



NEBRASKA CHAPTER

Big Red Factor

Our Mission

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

The material in this newsletter is provided for your general information only. The Nebraska Chapter does not give medical advice or engage in the practice of medicine. NBDF-NE does not recommend particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment

In this newsletter you will find:

Upcoming programs, recaps on past events, news, and more. Keep Reading!



Letter from the Nebraska Chapter

Dear Nebraska Chapter Community,

As many of you know, our chapter recently experienced a significant change with the departure of our Executive Director after 10 years of leadership. This transition marks the end of an era, and while change can feel uncertain, I want to reassure you that our mission remains unwavering: to support, educate, and empower individuals and families in the bleeding disorders community.

This community has personally empowered me in ways I never imagined. As a caregiver and spouse, I've felt the strength, compassion, and resilience that define who we are. It's because of that experience that I am so passionate about continuing to serve and uplift each of you. My commitment is to ensure that every family and individual feels supported, heard, and valued.

Moving forward, I am excited to explore new opportunities to expand our outreach across Nebraska. We want to reach families in every corner of the state, and your connections can make a huge difference.

If you know of organizations, healthcare providers, or community groups that could help us spread awareness and resources, please reach out to me. Together, we can build bridges and strengthen our network.

Please remember—I am here for you. Whether you need guidance, resources, or simply someone to listen, don't hesitate to contact me. Your ideas, feedback, and involvement are what keep this community thriving.

Thank you for being such an essential part of our chapter. Your resilience and support inspire everything we do, and I look forward to continuing this journey with you.

Let's stay connected! You can reach me anytime at mdietrich@gmail.com or 402-621-0419. I'd love to hear your thoughts and ideas.

Year at a Glance

2026

Jan	Feb	Mar
	Advocacy Day (25)	Cornhole Tournament (28) Livestream Event (28)
Apr World Hemophilia Day (17) Adult Retreat (25-26)	May Rising Voices (9)	Jun Teen Event (13)
Jul Factor Families (11)	Aug BDC (13-15) Family Camp (28-30)	Sep FED (26) Walk (27)
Oct Harvest Festival (17) NE/IA Men's Retreat (23-25)	Nov Rising Voices (7)	Dec Factor Families (12)



Nebraska Chapter

NATIONAL BLEEDING DISORDERS FOUNDATION

Chapter Advisory Committee:

PRESIDENT: JOHN ASHLEY

VICE PRESIDENT:

SECRETARY: SUE COLLINS

MEMBERS: PETER SENIOR, JANE GENTRY, ANDREA QUIROZ,
DALE GIBBS

ADVOCACY COMMITTEE: DALE GIBBS

GOVERNANCE COMMITTEE: PETER SENIOR, SUE COLLINS

FUNDRAISING COMMITTEE: JANE GENTRY

PROGRAMS COMMITTEE: ANDREA QUIROZ



Recruitment for the Advisory Committee:

THE NEBRASKA CHAPTER OF NBDF IS LOOKING TO EXPAND OUR ADVISORY COMMITTEE. WE ARE CURRENTLY RECRUITING BOTH AFFECTED AND UNAFFECTED MEMBERS. WE SPECIFICALLY ARE LOOKING FOR MEMBERS WITH DIVERSE BACKGROUNDS INCLUDING THOSE WHO RESIDE IN RURAL AREAS, SPANISH SPEAKING OR BILINGUAL, INDIVIDUALS COMFORTABLE IN THE RARE DISEASE SPACE, THOSE WITH FINANCIAL OR ACCOUNTING BACKGROUNDS, COMMUNITY CONNECTIONS OR A KNACK FOR FUNDRAISING. THIS LIST IS NOT EXHAUSTIVE. IF YOU KNOW SOMEONE WHO WOULD BE A GOOD FIT FOR OUR COMMITTEE AND CHAPTER, PLEASE REACH OUT TO MAKENNA AT MDIETRICH@BLEEDING.ORG.



Adult Retreat Recap

BRINGING OUR COMMUNITY TOGETHER TO EXPLORE
GRATITUDE, RESILIENCE, AND THE JOURNEY OF LIVING
WITH A BLEEDING DISORDER.

We're excited to share highlights from our 2025 Nebraska Chapter Adult Retreat, a weekend filled with connection, reflection, and inspiration. The retreat began with a creative painting project that invited participants to explore and express the gratitude in their lives. This activity set a thoughtful tone and opened the door for meaningful conversations throughout the weekend.

A central focus of the retreat was addressing the emotional and physical challenges of living with a bleeding disorder. We held open discussions on coping with medical burnout and the importance of prioritizing personal well-being and relationships alongside managing a chronic condition. These conversations created a supportive space for sharing experiences and strategies.

We were honored to welcome Dr. Nestor, who led an insightful session on aging with a bleeding disorder. His expertise and compassionate approach provided valuable guidance for navigating health and wellness as we grow older.

One of the most moving moments of the retreat was an evening of wine tasting paired with a powerful film screening that honored the generation impacted by the HIV and AIDS epidemic. This tribute sparked heartfelt dialogue and reminded us of the resilience and strength within our community.

To close the weekend, we collaborated on building a visual timeline of bleeding disorders. This hands-on activity allowed us to reflect on the incredible progress made in treatment and advocacy over the years, and it left us feeling hopeful and motivated for the future. Thank you to everyone who joined us and contributed to making this retreat such a meaningful experience. We look forward to continuing to grow together as a community.

Women's Retreat Recap

A POWERFUL WEEKEND OF ADVOCACY, WELLNESS, AND CREATIVITY—BRINGING WOMEN TOGETHER TO SHARE, SUPPORT, AND STRENGTHEN ONE ANOTHER IN EVERY PART OF LIFE.

We gathered for our Nebraska Chapter Women's Retreat, a weekend dedicated to empowerment, wellness, and community. The retreat opened with an honest and energizing conversation about the importance of advocacy for women in the bleeding disorders community. Participants shared personal experiences and explored practical tools to become more effective and confident advocates for themselves and others.

We also focused on living our best lives through nutrition and movement, discussing foods and exercises that support physical and emotional well-being. These sessions encouraged participants to take small, meaningful steps toward healthier lifestyles.

Another highlight was our discussion on how to uplift and empower the women in our community. This conversation sparked ideas for mentorship, support networks, and ways to celebrate each other's strengths. We also took time to talk about grief—how it shows up in our daily lives and how we can navigate it with compassion and resilience.

Creativity and expression were woven throughout the retreat. We made beautiful pressed flower frames as a symbol of growth and remembrance, and ended the evening with a fun and cathartic experience in a smash and paint splatter room—releasing stress and embracing joy together.

Thank you to all the incredible women who joined us. Your voices, energy, and openness made this retreat truly unforgettable.





Family Education Weekend Recap

A JOYFUL CELEBRATION OF 40 YEARS OF COMMUNITY, LEARNING, AND PROGRESS—BRINGING FAMILIES TOGETHER FOR A DAY OF EDUCATION AND AN UNFORGETTABLE 80S-THEMED BIRTHDAY BASH.

This year's Family Education Weekend was extra special as we celebrated 40 years of serving the bleeding disorders community! The event brought together families of all ages for a day filled with learning, laughter, and celebration.

We kicked off the weekend with a full day of educational sessions tailored for every age group, offering valuable information, resources, and support for individuals and families navigating life with a bleeding disorder. From hands-on activities for kids to in-depth discussions for adults, there was something for everyone to learn and enjoy.

To cap off the celebration, we turned back the clock and threw a true 80s birthday bash—complete with a live DJ, retro décor, and plenty of dancing! It was a joyful and nostalgic way to honor four decades of community, progress, and connection.

Thank you to everyone who joined us to celebrate this milestone. Here's to the next 40 years of education, empowerment, and togetherness!



Regional Men's Retreat Recap

WRITTEN BY COMMUNITY MEMBER TYLER DIETRICH

This year, the Men's Retreat took place at Jester Park in Iowa. The weekend was filled with camping, activities, and great food that brought a community of men together. For the first time, the Nebraska Chapter teamed up with the Iowa Chapter to bond over a shared purpose.

Hosted by Trails for Healthy Living, the weekend kicked off with a steak dinner cooked over the campfire. As one attendee put it, "That's the way our ancestors did it." Friday night was full of relaxation, campfires, and laughter. Both new and familiar faces shared stories late into the night—until the last man tapped out.

Saturday began with breakfast cooked on the griddle and over the fire, followed by plenty of coffee and energy drinks. The group headed to the lake, where they caught massive $\frac{1}{2}$ -inch fish and enjoyed kayaking, with a paddleboard tagging along for the ride. Lunch featured chicken tacos and salad, though one member joked, "Who needs green veggies when I have cheese poofs?" The afternoon brought a high-stakes game of the manliest sport known to man—mini-golf—played under the summer sun.

Dinner took place in downtown Des Moines, and the day gradually faded into Sunday morning. The weekend wrapped up with a time of reflection and a few final hours at TopGolf.



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Family Camp

MISSION: POSSIBLE CAME ALIVE AT OUR 2025 FAMILY CAMP, WHERE FAMILIES CONNECTED, BUILT CONFIDENCE, AND HAD FUN. THROUGH SHARED CHALLENGES, THEY DISCOVERED THAT TOGETHER, ANYTHING IS POSSIBLE.

Our 2025 Family Camp was held at Camp Carol Joy Holling and was truly a memorable weekend for our community. We were excited to welcome a record number of families to camp this year, including four families who joined us for the very first time. From arrival to departure, the weekend was filled with connection, laughter, and meaningful moments shared among families who understand the bleeding disorders journey.

This year's theme, Mission: Possible, set the tone for an exciting and interactive camp experience. Families were divided into "spy teams" and given a series of quests to complete throughout the weekend. Each challenge earned teams points as they worked together toward the goal of becoming the top spy team, encouraging teamwork, communication, and problem-solving for all ages.

The quests challenged families both physically and mentally while keeping fun at the center of every activity. Families tackled the high ropes course, enjoyed water activities, competed in team relay races, and participated in our infusion clinic. These activities not only built confidence and independence but also reinforced important skills in a supportive and encouraging environment.

Beyond the activities, Family Camp provided a space for families to connect, learn, and grow together. New friendships were formed, experiences were shared, and families left camp feeling empowered and supported. Weekends like this remind us how important community is and why Family Camp continues to be one of the most impactful experiences our chapter offers.





Factor Families

FAMILIES FROM ACROSS NEBRASKA GATHERED AT THE OMAHA CHILDREN'S MUSEUM FOR OUR FACTOR FAMILIES EVENT, A DAY DESIGNED TO EDUCATE AND CONNECT. WITH INTERACTIVE ACTIVITIES AND EXPERT GUIDANCE, THE EVENT TURNED LEARNING ABOUT BLEEDING DISORDERS INTO A FUN AND MEMORABLE EXPERIENCE.

The Nebraska Chapter recently hosted its Factor Families Event at the Omaha Children's Museum, creating a memorable day of learning and connection for families in the bleeding disorders community. Designed for families with children under 14, the event combined education with interactive activities to strengthen bonds and build confidence.

Partnering with industry leaders, the event offered families a unique opportunity to engage with experts and learn more about managing bleeding disorders. Our featured partner, Sanofi, delivered an engaging presentation that captured the attention of both kids and parents. Their program emphasized practical skills in a fun and approachable way.

One of the most popular activities was Sanofi's interactive session teaching kids how to find their veins. Children traced and drew veins on paper, turning an important health lesson into a creative and enjoyable experience. This hands-on approach not only entertained the kids but also helped them understand a vital aspect of their care.

Parents appreciated the chance to connect with others who share similar experiences, while kids enjoyed exploring the museum and participating in educational games. The event fostered a sense of community and reminded families that learning can be empowering and fun.

Events like Factor Families are at the heart of our mission—to provide support, education, and connection for families living with bleeding disorders. We look forward to hosting more opportunities like this in the future, where families can learn, grow, and thrive together.

T.H.R.I.V.E. with NBDF

THE T.H.R.I.V.E. CAMPAIGN IS AN INITIATIVE TO EDUCATE INDIVIDUALS WITH BLEEDING DISORDERS AND THEIR SUPPORT NETWORKS ABOUT SIX KEY STEPS FOR LEADING A HEALTHY LIFE WITH A BLEEDING DISORDER.

Living with a bleeding disorder isn't always easy, but there are essential steps people can take to thrive despite their diagnosis.

The T.H.R.I.V.E. campaign was developed in collaboration with the Centers for Disease Control and Prevention (CDC), to educate and empower people with bleeding disorders and their loved ones on 6 key steps for leading a healthy life. The T.H.R.I.V.E. campaign includes multiple resources, in-depth information, and helpful tools for each of the 6 key steps to support you to thrive.

The T.H.R.I.V.E. campaign includes a full breakdown detailing each of the 6 key steps and resources like questions to ask health care providers and an activity book for children.



THRIVE

NATIONAL BLEEDING DISORDERS FOUNDATION

6 Steps to Living Healthy with a Bleeding Disorder

Questions to Ask Your Health Care Provider About Inhibitors



General Information

- What is an inhibitor?
- What are the risk factors for developing an inhibitor? Can I do anything to prevent getting an inhibitor?
- What signs should I look for?
- Is there a certain age when I can stop worrying about an inhibitor?

Testing Information

- Why is it important to receive inhibitor testing?
- How often should I be tested for an inhibitor?
- I do not use factor replacement products, do I still need to be tested for an inhibitor?
- I am using emicizumab, do I still need to be tested for an inhibitor?
- Where can I get tested for an inhibitor?

Patient Specific Information

- Is an inhibitor test included in my annual blood tests? Will you automatically test for an inhibitor, or should I ask/remind you each time?
- How will I find out about the results?
- Does my insurance cover inhibitor testing?
- What happens next if I test positive for an inhibitor?
- Where can I find more information or resources on inhibitors?

www.bleeding.org/educational-programs/outreach/thrive

Learn more at:
bleeding.org/educational-programs/outreach/thrive

Budget Reconciliation Update

THE NBDF PUBLIC POLICY & ACCESS TEAM SHARE INSIGHTS ON HOW THE NEW BUDGET WILL AFFECT ACCESS TO HEALTH CARE.

Medicaid cuts in the budget reconciliation bills:

- The House and Senate bills would require all states, by December 31, 2026, to implement work reporting requirements for their Medicaid expansion population (non-disabled adults ages 19-64) – but the Senate bill goes even further than the House version by applying the work reporting requirements to parents of children above the age of 14.
- The Senate bill, like its House counterpart, would apply mandatory cost-sharing requirements to the Medicaid expansion population. Beginning in October 2028, states would be required to impose cost-sharing of up to \$35 per item or service, capped at 5% of the individual's income. Providers could at their option reduce or waive cost-sharing on a case-by-case basis.
- Both bills would require more frequent eligibility checks on Medicaid enrollees, requiring renewals every six months rather than annually, and the Senate bill would repeal (rather than delay, as per the House bill) certain Biden-era rules designed to streamline and facilitate enrollment. The Senate legislation also goes further than the House bill in targeting Medicaid expansion states with devastating cuts to the mechanisms (i.e., state provider taxes) that states use to fund their share of Medicaid program costs. (Whereas the House bill prohibited all states from establishing new provider taxes, or increasing the rates of existing taxes, the Senate bill reduces provider tax rates in expansion states only.) This provision has caused widespread concern among Senate moderate Republicans.

Affordable Care Act (ACA) Marketplace cuts in the budget reconciliation bills:

The Senate bill, like the House version, contains numerous policies that would make ACA insurance more expensive and less accessible: fewer and shorter enrollment periods, less eligibility for advance premium tax credits (APTCs), more stringent eligibility verification requirements, and almost no pathway to coverage for many groups of lawfully present immigrants.

As on the House side, a notable feature of the Senate bill is something it does NOT do. The bill does NOT extend the enhanced APTCs for ACA insurance, which have been in place since 2022 and are set to expire at the end of 2025. If the enhanced APTCs are not extended, premiums for 2026 ACA health insurance are expected to increase by over 75% on average. Lower-income and older enrollees, as well as people living in non-Medicaid-expansion states, would face the highest premium increases, and nationwide up to 5 million people are projected to lose coverage.