

# BIG RED FACTOR

2022—Issue 4



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Thank you for a wonderful 2022 full of wonderful programs, events, new families and connection. It was so great to have an entire calendar year of in person events where we were able to bring back long lost families and welcome newly diagnosed families as well. Sarah has worked hard to revamp our programming and grow our teen program, including a new teen council. We've seen growth in our VWD programming, adult men's events and engaging with the sickle cell community.

We hope to see 2023 bring even more growth, connection and renewed engagement. We hope with your help and your community power we can continue to serve the Nebraska Bleeding Disorders community even more for years to come. We may not know what the future holds but we plan to do it together. Sarah, the board and myself wish you a happy and healthy new year and we cannot wait to see you in 2023.

Thank you for allowing us to serve you.  
*Maureen Grace, Executive Director.*



**NEBRASKA CHAPTER  
NATIONAL HEMOPHILIA FOUNDATION**

[www.nebraskanhf.org](http://www.nebraskanhf.org)

**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**

President - Peter Senior  
Vice President— John Ashley  
Secretary - Suellen Colin  
Treasurer— Bob Dick  
Joe Mickeliunas  
Zach Fischer

*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**

Please see the next page for our 2023 calendar overview.

Other events that will take place in 2023 but are not on the calendar:

- Teen Programming
- VWD Education
- Industry Dinners
- Outreach events
- Spanish Education

Please follow our Facebook or Check the website to be up date on all upcoming programs and events for 2023.



**combined health  
agencies drive**  
MEMBER CHARITY

# 2023 Calendar

January

February  
18-19th  
Couple's  
Retreat

March  
20th  
Advocacy  
Day

April  
22-23  
Adults with  
Bleeding  
Disorders

May  
13th  
Women's  
Retreat

June  
24-25th  
Family  
Education  
Weekend

July  
PING  
23rd  
Infusion

August  
11-13th  
Family  
Camp

September  
Men's  
Retreat  
TBD

October  
7th  
Walk  
12st  
Harvest fest

November  
4th  
Industry  
Symposium

December  
10th  
Winter  
PING

## Advocacy Update

The advocacy committee of the board, headed up by Dale Gibbs, has started a venture to bring together other health related organizations together to combine our advocacy efforts as many issues affect more than just our organization. Along with the help of CHAD, we brought several organizations together to start our conversations around an access to care health coalition.

The meeting was held in mid-December attended by representatives from CHAD; Nebraska Chapter Alzheimer's Association; ALS Association, Nebraska Office; Team Jack Foundation; Autism Action Partnership; Brain Injury Alliance of Nebraska; the Leukemia and Lymphoma Society and the Nebraska Chapter of the National Hemophilia Foundation.

During introductions, attendees discussed their current advocacy efforts on a state and local level. Many belonged to national organizations that followed federal legislation closely but not so much state legislation. A few organizations relied on help for state advocacy from other organizations who were following a variety of legislative topics but everyone felt that they could do a better job on the state level and were open to explore opportunities for doing so.

We went into a bit of sidebar discussion on what "lobbying" meant as 501c3 organizations and decided that it would be a good idea if we could have some education on the current laws governing what we could do. There will be a couple of avenues to explore on who might do this for us and we will decide later on who we want to provide the training. We want to make the training available to not only the agency staff and board members but also the communities we serve since they are the most powerful voices for advocacy efforts.

Finally, we agreed that we would each monitor upcoming state legislation and share what we were following, why it was important to our communities and perhaps form a collaborative approach. We felt that the more information we shared with each other, the more likely we would not miss legislation that might affect us.

NENHF will be helping to form and lead this advocacy coalition to better serve those with rare diseases here in Nebraska and form alliances with other organizations who face the same advocacy issues that we are.

We believe this will be a wonderful coalition with a focused center on Access to Care.

# Save The Date



**NEBRASKA CHAPTER  
NATIONAL HEMOPHILIA FOUNDATION**

**Couple's Retreat**

**February 18th-19th, 2023**



**Arbor Day Lodge, Nebraska City**

**Registration will open soon for our second  
annual couple's retreat featuring  
Dave Robinson, education, time  
for connection, dancing and so much more..**

## FAB Conference 2022

The second annual Females and Bleeding (FAB Conference) took place at Margaritaville in Lake of the Ozarks October 14th-16th bringing together over 60 women from four chapters, Nebraska NHF, Hemophilia of Iowa, Gateway Hemophilia Association and Midwest Hemophilia Association. This event was sponsored by Octapharma. Topics included Treatment Strategies for Heavy Menstrual Bleeding, Mental Health and Positive Outcomes, Anatomy of the Nose and breakouts on Bone Mineralization, Mental health round tables and vWD shared decision making. Saturday afternoon we hosted a period party where we brought together feminine hygiene products and other supplies for people who menstruate that were donated to the Micah House in Council Bluffs, Iowa. We enjoyed a fun pizza party on Saturday night and finished out Sunday morning with a yoga session.

We thank everyone who took the time to drive to our beautiful venue in Lake of the Ozarks and look forward to coming together again in 2023.





## 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!

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**SCAN QR CODE OR VISIT  
OUR WEBSITE TO COMPLETE**

Your voice matters and  
will help shape the future of NENHF

## Family Education Weekend 2022



It was a day that was all about the ladies, and was filled with connection, crafting, and goodies at the Nebraska Women's Retreat. This event took place on December 17th, 2022, and was the first event held at the new NENHF suite. We're located in the same building but have upgraded to a new space that will allow us to do more in person programs and small group events. We talked about self-care and mindfulness, enjoyed a delicious lunch from Green Belly, and enjoyed some relaxing chair massages. We loved to catch up with our friends in our new office space, and we're looking forward to hosting more events here in 2023. Thank you to Sanofi, CSL Behring, Superior Biologics and Octapharma for their support of this event.



## Board Update

### Peter Senior Board Chair— Thank you!

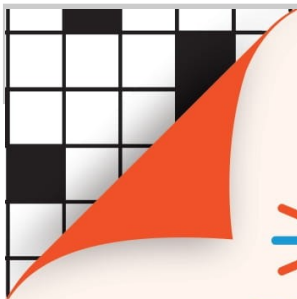
We would love to thank our outgoing board chair, Peter Senior, for six years of service on the Nebraska NHF board. Peter has served as the Board President for the last three years. His leadership has brought a strategic plan for the next several years of the organization, helping to create and grow an adult men's program, hosted a golf fundraiser the Re:Pete Golf Tournament benefitting the chapter, raised thousands of dollars through our Unite for Bleeding Disorders Walk and been a great voice and advocate for the bleeding disorders community in Nebraska. We want to thank Peter for his unwavering support, his time and his commitment to the chapter. You will be missed on our Board.



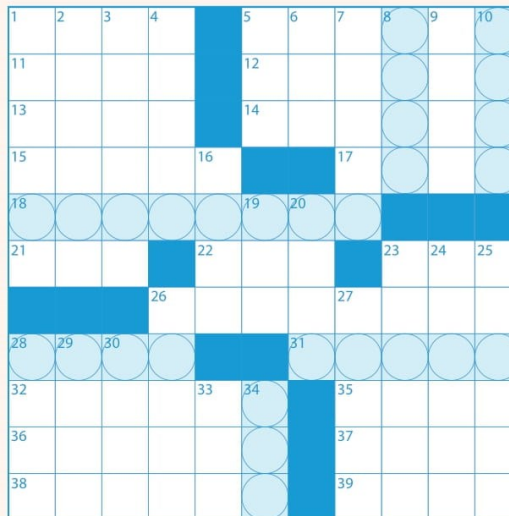
### Board & Committee Recruitment

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](mailto: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. Please reach out.



**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

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

- 32. Small hole in lace cloth
- 35. Central Plains tribe
- 36. Melodic
- 37. Towering
- 38. Reduce
- 39. Spanish cheers

**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. chasm, 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. eyelid, 35. Choc, 36. arena, 37. tall, 38. lesson, 39. ales  
 DOWN: 1. catchy, 2. adorer, 3. serum, 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. steel, 26. polos, 27. photo, 28. zeal, 29. Eye, 30. Reis, 33. ESC, 34. ten

Discover more at [HEMLIBRA.com/answers](https://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**.



**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  
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For more information, go to [www.HEMLIBRA.com](http://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



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## Harvest Festival 2022



We loved seeing some new faces and some familiar faces at the Harvest Festival this year. This event took place at the Roca Berry Farm in Roca, Nebraska on October 22nd, 2022. We enjoyed some tasty treats together, and families were free to explore the many attractions. The weather was perfect and it was a great time to get into the fall spirit. Thanks to all who joined us and to our sponsors who helped make this event an annual family favorite! Shout out to Bayer, Superior Biologics, Novo Nordisk for supporting this wonderful family centered fall fun day. We can't wait to see you back next year!

## December PING! And Holiday Party

The December PING! (Parent Information Networking Group) and Holiday Party was held at the Lincoln Children's Museum on December 10th. This event was for families with children under the age of 14 affected by bleeding disorders. We had a delicious taco bar and education was provided by CSL Behring. We had so much fun visiting with Santa, doing crafts, and exploring the exhibits at the Lincoln Children's Museum. This event is a great way for kids and parents alike to connect, have fun and build community while learning how to best manage the health and wellness of our bleeding disorders families.

Thank you to our sponsors CSL Behring, Superior Biologics, Soleo Health, CVS Health and to the Colburn Keenan Foundation.



APPLICATIONS AVAILABLE DEC. 12, 2022 - FEB. 27, 2023

# Apply to NYLI!



## NYLI ACTIVITIES

- Enhance leadership skills
- Develop professional skills
- Networking
- Chapter Events
- BDC
- 3 Tracks
  - Advocacy
  - Education & Outreach
  - Research
- Other opportunities as they become available!

## WHO SHOULD APPLY?

Young adults between the ages of 18-23 who:

- have a bleeding disorder or have a parent or sibling with a bleeding disorder.
- are interested in enhancing their professional and leadership skills.

## FOR MORE INFORMATION

Contact Heather Hicks or apply online:  
[hhicks@hemophilia.org](mailto:hhicks@hemophilia.org)

<https://www.hemophilia.org/educational-programs/training/youth-leadership-nyli>

**NYLI**  
national youth  
Leadership institute



## Teen Programming

### **NENHF Teen Council**

The NENHF Teen Council was launched in 2022. The Teen Council is a program for children ages 12-19 that are affected by a blood disorder and their siblings. This program will provide opportunities for learning leadership and life skills, as well as professional development opportunities. We will be accepting applications to join the Teen Council soon, so please keep an eye out for that coming soon in 2023.

The Teen Council has also been working on a service program in partnership with Children's Hospital. We are creating care packages for children staying at the hospital, as well as thank you gifts for HTC workers. If you are interested in donating or contributing to this project, please contact Sarah Arrieta at sarrieta@hemophilia.org or (402) 889-0572 for more information.

### **2023 YETI Conference**

The Nebraska Chapter is excited to provide the opportunity for one teen to join one staff member and one HTC representative to attend the 2023 YETI Conference in Oregon this February. This year, Nicolas Quiroz was selected to join Sarah Arrieta and Kylie Underwood to attend the conference at Camp Collins. Yeti is an experiential weekend, and the teen programs address topics that involve successfully transitioning to young adulthood and community building. By accepting this opportunity, Nicolas has agreed to step up as an active leader in the NENHF Teen Council and teen programming. Congrats to Nicolas Quiroz for accepting this opportunity!

### **National Youth Leadership Institute (NYLI)**

NHF is currently accepting applications for NYLI and we would love to have some representation from the Nebraska Chapter. If you know someone who would benefit from the program, please send them the flyer. More information about NYLI can be found here: : <https://www.hemophilia.org/educational-programs/training/youth-leadership-nyli/join-the-nyli>

## Common Questions About von Willebrand Disease

By: Michael Hickey– Posted in Hemaware 2022

von Willebrand disease is the most prevalent, yet lesser known, bleeding disorder. Here's what you need to know about VWD.

### What Is von Willebrand Disease?

Named after Finnish physician Erik von Willebrand, VWD is an inheritable bleeding disorder that, like hemophilia, is a result of missing or low levels of certain factor proteins that are needed to make a person's blood clot properly. People with VWD are either missing or low in the clotting protein known as von Willebrand factor (VWF) — or the VWF doesn't work as it should.

VWF is supposed to bind to factor VIII, another clotting protein, and platelets in blood vessel walls. This process helps form a platelet plug during the clotting process. People with VWD are not able to form this platelet plug, or it will take longer to form.

### There are three main types of VWD:

- Type 1: The most common and mild of the three, affecting 60% to 80% of people with VWD. Type 1 results in low levels of VWF and either mild or no symptoms.
- Type 2: Effects 15% to 30% of people with VWD. In this case, levels of the VWF protein are normal, but it doesn't operate as it should. This could happen for a few different reasons, such as VWF not being the right size, VWF attaching to platelets at the wrong time, or VWF attaching to platelets but not factor VIII.
- Type 3: Found in 5% to 10% of people with VWD, the third type is the most severe. People with type 3 have little or no VWF and usually suffer from severe bleeds.

**There is a fourth type, known as acquired VWD, that isn't hereditary. This type found in adults comes after a diagnosis of an autoimmune disease — such as lupus — or from heart disease, some types of cancer, or certain medications.**

### What Are the Differences Between VWD and Hemophilia?

Hemophilia and VWD are both passed on genetically from parent to child, though VWD is much more common and usually milder than hemophilia. Another difference: Men and women have an equal chance of getting VWD, whereas hemophilia is much rarer in women than in men.

**And compared with hemophilia, people with VWD are less likely to bleed into their joints. VWD most often causes easy bruising and nosebleeds, and women with VWD can experience very heavy menstrual periods.**



## Common Questions About von Willebrand Disease

### What Are the Symptoms of von Willebrand Disease?

Von Willebrand disease shares many of the same symptoms as hemophilia. Symptoms of VWD include:

- Frequent nosebleeds that last longer than 10 minutes
- Bleeding from cuts or injuries that lasts longer than 10 minutes
- Bruising easily, with bruises that are raised and larger than a quarter
- Heavy bleeding after any surgery
- For women, girls, and those who menstruate: Heavy periods, also called heavy menstrual bleeding, (having to change one pad or tampon every hour) or periods that last longer than seven days; and heavy bleeding after childbirth or miscarriage

VWD is diagnosed through a combination of blood tests including a VWF antigen test — which measures the amount of VWF in the blood — tests that measure clotting time and ability to form a clot, and tests measuring platelet function.

If VWD is discovered, an additional test is given to determine the type. The recommended facilities for diagnosis and treatment are any federally funded hemophilia treatment centers.

### What Are the Treatments for VWD?

VWD is treated in several ways depending on the diagnosis and severity, and some bleeds are mild enough not to require treatment at all. The most common treatment is desmopressin acetate (DDAVP), a drug that stimulates the release of VWF from cells and increases the level of factor VIII, but was recently recalled from one manufacturer. As with hemophilia, more severe forms of VWD are treated with factor replacement therapy.

Birth control pills can be taken to reduce menstrual bleeding and increase the levels of VWF and factor VIII in the blood. Antifibrinolytics, medications that keep blood clots from breaking down, are another treatment option.

Nebraska NHF will be focusing on VWD outreach and education in a continued effort in 2023. This will include provider education, outreach and engagement of the greater VWD community across the entire State of Nebraska. We hope to ensure better knowledge and understanding of the VWD Guidelines for diagnosis and treatment for all those with inheritable bleeding disorders, especially those underserved with VWD.

# CSL Behring

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Manager, Coagulation Products

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



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Mimi, Anna & Noel to BROTHERS HEALTHCARE

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ANNA MACDONALD: 760.540.3118 | annam@brothershealthcare.com

NOEL MINOR, RN, BSN: 316.866.0114 | noelm@brothershealthcare.com

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For Hemophilia A patients,

# YOU USE YOUR JOINTS MORE THAN YOU THINK.

That's why you need a Factor VIII treatment you can  
Count On to protect\* you and your joints from bleeds.

1.6

**MEDIAN OVERALL  
BLEEDS PER YEAR†**

0

**MEDIAN JOINT  
BLEEDS PER YEAR†**

#1

**PRESCRIBED FACTOR VIII  
FOR PROPHYLAXIS IN US‡**

\*ELOCTATE has been proven to help patients prevent bleeding episodes using a prophylaxis regimen.

†In the A-LONG study, 164 previously treated adults and adolescent males with severe Hemophilia A ages 12-65 received Eloctate either every 3 to 5 days, once weekly, or on demand.

‡#1 prescribed based on HTC reported data as of September 2020.

## A CONNECTION YOU CAN COUNT ON

Learn more about how to protect you and your joints  
from bleeds by connecting with your local CoRe.



**Danielle Kempker**  
danielle.kempker@sanofi.com  
(816) 946-1870

[Connect](#) with your CoRe

### INDICATION

ELOCTATE<sup>®</sup> [Antihemophilic Factor (Recombinant), Fc Fusion Protein] is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ELOCTATE when you have surgery.

### IMPORTANT SAFETY INFORMATION

- Do not use ELOCTATE if you have had an allergic reaction to it in the past.
- Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.
- Allergic reactions may occur with ELOCTATE. Call your healthcare provider or get emergency treatment 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 ELOCTATE, which may stop ELOCTATE from working properly.
- Additional common side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort.
- If you have risk factors for developing abnormal blood clots in your body, such as an indwelling venous catheter, treatment with Factor VIII may increase this risk.
- These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, or if bleeding is not controlled after using ELOCTATE.

Please see [full Prescribing Information](#).

**SANOFI GENZYME** 

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MAT-US-2020798-v2.0-02/2021

Keep track of your bleeds, infusions, and activity.

# HemMobile™

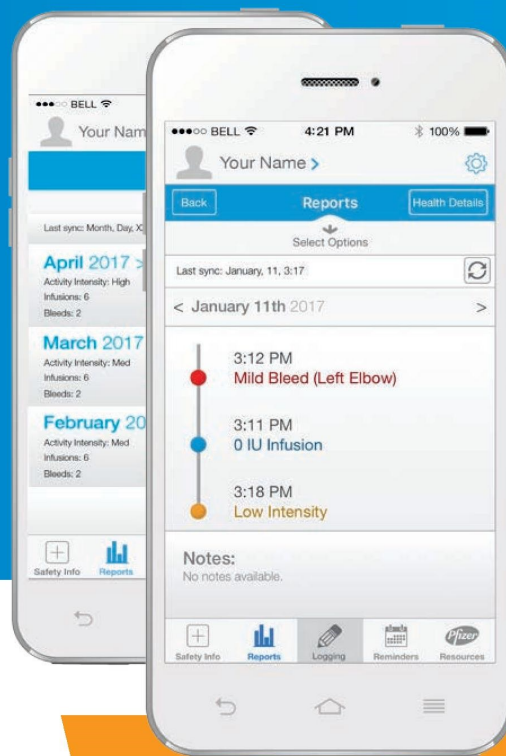
with *enhanced* activity tracking

## The little app is getting bigger.

Talk to your doctor about HemMobile™—  
and which activities may be right for you.



- Log daily activities, infusions, and bleeds
- Share single consolidated reports with your treatment team
- Set reminders for resupply, appointments, etc
- Sync with fitness apps and wearable devices



## Hemophilia can be difficult. Tracking it shouldn't be.

HemMobile™ was designed to help you keep track of your bleeds, infusions, and factor supply.\*

Now it can also help you keep track of your daily activities and, when paired with our custom wearable device, track your heart rate, steps, distance, and activity duration. You can have an even more informed discussion with your treatment team about your activity level as well as your dosing regimen.

Download the app,  
pair your device,  
and start tracking



For iPhone® and Android™



For more information, contact Pfizer Hemophilia Connect, one number with access to all of Pfizer Hemophilia's resources and support programs.

Call **1.844.989.HEMO (4366)** Monday through Friday  
from 8:00 AM to 8:00 PM Eastern Time.

\*HemMobile™ is not intended for curing, treating, seeking treatment for managing or diagnosing a specific disease disorder, or any specific identifiable health condition. iPhone is a trademark of Apple Inc., registered in the US and other countries. App Store is a service mark of Apple Inc. Android and Google Play are trademarks of Google Inc.