BIG RED FACTOR

2023—Issue 1

NATIONAL HEMOPHILIA FOUNDATION
CHAPTER OF EXCELLENCE
2018-2020

Inside this issue:

It's hard to believe that it's already the end of March! We had an amazing Bleeding Disorders Awareness month with a lot of work on advocacy and bleeding disorders awareness. We are gearing up for our busy program and event season and we cannot wait to see you at our upcoming events.

We are welcoming new families into our community every month and I know the connections built are so impactful and life changing. Thank you for having such a wonderful family and community and allowing Sarah and I to be a part of it. We are truly so lucky to be serving such a dynamic group of individuals and families across Nebraska.

We are trying to have more purposeful small group programs this year that really focus on what you may be needing at any given time. We hope to see you at these events or on committees to help plan them and make them even better. We value and want your input and engagement on what we do.

See you soon and enjoy the sunshine as spring comes around again.

Maureen Grace, Executive Director.

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

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Our Mission:

The National Hemophilia Foundation—Nebraska Chapter is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy & research.

Staff

Executive Director
Maureen Grace

Program Manager
Sarah Arrieta

Advisory Board of Directors

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Secretary - Suellen Colin
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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. NHF-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.

2023
Events

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

April 22nd
Adults with Bleeding Disorders
Kearney, Nebraska

May 13th
Women's Retreat
Omaha, Nebraska

June 4
Education Dinner with Novo Nordisk
North Platte, Nebraska

June 24– 25th
Family Education Weekend
Marriott Cornhusker Hotel
Lincoln, Nebraska

July 23rd
Infusion: Bloody Mary Mix Off

combined health agencies drive
MEMBER CHARITY

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

FAMILY EDUCATION WEEKEND 2023

JUNE 24-25TH
LINCOLN, NEBRASKA
CORNHUSKER MARRIOTT

FEATURING:

ADULT PROGRAMMING
TEEN PROGRAM
CHILDCARE
EDUCATION FOR 7-12
INFUSION CLINIC
FUN
CONNECTION

WOMEN'S RETREAT

5.13.23

OMAHA, NEBRASKA- AKSARBEN

WWW.NEBRASKANHF.ORG

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

Advocacy Update

By Dale Gibbs
Advocacy Chair

On March 9, Kari Quintana, Hunter Quintana, Maureen Grace and Dale Gibbs attended NHF's annual Washington Days. We learned about the current effort to curb insurance companies attempts disallowing copay assistance for hemophilia medications. More and more insurance companies are moving to this practice called "Copay Accumulator Adjustment Programs", in order to drive consumers to less expensive generic medications. Through the insurer's eyes, this is a good way to avoid spending money on expensive medications. However, there are no generic factor medications. Not allowing copay assistance makes it very expensive for hemophilia patients and families to burden the cost of copays with each factor medication. Consequently, if patients can't afford the copay each time, they may be forced to seek infusions in emergency departments, which then drives the cost of healthcare for all of us.

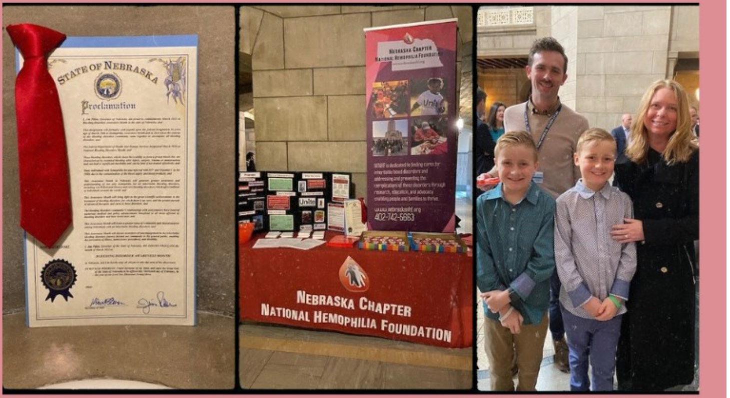
We were able to relate this message to Senator Fischer and Congressman Smith personally and the health aides of Senator Ricketts and Representatives Bacon and Flood. We also asked our three representatives to sign on to HR 380 which addresses this copay issue and also asked our two senators to consider sponsoring a companion bill on the Senate side. Although, we did not get commitments on either request, we remain very hopeful.

Similar to Washington Days, the Nebraska Chapter holds an annual Nebraska State Advocacy Day and this year, Makenna and Tyler Dietrich, Hayden, Max and Kristin Henson, Kelsey Cunningham, Maureen Grace, and Dale Gibbs attended. We provided a table with information on bleeding disorders for anyone who was interested and also and talked with the groups respective State Senators or offices.

This year, there has been no legislation introduced that affects our community so we took the opportunity to educate about hemophilia and how legislation could impact us. We visited with Senators Anna Wishart, Bruce Bostelman and the offices of Senators John Cavanaugh and John Lowe.

We also had the opportunity to visit with Senator Eliot Bostar from Lincoln (District 29) about the copay accumulator adjustment program. In the 2022 state legislative session, a bill was introduced by Senator Adam Morfeld (term limited in 2023) but didn't get voted out of committee. Senator Bostar is a member of the committee where that bill was heard and is interested in exploring with us a reintroduction of a bill in the 2024 legislative session to not allow the practice in Nebraska. We will be collaborating with Senator Bostar in the near future and hope to be successful next year.

MARCH IS Bleeding Disoders Awareness Month



APRIL 22 & 23, 2023 IN KEARNEY, NE

ADULTS WITH BLEEDING DISORDERS CONFERENCE

EDUCATION, COMMUNITY, & CONNECTION

REGISTER AT WWW.HEMOPHILIA.ORG OR CONTACT SARAH ARRIETA WITH QUESTIONS AT (402)889-0572 OR SARRIETA@HEMOPHILIA.ORG

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

JOIN US FOR AN EDUCATIONAL DINNER CELEBRATING

World Hemophilia Day

Monday

17

April

2023

6 pm - 9 pm

At The Old Mattress Factory Bar & Grill

501 N 13th St Omaha, NE 68102

Register online at www.nebraskanhf.org

Sponsored by Sanofi

Contact Sarah Arrieta with questions at (402) 889-0572

sarrieta@hemophilia.org

SANOFI

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THE 2023 COUPLE'S RETREAT

We hosted our 2nd annual couple's retreat this February at the Lied Lodge in Nebraska City at the Lied Lodge. The venue was a beautiful new location and we hope to revisit this venue again. We brought back Dave Robinson as our Keynote speaker who spoke about marital enrichment and nurturing relationship intimacy which was incredibly insightful and interactive. Thank you to our industry sponsors who also provided educational topics. We finished out Saturday night with a formal dinner, ball room dancing instruction and our very own prom complete with photo booth. 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 2024.

THANK YOU TO OUR SPONSORS:

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HEMA Biologics™
Pfizer
novo nordisk
BIOMARIN
BAYER

Board Update

Board & Committee Recruitment

The Nebraska Chapter of NHF 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.

Save the Dates - 2023

Adults with Bleeding Disorders Conference
April 22nd- Kearney, NE

Women's Retreat
May 13th- Omaha, NE

Family Education Weekend
June 23rd-24th- Lincoln, NE

New Parent Information Group
July 8th- Omaha, NE

Infusion: Bloody Mary Mix Off
July 23rd- Omaha, NE

Family Camp
August 11-13th - Ashland, NE

Men's Retreat
September- Location TBD

FAB Women's Conference
October 13-15th Lake of the Ozarks, MO

Unite for Bleeding Disorders Walk
October 7th- Omaha, NE

Harvest Festival
October 21- Roca, NE

Teen Update

We have been gearing up for a great year of teen programming at the Nebraska Chapter. The YETI (Youth Effectively Transitioning to Independence) conference was held in February at Camp Collins in Oregon. YETI is an experiential weekend that provides connections for youth within the bleeding disorder community. This year program manager, Sarah Arrieta, was joined by Teen Council member, Nicolas Quiroz, and HTC social worker, Kylie Meyer. Together they discussed current challenges that young people with bleeding disorders are faced with, and made plans for future programming at the chapter. Our teen participant, Nicolas, has agreed to take on a leadership role in teen programming and the Teen Council, and we are really looking forward to see what exciting things he will do in the future.

To be considered to participate in the Yeti conference, youth must be between the ages of 14—20 and be an active participant in teen programming and the NENHF Teen Council. Youth will experience a weekend at Camp Collins in Oregon as part of the Oregon Teen PEAK (Providing Education, Advocacy and Kinship) program. Teens that attend should be willing to contribute to the design and creation of future teen programming. For more information about this program or the Teen Council, please contact Sarah Arrieta at sarrieta@hemophilia.org or (402)889-0572.

Bleeding Disorders Conference Travel Grants

Bleeding Disorders Conference
#BDC2023
75

Every year the Nebraska Chapter sends members of our community to NHF's Bleeding Disorders Conference. This year the meeting will be held in Washington DC from August 17th-19th. If you are interested in attending, the deadline to fill out the application is May 15th, 2023! 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 75th Annual Bleeding Disorders Conference (BDC) will take place from August 17 to 19, 2023 at the Gaylord National Resort & Convention Center in National Harbor, Maryland. Located on the historic Potomac River and within short distance of national landmarks in nearby Washington, DC, this will be the perfect setting for BDC 2023 as we mark our 75th anniversary and embark on a new phase for our organization and bleeding disorders community.
This 75th anniversary edition of the Bleeding Disorders Conference will be a momentous celebration for our community. Join us for three days of educational sessions, exploring the exhibit hall, and spending time with the incredible bleeding disorders community.

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/2G6NL9P
due May 15, 2023

Ask a Social Worker: Dealing with your Child’s School

Dear Ashley and Lucy,

My child’s school downplays my concerns about care and preparedness for his bleeding disorder in the classroom and on the playground. How do I get them to understand the importance of school safety and not see me as an overly worried parent?

As a parent of a child with a bleeding disorder, you probably appreciate better than most the difficulty of keeping a healthy balance as you manage their condition.

On one hand, overprotectiveness can lead children to be fearful or withdrawn and have less self-confidence. On the other hand, being too complacent about the bleeding disorder can have serious consequences for your child’s health and safety.

It is for this reason that 504 education plans exist in public schools across the country. A 504 plan is a federally mandated individualized education plan created by a multidisciplinary educational team to provide specific accommodations for a student with a chronic medical condition. The law requires that parents be included in the 504 plan’s development and have a voice in the accommodations given to their child.

Preparing parents to advocate for their children in the 504 meeting is often part of the education provided by the hemophilia treatment center (HTC) team during comprehensive clinic visits. During these visits, you and the medical team can discuss suggested accommodations for your child.

A letter from the treatment team to the staff at your child’s school can help increase understanding and awareness of bleeding symptoms and the necessary response. This letter should include information about the diagnosis, treatment plan, first-aid guidelines, suggestions for participation in activities and physical education, and emergency bleeding management.

Many treatment centers have staff who may be able to meet with your child’s teachers and school nurse. This meeting may include a presentation about managing a child’s bleeding disorder at school. If possible, we request that every staff member who will have contact with the student attend the meeting. However, we have found that even a one-on-one meeting with the child’s teacher or school nurse can make a tremendous difference.

Whenever asked, we also participate in the student’s 504 planning meeting. In every contact with the school, we emphasize that communication is key and that parents are typically the first point of contact when a child has symptoms at school. We also inform them that while most bleeding episodes that happen at school require only basic first aid, a traumatic injury in one of the three high-risk areas (head, neck, and stomach) is potentially dangerous and may require them to call 911, so the entire staff needs to be aware that there is an emergency plan in place.

Ask a Social Worker Continued

These interventions generally create a better understanding among the school staff, who are probably encountering a student with a bleeding disorder for the first time. When there is a plan in place and everyone feels prepared in case something happens, that sets your child up for success.

As always, consult with your child's HTC team about any questions or issues that come up that you are uncertain about how to handle on your own. Our goal is for children to receive the accommodations they need to be successful in school, with as few restrictions on their lives as possible.

— Ashley Parmerlee, MSW, LCSW

Parmerlee is a social worker at the Indiana Hemophilia & Thrombosis Center in Indianapolis and a member of the Social Work Working Group.

— Lucy Ramirez, MSW, LCSW

Ramirez is a social worker at Rush Hemophilia and Thrombophilia Center in Chicago and a member of the Social Work Working Group.

This article was first published in HemAware January 2023.

Join us at our Family Education Weekend 2023 to attend a breakout on 504 plans in schools.

ALTUVIIIO™
Antihemophilic Factor (Recombinant),
Fc-VWF-XTEN Fusion Protein-ehtl

FACTOR UP with ALTUVIIIO™

Higher-for-longer Factor VIII levels in the near-normal to normal range **(over 40%)** for most of the week

HIGHER FACTOR LEVELS FOR LONGER

Above 40% for most of the week (near-normal to normal range).[*][†]

48 HOUR HALF-LIFE IN ADULTS

In a Phase 3 study,[†] ALTUVIIIO offered adults the longest half-life of any Factor VIII therapy.

0.7 BLEEDS PER YEAR[‡]

Mean annual bleed rate observed in 128 people previously treated with prophylaxis therapy.[†]

In people taking ALTUVIIIO in the XTEND-1 study, 21% of people had headache, 16% had joint pain, and 6% had back pain

[*] Average trough levels were 18% for adults 18 years and older, 9% for adolescents aged 12 years to under 18 years, 10% for children aged 6 years to under 12 years, and 7% for children aged 1 year to under 6 years.

[†] 159 adults and adolescents with severe hemophilia (aged 12 years and older) were enrolled in the XTEND-1 study; 133 people were in Group 1 and switched to ALTUVIIIO prophylaxis from prior prophylaxis therapy. Efficacy of prophylaxis was evaluated in 128 of these patients.

[‡] Data based on treated bleeds.

CONNECT WITH YOUR CoRe TODAY

Learn more about ALTUVIIIO, living with hemophilia, and treatment options from your local CoRe.

Jess Hutchison
jess.hutchison@sanofi.com
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INDICATION

ALTUVIIIO™ [antihemophilic factor (recombinant), Fc-VWF-XTEN fusion protein-ehtl] is an injectable medicine that is used to control and reduce the number of bleeding episodes in people with hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ALTUVIIIO when you have surgery.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about ALTUVIIIO?

Do not attempt to give yourself an injection unless you have been taught how by your healthcare provider or hemophilia center. You must carefully follow your healthcare provider's instructions regarding the dose and schedule for injecting ALTUVIIIO so that your treatment will work best for you.

Who should not use ALTUVIIIO?

You should not use ALTUVIIIO if you have had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ALTUVIIIO?

Tell your healthcare provider if you have had any medical problems, take any medications, including prescription and non-prescription medicines, supplements, or herbal medicines, are breastfeeding, or are pregnant or planning to become pregnant.

What are the possible side effects of ALTUVIIIO?

You can have an allergic reaction to ALTUVIIIO. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called "inhibitors" against ALTUVIIIO. This can stop ALTUVIIIO from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

The common side effects of ALTUVIIIO are headache, joint pain, and back pain.

These are not the only possible side effects of ALTUVIIIO. Tell your healthcare provider about any side effect that bothers you or does not go away.

Please see full Prescribing Information.

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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