Nebraska Chapter
NATIONAL BLEEDING DISORDERS FOUNDATION

Spring 2024 Newsletter

From the Executive Director

by Maureen Grace

As we wrap up the first quarter of the year with a focus on advocacy for the bleeding disorders community, we are happy with our progress in this area. Be sure to check out our advocacy update to learn everything we've done locally and nationally around accumulator adjustor programs.

Sarah is working hard on our next few months of programming which will be fantastic. We have programs for adults, teens and women coming up in April through June. We are trying to make specialized programming that targets the needs of each group in our community. If you want to help plan our programs with us, we would welcome your help!

We have welcomed two new board members and one returning. Please welcome Andrea Quiroz and Jane Gentry to the Nebraska NBDF Board and welcome back Peter Senior. We are still accepting board members at this time.

World Hemophilia Day is April 17th and we hope to see you all for a celebration dinner with Sanofi and the Pedestrian Bridge lit up red again!

We can't wait to see you this spring and summer for our programs and events. It's going to be a great year for the Nebraska Chapter and bleeding disorders community.

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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

April 17th
World Hemophilia Day
Education Dinner with Sanofi
Omaha, NE

April 27th
Adults with Bleeding Disorders
Bayer Education Dinner
Lincoln, NE

May 11th
Women's Retreat
Omaha, Nebraska

May 22nd
Education Dinner with Takeda
Omaha, Nebraska

June 15th—16th
Teen Retreat
Kearney, Nebraska

September 28th—29th
Family Education & Unite Walk
Weekend
Regency Marriott
Omaha, Nebraska

combined health
agencies drive
MEMBER CHARITY

Save the Dates - 2024

Adults with Bleeding Disorders Conference
April 27th- Lincoln, NE- Graduate Hotel

Women's Retreat
May 11th- Omaha, NE

Teen Retreat
June 15th-16th- Kearney, NE

New Parent Information Group
June 29th- Omaha, NE

Infusion: Bloody Mary Mix Off
July 28th- Omaha, NE

Family Camp
August 9th-11th - Ashland, NE

Men's Retreat
September- Location TBD

FAB Women's Conference
October 11-13th Lake of the Ozarks, MO

FEW/ Unite for Bleeding Disorders Walk
September 28th - September 29th Omaha, NE

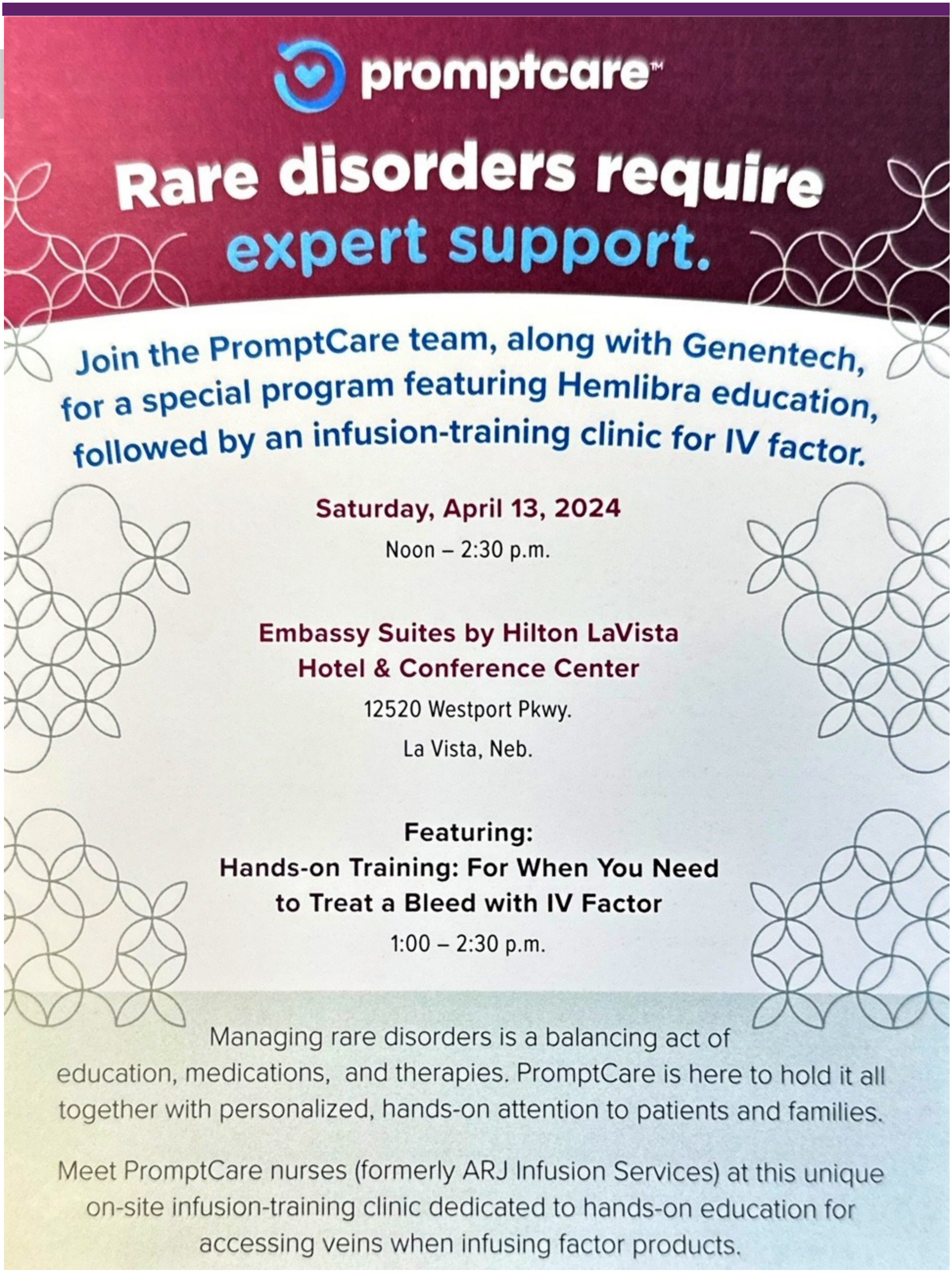
Harvest Festival
October 19th- Roca, NE

Advocacy Update

Here’s the highlights for our advocacy efforts in 2024:

- March was Proclaimed as Bleeding Disorders Awareness Month
- We sent 4 new advocates to Washington Days– Andrea and Nicolas Quiroz and Tyler and Makenna Dietrich
- Advocated for the HELP Co-Pays Act to ban accumulator adjustor programs federally. Met with Congressman Bacon’s, Senator Fischer and Senator Rickett’s offices on these issues
- Hosted an advocacy dinner on Wednesday, May 20th for our local advocates
- Met with local senators at the Capitol to speak about Bleeding Disorders and bring awareness to accumulator adjustors in Nebraska.
- Working with Senator Dungan and Senator Bostar to introduce an accumulator adjustor ban bill in the 2025 Legislative Session.

Thank you to all our advocates to work to better the lives of those with Bleeding Disorders in Nebraska!



promptcare™

Rare disorders require expert support.

Join the PromptCare team, along with Genentech, for a special program featuring Hemlibra education, followed by an infusion-training clinic for IV factor.

Saturday, April 13, 2024

Noon – 2:30 p.m.

Embassy Suites by Hilton LaVista
Hotel & Conference Center
12520 Westport Pkwy.
La Vista, Neb.

Featuring:
Hands-on Training: For When You Need to Treat a Bleed with IV Factor

1:00 – 2:30 p.m.

Managing rare disorders is a balancing act of education, medications, and therapies. PromptCare is here to hold it all together with personalized, hands-on attention to patients and families.

Meet PromptCare nurses (formerly ARJ Infusion Services) at this unique on-site infusion-training clinic dedicated to hands-on education for accessing veins when infusing factor products.

Nebraska Chapter
NATIONAL **BLEEDING DISORDERS** FOUNDATION

ADULTS WITH BLEEDING DISORDERS CONFRENCE

April 27th, 2024 10:00am
Location: Graduate Hotel , Lincoln NE

Contact Sarah Arrieta with questions at 402-889-0572 or sarrieta@hemophilia.org

Are you an adult living with a bleeding disorder? Are you a care giver who wants to know more about what to expect for your child as you age? This one conference will touch on issues and education focused on topics that affect the adult population in the Bleeding Disorder Community.

This event will be held at The Graduate Hotel in Lincoln.
An entire teen event will take place at this Conference!

We would love your teens to come to participate.

We look forward to sharing knowledge, connecting with our adult and teen community and having some fun along the way.

Registration for the Adults with Bleeding Disorders Conference is free and includes your hotel accommodations if you are coming in from more than 120 miles, food and child care.

Education Dinner with Bayer at the Graduate Hotel will be at 6 pm.

Topic: Hemophilia Health Insurance Benefits

Register at: www.nebraskanhf.org

You're invited!

Join us for a World Hemophilia Day 2024 generation celebration

This community shares a connection that spans generations. Our 2024 One Family program is a celebration of the bond that comes from living with hemophilia: young and old, near and far, where we are now and where we want to be. RSVP today to join us for hands-on activities like:

- Personal time capsule kits
- Selfie stations and DIY photo frames
- Wish ribbons for the global community
- Space to share your story and voice

It's all happening on World Hemophilia Day.

When:

Wednesday, April 17, 2024 06:00 PM - 08:30 PM CDT

Where:

Upstream
514 S 11th St
Omaha
NE
68102

RSVP:

Contact your local chapter.
RSVP to Sarah: sarrieta@hemophilia.org -or- (402) 889-0572

A Nebraska Chapter,national Hemophilia Foundation & Sanofi Event

2024 Couple's Retreat

WE HOSTED OUR 3RD ANNUAL COUPLE'S RETREAT THIS FEBRUARY AT THE LIED LODGE IN NEBRASKA CITY. WE HAD A NEW SPEAKER THIS YEAR, REV. CAZANDRA MACDONALD, WHO LED INCREDIBLY INSIGHTFUL AND INTERACTIVE CONVERSATIONS AROUND THE TOPICS OF KEEPING THE COUPLE CONNECTION THROUGH TOUGH TIMES AS WELL AS GRIEF AND LOSS. WE ENJOYED A COUPLE'S PAINTING CLASS AND FINISHED OUT SATURDAY NIGHT WITH A DINNER AT TIMBERS RESTAURANT FOLLOWED BY A COZY COUPLE'S GAME NIGHT. SUNDAY MORNING, WE ENJOYED A COUPLE'S MASSAGE CLASS AS WE REFLECTED ON THE HIGHLIGHTS FOR THIS YEAR AND MADE PLANS FOR NEXT YEAR. THANK YOU TO THE COUPLES WHO ATTENDED AND WERE OPEN AND VULNERABLE WITH US. THIS EVENT IS SO IMPACTFUL, AND WE HOPE TO SEE IT GROW AGAIN IN 2025.

THANK YOU TO OUR SPONSORS:

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novo nordisk
BAYER
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THE HEMOPHILIA ALLIANCE

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@hemophilia.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 Sarah at sarrieta@hemophilia.org

Thank you to our Industry Sponsors who support our programming, advocacy and outreach efforts throughout Nebraska for all bleeding disorders.


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Teen Program Update

Exciting developments are underway within our adolescent programs and events! The Nebraska Chapter Teen Council, a leadership group for individuals aged 12 to 19, successfully concluded their 2023 service initiative focusing on careers in the medical field, which included an educational Ask-A-Nurse project. The results of this endeavor will be presented to community members at the Adults with Bleeding Disorders (AWBD) conference on April 27th.

Currently, teenagers are actively involved in planning our next service endeavor, which will center on a different career theme, details of which will be disclosed shortly. Additionally, both the Chapter and the Teen Council are in the process of establishing a mentorship program in partnership with adult mentors from the community. Our inaugural mentorship session will take place at AWBD.

If you have a teenager interested in participating in the 2024 service project or joining the NENBDF Teen Council, or if you are an adult interested in engaging in the mentorship program, please reach out to Sarah Arrieta at sarrieta@hemophilia.org or (402)889-0572.

Nebraska Chapter
NATIONAL BLEEDING DISORDERS FOUNDATION

2024 TEEN RETREAT

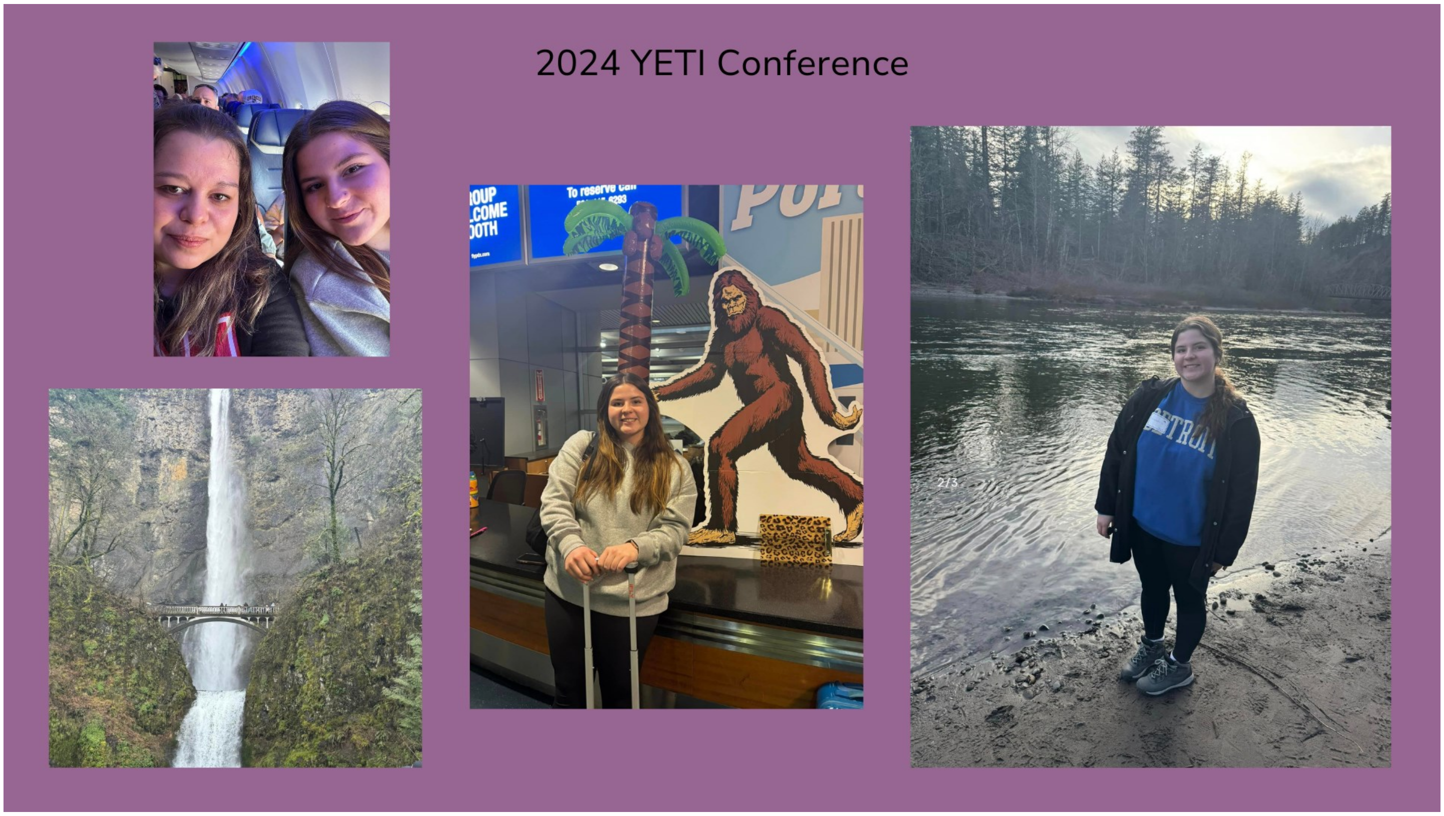
JUNE 15-16, 2024

CONTACT SARAH ARRIETA WITH QUESTIONS AT 402-889-0572
SARRIETA@HEMOPHILIA.ORG

EDUCATION AND CONNECTION FOR AGES: 12 - 19

YOUNES CONFERENCE CENTER NORTH
707 TALMADGE RD, KEARNEY, NE
TRANSPORTATION WILL BE PROVIDED FROM LINCON AND OMAHA TO KEARNEY

Youth Effectively Transitioned to Independence (YETI)



2024 YETI Conference

The Yeti Conference took place on February 22—25, 2024, at Camp Collins in Gresham, OR. The conference was attended by Teen Council member, Liz Quiroz, and Chapter Senior Program Manager, Sarah Arrieta. YETI is an experiential train-the-trainer weekend conference created by Pacific Northwest Bleeding Disorders (PNWBD) YETI was designed to promote confidence and support teens with bleeding disorders (and their siblings) ages 14-20, as they transition into independence. YETI also provides for the beginnings of a national network of teens by providing the chance for teens to build relationships across state borders.

Topics covered included the history of hemophilia, new medical and scientific developments related to hemophilia and bleeding disorders, as well as strategic planning for the upcoming year of youth and teen programming at the Nebraska Chapter. Areas of focus for collaboration include mentorship development, the 2024 Teen Council service project, and 2024 Teen Retreat. Liz also went to new heights on the Camp Collins ropes course. At the retreat, teens took on the challenge of putting themselves in the shoes of chapter staff by planning an outing for the adults, which included key components of event planning such as transportation, budgeting, timing, and accessibility for the event. The group visited Multnomah Falls and Dabney State Recreation Area, and dined at some amazing local food trucks. It was an awesome experience to see the teens collaborate and navigate the challenges that come with event and program planning throughout the weekend. Liz and Sarah both agreed that the weekend was a great success filled with creativity and team building.

Bleeding Disorders Conference Travel Grants

Every year the Nebraska Chapter sends members of our community to NBDF's Bleeding Disorders Conference. This year the meeting will be held in Atlanta from September 12-14th. If you are interested in attending, the deadline to fill out the application is May 15th, 2024! Please keep in mind that the grant may not cover all the expenses that go along with this trip. A committee will determine who we will send and how much of the budget will go to each family or individual chosen. Preference will be given to families who have not attended the meeting before.

The National Bleeding Disorders Foundation (formally NHF)'s 76th Annual Bleeding Disorders Conference (BDC) will take place September 12-14, 2024 in Atlanta! We are excited to bring the bleeding disorders community together again for three incredible days of educational sessions, valuable networking opportunities, and exciting exhibits at the Georgia World Congress Center.

Each year the Chapter will send 1-2 staff and one board member to the conference. The remaining number of travel grants will be awarded based up the amount the Nebraska Chapter has allotted in their yearly budget, and this amount is discussed and approved by the Advisory Board of Directors.

Travel Grants will be awarded in the following amounts:

Families of 1-4 - $1500 | Families of 5-8 - $2500

Preference will be given to applicants who are 1st Time Attendees (those who have never attended a National Conference), to applicants who did not attend the National Conference the previous year, and who are actively involved in Nebraska Chapter activities.

Fill out the application at https://www.surveymonkey.com/r/6DJ3S3J
due May 15, 2023

Are Bleeding Disorders Patients Getting the Most Out of Physical Therapy?

Are Bleeding Disorder Patients Getting the Most Out of Physical Therapy (PT)?

By Vita Staff

For those who live with bleeding disorders, joint problems can reduce their mobility and keep them from being active. When blood doesn't clot as it should, bleeds can occur inside joints, causing pain. Older patients are especially affected because they didn't benefit from treatment advances until later in life. Then they experience the compounding effects of age-related joint problems, like arthritis.

That makes physical therapy an important aspect of health care delivered at Hemophilia Treatment Centers, which are comprehensive clinics that take a holistic approach to the patient's overall health and well-being. A survey from the National Bleeding Disorders Foundation (NBDF) looked at how closely physical therapists at HTCs are following treatment guidelines from the foundation's Medical and Scientific Advisory Council (MASAC). The council issues annual recommendations for treatments that are evidence based, meaning that research has shown their usefulness and effectiveness.

The current guidelines for physical therapists include frameworks for managing joint health and rehabilitating patients after major bleeds. The guidelines also advise on how best to use cold packs to reduce swelling and when shoe inserts and braces can be most helpful. But it can take up to 17 years for these guidelines to be implemented and only 14% of interventions are impacting the intended patient population, physical therapist Lena Volland said at a recent NBDF webinar. She has hands-on experience providing PT at hemophilia treatment centers and she's also NBDF's Director of Education.

MASAC's strategies have their roots in research and expertise, but putting these guidelines into action is not always a straightforward task.

"There are many compounding factors that will prevent something from being implemented in the clinical practice," said Volland. For MASAC's recommendations to be fully effective, a well planned and executed strategy for implementation is necessary.

Barriers to Implementation

NBDF surveyed physical therapists at HTCs about barriers that prevent the application of best practices recommended in the MASC guidelines. The survey found a high percentage of alignment with MASC guidelines – 82%. But an analysis of survey results also identified reasons why the treatment guidelines aren't always followed. They included patient preference, limitations of the physical space in therapy areas, a lack of funding and problems with health insurance coverage. 5 Continuing education programs are necessary to spread specialized information, according to Volland. Experienced professionals can share their skills through mentorship programs, she said. Volland also noted that providing financial support for full-time physical therapist positions helps address staff limitations in hemophilia treatment centers.

Watch the webinar: Recommendations vs. Practice: Physical Therapy at HTCs

Nebraska Chapter
NATIONAL **BLEEDING DISORDERS** FOUNDATION

WOMEN'S RETREAT

MAY 11, 2024

JOIN US FOR A DAY OF COMMUNITY AND CONNECTION

HILTON GARDEN INN AKSARBEN, OMAHA NE
CONTACT SARAH ARRIETA WITH QUESTIONS
AT 402-889-0572 OR
SARRIETA@HEMOPHILIA.ORG


sanofi

NEBRASKA CHAPTER NEEDS ASSESSMENT

- NEW SURVEY DEVELOPED BY SARAH, MARIA, & MAUREEN
- CHANCE FOR THE COMMUNITY TO SHARE THEIR OPINIONS & PREFERENCES
- HELP US BETTER UNDERSTAND YOUR NEEDS
- IMPROVE PROGRAMS & SERVICES

We need your feedback!

SCAN QR CODE OR VISIT
OUR WEBSITE TO COMPLETE

Your voice matters and
will help shape the future of NENHF