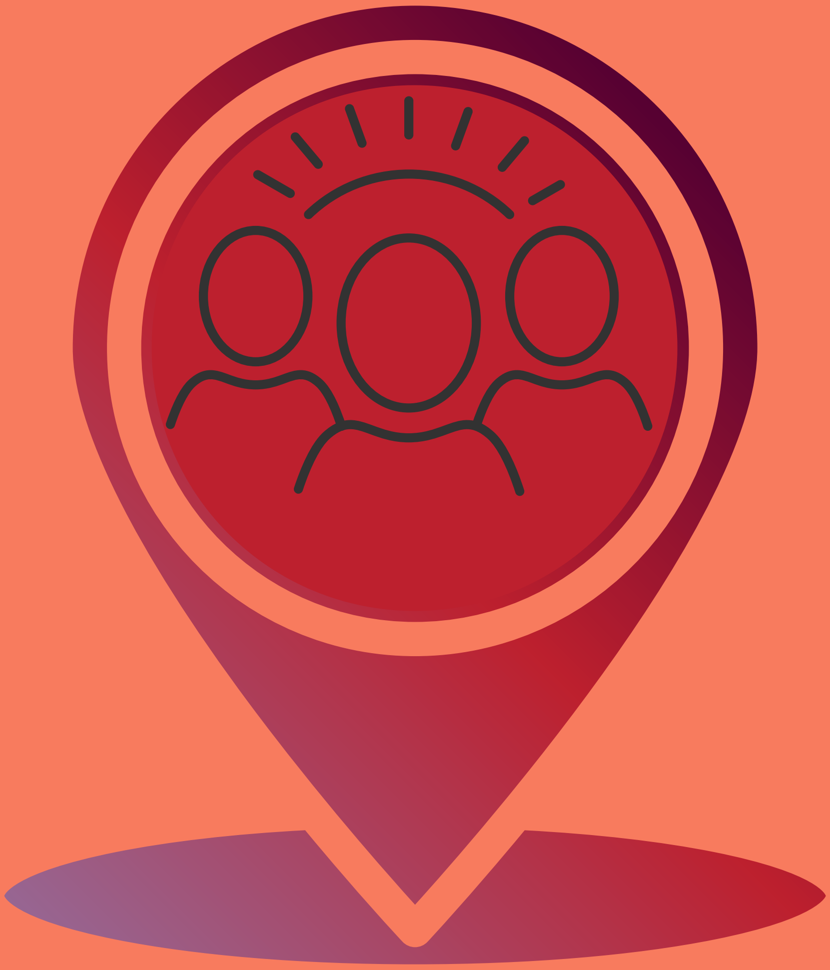
SPRING 2023

HEMOPHILIA

NEWS & VIEWS



NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

GREETINGS

To our dear community friends and families,

Our Nevada Chapter team would like to say congratulations to Mariana Peña, our Community Outreach Coordinator, and wish her the best on her professional journey as she takes on a new role with the National Hemophilia Foundation's Conference & Travel Services team. Although she is no longer serving the Nevada Chapter, we know she will continue to make a lasting contribution to the larger Bleeding Disorder community in this new position. With Mariana's transition, we understand that this may impact your connection and communication with our team. For those in the community utilizing our financial assistance and/or counseling assistance, our Program Manager, Danielle Bell, will be managing those programs. Our entire team is available to talk, or if we can provide any other assistance or opportunities for connection please do not hesitate to reach out.

While we move forward without a fluent Spanish speaker on our team, we have resources and processes in place to ensure we can communicate with all our community. We will continue to translate communications and documents into Spanish and continue to provide Spanish language education programs. Thanks to the Hemophilia Alliance, we will have access to a hotline that allows us to have a live translator on both phone calls and video calls with our community members. If there are ways that we can best communicate with you, please let us know. Our desire to serve the entire Bleeding Disorders community in Nevada continues to hold true.

We hope that you are as excited about our 2023 programs and activities as we are! We have our first in-person advocacy day in Carson City since 2019 on April 17th. We also have our first visit to Elko later in April. In May we return to Reno for our Northern Nevada Education Day & Reno Unite for Bleeding Disorders Walk. In June, we are very excited to hold our first Nevada Chapter Family Camp from June 21st – 24th! This will be an incredible opportunity to enjoy the beauty of the mountains above Riverside, CA while being in fellowship with other members of the Nevada Bleeding Disorders community.

So far in 2023, we hosted our first in-person event for Women since 2020, and an event focused on mental health featuring community mental health resources. At the start of this year, we have also kicked off in-person and virtual support groups that meet each month. These are great opportunities to meet other members of the community and to seek and provide support from those who understand what you may be going through. These programs were a direct result of feedback shared in our Annual Community Survey.

We look forward to seeing you in 2023.

Warmest regards and heartfelt thanks,

Jacob, Danielle, Stephanie, and Mariana

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

Who: You like to discover and organize.
What: Sorting and scanning documents, pictures, and some shredding.
Why: To work on digital archives out of an array of file boxes
Where: At the NV Chapter Office, using our devices.
When: Beginning May, any weekday, between 8am to 5pm, as available
Contact: Danielle Bell, dbell@hemophila.org, 702-306-5513

Who: You like the outdoors, early mornings, & cheering people on
What: Bikes in Your Blood, cycling event fundraiser
Why: To help set up and check in attendees
Where: Equestrian Park S, 1298 Equestrian Dr, Henderson, NV 89015
When: Saturday, April 8th, Call time for volunteer help is at 6:00am
Contact: Stephanie for more information, 646-527-0442

Who: You are a Reno Unite Walk participant and/or enjoy the outdoors and supporting others.
What: Many levels of volunteer support.
1) Reading the Unite Walk pledge during the pinwheel ceremony to kick-off the walk.
2) Helping with event set-up.
Why:
1) Extra help always makes the event run smoothly for all involved.
2) To have a representative of the bleeding disorder community share in this ceremony.
Where: Bartley Ranch Park, Reno Unite Walk, 6000 Barley Ranch Road
When: Sunday, May 21st at 8:am
Contact: Stephanie, 646-527-0442

A NV Chapter
ALL HEARTS IN
thank you to our volunteers at
Wine Fest,
Women's Empowerment Event,
and Spring Education Day

Carla C.
Rodney D.
Aiyana E.
Craig F.
Sochti F.
Ivan G.
Juana G.
Jamie C.
Melissa K.
Reagan K.
Kimberly L.
Julie O.
Gabriel R.
Ilia S.
Sarah S.

for their incredibly gracious service & support this quarter.

Don't see something of interest here?

Please visit our volunteer page and complete an interest form.

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

COMMUNITY

Nevada Chapter Services for the Bleeding Disorder 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 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. We can provide assistance due to the support of the Hemophilia Alliance and 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 Danielle Bell, dbell@hemophilia.org or 702-306-5513

Counseling Referral Program

The Nevada Chapter of the National Hemophilia Foundation (NHFNV) has created a program in collaboration with Nevada Counseling Providers.

Counseling services are provided both in-person, via tele-health, and/or group counseling for approved applicants.

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 facilitates the funding of the program and follows all federal and state laws, to include HIPAA privacy standards.

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@hemophlia.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

Important Changes Coming to Nevada Medicaid

[This content was authored and reused with permission by the Centers for Medicare & Medicaid Services (CMS)]

Do you or a family member currently have health coverage through Medicaid or the Children's Health Insurance Program (CHIP)? If so, you may soon need to take steps to find out if you can continue your coverage. Soon, states will resume Medicaid and CHIP eligibility reviews. It's important that you respond to any communications you receive from your CHIP or Medicaid program. This means some people with Medicaid or CHIP could be disenrolled from those programs.

Here are some things you can do to prepare right now.

1. **Make sure your address is up to date.** Make sure The State of Nevada has your current mailing address, phone number, email, or other contact information. This way, they'll be able to contact you about your Medicaid or CHIP coverage.
2. **Check your mail.** The State of Nevada may mail, email you, or even text you about your Medicaid or CHIP coverage. This message will also let you know if you need to complete a renewal form to see if you still qualify for Medicaid or CHIP. If you get a renewal form, fill it out and return it to your state right away. This may help you avoid a gap in your coverage.
3. **What if you don't qualify for Medicaid or CHIP?** If you or a family member no longer qualify for Medicaid or CHIP, you may be able to buy a health plan through the Health Insurance Marketplace.

Plans are:

- Affordable. 4 out of 5 enrollees can find plans that cost less than $10 a month.
- Comprehensive. Most plans cover prescription drugs and provider services such as, doctor visits, urgent care, hospital visits, and more.

Visit HealthCare.gov to find Marketplace plans and see if you might save on premiums. When you apply, don't forget to include current information about your household, income, and your state's recent decision about your Medicaid or CHIP coverage.

Get more information

Find contact information for your state Medicaid office here and follow instructions for how to contact them.

Or visit Medicaid.gov for more information about Medicaid or CHIP renewal.

Call the Marketplace Call Center at 1-800-318-2596 to get details about Marketplace coverage.

Visit the Nevada Medicaid Website Here
or call
877-638-3472

Have Medicaid or CHIP?

SCAN THE QR CODE TO LEARN MORE, OR VISIT:

MEDICAID.GOV/RENEWALS

Take these steps to find out if you can keep your coverage:

Make sure your state has your current contact information.

Check your mail for a letter.

Complete your renewal form (if you get one).

Medicaid.gov
Keeping America Healthy

ADVOCACY

NHF's Washington Days is an opportunity for people affected by inherited blood disorders to advocate for issues that are important to them. In 2021, Washington Days had more than 400 volunteer advocates from 45 states that met with legislators and staff to discuss federal funding for bleeding disorder programs and support policies that increase affordability of coverage and access to care.

Jamie, Connor, Cora, Rep. Susie Lee and Jacob

NHF Washington Days

A community member's perspective.

In 2019, I got called with an opportunity to advocate at our State's Capital in Carson City. Of course, I went and spoke to our State Senator. At first, I was scared and didn't know what to expect as it was my first time. In the meeting, I was more confident, and I just told my story as I knew it. He listened and change for the better came out of our advocacy there.

After that, I got called to go to Washington D.C. to advocate on Capitol Hill! Wow! What an awesome experience! It was an empowering experience, and I knew that someday, I would have to go again! That day finally came this year.

I am very passionate about making a difference and having my voice be heard. Going to Washington Days is the BEST way. The NHF makes the whole experience amazing from start to finish. They prepare you for how things will go and answer all the questions. You are there to tell your story and to make a difference.

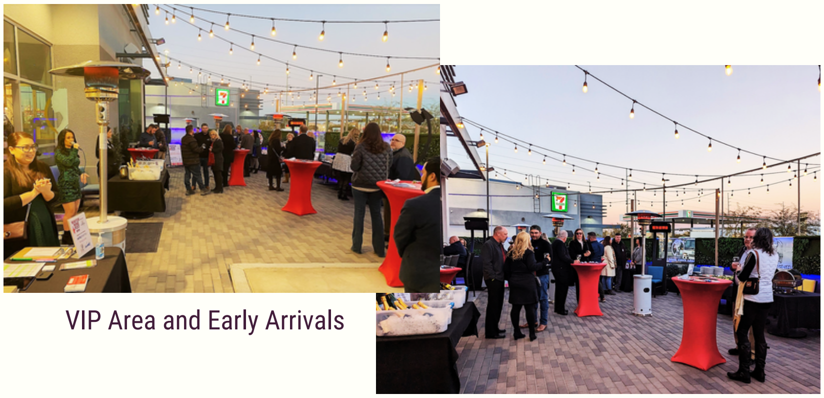
I encourage anyone and everyone with a bleeding disorder to let your voice be heard and show your interest in going to Washington Days! Their motto is "Your Health, Your Fight, Your Voice!" That is exactly what I did, and I hope you do too!

By Jamie Coutts

EVENT RECAP

Winter Wine Fest 2023 -January 2023

At the Nevada NHF 8th Annual Winter Wine Fest on January 28th, we had one of our biggest turnouts yet. Over 125 people came out to raise a glass and raise some money for Nevadans living with an inherited bleeding disorder. We had over 30 fun baskets to bid on during the silent auction, as well as Wine Wheel to spin and win a bottle to take home. BIG thank you to our event sponsors Octapharma and InfuCareRX, as well as our event volunteers from HTC Nevada and Optum…. CHEERS! We raised $18,000 for the Nevada bleeding disorder community, and we are looking forward to making Wine Fest bigger and better next year.



VIP Area and Early Arrivals

Silent Auction Table Bidding

Wine, food, and community!

Winner guaranteed as this guest takes the Wine Wheel for a spin.

Entertainment all night,
also ended in dancing and
sing-alongs by evenings end.

The night was a display of community in action.

EVENT RECAP

YETI (Youth Effectively Transitioning to Independence) - February

Camp Collins at Gresham, Oregon

Danielle just trying to hang with the teens.

Once again the NV Chapter is honored to be a part of YETI 2023 at Camp Collins in Gresham, Oregon. We were able to bring two Nevada teens with us this year, Gracie C from Fallon and Tatiana H from Las Vegas. This is truly an immersive experience for both teens and adult attendees. Together they collaborate and explore ideas to strengthen teen programming and find ways to understand and best meet the needs of teens through effective, engaging camp programming.

Tatiana, working on trusting the process. Also, a great support partner on the ropes course.

With a very involved and interactive game of Life (including a mole), a Wellness and Mental Health circuit, and plenty of deep level processing, a common sentiment shared among adults is if we are to encourage young people to be vulnerable, we need to be willing and able to be vulnerable too. This is primarily an adult conference for folks that are involved with teen centered programming, chapter staff, HTCs, and camp program specialists, yet the intent to invite youth into this setting is to empower them with tools and ideas that they will in turn bring back to their own bleeding disorder communities and work with their chapters, camps, and HTCs to help build up their teen programs. We have so many engaged teens in Nevada, and we look forward to finding ways to bring them together more often.

Gracie always stepping up. Taking it next level the more challenging routes.

32 Organizations and HTCs trained at YETI in 2023.

EVENT RECAP

Women's Empowerment Event - February

Write Yourself A Love Letter

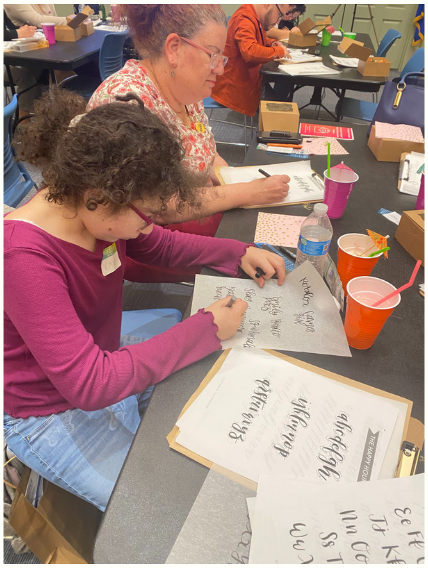
We invited our participants to think about if they were to write a love letter to themselves, where would they begin. We started with a presentation from Takeda about resilience. What does it mean to be resilient? This helped participants recognize the many strengths they have that can sometimes be taken for granted, or not recognized, even by our own selves. We then invited Grace Chen, a local professional calligrapher from Sip & Script to give us a scripting workshop. Grace gave each participant individualized support and feedback. The final piece to our evening was the presentation about gratitude. Learning to love ourselves often starts with practicing gratitude. It can be challenging at times when life is filled with hurdles and challenges. It was really great to see folks come up with many things for that they are grateful, including being together in community. Participants enjoyed fun mocktail beverages and individualized graze boxes to snack on during the event. We got terrific feedback from our participants and look forward to doing it again soon.

Graze boxes and scripting kits for each participant.

Look at all these empowered humans!!!

Delicious mocktails being served up.
Who wants a No-Drama Colada?

Calligraphy artist, Grace Chen



All of our participants taking scripting very seriously and even creating their own styles.

Let's do it again!

It was a great evening!

EVENT RECAP

EXPLORE

Spring Education Day - March

Potosi Pines Camp & Conference Center

A snowy spring day up in the Las Vegas mountains!

CONNECTION
EDUCATION
COMMUNITY
ADVOCACY
PARTNERSHIPS
SUPPORT
PLAY

NHF-NV CHAPTER

Up at the lodge we could hear YMCA ringing through the camp.

Indoor crafts, outdoor bubbles, and snow- basketball

It was a full house! Our community members shared a lovely spring day mixed with a little snowfall. A total of 75 people made their way to Potosi Pines for a full day of programming. We were honored to be one of nine chapters to be chosen to have the Leading-Edge Program for our teens. Our NHF and Industry Partners brought great presentations to engage the community. And our first Kid's Day Camp was a big hit.
Thank you to all the incredible support we received.

After a full day with GutMonkey's Leading Edge program, we had our Teen Overnight with games, s'mores, movie night, and night tag in the snowy mountains. And Rocky the Cat!

SPRING 2023

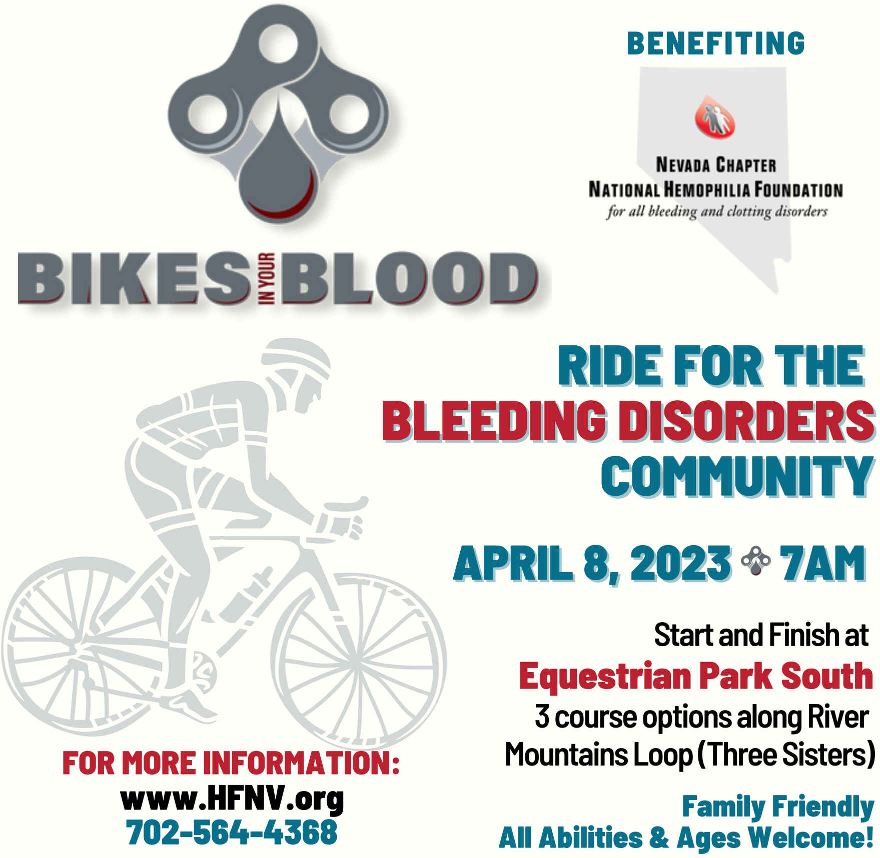
UPCOMING EVENTS

FUNDRAISING

The 2023 Bikes in Your Blood cycling event registration is now open! Back in-person for the first time since 2019, this annual cycling event benefits the Nevada Bleeding Disorders Community while cycling along the picturesque River Mountains Loop. All pre-registered participants will receive a T-shirt and goody bag and are welcome to join us for the post-ride celebration and lunch!

When: Saturday, April 8th, 2023
Where: Equestrian Park South, 1298 Equestrian Dr. Henderson, NV 89105
Route: River Mountains Loop Trail
Start Times: 36 Mile Ride - 7 AM, 14 Mile Ride - 8 AM, 6 Mile Ride - 9 AM

More Info: NVHF.org Ready to sign up? Click Here to Register



BIKES IN YOUR BLOOD

BENEFITING
NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

RIDE FOR THE BLEEDING DISORDERS COMMUNITY

APRIL 8, 2023 ✥ 7AM

Start and Finish at
Equestrian Park South
3 course options along River Mountains Loop (Three Sisters)

Family Friendly
All Abilities & Ages Welcome!

FOR MORE INFORMATION:
www.HFNV.org
702-564-4368

Bikes In Your Blood is a fundraiser and awareness raising event with an emphasis on encouraging safe, active lifestyles. All proceeds support families in Nevada with inherited bleeding disorders. The bike event has opportunities for extreme bike enthusiasts to ride the 36 Mile River Mountain Loop through Lake Mead National Park, as well as casual participants to ride a 6 and 14-mile course. Bikes In Your Blood is a great family friendly event open to all ages and abilities. E-bike riders are welcome!

Thank you to our sponsors for making this event possible:
Dignity Health - St. Rose Dominican
Hemostasis & Thrombosis Center of Nevada (HTCNV)
The Infusion Pharmacy

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.

SPRING 2023

UPCOMING EVENTS

COMMUNITY

Carson City Day

State advocacy days are one of the major highlights of local chapter advocacy programs. NHF Nevada's State Advocacy Day occurs in odd numbered years and includes volunteer representatives from the entire state of Nevada. Volunteer representatives include individuals with a bleeding disorder and/or their family members, community volunteers and other organizations. We come together to host a day at the state capitol. The event usually consists of a training session where we provide talking points and engage in role-playing activities. Training is followed by a day at the capitol where volunteers meet with their elected officials to educate them about hemophilia, von Willebrand disease and other related bleeding disorders. Constituents may visit representatives for various reasons, including to educate them, build relationships, thank them, and advocate for or against a piece of legislation.

State advocacy days give elected officials the opportunity to learn firsthand from affected individuals and families how expensive treating bleeding orders can be, and how important it is to have access to comprehensive care and continuity of care. Legislators learn how not having access to the proper treatment can be detrimental to the health of someone with a bleeding disorder, and potentially cost the state a lot of money in the long run.

All members of the Nevada Bleeding Disorders Community are welcome to attend. The Nevada Chapter will be paying for transportation & hotel costs for up to 4 families from across the state to attend. Training & meals will be provided for all members of the community who attend. Families with members employed by a pharmaceutical manufacturer or a specialty pharmacy serving the bleeding disorders community are not eligible to receive assistance with transportation & hotel costs.

Deadline: In order to be considered for assistance, you must apply by March 27th, 2023. Registration for the event closes on 3/31. Registering early allows a better chance to meet with your representatives on 4/17.

Register at: https://form.jotform.com/230746543292155

NV Chapter State Advocacy Days
April 16th - April 17th, 2023
Carson City, NV

Nevada Chapter
National Hemophilia Foundation

EDUCATION DINNERS

4/18/2023 Sanofi Education Dinner (Reno)
Register Here

4/19/2023 Sanofi Education Dinner (Elko)
Register Here

4/25/2023 Sanofi Education Dinner (Las Vegas)
Register Here

5/22/2023 Octapharma & Infucare Rx Education Dinner (Las Vegas),
registration opening soon

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

Reno Unite Walk

Bartley Ranch Regional Park on Sunday, May 21st, 2023

We walk to support all those who are affected by bleeding disorders - hemophilia, von Willebrand disease and other rare factor deficiencies. This event is open to everyone who wants to support improving the lives of those with bleeding disorders in Nevada.

Much more than just a fundraising event, the Unite for Bleeding Disorders Walk brings together individuals affected by bleeding disorders, their families, friends, and supporters who want to support a great cause. The Unite for Bleeding Disorders Walk attracts people of every age and background from parents with infants to grandparents and everyone in between – including more than a few four-legged friends. Everyone shows up on Walk day to share experiences and enjoy each other's company.

The Unite Walk is our biggest fundraiser to support our mission and programming efforts. Funds raised from the Unite Walk will not only allow our programming efforts to continue but will allow us to assist more families in our community that need an extra hand during difficult times. Whether you've been with us from the beginning, or you are new to the Walk program, we invite you to join us in making this the best walk possible. We're challenging our northern Nevada community with a goal of $10,000. We know you can do it!

Unite
for Bleeding Disorders

Schedule of Events

9:00AM: Registration opens, visit sponsor booths, light breakfast & refreshments available

10:00AM: Unite for Bleeding Disorders Walk Ceremony will begin

10:30AM: Unite Walk will begin!

11:00AM: Unite Walk Awards Ceremony

11:15AM: Lunch and dessert, a picnic in the park!

Recognitions & Prizes

Top Fundraising Team

Top Fundraising Industry Team

Top Individual Fundraiser

Top Youth Fundraiser

Register Now

EDUCATION

NV Chapter Presents

NORTHERN NV EDUCATION DAY

MOVEMENT is MEDICINE

RENO

Saturday, May 20, 2023
10:30am to 3:30pm
Education Day at Sparks Library
1125 12th Street, Sparks, NV 89431

Northern Nevada Education Day
"Movement is Medicine"
Sparks Library
10:30 am to 3:30 pm
REGISTER HERE

Movement can be anything from fidgeting to stretching to low-impact aerobics to interval training.

All-ages, family style program, we will...

- Explore different ideas about best exercises and styles of movement that help benefit our certain needs, and physical goals.
- Take a closer look at Playing it Safe, the National Hemophilia Foundation's resource on Bleeding Disorders, Sports, and Exercise.
- Pre and post exercise care tips
- Enjoy snacks, sips, and lunch.
- Meet and greet time with exhibitors

After our day of education, we will gather at Wild Island Adventure Theme Park to celebrate our day of learning and kick-off the Reno Unite Walk with Garage Bowling, Arcade Games, and Pizza Dinner!

NNV Education Day After-Party and Unite Walk Kick-off
Event Time: 5:00pm - 7pm
Event Address: Wild Island Adventure Theme Park, Coconut Bowl
250 Wild Island Ct., Sparks NV 89434

TEEN CAMP

Teen River Camp 2023, July 10 – 14

Registration is now open!

Camp is open to teens (diagnosed patients and siblings) who will be 13 to 18 years of age at the time of camp.

For more detailed information about Teen River Camp, registration, and required documentation, please **visit our webpage**.

This camp is at no cost to our qualified community members. Space is limited and dependent on timely completed medical documentation for every camper.

TEEN
RIVER CAMP
CAMP **DRAGONFLY**

Lotus, CA

Monday, July 10 – Friday, July 14, 2023

Open to teens, ages 13 to 18. Ten open camper spots.

LET'S GO!
NV CHAPTER FAMILY CAMP 2023
JUNE 21 TO JUNE 24

WHAT: NV CHAPTER FAMILY CAMP

WHEN: WEDNESDAY, JUNE 21 -
SATURDAY, JUNE 24, 2023

WHERE: CAMP DE BENNEVILLE PINES
41750 JENKS LAKE RD
ANGELUS OAKS, CA

REGISTER HERE: SIGN US UP

Join us for our NV Chapter 2023 Family Camp experience.

We know that each family is unique and can present in many varieties. Our hope is to encourage all NV Chapter families and their immediate family members to attend our Family Camp this year.

Registration is open, and will close on June 1st, or when space is full.

Cost is $100 per family.
Fee waivers are available and can be initiated on the registration form.
Travel Stipends will also be made available to all registered attendees.

For more information visit our Family Camp page at
https://hfnv.org/get-involved/programs/camp-programs/family-camp.html

Our Family Camp will be Camp de Benneville Pines in Angelus Oaks, California. It is located in the center of the San Bernadino Forest surrounded by tall pines, cedar, and oaks. This camp provides a beautiful setting for families to connect with nature, and one another.

Families will enjoy cabin-style living furnished with bunkbeds, with a bathroom and shower in each cabin so that they can enjoy the simple joy of camping with modern conveniences.

Fun for all ages, all families, and all levels of camp experience.
Outdoor and indoor experiences can be enjoyed by all.

NATURE
JOYFUL
CONNECTION
COMMUNITY
EXPLORATION
RELAXATION

Family activities & workshops
Kids and Teen independent workshops
Variety Game Night
Swimming
Archery
Educational Workshops
Crafts
Hiking
Campfire nights and so much more.

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
FAMILY
CAMP

If you have registered for camp, and would like to be part of the camp planning team, please contact Danielle Bell, dbell@hemophilia.org

Your Donation Makes A Difference

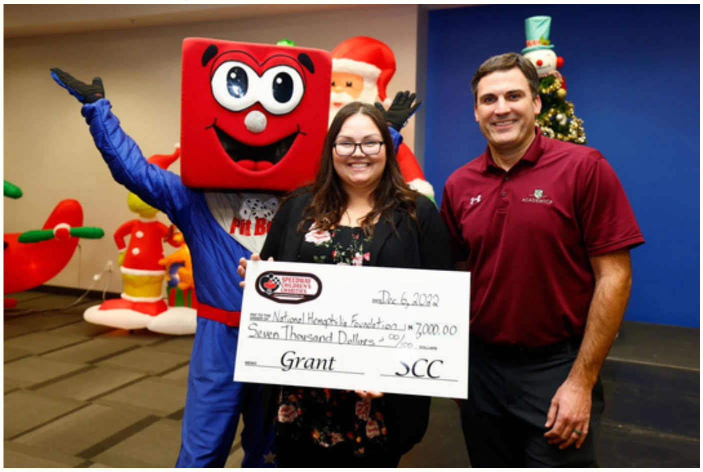
For over 30 years, Nevada NHF has been assisting and advocating for the bleeding disorders community of Nevada. We are especially proud of the strides and growth we've made by touching the lives of thousands of individuals through our programs and services. We have remained focused on empowering you and your family with the necessary tools, education, and training to become strong self-advocates.

With your help and support, we will continue to do great things for the Nevada bleeding disorders community.

Thank you for your support!

Did you know…

- By donating just $5, you can provide one hour of education to a newly diagnosed family.
- By donating just $20, you can help a child gain confidence at one of our summer camp programs.
- By donating just $25, you can provide a member of the bleeding disorder community the opportunity to meet with a professional about their mental health.
- By donating just $50, you can send advocates to meet with lawmakers to protect our access to quality healthcare and treatments.



*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 bleeds[1]

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.

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.

Reference: 1. ADVATE Prescribing Information.

Takeda

ADVATE

[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
sore throat
unusual taste
abdominal pain
diarrhea
nausea/vomiting
headache
fever
dizziness
hot flashes
chills
sweating
joint swelling/aching
itching
hematoma
swelling of legs
runny nose/congestion
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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HTCNV
HEMOSTASIS & THROMBOSIS CENTER OF NEVADA

SCCNV
SICKLE CELL CENTER OF NEVADA

Welcome to our new staff!

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Physical Therapist

Jeniffer Sipots
Medical Assistant

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JOIN OUR NEW NV CHAPTER COMMUNITY MEMBER FACBOOK 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.