Nebraska Chapter

NATIONAL BLEEDING DISORDERS FOUNDATION

BIG RED FACTOR

2023—Issue 4

Inside this issue:

As we bid farewell to 2023, a year that has been filled with both challenges and triumphs, I am compelled to express my heartfelt gratitude to each and every one of you who has contributed to the strength and resilience of our community. Your unwavering support has been the driving force behind our shared journey, and I am humbled by the unity and determination that define our chapter.

Throughout the past year, we have faced obstacles head-on, navigated uncharted territories, and witnessed the incredible spirit that unites us all. It is in these moments of adversity that our community truly shines, proving that together, we can overcome any hurdle. From fundraising initiatives to awareness campaigns, your dedication has propelled our mission forward, bringing hope and support to those affected by bleeding disorders.

Looking ahead to 2024, I am filled with anticipation for the opportunities and growth that await us. As we embark on a new chapter, let us carry the lessons learned from the past into the future. Together, we will continue to raise awareness, provide vital support, and foster a sense of belonging within our community.

I am excited about the projects and initiatives we have planned for the coming year, each designed to strengthen our bonds and amplify our impact. Your involvement, whether through volunteering, fundraising, or spreading awareness, is the driving force behind our success. Let us celebrate the victories, both big and small, and support one another through the challenges that may arise.

Wishing you all a joyous holiday season and a new year filled with endless possibilities.

Maureen Grace, Executive Director

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.

Staff

Executive Director
Maureen Grace

Senior Program Manager
Sarah Arrieta

Advisory Board of Directors

President - Joe Mickeliunas
Vice President– John Ashley
Secretary - Suellen Colin
Treasurer– Bob Dick
Zach Fischer
Dale Gibbs

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
Upcoming Events

February 10th-11th
Couple's Retreat

March 18th and 19th
Nebraska Advocacy Day

March 6-8th
Washington Days

Please keep up to date with upcoming events on our website and our Facebook page.

If you want to receive text notifications for events and updates, please text HEMO to 402-356-5440

combined health agencies drive
MEMBER CHARITY

2024 Calendar

January

February

10th–11th
Couple's
Retreat

March

18th/19th
Advocacy
Day

April

27th
Adults with
Bleeding
Disorders

May

11th
Women's
Retreat

June

8th–9th
Teen
Retreat

July

Men's
Retreat
28th
Infusion

August

9th–11th
Family
Camp

September

28th
FEW
29th
Unite Walk

October

19th
Harvest fest

November

9th
Industry
Symposium

December

7th
Winter
PING

Resume and Public Speaking Workshop

On November 6, 2023, our office buzzed with enthusiasm as we hosted a dynamic professional development event, offering both in-person and virtual attendance options for individuals beyond our locale. Geared towards ages 12 and up, participants engaged in insightful discussions covering key topics such as resume creation, public speaking, mentorship program initiation, scholarship opportunities, and guidance on applying to the prestigious National Youth Leadership Institute (NYLI).

For those seeking personalized assistance in crafting impactful resumes, we encourage you to connect with Sarah Arrieta at sarrieta@hemophilia.org or (402)889-0572. Our commitment to nurturing talent and fostering growth remains unwavering, and we look forward to supporting your journey toward personal and professional excellence.

Industry Symposium

A fantastic time was enjoyed by all at the recent Industry Symposium held on November 4th, 2023, at the Hilton Garden Inn in Omaha. Attendees were treated to insightful presentations from industry leaders such as BioMarin, Bayer, CSL Behring, Novo Nordisk, and Sanofi with support from Genentech and Takeda. The event fostered community connection, as participants not only shared a delicious meal but also engaged in educational discussions. A thoughtful touch was the provision of childcare, ensuring everyone could fully participate. We extend our gratitude to the sponsors and contributors for making this symposium a memorable and enriching experience for our community. Following the Symposium, community members came together to cheer on the UNO Maverick Hockey Team. Cheers to future collaborations and growth in 2024.

Teen Program Update

Youth in the bleeding disorders community and sickle cell community (affected and siblings) ages 12 – 19 are invited to join the NENBDF Teen Council. NENHF Teen Council provides opportunities for learning leadership and life skills, as well as professional development.

Through this program teens will:

- Have an active role in planning NHF Teen events/programs.
- Serve their community through an annual service/volunteering project.
- Prepare for application to the National Youth Leadership Institute
  Participate in mentorship program

2023 Service Project – Partnership with Omaha Children's Hospital

The teens in this program decided to learn about nursing and the medical field. This service project has two components, an educational component, and a service component.

Ask A Nurse Project – Teens created a short video introducing themselves and asking three questions for either a nurse or CNA. The healthcare workers at Children's Hospital created video responses for the teens. Our goals were to teach teens more about working in the healthcare field and to strengthen the connections between youth in our community and the healthcare workers that work at Children's Hospital where many of our youth are often treated.

Care Packages - The service portion of the project was completed on November 8th, 2023. We delivered gifts from the community and the chapter to Children's Hospital for the healthcare workers that participated in our project as well as for children staying at the hospital. These gifts included coffee cups, sunglasses, handmade cards from the Teen Council, popcorn, books, coloring books, and art supplies.

We are currently in the process of determining the focus of our next service project for 2024. Please contact Sarah Arrieta at sarrieta@hemophilia.org if your teen has an idea for a service project.

December PING! Holiday Party

On December 9th, 2023, families gathered at the Auld Pavilion Recreation Center in Lincoln, NE, for the December edition of PING! (Parent Information Networking Group) and a festive Holiday Party. Tailored for families with children under the age of 14 affected by bleeding disorders and sickle cell, the event provided a heartwarming space for connection, celebration, and education.

Against the backdrop of laughter and joy, attendees engaged in delightful activities such as decorating gingerbread houses and playing games, fostering a sense of community and camaraderie. The event also featured an insightful educational presentation courtesy of Takeda, offering valuable insights for managing the health and wellness of families dealing with bleeding disorders.

The PING! and Holiday Party proved to be more than just an event; it was a vibrant tapestry of shared experiences, rekindling old friendships and forging new ones. Beyond the festivities, this gathering exemplifies our commitment to building a supportive community where families can connect, have fun, and learn together.

Thank you to everyone who participated, making this event a memorable and cherished occasion for all.

Also a big thank you to our sponsors Takeda, Superior Biologics, Genentech, & Novo Nordisk.




'tis the season

TO BE JOLLY




Washington Days 2024

Nebraska NBDF is looking for advocates to join us in Washington DC, March 6-8th for Washington Days. Limited travel grants are available to help cover the cost of hotel and airfare. Registration for Washington Days is free. If you are interested in travel funds please complete the application by Friday, January 5th. Deadline to register for Washington Days is January 15, 2024.

https://www.surveymonkey.com/r/HWJTL2Y

Research– Judith Graham Pool Recipients

NATIONAL BLEEDING DISORDERS FOUNDATION
Formerly NHF

2023 RESEARCH AWARDEES

NBDF Judith Graham Pool (JGP) Postdoctoral Research Fellowship

TOMASZ W. KAMINSKI

Neutrophil Extracellular Traps Promote Joint Injury in Hemophilia

Tomasz received his Pharm.D. degree in 2019 in Pharmacology and Toxicology science from Medical University of Bialystok, Poland, and immediately started his postdoctoral appointment at Vascular Medicine Institute at the University of Pittsburgh, PA. Tomasz's research focuses on the innate immune mechanisms in platelets and neutrophils as well as thrombo-inflammation pathophysiology. He uses cutting-edge intravital microscopy techniques to image in real-time the interplay between neutrophils and platelets during the initial stages of immune system activation. His work has authentic interdisciplinary nature since he studies cross-talk between innate immune signaling in neutrophils, Factor VIII deficiency, liver diseases and macroscale proteomics and genomic profiles of neutrophils and platelets under inflammatory stress. Until now, he proved that neutrophil activation seems to be a key player in the hemophilic arthropathy progression, dedifferentiated sinusoidal endothelium impacts liver-directed gene transfer in Hemophilia-a mice, and that liver to lung microemboli NETs promote Gasdermin-D-dependent inflammatory lung injury in Sickle Cell Disease. Tomasz has been appreciated with multiple awards from national and international societies and institutions as well as his research activities were supported by numerous extramural funding sources. In his scientific and personal life, he proudly follows the University of Pittsburgh's motto - Veritas et Virtus.

DR. QIAN LIANG

Mapping inter-domain interactions in VWF with new type 2B von Willebrand disease mutations

This JGP award was generously sponsored by Hemophilia of Georgia

Dr. Qian Liang received the MBBS degree in 2010 from Sichuan University and the M.S. degree in 2013 from Shanghai Jiaotong University in China. Dr. Liang worked as a Research Fellow in the Department of Laboratory Medicine in Shanghai Ruijin Hospital, which is a Heamophilia Treatment Centre for hard-to-treat patients in the Southeastern region of China. She received her Ph.D. degree in Laboratory Medicine in 2022, and is currently a visiting postdoctoral fellow in Professor Renhao Li's lab in the Aflac Cancer and Blood Disorder Center, Department of Pediatrics at Emory University School of Medicine. Her research work focuses on the structure and function of von Willebrand factor, as well as the development of related diagnostics and therapeutics, and she has published 6 research papers.

DR. KENNETH CHILDERS

Structural Investigation of Activated Factor VIII and the Intrinsic Tenase Complex by Single-Particle CryoEM

I received by BS in Biochemistry from the University of Arizona in 2012. I then received my PhD at the University of Maryland, Baltimore County while studying under Dr. Elsa D. Garcin. I am currently a postdoctoral scholar at Western Washington University under Dr. P. Clint Spiegel. Our research focuses on the structure/function of activated coagulation factor VIII and factor IX and how the two proteins bind to lipid membranes to form the intrinsic tenase complex. The results from this research will elucidate the mechanism behind hemophilia A/B-associated missense mutations and how factor replacement therapeutics can be rationally designed for increased pharmacokinetic properties.

Thank you!

The Foundation's Research Department is incredibly thankful for the support and generosity of Chapters raising funds to advance research through the JGP Fellowship. We look forward to partnering with you, please don't hesitate to contact us! We can brainstorm events, options, speaking engagements, webinars, assist with newsletters, and so much more! Thank you for your support and partnership! Please contact Samantha Carlson at scarlson@hemophilia.org for coordination.

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 Outgoing Board Members

It is with a deep sense of gratitude and appreciation that we bid farewell to two remarkable individuals, Joe Mickeliunas and Bob Dick, who have dedicated six years of unwavering service to the Nebraska Chapter of the National Bleeding Disorders Foundation.

Joe Mickeliunas, who served as our Board Chair this past year, has been a beacon of leadership and inspiration. His commitment to our cause, coupled with his strategic insights, has propelled our chapter forward. Joe's dedication to fostering a supportive and united community has left an indelible mark on all of us.

Bob Dick, our Treasurer for the past six years, has been the financial steward of our organization, ensuring that our resources are managed with the utmost care and integrity.

As they transition off the board, we extend our heartfelt thanks to Joe and Bob for their exceptional contributions. Their impact reaches far beyond their respective roles, influencing the very fabric of our community.

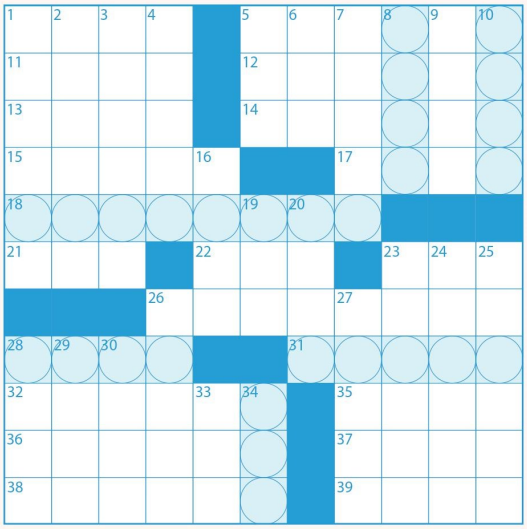
While we will miss their day-to-day involvement, we know that their passion for our mission will continue to resonate. Join us in expressing gratitude to Joe and Bob for their selfless service and wishing them continued success in their future endeavors.

Thank you, Joe and Bob, for six years of dedicated leadership and service to the Nebraska Chapter. Your legacy will endure, and your impact will be felt for years to come.

CAN YOU SOLVE

FOR A DIFFERENT HEMOPHILIA A TREATMENT?

Test your HEMLIBRA knowledge



ACROSS

1. Wine barrel
5. Deep fissures
11. Mideast gulf port
12. District
13. Ripped
14. Familiar with
15. Mean
17. Roost
18. The #1 prescribed prophylaxis for people with hemophilia A without factor VIII inhibitors*

*According to IQVIA claims data from various insurance plan types from April 2020 - May 2021 and accounts for usage in prophylaxis settings in the US.

21. Calendar divs.
22. Regret
23. Banquet hosts (abbr.)
26. International travel necessity
28. Check out the _____ treated bleeds data with HEMLIBRA
31. Number of dosing options HEMLIBRA offers
32. Small hole in lace cloth
35. Central Plains tribe
36. Melodic
37. Towering
38. Reduce
39. Spanish cheers

†Number of people with hemophilia A treated as of October 2021.

DOWN

1. Memorable, as an earworm
2. Devotee
3. Medical fluids
4. Prepare to propose, perhaps
5. PC's "brain"
6. Owns
7. Concert venue
8. See Medication Guide or talk to your doctor about potential _____ effects
9. Winter hrs. in Denver and El Paso
10. HEMLIBRA is the only prophylactic treatment offered this way under the skin
16. Pre-Euro currency in Italy
19. Subway alternative
20. Relax
23. Human
24. New Orleans cuisine
25. Mentally prepares
26. Collared shirts
27. Instagram post
28. Ardent enthusiasm
29. Brontë heroine Jane
30. Old Portuguese coins
33. Opposite of WNW
34. More than_____ thousand patients have been treated with HEMLIBRA worldwide†

SOLUTIONS

Across: 1. cask, 5. chasms, 11. Aden, 12. parish, 13. tore, 14. used to, 15. cruel, 17. nest, 18. HEMLIBRA, 21. yrs, 22. rue, 23. MCs, 26. passport, 28. zero, 31. three, 32. eyelet, 35. Otoe, 36. arose, 37. tall, 38. lessen, 39. oles
Down: 1. catchy, 2. adorer, 3. serums, 4. kneel, 5. CPU, 6. has, 7. arena, 8. side, 9. MSTs, 10. shot, 16. lira, 19. bus, 20. rest, 23. mortal, 24. Creole, 25. steels, 26. polos, 27. photo, 28. zeal, 29. Eyre, 30. Reis, 33. ESE, 34. ten

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA),** a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events),** which may form in blood vessels in your arm, leg, lung, or head

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects.**

HEMLIBRA® emicizumab-kxwh injection for subcutaneous use 150 mg/mL

Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Your body may make antibodies against HEMLIBRA, which may stop HEMLIBRA from working properly. Contact your healthcare provider immediately if you notice that HEMLIBRA has stopped working for you (eg, increase in bleeds).

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised: 12/2021

Genentech
A Member of the Roche Group

Advocacy Update– Nebraska

Advocacy Update: Progress and Persistence on Accumulator Adjustors in Nebraska

Over the past months, our dedicated team, led by Dale Gibbs and myself, has been collaborating with various health agencies across the state to address the pressing issue of accumulator adjustors.

Together, we've engaged in constructive discussions with the offices of Senator Bostar, Auguliar, Slama, Kauth, and Dungan to shed light on the detrimental impact of accumulator adjustor programs on individuals with bleeding disorders. We've shared personal stories, compelling data, and the collective concerns of our community to underscore the urgency of the matter.

While we do not anticipate the introduction of legislation on this front in 2024, our commitment remains unwavering. We understand the importance of laying a solid foundation for change, and we are steadfast in our determination to see this through. The complexities surrounding accumulator adjustors demand a comprehensive and thoughtful approach, and we want to ensure that when legislation is introduced in 2025, it is well-informed and impactful.

Your support has been instrumental in bringing attention to this critical issue, and we are grateful for the solidarity within our community. As we look toward the future, we remain hopeful that our collective efforts will pave the way for positive change, advocating for the rights and well-being of those affected by bleeding disorders in Nebraska.

Thank you for your continued support and dedication to our advocacy initiatives.

Why Strong Relationships Encourage Healthy Aging with a Bleeding Disorder

Author: Christina Frank

For Dan Liedl, 55, getting out of the house can be difficult. One reason is his physical disability—his right leg locked after a severe bleed when he was 12, and he has not been able to bend it since. But perhaps more significant than his limited mobility is the effect his severe hemophilia A has had on his social life. "I feel extremely self-conscious about walking stiff-legged," says Liedl, of Morgantown, West Virginia. "People stare at me.

As a kid, I spent a lot of time lying in bed in pain and not being able to go out and play. My best friends were books, and they still are."

Several recent studies have shown that loneliness, depression and a sense of isolation are common for older adults. These feelings may be especially acute among older adults with chronic diseases. And although they probably share many of the same concerns as their unaffected peers, older adults with bleeding disorders face unique challenges.

A Lonely Generation

Depression and isolation among older people with bleeding disorders can be attributed in part to their place in the history of the disease, says Dana Francis, MSW, a social worker in the adult hemophilia program at the University of California San Francisco Hemophilia Treatment Center.

"The average life span for someone with hemophilia used to be 30 to 40 years," Francis says. He also points out that more than half of the men with hemophilia who acquired HIV or AIDS in the early to mid-1980s through their exposure to contaminated blood or blood products died of AIDS.

"These guys lost a lot of friends, and they may struggle with survivor's guilt," Francis says of older men with bleeding disorders. "The older guys today are facing physical and emotional challenges that people with bleeding disorders never had to before because they didn't live long enough."

Three Ways to Combat Loneliness and Isolation

Studies have shown that having strong social relationships in later life conveys a number of health benefits, including increased longevity, a stronger immune system and lower levels of stress and depression. If you're feeling alone, here are some options that can help.

1. Reach out for support

Therapy is anathema to a lot of men, who are socialized to want to appear strong and invulnerable. But keeping feelings inside can lead to depression, anxiety and loneliness. Social worker Dana Francis recommends joining a support group specifically for people with bleeding disorders, whether in person or online.

Healthy Aging continued

I try to encourage guys to do whatever they're comfortable with—in whatever way they are able," he says. "It can be incredibly important to feel like you don't have to explain your situation to others and to know you're not alone. And it doesn't always have to be about commiserating. I want men to talk about all of it, whether it's sadness, loneliness or joy."

2. Venture out of your comfort zone
Dan Liedl is an introvert, but, somewhat paradoxically, he's learned that he loves public speaking. He regularly speaks to groups about bleeding disorders and HIV. "I feel confident in front of groups, and I believe that education is the greatest way to overcome misunderstandings, stereotypes and ignorance," he says. "It is energizing and validating, and I'm not being confronted with making chitchat or socializing."

3. Get involved in your community
It can be tough to go outside when you're not feeling good, but take the opportunity when you can. "Get involved," advises Mike Clancey, 70, of Grove City, Pennsylvania, who has hemophilia A. "Whatever it is—volunteering, working part time, participating in religious activities—stay active in the community somehow." Francis adds: "Do anything that floats your boat, whether it's music, art, whatever. Just get up and get out."

- Reprinted from Hemaware 2019

FACTOR UP with ALTUVIIIO™

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

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
651-303-6774
Serving Great Plains

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.

sanofi

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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