



# Nebraska Chapter

NATIONAL BLEEDING DISORDERS FOUNDATION

## Fall 2024 Newsletter

### From the Executive Director

by Maureen Grace

I want to take a moment to express my deepest gratitude for your incredible support of this year's Unite for Bleeding Disorders Walk. Thanks to each of you, we had a fantastic turnout—welcoming many new families and growing our community in ways that inspire hope and connection. Seeing new faces and long-time friends come together to support the bleeding disorders community reminds me of the power we have when we unite for a common cause.

But our work isn't done yet! We are just **\$4,400 away** from reaching our \$40,000 fundraising goal, and we have a wonderful opportunity to make an even bigger impact. If we can raise this final amount by the end of the year, a generous anonymous donor has pledged to give us an additional **\$5,300**—helping us extend our support to even more families in need.

Every dollar you donate stays right here in Nebraska, ensuring that vital programs and services are available to those living with bleeding disorders. Your contributions go directly toward:

- Educational programs that empower families with the knowledge to navigate their diagnosis.
- Advocacy efforts that amplify the voices of those living with bleeding disorders, fighting for better access to care and resources.
- Emergency assistance for families facing unexpected financial hardships related to their diagnosis.
- Support family events that provide a sense of belonging and connection within our community.

This matching gift is a tremendous opportunity to maximize the impact of every dollar you give, making your generosity go twice as far in supporting local families.

Thank you for standing with us, for walking with us, and for helping us get even closer to reaching our goal. Let's finish this year strong and continue to build a brighter future together!

**[Help us hit \\$40,000 by donating here!](#)**

## This issue:

2025 At a Glance  
Page 3

Welcoming Makenna  
Page 4

New Parent Group  
Page 5

Industry Symposium  
Page 6

Program Highlights  
Page 7-11

Virtual Support Group  
Calendar 2025  
Page 13

2025 World Hemophilia  
Day Theme  
Page 14

Board Recruitment  
Page 16



# Nebraska Chapter

## NATIONAL BLEEDING DISORDERS FOUNDATION

### 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.*

### 2024 Events

Harvest Festival  
Roca, Nebraska  
October 19th

North Platte Education Dinner  
Monday, November 4th

Industry Symposium  
Omaha, Nebraska  
November 9th

Norfolk Education Dinner  
Monday, December 2nd

New Parent Information Group  
Lincoln, NE  
December 7th

We are currently working on scheduling two VWD dinners for December. We hope to have one in each Omaha and Lincoln.

Stay up to date on our calendar on our Facebook and our Website!



combined health agencies drive  
MEMBER CHARITY

# Year at a Glance 2025

<b>Jan</b>	<b>Feb</b> Advocacy Days (17-18)	<b>Mar</b> Washington Days (5-7) Teen Retreat (15)
<b>Apr</b> Adult Retreat (5-6) World Hemophilia Day (17)	<b>May</b> Women's Retreat (10)	<b>Jun</b> FEW Lincoln, NE (28-29)
<b>Jul</b> PING TBD	<b>Aug</b> Family Camp (8-10) BDC (21-23)	<b>Sep</b> Men's Retreat (5-7)
<b>Oct</b> Walk (4) Harvest Festival (18)	<b>Nov</b> Industry Symposium (8)	<b>Dec</b> PING TBD



**Nebraska Chapter**

NATIONAL BLEEDING DISORDERS FOUNDATION

## Welcoming Makenna Dietrich Community Outreach Coordinator



We are so excited to welcome a new staff member to the Nebraska Chapter of the National Bleeding Disorders Foundation. Makenna Dietrich is starting today, September 23rd as our new Community Outreach Coordinator. We are thrilled to have her join the chapter in her official capacity. She will be working closely with community members around programs, events and communication from the chapter.

Here's a little bit about Makenna:

With a personal connection to individuals affected by bleeding disorders, Makenna is deeply committed to fostering community engagement and support. For the past two years, she has been actively involved with the Nebraska Chap-

ter of the National Bleeding Disorders Foundation, where she has played a key role in organizing impactful events, delivering educational resources, and building meaningful relationships within the community.

As the wife of someone with severe hemophilia A and the mother of an unaffected son and two daughters with hemophilia, she has firsthand experience navigating the challenges faced by families living with bleeding disorders. This personal insight drives her passion for creating inclusive, supportive spaces where individuals and families can find the same sense of connection and understanding that has been invaluable to my own family.

In her free time, she enjoys spending quality time with my family and rewatching *The Office* for the 100,000 time!

You can reach Makenna at [mdietrich@bleeding.org](mailto:mdietrich@bleeding.org) or at 402-621-0419.



WINTER  
PING

DECEMBER

SATURDAY | 7 | 1:30-4 PM

MALINOVSKIS AUDITORIUM  
3201 S CODDINGTON AVE LINCOLN, NE 68522

COMMUNITY CONNECTION, HOLIDAY FUN, EDUCATION &  
SEASONAL TREATS

THIS EVENT IS OPEN TO ALL BUT FOCUSED ON FAMILIES  
WITH YOUNGER CHILDREN AGRES 12 AND UNDER

CONTACT MAKENNA DIETRICH AT  
MDIETRICH@BLEEDING.ORG  
WITH ANY QUESTIONS.



**Nebraska Chapter**

NATIONAL BLEEDING DISORDERS FOUNDATION



# 2024 INDUSTRY SYMPOSIUM

**NOVEMBER 9TH, 2024**  
**9:00 AM - 12:30 PM**  
**EMBASSY SUITES LA VISTA**

Join us for education about the latest therapies, treatments, and products used to treat bleeding disorders.

**Smash Park Lunch & Activity  
immediately afterwards!**

Register by November 1st at:  
[www.nebraskanhf.org](http://www.nebraskanhf.org)

# Unite for Bleeding Disorders Walk

The Unite for Bleeding Disorders Walk was truly inspiring! We had an incredible turnout, with nearly 175 walkers joining us to raise awareness for those living with bleeding disorders in Nebraska. Thanks to everyone's efforts, we raised just over \$35,000 for our community members.

Remember, we're still accepting donations until the end of 2024! We have about \$5,000 left to reach our \$40,000 goal, and to sweeten the deal, an anonymous donor has pledged an additional \$5,000 if we meet our goal by year-end.

Let's keep the momentum going and continue raising awareness for this important cause! We're proud to have EIGHTEEN Factor Club members, each of whom raised at least \$500. A huge congratulations to each of you—you should be incredibly proud of your achievements!



## Family Camp Highlight

# Family Camp

This year, Family Camp returned to the beautiful Camp Carol Joy Holling, and we were blessed with stunning weather throughout our stay! The theme for this year's camp was the "Bleeding Disorder Olympics," adding an exciting twist to our activities. Each family formed their own team, getting creative by decorating unique flags to proudly wave during the various events.

Our days were filled with laughter and bonding as we engaged in classic camp traditions—like crafting tie-dye shirts, soaring through the trees on the zip line, and splashing around in the pool. We also competed in spirited team events and gathered around the fire to roast marshmallows under the stars. It was a wonderful experience of connection, fun, and memories that will last a lifetime!







# FAMILY CAMP



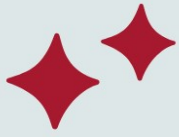
# Family Education Conference

The 2024 Family Education Conference was an exhilarating weekend brimming with unforgettable moments. We kicked off Friday night with a sponsored event by CSL Behring at Top Golf, where an inspiring speaker shared his journey of participating in sports while living with hemophilia.

His story resonated with our community members, igniting their determination to pursue their own goals and setting the stage for a fantastic evening of friendly competition among family and friends. Saturday began bright and early, filled with enriching educational sessions designed to empower our community. We were fortunate to hear from expert speakers from our Hemophilia Treatment Centers. Dr. Alex Nester addressed the adults on the complexities of aging with a bleeding disorder, spotlighting advancements in hemophilia treatment, including gene therapy. He also engaged with our teens in a Q&A session, offering them the opportunity to connect one-on-one with someone who understands the daily realities of living with a bleeding disorder. Lori Schmaderer, the adult HTC physical therapist, provided valuable insights into joint health and shared exercises to promote overall well-being.

We wrapped up the conference with a lively night at Dave & Buster's, where attendees enjoyed a variety of games and won an impressive array of tickets and prizes. A heartfelt thank you to everyone who contributed to making this conference a resounding success!





# SUMMER PING



Our Summer 2024 New Parent Group was an unforgettable adventure at the Henry Doorly Zoo! We kicked off the day with a speaker who unpacked the ins and outs of 504 plans, IEPs, and effective advocacy strategies for our children in the school system. Parents had the chance to share their own tips and tricks, creating a rich exchange of wisdom and support.

The excitement didn't stop there—our attendees had an incredible experience of getting up close and personal with a snake! We even had some brave enough to pet it!

The rest of our time was spent discovering the zoo's incredible exhibits and animals. It was a fantastic blend of learning, connection, and fun for both parents and kids!



# 2025 Virtual Support Group Zooms

## 2025 Zoom Calls

<b>January</b> 6-Women's @ 7pm 15-Men's @ 7pm 21-Teen's @ 7pm	<b>February</b> 3-Women's @ 7pm 11-Men's @ 7pm	<b>March</b> 3-Women's @ 7pm 19-Men's @ 7pm
<b>April</b> 7-Women's @ 7pm 16-Men's @ 7pm 22-Teen's @ 7pm	<b>May</b> 12-Women's @ 7pm 21-Men's @ 7pm	<b>June</b> 2-Women's @ 7pm 18-Men's @ 7pm
<b>July</b> 7-Women's @ 7pm 16-Men's @ 7pm 22-Teen's @ 7pm	<b>August</b> 4-Women's @ 7pm 13-Men's @ 7pm	<b>September</b> 8-Women's @ 7pm 17-Men's @ 7pm
<b>October</b> 6-Women's @ 7pm 15-Men's @ 7pm 21-Teen's @ 7pm	<b>November</b> 3-Women's @ 7pm 12-Men's @ 7pm	<b>December</b> 1-Women's @ 7pm 17-Men's @ 7pm

\*Dates are subject to change\*



**Nebraska Chapter**

NATIONAL BLEEDING DISORDERS FOUNDATION

## WFH Unveils 2025 World Hemophilia Day Theme: "Access for All: Women and Girls Bleed Too"



By Kyla Clark, NBDF Director of PR and Communications

On April 17, 2025, the global bleeding disorders community will unite to commemorate **World Hemophilia Day** with a groundbreaking theme that shines a spotlight on a critically underserved population. The World Federation of Hemophilia (WFH) announced on October 1st the new theme, "Access for All: Women and Girls Bleed Too" as the central focus for the upcoming year's observance.

This theme represents a significant step forward in addressing the often-overlooked needs of women and girls with bleeding disorders (WGBDs). Despite advancements in hemophilia treatment and care, WGBDs continue to face challenges in diagnosis, treatment, and overall quality of life.

**The National Bleeding Disorders Foundation (NBDF)** has expressed enthusiasm for this theme, recognizing its potential to drive meaningful change within the community. *"We are thrilled to see the WFH, inspired by the International Women & Girls with Bleeding Disorders Committee's advocacy prioritizing the needs of women and girls with bleeding disorders,"* said **Dawn Rotellini, Chief Operating Officer of NBDF**. *"This theme aligns perfectly with our ongoing efforts to ensure equitable care for all individuals affected by bleeding disorders."*

## The 2025 theme addresses several key issues:

- **Underdiagnosis:** Many women and girls with bleeding disorders go undiagnosed or face significant delays in diagnosis due to misconceptions about the prevalence of these conditions in females.
- **Inadequate Treatment:** Even when diagnosed, WGBDs often receive suboptimal care compared to their male counterparts.
- **Lack of Awareness:** There is a general lack of awareness about how bleeding disorders manifest in women and girls, both among the public and healthcare providers.
- **Impact on Quality of Life:** Undiagnosed or poorly managed bleeding disorders can significantly impact the quality of life for women and girls, affecting education, career, and personal relationships.

As April 17, 2025, approaches, the bleeding disorders community stands united in its commitment to ensuring that all individuals, regardless of gender, have access to the diagnosis, treatment, and care they need. The theme "**Access for All: Women and Girls Bleed Too**" serves as a powerful reminder that bleeding disorders do not discriminate, and neither should our healthcare systems.

For more information on World Hemophilia Day 2025 and how you can get involved, visit [NBDF's website](#), [WFH's website](#) or [contact your local NBDF chapter](#). Remember to use the official hashtags #WHD2025 #NBDFUnites

## Board Update

### Board & Committee Recruitment

The Nebraska Chapter of NBDF is looking to expand our Advisory Board of Directors. We are currently recruiting both affected and unaffected board 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 Board and Chapter, please reach out to Maureen at [mgrace@bleeding.org](mailto:mgrace@bleeding.org).

Additionally, there's always room on committees for non board members at all. If you want to get involved and help with Advocacy, Programs and Education, Fundraising and Events or more. We will be hosting monthly virtual committee meetings for the following programs and events:

- ⇒ Family Education Weekend
- ⇒ Family Camp
- ⇒ Infusion: Bloody Mary Mix Off
- ⇒ Unite for Bleeding Disorders Walk

Please join us for these virtual meetings to help us make these programs and events even more dynamic. Keep an eye out on your email and social media for the dates for these meetings. If you would like a reminder– please reach out to Makenna at [mdietrich@bleeding.org](mailto:mdietrich@bleeding.org)

## FINANCIAL AID

### **HOW NE NBDF CAN HELP IN 2024 and beyond!**

The Financial Assistance program is part of NENBDF's continuing effort to improve the quality of life of individuals and families affected by bleeding disorders by providing financial support. Families can request up to \$500 per year of support.

Example eligible expenses include, but are not limited to, the following:

- Expenses incurred in the care, treatment, or prevention of a bleeding disorder
- Transportation services to medical appointments and HTC's
- Medical supplies not covered by insurance
- Basic living expense emergencies (rent, mortgage, utilities, food, etc.)
- Unexpected home or car repairs
- Medic Alert Bracelets
- Dental expenses
- Health insurance premiums

**Find more information and apply at: <https://www.nebraskanhf.org/support-resources/financial-assistance-program.html>**



# BLOODY MARY MIX OFF

Our annual Bloody Mary Mix Off was a resounding success! This year, we welcomed eight fantastic local bars to showcase their best creations.

Voodoo Taco claimed the title for Best Bloody Mary, while Tracks dazzled everyone with the Best Garnish. Spirit World earned the title of Most Inventive, and Krug Park won for Best Infusion.

We were thrilled to see such a great turnout from supporters of the bleeding disorders community, all coming together for a worthy cause. As always, our raffle was a crowd favorite, adding even more excitement to the event! Thank you to everyone who participated and made this event so memorable!



**ALTUVIIIIO**<sup>®</sup>  
Antihemophilic Factor (Recombinant),  
Fc-VWF-XTEN Fusion Protein-ehtl



Brian

Real ALTUVIIIIO<sup>®</sup> patient

# SWITCH IT UP like Brian did!

Brian is a promotional speaker compensated by Sanofi.

Sanofi Community Relations and Education (CoRe) Managers are dedicated professionals who can provide personalized education about ALTUVIIIIO, and point you toward helpful support and resources.

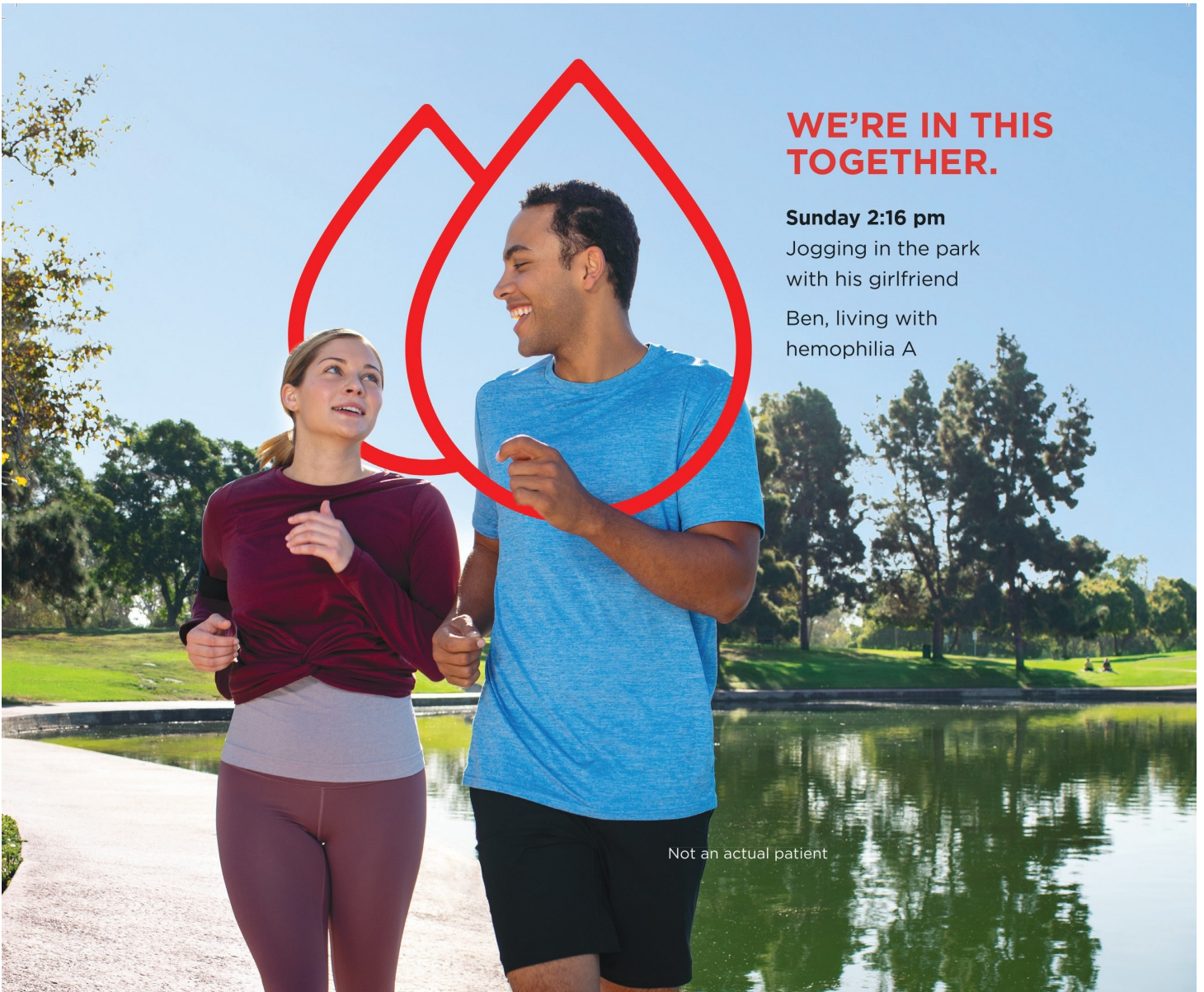


## CONNECT WITH YOUR CoRe TODAY

**sanofi**

© 2024 Sanofi. All rights reserved.  
ALTUVIIIIO and Sanofi are registered trademarks of Sanofi or an affiliate.

MAT-US-2307604-v2.0-05/2024



## WE'RE IN THIS TOGETHER.

**Sunday 2:16 pm**

Jogging in the park with his girlfriend

Ben, living with hemophilia A

Not an actual patient

### Let's make today brilliant.

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever.

[bleedingdisorders.com](https://bleedingdisorders.com)





**ROCTAVIAN™**  
(valoctocogene roxaparvovec-rvox)  
Suspension for intravenous infusion

# IMAGINE WHAT'S POSSIBLE WITH ROCTAVIAN



**Explore more**

[ROCTAVIAN.com](https://ROCTAVIAN.com)