Nebraska Chapter
NATIONAL **BLEEDING DISORDERS** FOUNDATION

Q1 2026

NEBRASKA CHAPTER

Big Red Factor

Our Mission

The National Bleeding Disorders Foundation—Nebraska Chapter is dedicated to finding cures for inheritable bleeding 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,

The news is out that the Nebraska Chapter of the National Bleeding Disorders Foundation has a new Executive Director. I am thrilled and honored to join Makenna at the Nebraska Chapter to continue serving the bleeding disorders community across the state. I am excited to meet you all in-person over the next few months as this transition takes place.

I am honestly so thrilled to join forces with Makenna and keep supporting our community across the state. I can't wait to meet you all in person as I get settled over the next few months.

I wanted to share a bit about myself:

- **My Background:** I've been with the National Bleeding Disorders Foundation since 2021 as the Nevada Chapter's Executive Director. Before that, I spent a decade in the Las Vegas non-profit world and several years in higher education, focusing on leadership and community service.

My "Why": My passion for patient advocacy is personal. Dealing with a rare condition in my own family is what brought me to this community, and I'm so grateful for everything I've learned along the way.

- **The Goal:** I'm ready to jump in and help expand our resources, create new education and advocacy opportunities, and build stronger bridges with our local medical providers.

A quick heads-up on logistics: I'll be splitting my time between Las Vegas and Omaha (with plenty of trips across Nebraska). When I'm not physically in-state, Makenna will still be right there on the ground to support you.

I'm looking forward to everything we'll accomplish together. See you soon!

Please feel free to reach out if you have any questions or concerns at jmurdock@bleeding.org or 646-901-6442. I look forward to meeting you all soon!

Year at a Glance
2026

Jan

Feb

Advocacy Day
(25)

Mar

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.

Washington Days

ADVOCATING FOR NEBRASKANS WITH BLEEDING DISORDERS IN WASHINGTON, D.C.

BY COMMUNITY MEMBER: MOLLIE LOVELL

This March, my boyfriend, Matt Rosales, and I traveled to Washington, D.C. with the Nebraska Chapter of the National Bleeding Disorders Foundation (NBDF) for the annual Washington Days advocacy event. Our mission was to ensure Nebraska's federal leaders understand the real challenges faced by people living with hemophilia and other rare bleeding disorders.

Meeting With Nebraska's Congressional Delegation

Throughout the week, our Nebraska team met with staff from each member of the state's federal delegation:

- Rep. Don Bacon (NE-02)
- Rep. Mike Flood (NE-01)
- Rep. Adrian Smith (NE-03)
- Sen. Deb Fischer
- Sen. Pete Ricketts

In every meeting, we shared personal stories that highlighted how federal policy directly affects the health, financial stability, and daily lives of families across Nebraska.

Our 2026 Legislative Priorities

We urged lawmakers to champion several key initiatives essential to the bleeding disorders community:

- HELP Copays Act (H.R. 6423 / S. 864): Support ending harmful "copay accumulator" programs so that all payments made by or on behalf of patients—including copay assistance—count toward annual out-of-pocket maximums.
- FED Up with Bleeding Disorders Act: Advocate for improved diagnosis and care for women and girls with bleeding disorders, addressing long-standing gaps in treatment.
- Sustained Funding for HTCs: Ensure continued, robust funding for CDC and HRSA programs that support Hemophilia Treatment Centers (HTCs), which provide essential specialized care.

The Power of Showing Up

Across every office we visited, our message remained clear: Nebraskans deserve affordable, accessible care. I'm proud to have stood with the NBDF Nebraska Chapter to advocate for a future where every person with a bleeding disorder has the opportunity to thrive.

Copay Accumulator Adjustment Programs

QUICK OVERVIEW OF CAAPS

Over the years, healthcare costs have continued to rise. In response, insurance companies have started shifting more of those costs onto patients through higher deductibles and by placing specialty medications on higher-cost insurance tiers. Because of this, many pharmaceutical companies created copay assistance programs to help patients afford life-saving specialty medications—especially those that do not have generic options. Insurance companies responded by creating something called copay accumulator adjustment programs, or CAAPs.

Copay assistance cards can make a huge difference for patients. They help improve access to medication, make treatment more affordable, and help patients stay on track with taking the medication they need. However, many insurance companies argue that these programs increase prescription drug costs because they help cover part or all of a patient's out-of-pocket expenses. CAAPs target these copay assistance programs by changing how the payments are counted. When a patient uses copay assistance, the amount paid by the program no longer counts toward the patient's deductible or their maximum out-of-pocket limit for the year. Though the insurance company still pockets the money from the CAAPs. Insurance companies say they do this because they believe manufacturers use copay programs to push patients toward more expensive medications instead of lower-cost generic options.

Their argument is that if patients are not paying much out of pocket, they may not consider cheaper alternatives or think twice about tests, procedures, or other medical services. However, this approach does not work when it comes to life-saving specialty medications that have no generic alternatives. CAAPs can create serious financial challenges for patients who rely on these medications. For people living with chronic conditions, including bleeding disorders, specialty medications are often the only treatment option. When copay assistance no longer counts toward their deductible, patients can suddenly face thousands of dollars in unexpected costs.

This removes an important safety net and puts treatment further out of reach for many families living with rare or chronic diseases. We also know that when out-of-pocket costs increase, patients are more likely to stop taking their medication as prescribed. For people with rare diseases like bleeding disorders, the yearly cost of care can exceed hundreds of thousands of dollars, with more than 90% of that cost coming from medication. When patients cannot stay consistent with treatment, the results can be serious. It can lead to more emergency room visits, more bleeds and joint damage, missed work or school, and other health complications. In the long run, this often ends up costing insurance companies more than the savings they hoped to gain by shifting costs to patients.

Insurers Double Dip While Patients are Denied Life-Essential Medications:

Many Insurers and PBMs are now utilizing copay accumulators that stop copay assistance from counting towards a patient's deductible and maximum out of pocket spending. These practices are creating significant financial and health issues for patients.

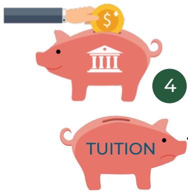
- All of the money paid through the copay assistance, which was intended to help the patient, goes directly to the health insurance company.
- Copay accumulators allow the insurance company to double dip and get paid TWICE - once from the copay assistance and then again by patients' deductibles
- This jeopardizes the health of patients and can ultimately result in the use of more expensive health care services, disability, unemployment and loss of independence.

Imagine if this same practice was applied to college tuition...

College tuition is $10,000

2 Student received a $3,000 scholarship

Student THINKS their new cost is $7,000



4 The college took the scholarship amount, but DID NOT apply it towards the students final tuition cost

5 The college tells student that the student still owes $10,000

*The college receives $13,000, when the bill was only $10,000.

What is NENBDF Doing to Fight CAAPs?

Right now, 26 states, including Puerto Rico and the District of Columbia, have passed laws that ban copay accumulator adjustment programs (CAAPs) at the state level. At the same time, the National Bleeding Disorders Foundation (NBDF) is working to pass similar legislation at the federal level.

Here in Nebraska, NENBDF is lucky to have a strong champion in the Unicameral. Senator Wordekemper from District 15 introduced LB 158, a bill that would ban copay accumulator adjusters in our state. If this bill passes, it would make it illegal for insurance companies to keep the copay assistance that is meant to help patients pay for their medication.

It is extremely important that this protection exists at both the state and federal levels. This is not an issue that only happens somewhere else. As of today, NENBDF has already heard from four families in Nebraska who have had a CAAP included in their insurance plans.

The language used in insurance plans can be confusing, and CAAPs are often hidden in the fine print. Some insurance companies may apply a CAAP as soon as you enroll in the plan, while others may wait until you have been on the plan for a while before implementing it.

What is important to understand is that once you realize a CAAP is part of your plan, you may be faced with a difficult choice. You could become responsible for the full cost of your medication—sometimes around $5,000 a month—or you may have to go without the medication entirely.

Our community understands the serious risks that come with missing or stopping treatment. If you believe you may have a copay accumulator in your insurance plan, please do not hesitate to reach out to Makenna for help.

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.

T **Take** advantage of regular care from health care providers focusing on bleeding disorders.

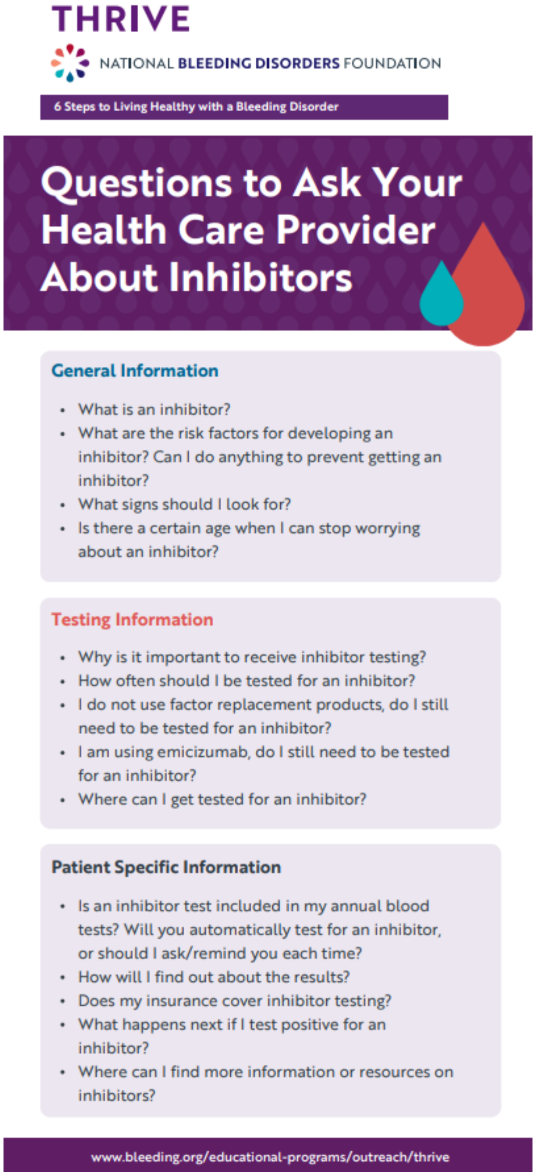
H **Have** a conversation with your health care provider about yearly inhibitor testing.

R **Review** the latest treatment options for you.

I **Identify**, treat, and fully heal bleeds.

V **Value** and make time for your emotional and mental health.

E **Embrace** your bleeding disorders community and get involved!



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