person and virtually.

## Advocacy

Local and National Advocacy efforts focused on ensuring policies, legislation, access, and insurance issues are met for our bleeding disorders community. Your voice matters, let it be heard.

## Awareness

Bring bleeding disorder awareness to the larger Nebraska community through events and outreach focused on diagnosis, support, and community connections.

## Support

We offer support in advocacy, navigating the health systems, financial assistance and whatever challenges that you may encounter related to having a bleeding disorder. We are here to support you in whatever way you need.

## Connection

Connect to a larger bleeding disorders community and family. You should never feel like you are going through this alone. We offer an extensive local community connection and network.

## Who do we serve?

We serve individuals and families affected by inheritable bleeding disorders in Nebraska and Western Iowa. These include but are not limited to: Hemophilia A, Hemophilia B, Von Willebrand Disease, Rare Factor deficiencies and other bleeding disorders.

Get Involved.

[www.nebraskanhf.org](http://www.nebraskanhf.org)

402.742.5663 | [nebraska@hemophilia.org](mailto:nebraska@hemophilia.org)

# Programs and Services

## Patient Education Programs

Conferences & Meetings – NENHF offers travel grants for families to attend the Bleeding Disorders Conference annually.

Family Education Weekend – A weekend of education that focuses on educational & networking opportunities. National speakers and experts in the field of bleeding disorders are brought in with breakout tracks for multiple subgroups.

Parent Information & Networking Group (PING) - Held twice yearly, PING brings together newly diagnosed or newly identified families and parents with children who have a bleeding disorder.

Industry Partner Dinners – educational dinner seminars in partnership with several Hemophilia Treatment Manufacturers & Home Health Care Infusion Companies.

## Advocacy Outreach State & Federal

Nebraska State Advocacy Day – Held yearly, this program brings families to their local state legislator to discuss bleeding disorders and the legislation that may be impacting them.

Washington Days – A three day conference in Washington, DC where a contingent of Nebraska Families meet with their elected officials and educate them on bleeding disorders and encourage them to support legislation that directly impacts them.

## Bleeding Disorder Children and Family Camp Opportunities

Family Camp – This weekend camping experience is for families and provides an opportunity to build bonds in a camp setting and challenge expectations on adventuring with a bleeding disorder.

Bleeding Disorder Camp - Full week kid's camp is available in partnership with Midwest Hemophilia Association, transport is provided.

## Publications

Big Red Factor Newsletter – Our digital newsletter contains current research, hemophilia treatment updates, and upcoming Programs.

## Financial Assistance Program

This fund is set up to help families who are in need of emergency financial assistance to cover such things as rent, utilities, insurance, co-pays, and medical expenses.

## Networking/Social Events

Harvest Festival – Held annually at Roca Pumpkin Patch, families come together for lunch & networking and then are able to go and enjoy a wonderful day at the Pumpkin Patch.

Specialty Programming – Teen Program, Adult Men and Women Programming and so much more.

## Awareness/Fundraising Activities

Unite For Bleeding Disorders Walk – The Unite Walk is the Nebraska Chapter's largest fundraising and awareness event held each fall.

Infusion: A Bloody Mary Mix Off – A bloody mary competition between local Omaha bars. This event brings awareness to the community about bleeding disorders who may not have known about them before.

**This list is not all inclusive. Visit our website for ongoing program updates.**

**Programs are being added and updated constantly. If you see a need we aren't meeting, please let us know.**

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[www.nebraskanhf.org](http://www.nebraskanhf.org)



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