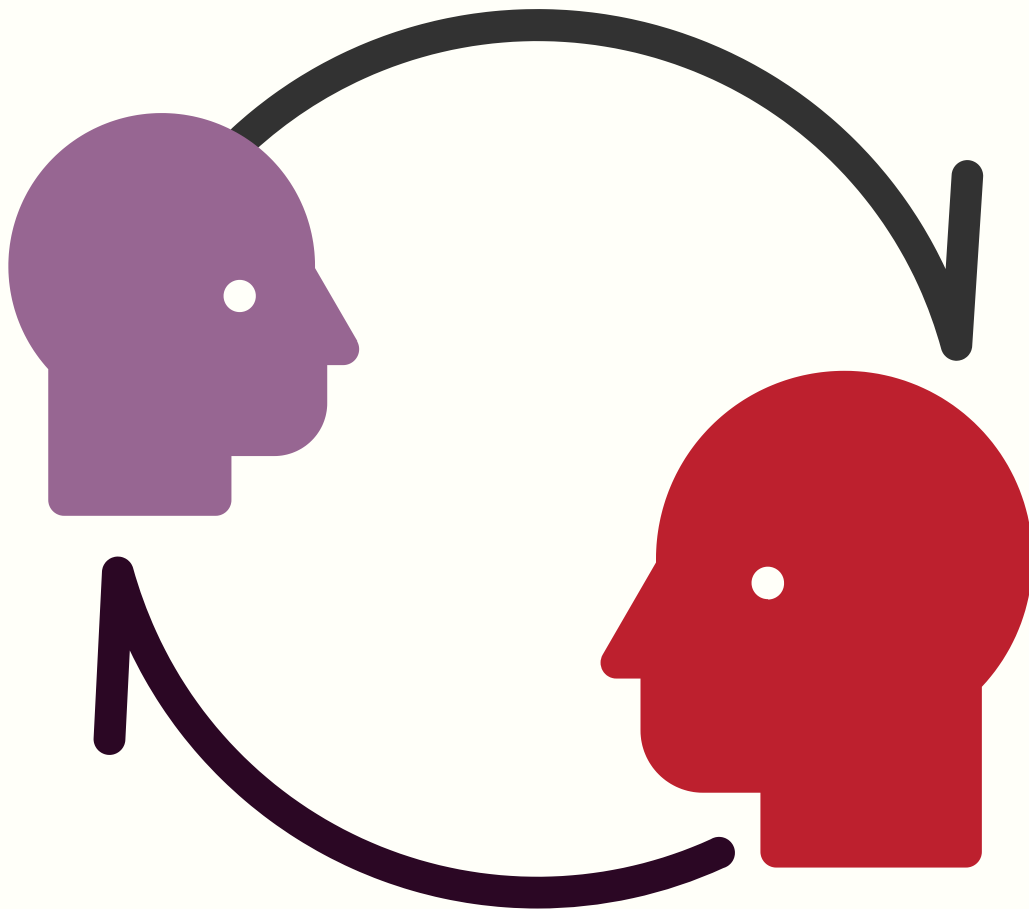


HEMOPHILIA

NEWS & VIEWS



**NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION**

GREETINGS

To our dear community friends and families,

As we enter the final few days of 2022, we choose to reflect on the first full year for our Nevada Chapter Team. 2022 has provided us with many wonderful opportunities to meet members of this incredible community. We've traveled to Elko, Reno, and all over the Las Vegas valley and have felt incredibly welcomed by everyone we have met. We are looking forward to spending more time meeting more of you and deepening the relationships that have been blossoming throughout this year.

We know that this year has looked very different from previous years. From COVID restrictions to new events, and other events not taking place. As you will see in this edition, we have included a link to our Annual Community Survey. We'd love to hear your honest feedback on what we have done this year, and what we can do better next year. Each of you can provide us with a look into the history of the Nevada Chapter.

In this edition of the newsletter, you will get a peek at our 2023 calendar and hear all about the events we have had over the past few months. We are incredibly excited about 2023 and we believe it will be a fantastic year for the Nevada Bleeding Disorders community. You will notice more events outside of Las Vegas, as we want to make sure we are serving the entire state of Nevada.

We hope that the end of the year and the holiday season brings you feelings of love and peace. We know this time is not the easiest for everyone, so please do not hesitate to reach out to us. We are here for you.



Warmest regards,

Stephanie, Danielle, Jacob & Mariana

"Winter is the time for comfort, for good food and warmth, for the touch of a friendly hand and for a talk beside the fire: it is the time for home." – Dame Edith Sitwell

Get to know your NV Chapter Staff Team

Jacob Murdock, Chapter Executive Director

What traditions do you most look forward to at the end of the year?

I really enjoy giving gifts to the ones I love. I also really enjoy making time for reflection on the year and going through the Top Album lists for the year.

New Year's Resolution for 2023:

Taking a walk every day. Exploring Reno and Elko more.

Mariana Peña, Chapter Outreach Coordinator

What traditions do you most look forward to at the end of the year?

Spending time with my family and eating tamales.

New Year's Resolution for 2023:

Prioritizing my overall health. Connecting more with our bleeding disorders community; both in NV and outside of NV.

Danielle Bell, Chapter Program Manager

What traditions do you most look forward to at the end of the year?

As often as possible during this time, I enjoy gathering friends and family together for slow-cooked meals, stories, and laughter. I'm not always sure who will be at the table, yet folks know they are always welcome.

New Year's Resolution for 2023:

I'm not one to set resolutions, I often feel resolutions are focused on problems or the lack of something. For many years, I've been choosing a phrase or a word to guide me in how I work, live, and play. Last year it was, "take risks." I started a new job, worked on a new musical project, and went out of my comfort zone in meeting new people, and going to new places. I reflect back and realize how much that helped me grow. This year, I am drawn to the word, "cultivate." We often think of cultivating as preparing or breaking up soil. I don't know what I'll be planting, but maybe it will have me digging deeper into new ideas, skills, or plans for myself, my family, and this community. Going beyond the surface is what I envision. Looking forward to what I'll uncover.

Stephanie Dupree, Chapter Development Manager

What traditions do you most look forward to at the end of the year?

I look forward to all the "Best of ..." lists that come out in December! So many good things to catch-up on that I may have missed during the past year, and this is the time when I can catch up on all those overlooked gems.

New Year's Resolution for 2023:

Spend more time working on myself and finding time for reflection amongst the chaos. Travel somewhere I have never been before.

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

Spend some time with the staff on these projects.

Who: You like to discover and organize.

What: Sorting and scanning documents, pictures, and some shredding.

Why: We are working on creating digital archives out of an array of file boxes

Where: At the NV Chapter Office, using our devices.

When: Beginning January, any weekday, between 8am to 5pm, as available

Who: You like data.

What: Transferring paper survey results into an e-form to collect data.

Why: We are wanting to ensure we have all survey results in one place to ensure accurate outcomes after survey closes on Jan. 3rd.

Where: At the NV Chapter Office, using our devices

When: Week of January 9, any weekday, based on availability, AM/PM

Interested, need more info? Contact Danielle Bell
dbell@hemophilia.org or call/text 702-306-5513



**We are casting a net for your stories:
VOLUNTEERS**

We are very excited to be rebuilding our volunteer engagement and recognition program here as the NV Chapter begins to ramp up the community and program events across the state. We are aware of the long history of support from this community's volunteers, yet we want to know more about you and your efforts. So many community members have contributed their time and talents to the bleeding disorders community and have been a vital part of helping the NHF-NV Chapter deliver its mission. It could not have been done without you. Would you be willing to tell us about your volunteer experience? Please share those details about the how, and the what, and especially about your "why" towards helping.

Please share your volunteer story through the link below. Help us identify your efforts and connect the dots to the impact our volunteers have made on this community through the years, however long ago. Every story is important to us. Every effort makes a difference. We look forward to celebrating our volunteers early next year with an appreciation and recognition event. Stay tuned for more details.

 **SHARE**
YOUR STORY



A NV Chapter
ALL HEARTS IN
thank you to
Josie & Tatiana Hatem
Jaime Coutts
Jackie Hernandez
Kaylah Faasse &
Marsha Cordell
for their gracious
volunteer service this
quarter.



**KEEP YOUR EYES OPEN
FOR CAMP VOLUNTEER
REQUESTS!**

COMMUNITY

2022 Financial Assistance Program Review at the Nevada Chapter

This year we've had over 30 applications for financial assistance that have been approved. As of today, we've been able to help those applicants within our bleeding disorder community with over \$20,000. This amount has helped with the applicant's rent, utility bills, household basic necessities amongst other things. 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.

Learn more about our Financial Assistance Program

Did you know that the Nevada Chapter offers Financial Assistance to our members?

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.)
- Medic Alert Bracelets
- 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 Hemophilia Alliance and the HTC of Nevada.

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 Mariana at 646-438-5434.

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

Your
VOICE
MATTERS

The Nevada Chapter wants to hear from you!

We are gathering information from our community members to improve the programs and services offered by the NV Chapter of the National Hemophilia Foundation. The information you provide will not be identifiable, and individual responses will only be seen by the Nevada Chapter team. We value your input and feedback, and this information will help better inform our work in 2023.

The questions are directed at individuals with bleeding disorders and/or family members of those with bleeding disorders. It should take 10-15 minutes to complete.

Please have only one person per household complete this survey. All responses are anonymous, and you will not be identified in any way through this survey.

**After submitting your responses,
you will be taken to a separate form to enter a drawing for a \$100 Gift Card.**

**This survey will close on January 3rd, 2023.
Thank you for your participation!**

Here are a few ways to complete the NV Chapter Community Support Survey.

You can, [click this link to take you directly to our JotForm Survey Page.](#)

OR

Scan the QR Code here with your SmartPhone to take you directly to the JotForm Survey Page.

OR

Contact jmurdock@hemophilia.org for a paper survey to complete and return by mail or office drop-off.

SCAN WITH YOUR SMARTPHONE



1. Open the Camera app from the Home screen, Control Center, or Lock screen.
2. Select the rear facing camera. Hold your device so that the QR code appears in the viewfinder in the Camera app. Your device recognizes the QR code and shows a notification.
3. Tap the notification to open the link associated with the QR code.



Ask a Social Worker:

How Can I Convince Someone to Seek Mental Health Treatment?

Advice for family members on how to bring up mental health treatment with loved ones.

Posted/Updated
September 26, 2022

Ask a Social Worker is a monthly column featuring questions from the community and answers from members of NHF's Social Work Working Group. If you have questions for our social workers, send them to askasocialworker@hemophilia.org.

Dear Kathaleen,

Do you have any advice for convincing someone to seek mental health care? I think my son is depressed.

I like that you're being aware and wanting to guide your son toward help. This can be a sensitive topic for some people, and your approach and timing are important considerations. Ask your son if he has time to talk with you. Setting the time and intention to talk can eliminate distractions; for example, you don't want to talk between activities or be limited by time. Also, talk in a space that is safe and private. This is a vulnerable conversation, so it would be best to avoid public spaces or family gatherings. It's also helpful to know the signs of anxiety and depression before these conversations to ensure the most impactful interaction with your loved one.

Bring compassion and empathy to the conversation. You noticed, you're concerned, and you want to offer support, so make sure to say so. Using "I" statements such as "I am worried about you" or "I want to check in on you" can open a conversation and potentially reduce defensiveness or a feeling of being attacked, which can happen depending on what your son's experience has been with mental health support. Please be patient, and keep in mind that this conversation is about him and letting him know that he is loved, supported and seen. Ask questions like "How have you been feeling?" or "How do you feel about going to therapy?" It's also good to normalize going to therapy. Mental health care is healthcare.

If at this point your son is interested in or open to finding a therapist, he might need support, so make sure to ask. Sometimes finding a therapist who is a good fit can be a daunting task (there are barriers such as insurance, location, scheduling, etc.), especially when someone is already feeling vulnerable. You can offer support such as providing a list of therapists or websites or offering transportation.

If your son is not interested in finding a therapist after your conversation, remind him that you are there and that you love him. You can ask questions about why he may not be interested. Listen, validate and resist giving advice or trying to "fix" anything. Continue to check in on him. And make sure you also have support.

While my response is built around the framework of allowing for choice, there are times when mental health care may not be a choice. If at any point you become concerned about your son being at risk of harming himself or others, you should call 911 or seek emergency medical care for him immediately (regardless of his age or ability to make his own decisions).

Here are two national support helplines and websites: The first is the National Suicide Prevention Lifeline, which you can reach by dialing 988. This is a national network of local crisis centers that provides free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a day, seven days a week. The second is the Substance Abuse and Mental Health Services Administration's National Helpline (800.662.4357), which is a free, confidential, 24/7, 365-day-a-year treatment referral and information service (in English and Spanish) for people and families facing mental health or substance use disorders. And as always, your local hemophilia treatment center social worker can be a resource.

—Kathaleen M. Schnur, LCSW

Schnur is a social worker at the Hemophilia Center of Western Pennsylvania in Pittsburgh and a member of the Social Work Working Group.



New Document to Help Residential Substance Use Disorder Placement for Individuals with Bleeding Disorders

Historically, many residential substance use disorder (SUD) facilities have denied admittance to individuals with bleeding disorders – the basis of these denials are most often the use of self-administered, intravenous medications such as factor replacement therapies. The lack of access to residential addiction treatment facilities, can have very serious, even fatal outcomes for bleeding disorder (BD) patients in acute need of help with their addiction.

Results of a national survey of hemophilia treatment center (HTC) providers suggest that the majority of attempts to place patients at a residential addiction treatment facility or at mental health facilities have met with failure. However, interviews with HTC providers who have bucked this trend and secured residential placements have helped generate a document that provides best practices and resources for HTCs endeavoring to successfully refer a BD patient. It is a comprehensive resource that is meant to encompass the various referral stages, including things to consider prior to making a referral, during the referral process, and in the event of a denial.

Best Practices For Accessing Residential Substance Use Disorder Treatment For Individuals With Bleeding Disorders is a product of the Bleeding Disorders Substance Use and Mental Health Access Coalition (BD SUMHAC), whose mission is to advocate for access to appropriate SUD and mental health (MH) treatment facilities for all individuals with BDs. The Coalition plans to develop a similar document centered on access to MH facilities.

Please note that the Coalition is very eager to collect as much information as possible relevant to denials for residential SUD treatment, so that they can continue to refine best practices and enhance support for individuals with BDs. Contact information for reporting these denials can be found in the document.

BD SUMHAC was formed via a partnership between the New England Hemophilia Association (NEHA), Hemophilia Federation of American (HFA), the National Hemophilia Foundation (NHF), HTC providers, and BD community members. Sponsoring organizations include NHF, NEHA, and the HTC at Rush University Medical Center.

EMERGENCIES	911
SUICIDE AND CRISIS LIFELINE	988
Ayuda en Espanol (Suicide Prevention Lifeline)	1-888-628-9454
Boys Town National Hotline	1-800-448-3000
Child Abuse and Neglect Hotline (NV)	702-399-0081
Child Help National Child Abuse Hotline	1-800-422-4453
Children's Mobile Crisis Response Team	702-486-7865
Children of the Night (Street Rescue)	800-551-1300
Combat Trauma ptsdusa.org	877-717-7873
COPLINE.ORG (Officer's Lifeline)	1-800-267-5463
Crisis Support Services of Nevada cssnv.org	1-800-273-8255
Crisis Text Line (Text TALK or CARE to)	741741 (TALK) Or 839863(CARE)
Crisis Text Line EN ESPANOL (442-AYUDAME)	741741 (AYUDA)
Disaster Distress Helpline (natural/human)	1-800-985-5990
DOD Safe Helpline (affected by sexual assault)	877-995-5247
Domestic Violence (National Hotline)	1-800-799-7233
Domestic Violence (SafeNest)	702-646-4981
Domestic Violence (S.A.F.E House)	702-564-3227
Fire/EMS (First Responders) nvfc.org/help	1-888-731-3473
Gamblers Anonymous (GA) So NV Hotline	702-529-0202
Human Trafficking Hotline	1-888-373-7888
Military Helpline militaryhelpline.org	888-457-4838
Na. Center Missing & Exploited Children	1-800-843-5678
Poison Control poison.org	1-800-222-1222
Rape, Abuse, & Incest National Network (RAINN)	1-800-656-4673
Runaway Hotline 1800runaway.org	1-800-786-2929
SafeVoice Nevada (students, parents, faculty)	1-833-216-7233
Safe Place Hotline (Youth)	1-866-827-3723
SAGE Hotline (LGBT Elders)	1-877-360-5428
Signs of Hope (formerly Rape Crisis Center So NV)	702-366-1640
Teen Dating Abuse loveisrespect.org	1-866-331-9474
The Network La-Red (LGBTQ Domestic Violence) en Espanol	800-832-1901
Trans Lifeline translifeline.org	1-877-565-8860
Trevor Project Crisis Line (LGBTQ < 25)	1-866-488-7386
Veteran Crisis Line veteranscrisisline.net	1-800-273-8255 (Press 1)

EVENT RECAP

LV Walk

Unite for Bleeding Disorders Walk is our annual community event that celebrates the resilience, dedication, and perseverance of the bleeding disorder community in Nevada. This important event also raises vital funds needed to allow our organization to continue to fulfill its mission of providing education, support, and advocacy for people in Nevada. Each year, community members, their families, friends, supporters, local businesses, and our industry partners unite together to support each other and build a stronger community.

On Saturday Oct 8, over 200 people came together in Las Vegas for the 2022 Unite Walk, and we have raised over \$33,000! These funds directly improve the quality of life for people in Nevada with a bleeding disorder. We had a visit from Sonic the Hedgehog, face painters, an Ice Cream truck giving out free treats thanks to Takeda, and live DJ keeping us dancing the whole afternoon! We could not be more thankful for all our Team Captains and Sponsors that made this event so special.

This year, the Unite Walk was followed by the Renee Paper Picnic. Renee was a nurse here in Las Vegas in the late 1980s and she literally wrote the book about von Willebrand Disease that has helped thousands of people all over the world and opened the discourse around bleeding disorders and symptoms that predominantly effected women. She is also the founder of our organization, she founded the Hemophilia Foundation of Nevada, which is now the Nevada Chapter of NHF, and her support and dedication brought Hemophilia Treatments Centers and expertise to the people living here in Nevada.



EVENT RECAP

Halloween Party

The NV Chapter partnered with the Hemostasis and Thrombosis Center of Nevada (HTC) to throw a fun Halloween party at the HTC Office! There was trick-or-treating around the office, carnival games and prizes, a fun 360 photo booth, and pumpkin painting! There was pizza and snacks available for dinner and it was the biggest pizza we have ever seen, 3ft across! Thank you HTC for hosting the Halloween gathering and for letting show off our costumes.



Paint & Sip

Our first ever paint night fundraiser was a super fun and raised \$150 for the Foundation! We had 8 participants join us in the NV Chapter office to create a painted pumpkin canvas and share a full table of snacks and drinks. Look for more small fundraising nights like Paint & Sip in the new year!



EVENT RECAP

SafeTALK

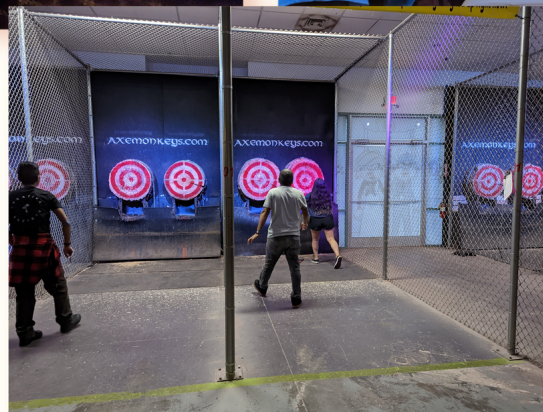
Early November with the support of the NV Office of Suicide Prevention, we hosted SafeTALK; Suicide Alertness for Everyone. Our entire NV Chapter Staff and six of our community members gathered for this important skills training. This training offered listening and awareness skills to help participants identify a person with thoughts of suicide. Practicing the most important skill, is the ASK, "Are you thinking about suicide?" Often folks shy away from such conversations, yet what we learned through safeTALK is that it can make an impact. We also received KEEP SAFE resources to help us guide those in crisis to the right people and services. We share a full list of 24/7 Crisis Hotline information on page 7. If you are interested in participating in a SafeTALK training, click [here](#) to visit the Office of Suicide Prevention Training Programs (nv.gov) to learn more about opportunities across Southern and Northern Nevada.



safeTALK

Education Dinner Recap

This quarter we had 4 education dinners with different sponsors. Novo talked about Food and Fitness Basics on 11/9. Sanofi talked about Gratitude Nation on 11/28. Takeda talked about resilience on 12/8. Infucare Rx and Bayer talked about infusion education on 12/12. Throughout these education sessions we've had various families attend and total attendance would be over 60 attendees. Thank you to all of our sponsors for supporting our chapter and helping us bring different education sessions to our community. We would also like to thank our community for attending these education sessions.



EVENT RECAP

Annual Meeting

Dec 3, 2022

When we received news that Potosi Pines had a malfunctioning well, and no water, we got that sunken feeling. It didn't take long to realize we had our very own well to draw from, our NHF-NV Chapter community. With a couple of phone calls, creative thinking, and all hearts on deck, we managed to smoothly transition our vision into the NV Chapter office building. We were grateful to our sponsors for having the trust in us to continue to go with the plan. The generosity of labor and support of the NHF Chapter team services really made an impact to create this fun-filled day.

Families enjoyed portrait sittings, sponsor exhibits, crafts, and a delicious taco buffet. We can't forget to mention the very popular Cocoa and Cookie Cart. Our education sessions, presented by Katherine Cabrera, NHF's Bilingual Education Specialist, were topics on improving our understanding of how pain affects people with bleeding disorders, and also exploring the shift to person-centered care and the concepts of shared decision-making. We also had a short presentation about advocacy priorities for 2023 by Bill Robie, Director of State Government Relations at NHF. All were very well attended.

We also had the opportunity to have breakout peer support group sessions. Always receiving meaningful feedback from our community, we will be introducing more peer support group sessions for 2023. Please stay tuned for more information as we develop our schedule and invite our community to learn and support one another.

It was great to see families trickle in throughout the day, attend the sessions, and fill our spaces with laughter and excitement. We cannot wait to see you all again soon at our Open House and Cookie Exchange, Thursday, December 29th.



UPCOMING EVENTS



YOU ARE INVITED
Open House & Holiday Cookie Exchange
Thursday 12/29
4:30pm - 6:30pm
222 S. Rainbow Blvd, Ste. 203 Las Vegas, NV 89145
RSVP via email at Nevada@hemophilia.org (let us know if you are bringing cookies), or
at: <https://hfnv.org/get-involved/event-calendar.html>

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

COMMUNITY

Open House & Cookie Exchange
Thursday 12/29 from
4:30 – 6:30pm
NV Chapter Office

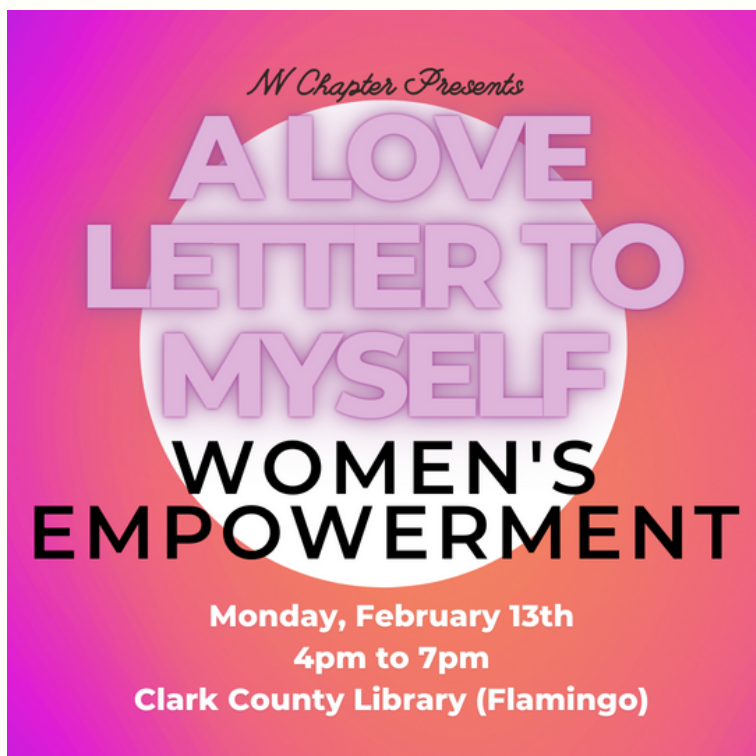
Celebrate the Holiday Season with friends and the Nevada Chapter Staff.

We will provide the festive location, hot cocoa, cider, and cookies.

We invite all members of the Bleeding Disorder community to bring a dozen cookies to share.

You don't need to bring cookies to participate - but it is encouraged.

EDUCATION



NV Chapter Presents
A LOVE LETTER TO MYSELF
WOMEN'S EMPOWERMENT
Monday, February 13th
4pm to 7pm
Clark County Library (Flamingo)



NV Chapter Presents
SPRING EXPLORATION
at Potosi Pines Camp
Saturday, March 25th, 2023
Education Sessions
Kids Day Camp
Teen Overnight
SAVE THE DATE

HOT TIP:

We are always adding events to our website. Be sure to check our EVENTS PAGE for the most current and up to date programs, events, and upcoming registrations for these events.

FUNDRAISING

8th Annual Winter Wine Fest

Saturday January 28, 2023 | 6pm-8pm

Bella Vita | Blue Diamond (New Location with Heated Patio!)
4965 Blue Diamond Rd, Las Vegas, NV 89139

Join Nevada NHF at our 8th Annual Winter Wine Fest, where we will have unlimited wine tasting, a silent auction, and a wine pull to raise much-needed funds to support the bleeding disorder community in Nevada. We are excited to bring this fun event back in person for the first time since 2020, so please join us to see some old friends and make a few new ones!

Tickets are now available for purchase on our website
(LINK: <https://hfnv.org/get-involved/special-events/wine-fest.html>)

*click
here!*

\$40 General Admission (\$50 at the Door)

General admission includes two hours of tasting a variety of wines and appetizers on the heated patio

\$75 VIP

Includes early entrance to the event at 5 pm, access to premium wines and high-end hors d'oeuvres in the VIP Tasting Room, custom Winter Wine Fest wine glass.
Limited to 30 tickets.

For event questions and information about sponsorships or donating silent auction prizes, please contact Stephanie Dupree, Nevada NHF Development Manager, at 646-527-8128 or Sdupree@hemophilia.org



WINTER WINE FEST

Save the Date!

Saturday, January 28th | 6pm-8pm

Wine Tasting & Silent Auction

2023 CALENDAR

JANUARY

28th - Winter Wine Fest
Las Vegas

FEBRUARY

13th - Women's Event
Las Vegas

MARCH

4th - Break for Mental Health
Las Vegas

25th - Spring Education Day
Las Vegas

APRIL

8th - Bikes in Your Blood
Las Vegas

17th - Carson City Day
Carson City

MAY

20th - Northern Nevada
Education Day
Reno

21st - Reno Unite for
Bleeding Disorders Walk

JUNE

Kids Camp
TBD

2023 CALENDAR

JULY

10th-14th - Teen River Camp
Lotus, CA

29th - Back to School
Las Vegas

AUGUST

5th - Back to School
Reno

SEPTEMBER

9th - Fall FUNdraiser
Reno

OCTOBER

7th - Las Vegas Unite
for Bleeding Disorders
Walk

NOVEMBER

4th - Parent Education Day
Las Vegas

DECEMBER

1st - 2nd - Annual Meeting
Las Vegas

TBD - Reno Holiday Party

TBD - Elko Holiday Party

Thank you to our
sponsors for all of their
generosity and support.
We look forward to
working with you in 2023

Do you know
your **on-demand
treatment** options
for hemophilia A?



Stay informed of product choice by speaking with your doctor
and learning more about a prescription treatment option by visiting
OnDemandHemophiliaA.com



MEET OUR NEW STAFF MEMBERS



Ha Tran RN



AJ Montgomery RN



Becky Ralph RN



Jeff Nelson RN



Malynda Russell



Lindsey Parnell

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P. 702-330-0555 F. 702-832-1128

6880 S. MCCARRAN BLVD, STE. 4. RENO NV 89509
P. 775-622-7371 F. 775-800-5748

www.htcnv.org

LIFE HAPPENS

AND ADVATE WILL BE THERE WHEN IT DOES

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

Not an actual patient.

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

ADVATE

[Antihemophilic Factor (Recombinant)]

REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

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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