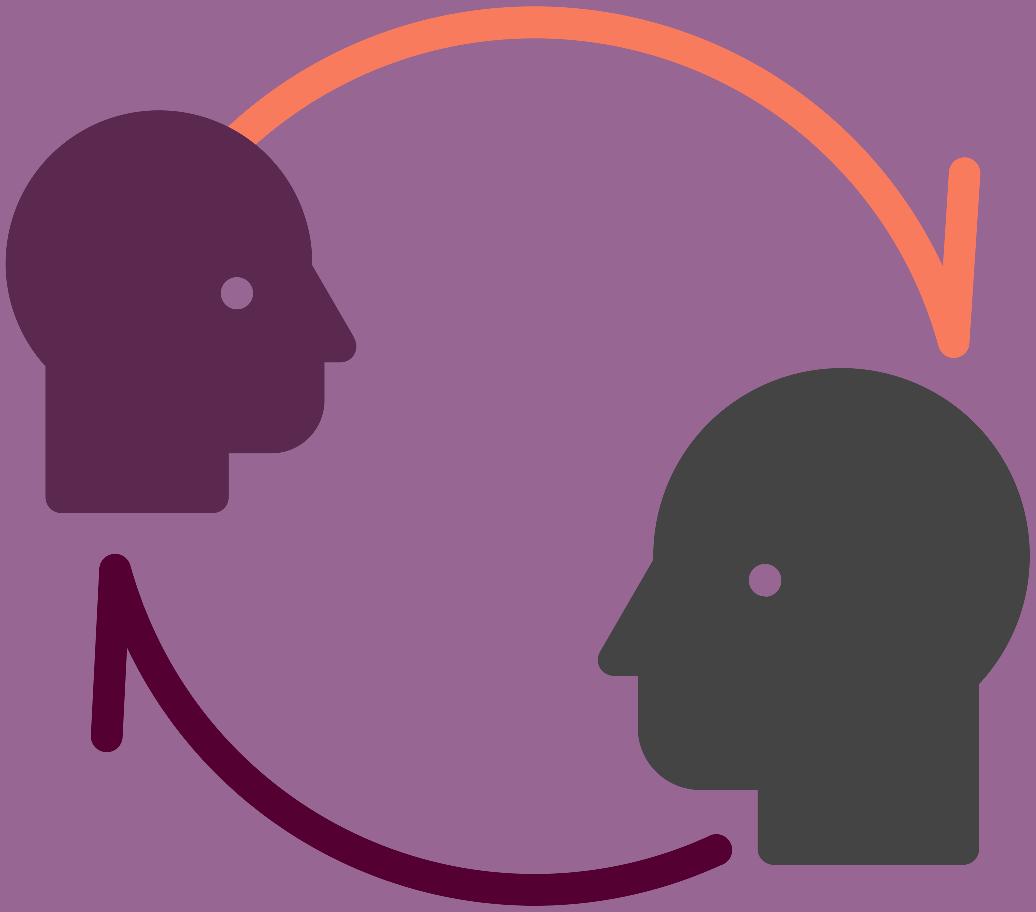
FALL 2022

HEMOPHILIA

NEWS & VIEWS



NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

GREETINGS

Dear Friends,

In the Chapter world, September is budgeting season. Our team has spent many hours over the past few months setting a course for 2023 that we hope will engage and invigorate our community. Over the next few weeks, you will start to hear about our programming for 2023. One of our major goals for 2023 is to prioritize being the Nevada Chapter. We know Nevada is a big state, and we want to make sure wherever you are in the state, the Chapter is there with you.

It is easy to focus on the future but let us not forget about the rest of 2022. We are just a few days away from our biggest fundraiser of the year, the Las Vegas Unite Walk. This year we are celebrating the history of the Nevada Chapter after the Unite Walk by holding our Renee Paper Picnic following the walk. We will also have memorabilia, pictures, and words documenting our past that we hope will inspire this community.

Throughout this edition of the Newsletter, you will hear about our upcoming events, as well as events from the past few months. We would love to know if there is anything that we've done this year that you want to see in 2023, or if there is something that we could do better. As a team, we are a couple of months shy of hitting our year anniversary and we want to hear from you about how we are doing.

We have had the pleasure of connecting with many of you over the past few months. We hope to continue to develop relationships and provide the support, education, and advocacy for this incredible community in Nevada.

With Warm Regards,

Jacob, Danielle,
Mariana, 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 8th.
If 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 placement of supplies and equipment.

Event Volunteer 8am-11am - Assigned as needed, includes monitoring tables, handing out supplies to participants, cheering along the walk path, keeping 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

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 Woodside Homes Girl Scout Troop #659 & Full Tilt Riders MC for helping with our back-to-school event!

Unite
for Bleeding Disorders

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.hfnv.org

Unite for **Hope**.
Unite for **Community**.
Unite to **Make a Difference**.

Raise Awareness and Funds for Nevada's Bleeding Disorders Community!

Las Vegas Unite for Bleeding Disorders Walk

Saturday, October 8th 2022 | 9am - Noon

Floyd Lamb Park at Tule Springs

Create a Team, Set Your Fundraising Goal and Make a Difference! Free Picnic after the Walk!

www.UniteforBleedingDisorders.org

Contact Stephanie Dupree for more details and sponsorship opportunities at
Sdupree@hemophilia.org or 646-527-0442

HALLOWEEN BASH 2022

October 27th from 5 - 7 PM

brought to you by:

HTC NV
HEMOSTASIS & THROMBOSIS CENTER of NEVADA

SCC NV

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

All Ages Welcome!

Costume Contest
Games & Prizes
Trunk or Treat
Food & Drinks

Call 702-330-0555
RSVP by 10/12

8352 W. Warm Springs Rd. Ste. 200
Las Vegas, NV 89113

Let’s Talk About It!

Mental Health: Maneuvering through adolescence and parenthood with a chronic illness.

Talking It Out Part 2: A Q&A with Stephanie

In this series, I mention previously that we want our community members to know when, where, and how to seek help. From navigating the world of mental health as a young adolescent, to where our teenage and adult years will take us. How we can mold our positive minds by understanding the importance of talking to someone, using strategies, and lessons to shift your mindset, and to always know we aren’t alone in this journey called life.

I pursued another community member to share their experience with understanding the importance of “talking it out”, seeking help, being a proactive parent, and knowing that when the light feels dim…there’s always a way to brighten it.

Please read as we share Part 2 on how we continue to work on breaking the cycle and scratching the taboo of therapy being for the broken by awakening ourselves to the idea of loving ourselves enough to truly understand our own minds… it might just be one of the most important forms of love we can share with ourselves and with those around us.

Stephanie tells us a bit about how her young son is already learning to maneuver through the obstacles he’s faced as a child with severe Hemophilia A and what that means for Stephanie to be proactive for herself, her family, and for children in the realms of mental health and breaking the taboo through advocacy all while teaching her son coping strategies and recognizing triggers that make him feel anxious or overly stressed.

How did you recognize your son’s need to seek counseling? *When my son was 3, he began having daily meltdowns. At first, we thought they were typical toddler tantrums. His meltdowns began to last up to three hours. He was completely inconsolable and could not pull himself out. He would hide and start biting his hand. We knew he needed professional help.*

Were you surprised to find out that your toddler could suffer from anxiety? *I was pretty surprised. I knew kids can suffer from anxiety, but I didn't expect someone so young could have this level of anxiety.*

What do you do to recognize his triggers even if he can't explain what he’s feeling? *I can tell when my son is becoming anxious. He starts putting anything and everything in his mouth to chew on. His breathing starts to pick up and he may begin to shut down.*

How do you share with him what you think he may be feeling? *My son will indicate what color emotion he is feeling (e.g. red - angry, blue - sad, etc.). If he is having bigger feelings that he cannot put into words, we will talk through his superheroes or stuffed animals. I will ask the toy how it is feeling and respond for it. After a few exchanges, my son will typically join in. Through play, his real feelings start to surface and sometimes solutions on how we can help will too.*

How has your son’s health affected his mental health even at a young age? *My son suffers from medical PTSD. He has gone through a lot of trauma in his five years that have affected his everyday life.*

Do you feel like your bit in advocacy will help promote positive change in mental health and how it may affect your family’s future? *I am hoping that my role in advocating for mental health will help other parents who may have a child suffering from anxiety and PTSD. If my story can relate to even just one other family, then I feel like sharing our story has done our job.*

Are you a proactive planner or a see it as it comes type of person? Is this helpful in maneuvering through the obstacles you face? *I am definitely a proactive planner. I always have to plan ahead. This has been extremely effective with my son. He heavily relies on being preempted even for the littlest changes in his daily routine. When he knows ahead of time what to expect, it greatly reduces his anxiety. It gives him time to process and ask any questions to help ease his anxiety.*

COMMUNITY

How do you choose the coping strategy that you use for different situations? *We typically begin with a breathing technique his therapist recommended. It's called "Smell the flowers. Blow out the candle." This helps him take deep breaths. Then depending on the level of anxiety he is experiencing; we may use different strategies such as going through his five senses or having him go to his "calm down corner." It is all trial and error on which strategy will be effective for the particular incident.*

Has counseling helped your overall family dynamic? *A chronic illness affects the entire family unit. Even though it was my son receiving counseling, it benefitted the entire family. His therapist not only gave us strategies to help him cope but also ourselves as his parents and his younger brother. It was essentially a life-changing experience for us all.*

What do you want our community members to know about seeking help and when they should seek help? *Don't ever be ashamed of reaching out for help. Please know you are not alone. The moment you think you or a loved one needs help, then it is time to reach out for help.*

Disclosure: The information provided in this article is not that of a medical professional. Please note that all information was obtained personally to raise awareness on speaking up for your mental health and feeling safe in seeking help. Please consult with a professional for mental health assistance and concerns for yourself or your loved one. If you need guidance on where to seek help, please contact your advocacy committee or NVNFH coordinators to provide information, assistance, and a listening ear in complete confidentiality.

By: AnnaMaria Donnadio

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

FALL

EXPLORATION

2022

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 HTCs
- 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. **In 2021 we provided over $20,000 in assistance to our community and are on track to provide over $25,000 in 2022.** 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/

Renee Paper Spotlight

In 1990, Renee Paper RN started the Hemophilia Foundation of Nevada in her home. As a nurse, Renee knew about the impact chronic diseases could have on her patients. As a woman diagnosed with Von Willebrand Disease, Renee was intimately aware of the impact that bleeding disorders can have on every aspect of life.

In 1990 there were no resources in Nevada for individuals with bleeding disorders. Renee was determined to change that. With the help of friends and professional associates, Renee created the Hemophilia Foundation of Nevada whose mission was "to improve the quality of care and life for persons with hemophilia, Von Willebrand Disease, and related inherited bleeding disorders, through education, outreach, peer support, and referral".

The legacy of this mission is felt to this day as the Nevada Chapter of the National Hemophilia Foundation celebrates and honors the life of Renee Paper at our 2022 Las Vegas Unite Walk. Renee passed away in 2007, but her presence in the bleeding disorders community is still felt, and the fight for the attention given to women with bleeding disorders is still ongoing.

If you have any memories or pictures of Renee to share, please contact us as we would like to display them at the Las Vegas Unite Walk.

Paper Features Q&A Resource on Shared Decision Making and Gene Therapy

As investigational hemophilia gene therapies move closer to regulatory authorization, community stakeholders have recognized the acute need for people with hemophilia (PWH) and healthcare professionals (HCPs) to be fully engaged in shared decision making (SDM). While the concept of SDM whereby patient and provider collaborate to reach informed treatment decisions has gained support in recent years, the arrival of such a paradigm-shifting will present unique challenges and opportunities.

Disparities in health literacy, the proliferation of inaccurate and contradictory content on social media, direct-to-patient marketing, plus the sheer complexity of gene therapy, may prevent a PWH from fully engaging in SDM. While some HCPs may also lack a thorough enough understanding of gene therapy, hindering their full participation in the SDM model. In addition, an HCP's perception of their patient's comprehension of this therapy may not align with their patient's actual understanding, a discordance that further compromises SDM, increasing the potential for delayed treatment decisions and other negative outcomes.

In light of these anticipated obstacles, an international and multidisciplinary group known of as the Council of the Hemophilia Community (CHC) was convened. Composed of independent advisors, HCPs, industry and patient representatives, the goal of the CHC was to fill these information gaps through the development of a resource that would help generate an ongoing dialogue between PWH/HCP, with patient-centricity as its guiding principle.

The CHC held three roundtable meetings between November 2020 and May 2021 wherein they fleshed out a series of questions and answers that would best foster a genuine SDM process amongst PWHs/HCPs. The majority of the decided-upon questions fell under several over-arching categories including treatment regimen/adherence requirements, treatment predictability and variability, treatment durability, and the risk/benefit profile.

Each of the questions were subsequently assigned to the five stages of the patient "decision making journey." These included 1) Pre-gene therapy information seeking 2) Pre-gene therapy decision making 3) Treat initiation 4) Short-term post-gene therapy follow up (less than one year since receiving gene therapy) 5) Long-term gene therapy follow up (more than one year after receiving gene therapy).

A recent paper published online in the journal Patient Preference and Adherence (PPA), describes in greater detail the process of developing the resource and context in which it was created. Read the open-access PPA article.

The authors highlight the value of this tool to enhance SDM relevant to hemophilia gene therapy, while also hinting at its potential utility in other disease groups.

"The educational and decision support resources described herein recognize that each patient's decision journey will evolve throughout their lifetime with their individual preferences at different life stages, and with the emergence of new therapies and a growing evidence base," explain the authors. "The Q&A resource provides HCPs and PWH with timely, relevant information, facilitates discussions, and empowers PWH to engage in shared decision-making. As gene therapy products enter the market, the themes and questions mapped here should stimulate discussion and aid interactions among HCPs, PWH, and family members, to ensure that they are fully informed and realize the clinical potential of this treatment. While the issues discussed here pertain to hemophilia, they could also be applied to other hereditary diseases with multiple treatment options."

Access "Hemophilia Gene Therapy: Your Questions Answered" in PDF.

Citation
Wang M, Negrier C, Driessler F, Goodman C, Skinner MW. The Hemophilia Gene Therapy Patient Journey: Questions and Answers for Shared Decision-Making. Patient Prefer Adherence. 2022 Jun 9;16:1439-1447. doi: 10.2147/PPA.S355627. PMID: 35707346; PMCID: PMC9191577.

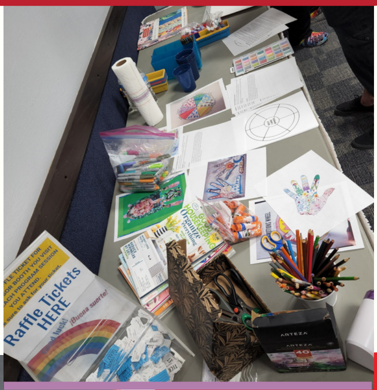
EVENT RECAP

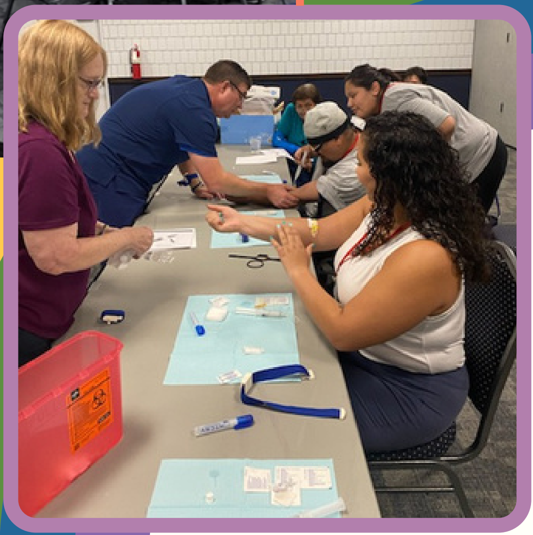
Over the Rainbow
Summer Fest
NNV Family Education Conference

We were so happy with the turnout in Elko with twenty-five families gathering together from all over Northern Nevada attending; Winnemucca, Elko, Owyhee, Wendover, Carson City, Spring Creek, Reno, and Sparks. Also welcoming HTC-NV staff, NHF presenters, children and youth program leaders, and volunteers.

We kicked off the weekend with a cosmic bowling outing where competition was running high. Delicious local meals throughout the weekend, where attendees participated in educational programs ranging from infusion classes, women's health talks, storytelling workshop, and a deeper dive into mental health. We also provided group support opportunities in the form of art therapy and a men's group lounge. Children enjoyed their play time, while teens participated in GutMonkey's *Leading Edge* program, ending the weekend in a backpack giveaway. Families also enjoyed an evening picnic and gratitude circle at Elko City Park.

A successful weekend for our NV Chapter! We received meaningful feedback, and look forward to bringing our families back together again real soon.





EVENT RECAP

Teen River Camp - Lotus, California
July 2022

Spending a week outdoors in Central California may not be everyone's idea of a good time, but for teens from Nevada & San Diego, a week camping riverside was an ideal way to learn how to be more independent and a great way to push outside of comfort zones to learn and grow. Teen Camp is a great opportunity for teens to learn more about themselves and spend time with others who share similar life experiences.

Three teens from Nevada and four from the Hemophilia Association of San Diego County traveled to Lotus, CA, and the American River for 4 days of river rafting and camping with the Environmental Traveling Companions in July.

Three full days were spent on the river learning the basics of white-water river rafting and working together to keep the raft afloat. In the evenings, participants engaged in leadership development and personal development activities facilitated by Gutmonkey. The teens also were responsible for cooking and cleaning the riverside outdoor kitchen.

Ethan, Nathan, and Nick from Nevada all shared that they would love to participate in Teen Camp again. Teen Camp will be back in July 2023 – keep an eye out for the application in late Spring.

EVENT RECAP

July Back to School Family Fun Event

We had 23 families come together for a fun day celebrating Back to School! This year's event took place at Las Vegas Mini Grand Prix, where everyone could race go-kart, ride the rides, and test their skills in the arcade. We had information about setting up 504 accommodation plans, a pizza & dessert buffet, and plenty of time to catch up with friends in the BD community. All school aged kids received a free backpack full of school supplies. Thank you to everyone who volunteered to make this event a success, including the Full Tilt Riders MC, Girl Scouts, and Woodside Homes Las Vegas.

Education Dinners

This quarter we had three different education dinners. Takeda talked about how women matter in bleeding disorders. We had a great group that talked about their personal experiences and they all celebrated each other. Sanofi celebrated the diversity of home infusions while the group shared their own personal stories and strategies to make the most of every infusion. Infucare Rx, Medexus and Octapharma all came together to talk about being active while having a bleeding disorder. The conversation was great, and the families got to do some axe throwing towards the end of the event.

Open House - July 27th and August 17th

The Nevada Chapter and the HTC of Nevada co-hosted two Open House events for the Bleeding Disorders Community. These events were an opportunity for community members in Southern Nevada to meet the staff of the Nevada Chapter & and to meet the new staff at the HTC and to reconnect with existing staff. Between the two events 35 participants attended. The August event at the Nevada Chapter Office saw many families visit for the first time since 2019.

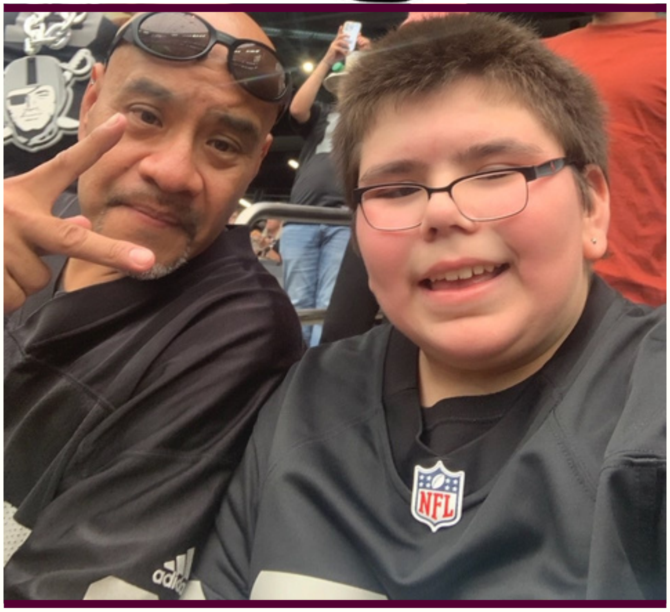
The Nevada Chapter and HTC are committed to host more opportunities to meet and mingle with the community. If you have any ideas or suggestions for future Open House or Community Pop-Up Events, please contact us!

EVENT RECAP

Raider Dad Experience

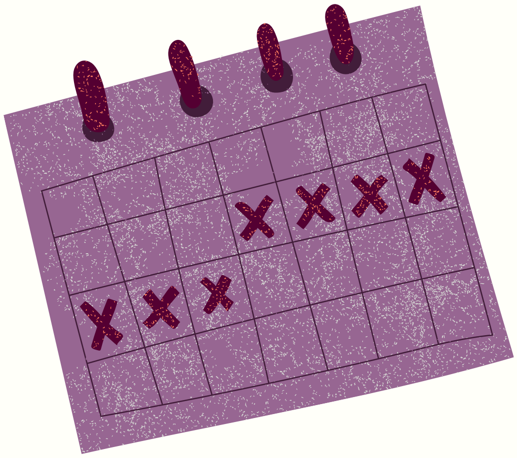
Raider Dad is a new organization in Las Vegas that is committed to creating valuable experiences for youth in Nevada. Through ticket donations from Las Vegas Raiders fans, Raider Dad can provide a once in a lifetime game day experience for kids and parents. In August, Raider Dad reached out to the Nevada Chapter to nominate a family for tickets to a pre-season game. Nancy and Angel were chosen by lottery to attend the Raider Dad tailgate and see the Raiders beat the New England Patriots in August. Angel is a huge Raiders fan and attending a game has been a dream of his. Fortunately, Raider Dad was also able to provide a Nevada Chapter family two tickets to see the season opener against the Arizona Cardinals. As life-long Raiders fans, Manuel and Manuel Jr had the time of their lives, despite the close loss to the Cardinals. We are hoping to work with Raider Dad to provide tickets to a Nevada Chapter for a future game.

If you would like more information on Raider Dad,
visit @vegasraiderad on Instagram or their website at http://www.vegasraiderdad.org/.



Bleeding Disorders Conference - Houston, Texas, August 25th - 27th 2022

The annual NHF Bleeding Disorders Conference was back with a primarily in-person conference for 2022. BDC is a great opportunity to learn and connect with folks from all over the country. BDC 2022 had education tracks for community members, Chapter Staff, Social Workers, Physical Therapists, and Nurses along with education sessions that were more general in content. The 3 days were filled with education, camaraderie, many emotions, and most importantly togetherness. Nevada Chapter Outreach Coordinator Mariana noted about the event, “Although we can connect with others within the bleeding disorders community every day virtually it was great to be able to connect with others in person. Hearing others talk about the community that they have within their own chapters was really inspiring”. She also commented, “I have felt how welcoming everyone has been since I started with the chapter over a year ago. I was very glad to hear that other chapters are the same and how everyone works together to help bring awareness and knowledge about bleeding disorders to others around them”. It is impossible to participate in every session at BDC, but due to the variety of information and education offered, Mariana noted that she was able to tailor her time at BDC to ensure that she was able to make the most of her time there. As a first-time attendee, Mariana commented, “I look forward to conferences that will come as this was a great experience”. The NHF Bleeding Disorders Conference in 2023 will take place in Washington D.C. we will have more information about it in Spring 2023.



UPCOMING EVENTS

More details available on our events page

Sat, Oct 8
Unite for Bleeding Disorders Walk, (LV)

Thur, Oct 27, 5-7 pm
Halloween Bash @ HTCNV, (LV)

Sat, Oct 29, 1-4 pm
Mental Health Event, location TBA, (LV)

Thur, Nov 4, 5-7 pm
Wine & Paint Fundraiser, Chapter Office, (LV)

Sun, Nov 6, 1 - 4:30 pm
safeTALK Suicide Alterness for Everyone Workshop @ West Charleston Library, (LV)

Thur, Nov 9, 6-8 pm
Education Dinner, location TBA, (LV)

Mon, Nov 28
Education Dinner, location TBA, (RNO)

Sat, Dec 3, 9:30 am
Annual Conference @ Potosi Pines, (LV)

Sat-Sun, Dec 3-4
Youth Overnight, @ Potosi Pines

Thur, Dec 8
Education Dinner, location TBA, (LV)

FUNDRAISER

Unite
for Bleeding Disorders

Unite For Bleeding Disorders Walk
Saturday, October 8th, 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 a Sonic the Hedgehog character 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. Thanks to our sponsor CSLBehring, we will also have the brand new edition of the book she helped create, A Guide to Living with Von Willebrand Disease, available for purchase.

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.

UPCOMING EVENTS

SUPPORT

safeTALK

suicide alterness for everyone

Sun, November 6, 2022
1:00 PM – 4:30 PM PST
West Charleston Library .
6301 W Charleston Blvd . Las Vegas, NV

CLICK HERE TO TAKE YOU TO REQUIRED REGISTRATION
SPACES ARE LIMITED

Join us for this in-person workshop that features a powerful presentation and skills practice. SafeTALK empowers everyone to make a difference to prevent suicide.

In this workshop, attendees will learn how to prevent suicide by recognizing signs, engaging someone, and connecting them to an intervention resource for further support.

A skilled, supportive trainer will guide you through the course, and a community resource will be on hand to support your safety and comfort.

THIS EVENT IS FREE OF CHARGE FOR NV CHAPTER COMMUNITY MEMBERS and THEIR EXTENDED FAMILIES. CONTENT SUITABLE FOR AGES 15+

FUNDRAISING

NV CHAPTER
PAINT & SIP
Save the Date

Friday November 4th
Nevada Chapter Office
6:00pm

$25 per adult
$10 per youth (18 & under)
Snacks & drinks provided

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

EDUCATION

NHF-NV Chapter Team Presents:
ELEVATE
ANNUAL MEETING 2022
save the date
Sat, December 2, 2022
Potosi Pines Camp & Conference Center
Southern Nevada

Let's elevate our community together.
REGISTER LINK CLICK HERE

Annual Meeting 2022 is a free education event for members of our Nevada Chapter bleeding disorders community. Join us as we escape from the city and gather at the beautiful Potosi Pines Camp and Conference Center. At this event, we will seek to elevate our community in knowledge, wellness, and advocacy. We will gather together to learn and share from one another, gain tools and insight to allow us to explore, and expand ourselves to new heights. We will also be offering a special opportunity to get family portraits taken by a professional photographer. We look forward to honoring you all!

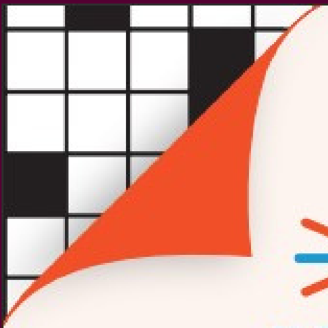
Sat, December 3, 2022
9:30 AM to 6 :00 PM
Potosi Pines Camp & Conference Center
10910 Mount Potosi Canyon Road
Las Vegas, NV 89161

EVENT OVERVIEW
Education Programming for Adults
Family Activities
Children & Youth Activities
Lunch and Dinner will be provided
Program Sessions in both English and Spanish

We are also hosting a Saturday night Teen (13-18) Overnight Camp Session!!
6pm Sat to 11am Sun
(we return the teens to you at area pick-up spots)

Sign up your teen through the above event registration link to receive more details.

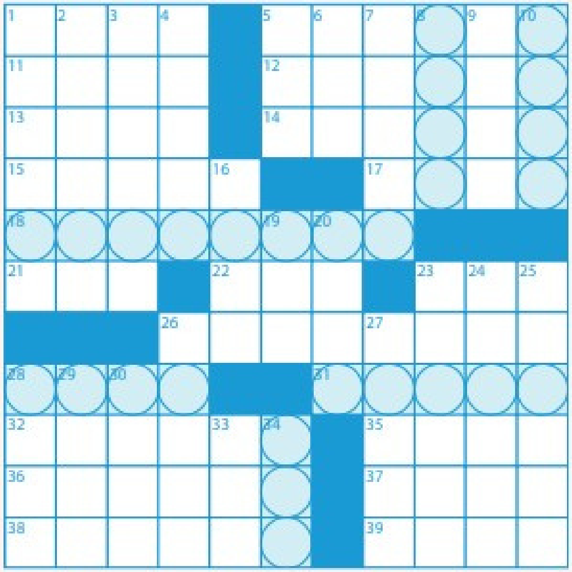
Be sure to check our EVENTS PAGE for the most current and up to date programs and events.
Schedule, dates, times, and locations are subject to change.



CAN YOU SOLVE

FOR A DIFFERENT HEMOPHILIA A TREATMENT?

Test your HEMLIBRA knowledge



ACROSS

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

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

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

DOWN

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

SOLUTIONS

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

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

Discover more at HEMLIBRA.com/answers

INDICATION & IMPORTANT SAFETY INFORMATION

What is HEMLIBRA?

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

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

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

These serious side effects include:

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

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

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

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
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan

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

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

Genentech
A Member of the Roche Group

National Hemophilia Foundation
Nevada Chapter
222 Rainbow Boulevard, Suite 203
Las Vegas, NV 89145

Phone: 702-564-4368
www.hfnv.org

@NevadaNHF @NHFNV @NevadaNHF

Chapter Staff

Danielle Bell
Program Manager

Stephanie Dupree
Development Manager

Jacob Murdock
Executive Director

Mariana Peña
Outreach Coordinator

Advisory Board

President: Kim Luong Velasquez
Vice President: Steve Findley
Secretary: Stephanie Hrisca-Kennedy
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Dedication and Personal Support

Pfizer Rare Disease | RARE DISEASE PATIENT AFFAIRS

Your Pfizer Patient Affairs Liaison is a professional dedicated to serving you and the hemophilia community by connecting patients and caregivers with Pfizer Hemophilia tools and resources. These Pfizer colleagues are committed to continuing Pfizer's more-than-20-year history of listening to the hemophilia community and working to meet its needs.

Patty Eastin

AZ, NM, NV, UT, CO, ID, WY, MT
patricia.d.eastin@pfizer.com
O: 480-734-4011

"Having worked at Pfizer for 17 years, I am passionate about supporting and educating the amazing rare disease community."

My work is guided by:

Compassion—Listening to your needs and addressing questions and concerns that you may have

Commitment—Educating you about Pfizer's tools and resources, including the Pfizer Community Connections Program, the HemMobile® app for logging bleeds and infusions, B2B materials, and more

Connection—Connecting you with hemophilia advocacy groups and programs like Leading Edge, the National Hemophilia Foundation, The Coalition for Hemophilia B, and others

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