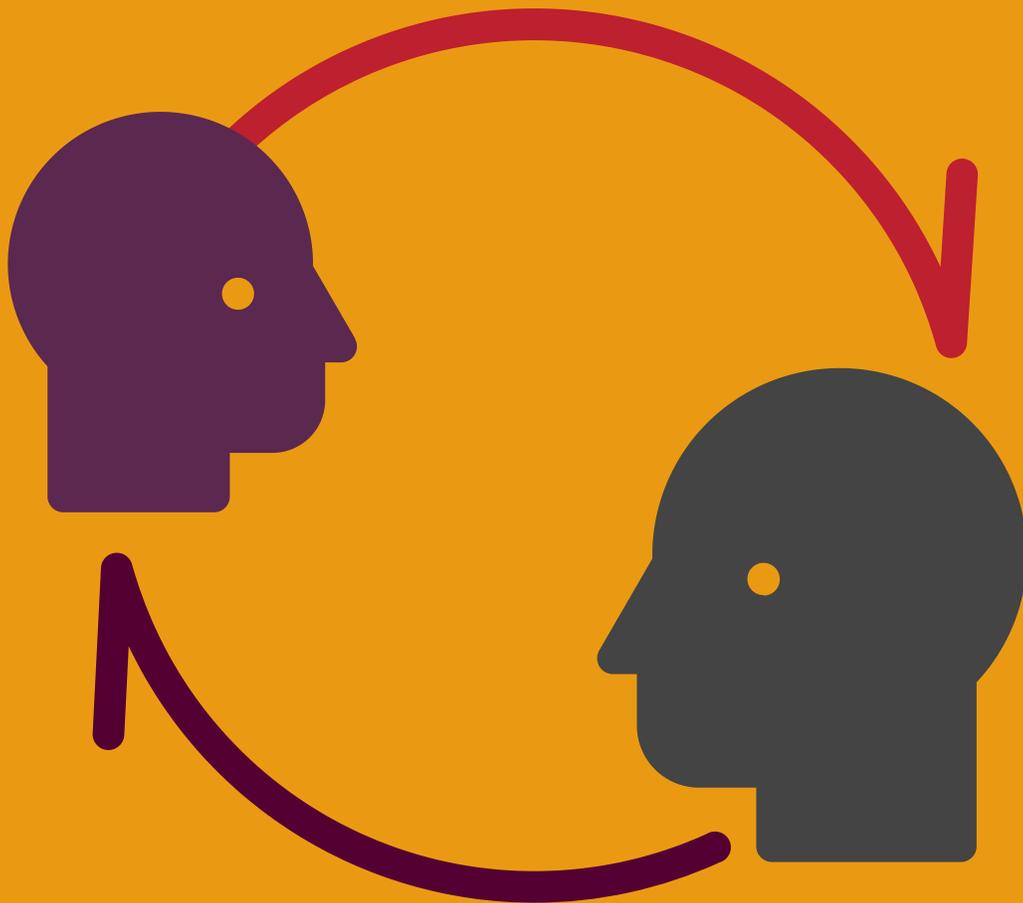


HEMOPHILIA

NEWS & VIEWS



**NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION**

GREETINGS

Dear Friends,

We don't know about you, but the past few months have flown by! After our Spring Education Day, we went up to Northern Nevada for our Carson City Advocacy Day and a couple of World Hemophilia Day events in Reno & Elko. We were back in Reno in May for Spring Education Day and the Reno Unite Walk. June saw our first Family Camp, which was a blast, as you will see from the many pictures. We also had the opportunity to see many more of you at our industry education dinners over the past few months.

Over the next few months, we will be celebrating Back to School in Las Vegas, Reno & Elko, and preparing for our biggest fundraiser of the year, our Unite for Bleeding Disorders Walk in Las Vegas on Saturday, October 7th. We also have more fun events coming up, so please make sure to check your email, your mailbox, and our social media and website.

In other organizational news, you may or may not have heard that the National Hemophilia Foundation is celebrating our 75th anniversary! In August, this celebration will be in high gear at the annual Bleeding Disorders Conference in Washington, DC. This year we have a large contingent of folks from Nevada attending, so there will be a lot of news about the conference at NHF coming to you.

Over the next two months, our Chapter Staff will be working hard to develop our calendar of programs and events for 2024. If there is something you would like to see in 2024, please reach out and let us know. We want to provide the best experiences and opportunities for our Bleeding Disorders community across Nevada.

With Warm Regards,

Jacob, Danielle, and Stephanie

The Nevada Chapter Team



The Nevada Chapter of the National Hemophilia Foundation 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.

Our vision is a world without inheritable bleeding disorders.

VOLUNTEER

COMMUNITY HELP REQUEST

We are seeking help for the Unite Walk on Sat, Oct 7th.
If you are interested in helping, please contact
Stephanie at sdupree@hemophilia.org

We need assistance with the following:

Set-up, 6am-8am - setting up tables, unloading the U-haul, and placing supplies and equipment.

Event Volunteer 8am-11am - Assigned as needed, includes monitoring tables, handing out supplies to participants, cheering along the walking path, keeping the event area tidy, handing out lunch

Event Breakdown Crew 10:30-1pm - This consists of breaking down the event, stacking up tables and chairs, loading the U-Haul, taking trash to the designated areas, collecting signs



A NV Chapter
ALL HEARTS IN
thank you to
MGM Event Production Team for
their assistance with our Back to
School backpack packing & all of our
Quarter 2 Volunteers:

Nurse Becki
Gayle C.
Constance D.
Rodney D.
Craig F.
Josie H.
Alissa K.
Xochi M.
Aiyana P.
Madison P.
Becky R.
Maureen SM.
Sarah S.
Aimee S.
Pam W.
Nick K.
HTC of NV



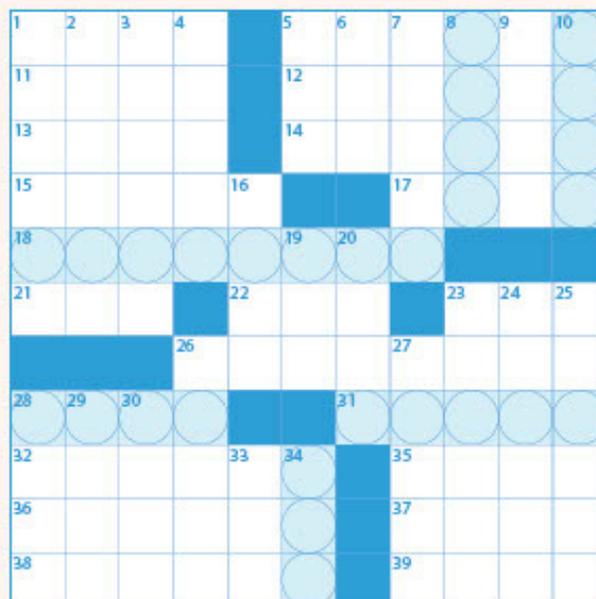
Don't see something of interest here?

Please visit our [volunteer page](#) and
complete an interest form.

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 ICMA 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

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. oak; 5. chiasm; 11. Aden; 12. parish; 13. tore; 14. used to; 15. cruel; 17. neat; 18. HEMLIBRA; 21. yr; 22. rue; 23. MCA; 26. passport; 28. zero; 31. three; 32. eyelid; 35. Crow; 36. arrose; 37. tail; 38. lessen; 39. olea; Down: 1. catchy; 2. adorer; 3. serum; 4. kneel; 5. CPU; 6. has; 7. arena; 8. side; 9. MSTB; 10. shot; 16. lira; 19. bus; 20. rent; 23. mortal; 24. Croatia; 25. steady; 26. poles; 27. photo; 28. real; 29. Eye; 30. Rial; 33. ESE; 34. inn

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

Discover more at [HEMLIBRA.com/answers](https://www.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
U.S. License No. 1048

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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



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A Member of the Roche Group

EXPLORATION

Inhibitor Risk Paper Informed by Genotyping Project

Between 2013-2017, the "My Life Our Future" (MLOF) project offered eligible individuals with hemophilia free genotyping, which is historically hard to access, expensive, and not covered by insurance. Conducted through the laboratory analysis of a single blood sample, genotyping can reveal the specific genetic mutation responsible for a patient's disease such as those located in the factor VIII and factor IX genes in the case of hemophilia A (HA) and hemophilia B respectively.

MLOF was a partnership between the hemophilia community, the National Hemophilia Foundation, American Thrombosis and Hemostasis Network (ATHN), Bloodworks Northwest, and Bioerativ/Sanofi (formerly Biogen). Individuals who participated in the program could also opt – via informed consent – to have a blood sample with their de-identified genome sequence data deposited into the MLOF Research Repository. Investigators could apply for access to the database to support their research, with acceptance contingent upon their ability to demonstrate both scientific merit and ultimate benefit to patients.

Ultimately, samples from more than 6,000 individuals were included in the repository to help advance the scientific understanding of the disorder. MLOF was a boon to researchers, particularly to those looking to better understand the genetic differences that affect bleeding severity and reactions to certain therapies. One such example is a new paper "Race, Ethnicity, F8 Variants, and Inhibitor Risk: Analysis of the 'My Life Our Future' Hemophilia A Database," published in the Journal of Thrombosis and Haemostasis.

Armed with ample collection of samples generated by MLOF, the authors of the paper sought to investigate some existing hypotheses related to inhibitor risk amongst individuals with HA.

A total of 4169 subjects were included in the primary analysis, 2,443 with severe HA and 1726 with mild or moderate HA – this analysis examined several key variables including demographic, clinical, factor VIII gene (F8) sequence data. Investigators found inhibitor incidences of 30.3% in those with severe HA and 7.9% in the mild/moderate group. In the severe group, 1075 (44%) had an intron-22 inversion mutation of the F8 gene, and of those, 388 (36.1%) developed an inhibitor.

The result of a crossing over between two linked gene pairs of the same chromosome, intron 22 inversions account for nearly 50% of severe hemophilia A cases.

Investigators sought to determine whether inhibitor risk associated with these type mutations are similar to those associated with other large structural changes in the F8 gene. They ultimately found no difference in inhibitor risk amongst those severe HA participants with an intron-22 inversion vs other large structural changes in the F8 gene.

The authors also looked at another hypothesis informed by earlier research which suggested that increased inhibitor risk could be caused by specific mutations known as non-HA causing, non-synonymous single nucleotide polymorphisms (nsSNPs). Often associated with disease, nsSNPs are caused by a change to the amino acid sequence of a genetically encoded protein. In fact, the analysis showed that nonpathogenic ns-SNPs in the F8 were not associated with inhibitor development.

The analysis also confirmed earlier studies suggesting an increased risk for FVIII inhibitor development in both Black/African American and Hispanic HA patients, relative to White non-Hispanic individuals with HA in the U.S.

Investigators signaled the potential implications of this study, and future research, in helping to inform therapeutic plans that better anticipate inhibitor risk.

"It is hoped that future studies, e.g., whole-genome sequence analyses to detect genetic variations contributing to inhibitor risk, will identify specific, clinically actionable genetic correlates indicating increased susceptibility to, or protection from, hemophilic inhibitor development and possibly suggesting novel therapeutic interventions to promote immune tolerance to FVIII," concluded the authors.

Citation

Ahmed AE, Pratt KP. Race, ethnicity, F8 variants, and inhibitor risk: analysis of the "My Life Our Future" hemophilia A database. *J Thromb Haemost.* 2023 Apr;21(4):800-813. doi: 10.1016/j.jtha.2022.12.017. Epub 2022 Dec 26. Erratum in: *J Thromb Haemost.* 2023 Apr 25; PMID: 36696179.

Visit the Journal of Thrombosis and Haemostasis to view the abstract.

NOTE: Corrigendum to 'Race, ethnicity, F8 variants and inhibitor risk: Analysis of the "My Life Our Future" Hemophilia A database' [*Journal of Thrombosis and Haemostasis* Volume 21, Issue 4, April 2023, Pages 800-813]

Disclaimer: NHF provides periodic synopses of articles published in peer reviewed journals, the purpose of which is to highlight papers that cover a wide range of topics and speak to a broad spectrum of the inherited blood disorders community. Topics include shared decision making, gene therapy, health equity, and more. NHF hopes you find this content to be informative and engaging.

Any questions about the articles featured here should be directed to the publishing journal and/or the study authors. This content is for general information only. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

COMMUNITY

Financial Assistance Program

The purpose of Emergency Financial Assistance is to improve the quality of life of individuals and families affected by bleeding disorders. We know that life circumstances can change, and it is okay to ask for help when it is needed.

We can offer support for:

Expenses incurred in the care, treatment, or prevention of a bleeding disorder
Transportation services to medical appointments and HTC's
Basic living expense emergencies (rent, mortgage, utilities, food, etc.)
Educational Needs

Emergency financial assistance depends on the availability of funds and applicant eligibility. Funding is not guaranteed, but we will try to accommodate as many requests as we can. We can provide assistance due to the support of the HTC of Nevada.

We are always happy to help this community as best as we can. If you ever need financial assistance, please feel free to look at our application and fill one out. See below for more information.

To apply for assistance, visit: <https://hfnv.org/support-resources/financial-assistance/>

If you have any questions about financial assistance, please feel free to reach out to us at 646-901-6442.



Did you know about the NV Chapter Counseling Services Program?

In response to requests from the bleeding disorders community, the Nevada Chapter of the National Hemophilia Foundation (NHFNV) has created a program in collaboration with Nevada Counseling Providers.

Counseling services will be provided both in-person, via tele-health, and group counseling for approved applicants.

More information about our provider partner can be found on their website:
The Practice at UNLV: <https://www.unlv.edu/thepractice>

Eligible applicants are individuals with a bleeding disorder or an immediate family member or designated caregiver of an individual with a bleeding disorder. If your application is approved, NHFNV will pay for up to eight (8) one-hour sessions that may also be renewable upon submission of an additional request in coordination with the Provider.

NHFNV will facilitate the funding of the program and follow all federal and state laws, to include HIPAA privacy standards.

All applicant requests are considered confidential to the full extent permitted by law. No personal information will be used or disclosed and at no time will personal information be shared with any individual, company, and/or organization outside The Nevada Chapter of the National Hemophilia Foundation.

For more information or to apply,
visit: <https://hfnv.org/support-resources/counseling-services.html>

COMMUNITY

Nevada Chapter Services for the Bleeding Disorder Community

Peer Group Support Program

As of January 2023, the NV Chapter has initiated a (PSG) Peer Support Group program based on feedback from our community support survey and previous needs assessments.

WHAT ARE PEER SUPPORT GROUPS?

Support groups - also often referred to as self-help groups - are groups of people who gather to share common issues and experiences associated with a particular problem, condition, illness, or personal circumstance. In a support group, people are able to talk with other folks who are like themselves - people who truly understand what they're going through and can share the type of practical insights that can only come from firsthand experience.

WHO MIGHT YOU FIND AT A NV CHAPTER PEER SUPPORT GROUP?

They are made up of peers - people who are all directly affected by a bleeding disorder, whether it be a caregiver, parent, sibling, spouse, friend, or person living with a bleeding disorder.

HOW DOES A NV CHAPTER PEER SUPPORT GROUP WORK?

They will be facilitated by a staff member or trained volunteer.

As people arrive, we may break into smaller groups to ensure everyone has a chance to talk. We do agree as a group to follow guidelines to ensure a safe, productive, and confidential experience. Children and youth that attend will have their own group space.

WHEN DO NV CHAPTER PEER SUPPORT GROUPS HAPPEN?

In 2023, support groups are scheduled once per month to gather in person, and once per month to gather virtually, see schedule below or visit our website's [event calendar page](#). No registration is required, and people can drop in and attend in person or virtually anytime. If the current schedule does not meet your needs, yet you would like to participate in a support group, please let us know.

HOW DO I GET TO BECOME A TRAINED VOLUNTEER PEER SUPPORT FACILITATOR?

Full training is provided to interested community members. If you are interested in learning more or attending training to become a Peer Support Group Facilitator, please contact Danielle Bell, at dbell@hemophilia.org to learn more.

2023 SCHEDULE

LAS VEGAS

THIRD THURSDAY 6PM TO 7PM IN-PERSON

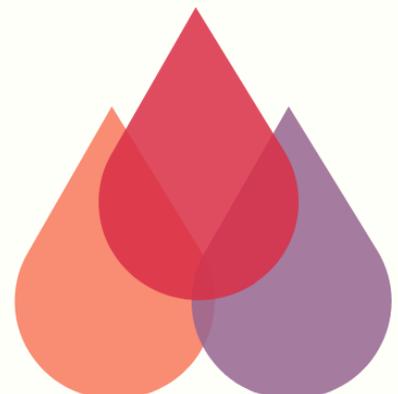
NV CHAPTER OFFICE

222 S. RAINBOW BLVD #203 LV, NV 89145

VIRTUAL ZOOM

SECOND TUESDAY 10AM TO 11AM

MEETING ID: 897 1705 1706 PASSCODE: 925097



**IN COMMUNITY
IN SUPPORT
IN CONVERSATION**



Explore Head-to-Head Pharmacokinetic (PK) Study Data

See half-life, clearance, and other PK data from the crossover study comparing Kovaltry[®] and Advate[®].

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Antihemophilic Factor (Recombinant)

EVENT RECAP

Bikes in Your Blood April 2023

After a 3 year hiatus, Bikes in Your Blood returned to Las Vegas as a cycling event to benefit the NV Chapter of NHF. We had 55 cyclists join in the fun this year to bike on the River Mountains Loop. All participants were treated to a Panera Bread box lunch after the ride to bring their energy levels back up. We were overwhelmed with the community support for this event- we had over 20 volunteers from organizations like The Infusion Pharmacy, Optum, HTC NV, REI, members of our BD community, and the Chapter Advisory Board. This fundraiser raised \$12,000 to directly support our programs and services. This event is open to cyclists of all ages and abilities, so please be sure to join in the fun next Spring! [Check out a video created by Adrian at the Green Valley Cyclist club here.](#)



BIKES IN YOUR **BLOOD**

EVENT RECAP

State Advocacy Day - Carson City April 2023

On April 17th, we had our first Carson City Advocacy Day since 2019. We had 3 families from Nevada Participate, along with the Nevada Chapter Staff, and NHF Director of State Relations, Bill Robie. Collectively we met with over 12 State Senators and Assembly members to talk about how bleeding disorders impact the daily lives of many Nevadans. We also advocated for the passage of SB 194, which provides exceptions to Step Therapy for individuals with chronic conditions. This legislation was signed by Governor Lombardo. Our next Carson City Advocacy Day will be in 2025, but our advocacy efforts will continue in 2024.



EVENT RECAP

**World Hemophilia Day
April 2023**

For World Hemophilia Day, we celebrated all around the state of Nevada! We had educational dinners and meet-ups in Las Vegas, Reno, and Elko centered around World Hemophilia Day on April 17th. Our friends from Sanofi provided some education about hemophilia and wonderful dinners for everyone. We love an excuse to gather around the dinner table with our Hemo family! Keep an eye out for more industry education dinner series opportunities on our events calendar at www.HFNV.org



EVENT RECAP

**Movement is Medicine - Northern Nevada Education Day
May 2023**

'Movement is Medicine' was the theme of this year's Northern Nevada Education Weekend held in May. Our speakers and activities revolved around promoting health and wellness, both in body and mind. We used crayons to trace our joints and bones, learned some great stretching techniques to keep injuries at bay, and even did some laughing yoga. We hope all the participants this year keep using the techniques to keep their minds calm and bodies healthy this summer!



EVENT RECAP

Reno Unite for Bleeding Disorders Walk May 2023

Reno Unite for Bleeding Disorders Walk 2023 was a big success this year- we hit all of our fundraising goals, had more community members than ever join us at Bartley Ranch Park, and the weather could not have been nicer. Your fundraising and support helped raise over \$12,000 for NV

Chapter programs and services, like Family Camp, Education Days, Teen River Camp, and more! Thanks to everyone who participated, and shared lunch and conversation together. We also thank our sponsors for helping make this event possible.



EVENT RECAP

Industry Education Events

Dave & Busters School's Out
May 2023

There was no better way for families in Southern Nevada to end the school year than with fun, friends and education at Dave & Busters on May 22nd. Over 30 attendees came out and celebrated the end of the school year and parents heard a presentation about being a part of a child with a bleeding disorder. Thanks to our friends at Octapharma & InfuCareRX for this great way to start the summer!

WNBA Basketball Night Out
June 2023

We were feeling like ballers back in June- a wonderful dinner at the Las Vegas Four Seasons and watching the World Champ LV Aces play basketball! We also heard from a professional bowler who shared his story about being active while having Hemophilia A. What an inspirational evening for us all! Thanks to our friends at Infucare RX and Octapharma for making this great night possible!



EVENT RECAP

**Family Camp
June 2023**

For 3 nights and 4 days in June, we embarked on a new Camp tradition at the first ever NV Chapter Family Camp! Nestled in the California mountains, Camp de Benneville Pines hosted 85 NV family members, staff, and volunteers (and one bear!). We enjoyed building community connections with everyone, and are so thankful to everyone working together to make this camp such a fun and transformative time. Traditional camp activities like swimming, archery, and hiking kept us entertained, as well as the super popular tie-dye and paracord crafting! Most important, campers had the chance to learn how to infuse their medicine. 5 people at camp earned their Silver Bells awards for doing a successful infusion.



EVENT RECAP

Family Camp
June 2023

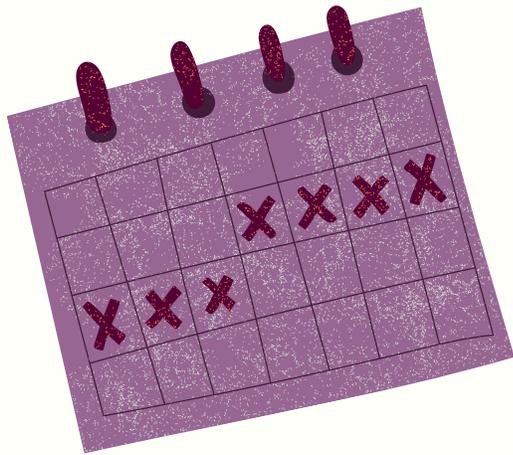


EVENT RECAP

Teen River Camp July 2023

6 NV Chapter Camp teens had the opportunity to experience the excitement of a rafting adventure on the South Fork of the American River with San Diego County Hemophilia Association's Camp Dragonfly camp community. Our crew camped five days and four nights at the ETC (Environmental Traveling Companions) River Camp's riverfront property located in Lotus, CA. Along with rafting, participants get to sleep under the stars (tent optional), cook meals in the outdoor kitchen, and enjoy group activities and nightly campfires. This was a memorable adventure, and we can hardly wait to do it again next year!





**More details available
on our [events page](#)**

Tue, Aug 8 10-11 am
Peer Support Group (Online)

Sat, Aug 12 1:30 - 7 pm
Infusion Education @ Chapter Office

Mon, Aug 28, 6 pm
Gene Therapy Industry Education
Bonfish Grill

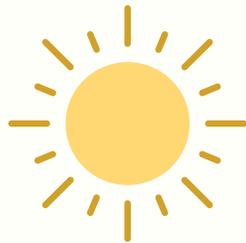
Tue, Sep 12 10-11 am
Peer Support Group (Online)

Wed, Sep 13 time TBD
Hispanic Heritage Month Event

Thur, Sep 21 6-7 pm
Peer Support Group @ Chapter Office

Thur, Sep 28 time TBD
Top Golf Industry Education w/CSL Behring

Sat, Oct 7th 9am - 12pm
Las Vegas Unite Walk @ Floyd Lamb



UPCOMING EVENTS

FUNDRAISER

Unite
for Bleeding Disorders

Unite For Bleeding Disorders Walk
Saturday, October 7th, 9 am-Noon
Floyd Lamb Park, 9200 Tule Springs Rd, Area 4

Celebrate, honor, and remember those with bleeding disorders at this year's Unite for Bleeding Disorders Walk Las Vegas. This is our biggest community event of the year, where we come together to support each other, reflect on the past year's accomplishments, and raise awareness of inherited bleeding disorders. It is also our biggest fundraiser of the year! Funds from this event will be used to provide programs and services to the bleeding disorder community throughout the State of Nevada, such as education weekends, advocacy at the state and national level, summer camps, peer support groups, and emergency assistance. Register online before the walk to build a team and raise much-needed funds.

[Follow this link for more info](#)

For the little ones, we will have face painting, bubble dance parties, and characters to take photos with. Community members can also get more information about NHF research and advocacy projects from national experts, the current state of gene therapy and other clinical trials, and connect with local industry partners. After an opening ceremony, we will walk around the lake with our pinwheels as a united group. After we all cross the finish line, we will announce the awards for top fundraisers and scholarship winners.

Renee Paper Picnic

After the Unite Walk, we will honor and celebrate the legacy of our Foundation founder, Renee Paper. Renee was a passionate advocate for people with von Willebrand Disease and all Nevadans with a blood disorder. Her work in the late 1980s helped people all over the world and opened the discourse around bleeding disorders and symptoms that predominantly affected women. We will be honoring her legacy with a special picnic lunch at the park and will have displays set up about Renee and the history of the Nevada Hemophilia Foundation, now the Nevada Chapter of NHF.

**Be sure to check our [EVENTS PAGE](#) for the most current
and up to date programs and events.**
Schedule, dates, times, and locations are subject to change.

LIFE HAPPENS

AND ADVATE WILL BE THERE WHEN IT DOES

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.¹



AdvateRealLife.com

*In clinical trials, ADVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

Not an actual patient.

Prophylaxis with ADVATE prevented bleeds¹

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment. 53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic-driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on-demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable.

- Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment.[†] This represented a 98% reduction in overall bleeds per year.
- Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis

[†]Median is the middle number in a group of numbers arranged from lowest to highest.

ADVATE Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?

Tell your HCP if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.

Reference: 1. ADVATE Prescribing Information.

What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE and Hemophilia A?

- Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Important Facts about ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.





[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

Do not attempt to do an infusion to yourself 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 infusing ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

Call your healthcare provider right away if your bleeding does not stop after taking ADVATE.

What should I tell my healthcare provider before I use ADVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:

cough	headache	joint swelling/aching
sore throat	fever	itching
unusual taste	dizziness	hematoma
abdominal pain	hot flashes	swelling of legs
diarrhea	chills	runny nose/congestion
nausea/vomiting	sweating	rash

Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ADVATE for a condition for which it is not prescribed. Do not share ADVATE with other people, even if they have the same symptoms that you have.

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at www.ADVATE.com or 1-877-825-3327.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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Patented: see <https://www.takeda.com/en-us/patents/>

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JOIN OUR NEW NV CHAPTER COMMUNITY MEMBER FACEBOOK GROUP

We are always working to stay in communication with our NV Chapter community members. Through emails, posts on all of our social media platforms, phone calls, texts, postcards, and this newsletter we work to keep you informed and up to date.

We have started a new group specifically for you to keep you updated on current events and current conversations.

Although we know not everyone utilizes the Facebook App, this will be another way to give people a space to stay connected.

We hope to see you there. We look forward to welcoming you.

Please note that this group is intended only for the Nevada Chapter Bleeding Disorder Community. Individuals or family members with a bleeding disorder (who do not currently work as a pharmaceutical or specialty pharmacy industry representative) are invited to participate in this group.

