Nevada Chapter Newsletter

Fall 2018

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.hfnv.org

Fall Calendar Full of Fun Family Events!

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Check out our community spotlight:

Aliyah Christmas
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Unite for Bleeding Disorders Walk & 5K a huge success!

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Hemophilia News & Views

Becki
RN
Michael
CEO
Maria
AA
Lisa
MA
Ariana
MA
Amber
APRN
Johnson
LSW
Danielle
DPT
JR
RN
Ofelia
MA
Jennifer
CPhT
Daisy
MD
Melissa
RHIT

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.hfnv.org

Mission

The Nevada Chapter of the National Hemophilia Foundation's mission is to improve the quality of care and life for people with hemophilia, von Willebrand disease and other inherited bleeding disorders through education, peer support and advocacy.

Vision

Our vision is to be the go to resource for people with bleeding disorders in Nevada by providing all the resources needed to successfully manage their quality of life.

The National Hemophilia Foundation is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. "Coming together is a beginning. Keeping together is progress. Working together is success."

Contact Us

Nevada Chapter of the National Hemophilia Foundation
222 S. Rainbow Blvd. Suite 203
Las Vegas, NV 89145

Phone: 702-564-4368
Fax: 702-446-8134
www.hfnv.org

Our Team

Betsy VanDeusen, Executive Director
Phone: 702-564-4368 x100
bvandeusen@hemophilia.org

Maureen Magana-Salazar, Chapter Bilingual Program Manager
Phone: 702-564-4368 x101
mmagana@hemophilia.org

Christine Bettis, Development Manager
Phone: 702-564-4368 x102
cbettis@hemophilia.org

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Miriam Calderon

Features:

In Every Issue:

A Letter from Our Executive Director

Dear Friends,

I cannot express how grateful I am for our Nevada bleeding disorders community. It was so moving to see everyone come together for our first ever Unite For Bleeding Disorders Walk – your support through your donations, and through your fundraising efforts will make it possible for the Nevada Chapter to continue to be here for you.

As the weather gets cooler it's time to spend more time outdoors – especially in southern Nevada. I encourage you to push yourself and try something new. The Nevada Chapter is introducing a new event this year "Bikes In Your Blood." Offering four courses for the novice to experienced cyclist, Bikes In Your Blood is a great chance to be active, and raise money to support a good cause.

The Nevada Legislative session will begin on February 4th, 2019. Now is the time to brush up on your advocacy skills and start to get the word out about issues that are important to you. To help raise grass roots support for access to healthcare, the Nevada Chapter is holding an Advocacy Boot Camp on October 20th in Las Vegas at the Springs Preserve.

Sincerely,

Betsy VanDeusen
Chapter Executive Director

TOP THREE

If you only do three things this Fall… try our top three actions for empowerment!

1.Get out and bike! Sign-up, donate, and volunteer for Bikes In Your Blood on 11/17! www.hfnv.org

2. Vote on 11/6! Local, state & national elections are crucial for access to healthcare. www.rockthevote.com

3. Give Back. 11/27 is Giving Tuesday. A day to give where you live. Support bleeding disorders on this national day of giving! www.hfnv.org

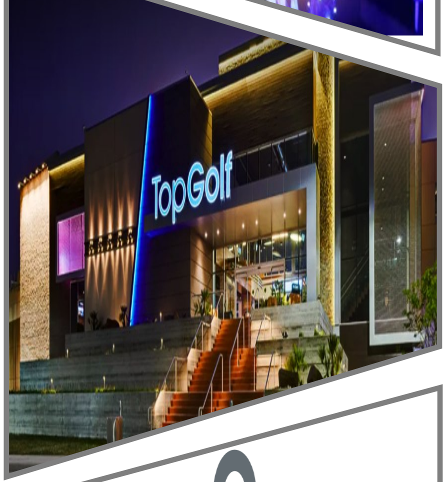
Featured Events

Fall Fam Jam
Saturday, October 20 & 21, 2018
Springs Preserve, Las Vegas, NV

Fall Fam Jam offers five tracks to empower the whole family! Sign-up for one or more tracks.

Saturday 10am-4pm: Advocacy Bootcamp
Saturday 10am-4pm: Couples Mini Retreat
Sunday 10am-12pm: New Family Infusion Class
Sunday 1pm-2pm: (Spanish) Steps For Living: Sugerencias para mejorar la comunicación con proveedores de servicios de salud
Sunday 10am-2pm: Teen Leadership Workshop

Those who attend at least one session will receive tickets for their family to attend the Haunted Harvest at The Springs Preserve on Sunday, October 21 from 7-9pm!



Las Vegas Men's Retreat
Saturday, November 10, 2018 - 12-3pm
Top Golf, Las Vegas, NV

Men only are invited for an exciting afternoon at TOPGOLF for an informal golf clinic, a chance to hear Perry Parker, a PGA Professional share his story of overcoming challenges related to bleeding disorders, and of course golfing!

RSVP by October 29th at www.hfnv.org

Bikes In Your Blood
Saturday, November 17, 2018
Equestrian Park South, Henderson, NV - 7am

Bike for the Bleeding Disorders Community! Join us for the first "Bikes In Your Blood" bike fundraiser benefitting the Nevada bleeding disorders community. Four course options make this a fun event for the whole family for novice to experienced cyclists. Bikers who donate or raise $25 or more will receive a Bikes In Your Blood T-Shirt and goody bag.

Register, create a team, and donate at https://www.eventbrite.com/e/bikes-in-your-blood-tickets-46234305051

Holiday Events

Las Vegas: Annual Meeting & Holiday Party December 1st, East Las Vegas Community Center, 12:30-7pm

Elko: December 5th, Hilton Garden Inn, 6-8pm

Reno: December 6th, Hunsberger Elementary School, 6-8pm

Register online at www.hfnv.org

2018 Calendar of Events

Shire

Monday, October 8, 2018
Shire Hello Talk & Dinner
Winnemucca

70th NHF Bleeding Disorders Conference ORLANDO • 2018

October 11 - 13, 2018
NHF Annual Meeting
Orlando, FL

Saturday & Sunday, October 20 & 21, 2018
Fall Fam Jam
Las Vegas


OCT 29 @ 5:30-7PM
TRUNK OR TREAT
6450 MEDICAL CENTER ST.
LAS VEGAS NV 89148
PLEASE RSVP BEFORE 10/19 TO 702-960-5991
CANDY, PIZZA, COSTUME CONTEST AND MORE...

Monday, October 29, 2018
HTCNV Trunk or Treat
Las Vegas

Genentech
A Member of the Roche Group

Tuesday, November 6
Education Dinner
Las Vegas

Saturday, November 10
Men's Retreat & Golf Event
Las Vegas

BAYER

Friday, November 16, 2018
Bayer Education Dinner
Las Vegas

BIKES IN YOUR BLOOD

Saturday, November 17, 2018
Bikes In Your Blood
Fun Ride Fundraiser
Las Vegas

Give Where You Live.

Tuesday, November 27, 2018
Giving Tuesday
Statewide

Saturday, December 1, 2018
Consumer Meeting &
Holiday Party
Las Vegas

Wednesday, December 5, 2018
Consumer Meeting &
Holiday Party
Elko

Thursday, December 6, 2018
Consumer Meeting &
Holiday Party
Reno

Thursday, December 13, 2018
Volunteer & Donor Appreciation Party
Las Vegas

ONGOING: 2nd Saturday of the Month
New Family Play Group
Various Locations
Las Vegas

Check out www.hfnv.org for updated information and to register for upcoming events.

Not getting invitations? Contact us to update your email and address:

mmagana@hemophilia.org
702-564-4368

Un Mensaje de nuestra Directora Ejecutiva

Queridos amigos,

No puedo expresar lo agradecida que estoy por nuestra comunidad de trastornos hemorrágicos de Nevada. Fue tan conmovedor ver a todos unirse para nuestra primera Caminata de Unite For Bleeding Disorders: su apoyo a través de sus donaciones y mediante sus esfuerzos de recaudación de fondos harán posible que el Capitulo de Nevada continúe aquí para ustedes.

A medida que el clima se enfríe, es hora de pasar más tiempo al aire libre, especialmente en el sur de Nevada. Los animo a que se esfuercen y traten algo nuevo. El Capítulo de Nevada presenta un nuevo evento este año "Bicicletas en tu sangre". Con cuatro cursos para ciclistas principiantes y expertos, Bicicletas en tu sangre es una gran oportunidad para estar activo y recaudar dinero para apoyar una buena causa.

La sesión legislativa de Nevada comenzará el 4 de febrero de 2019. Ahora es el momento de repasar sus habilidades de abogacía y comenzar a correr la voz sobre los asuntos que son importantes para usted. Para ayudar a aumentar el apoyo popular para el acceso a la atención médica, el Capítulo de Nevada realizará un Advocacy Boot Camp el 20 de octubre en Las Vegas en Springs Preserve.

Sinceramente,

Directora Ejecutiva

LOS TRES

Si solo haces tres cosas este otono ... ¡Trata nuestras tres acciones principales para empoderarte!

1. ¡Salir y andar en bicicleta! Regístrate, dona, o se voluntario para Bikes In Your Blood el 11/17!

www.hfnv.org

2. ¡Vota el 11/6! Las elecciones locales, estatales y nacionales son cruciales para el acceso a la atención médica.

www.rockthevote.com

3. Retribuye. 11/27 es Giving Tuesday. Un día para dar donde vives. ¡Apoye los trastornos de la coagulación en este día nacional de dar!

www.hfnv.org

Community Spotlight: Aliyah Christmas

Meet Aliyah.

Aliyah is a 10 year old girl who's health challenges inspired her to give back.

For a long time, Aliyah and her mother struggled to have her health concerns taken seriously. "Bloody nose, after bloody nose, after bloody nose!" shared her mother, "How frustrating to deal with that on a regular basis and be told over and over it's normal."

Aliyah and her mother knew something wasn't right, and fortunately they kept fighting. After almost a year of doctor visits and numerous tests, Aliyah finally was diagnosed with storage pool deficiency.

Never letting her disorder keep her down she's figured out the tricks to keeping her bleeds under control.

Her mother thanks the Nevada Chapter for their role in helping her daughter to feel empowered. "Thanks to the chapter's educational dinners and wonderful events she has learned what activities are best for her to keep herself healthy."

Aliyah enjoys learning why this disorder exists and likes to give back. She knows whenever she walks and raises money she's helping others learn about their disorders.

Aliyah's drive and commitment helped her raise $2,350 for the 2018 Unite for Bleeding Disorders Walk, winning her the Top Individual and Top Youth Fundraiser award.

Thank you to Aliyah and all of her friends and family for your support of the Nevada bleeding disorders community.

> **"...when she walks and raises money she's helping others learn about their disorder."**

Let's Get Social

August Social Media Contest Winner: Monique Lindsay, Team Briova
Self-Donate to Your Team!

Whether it's $5 or $50, your self-donation is critical to our mission. Did you know it costs an average of $550 per camper to attend Camp Independent Firefly? If each team raises $550 we could cover the cost of almost 30 kids! That's why your dollars are so important to our walk.

Special thanks to everyone who helped Nevada compete in the Bayer 5K Facebook Chapter Challenge:

Jacey Lynn, Christine Bettis, Mary Soto, Jenna Fox, Sarah Hoover, Lisa Perez, Josie Clark, Andrea Barragan, Kelly Gonzalez, Joseph Gonzalez, Debbie Anderson, Jamie Walls Suchocki, Lupe Torres, Serene Torres, Amber Brown, Maureen Salazar-Magana, Liliana Serrano, Dustin Wax, Sarah Townsend, Sandy Silvera, Araceli Osthed, & Marisa Perry

Upcoming Contests:

October: Active Fall fun! Post of picture in the comments of you being active to be entered into a giveaway!
November: Tell us about one person you're thankful to have met through the bleeding disorders community for the chance to win a Bikes in Your Blood tshirt!
December: Share our holiday giving campaign to your social media page for the chance to win a gift card!

Follow us on Social Media!
Like us on Facebook! facebook.com/NHFNV
Follow us on Twitter! @NevadaNHF
Follow us on Instagram @NevadaNHF
Subscribe to our YouTube Channel NHFNevada

National Program Spotlight: Better You Know

BETTER YOU KNOW

Betteryouknow.org is a website for women and men who may experience symptoms of a bleeding disorder but have not been diagnosed. With this site, the National Hemophilia Foundation (NHF) hopes to raise awareness and knowledge of bleeding disorders as part of our Better You Know campaign.

But we can't do it on our own. We need your help. You can help spread the word to your sister or brother, mother or father, son or daughter, aunt or uncle, neighbor or friend. That way they can begin to live a better life. Plus, there are some cool videos and social media posts that will get folks talking. We invite you to join the conversation.

Visit betteryouknow.org for tools and resources you can use to raise awareness in your community:

- Spread the word on social media
- Share a Better YouKnow Video
- Get Local Media Coverage
- Request Postcards or Brochures to Distribute
- ...and more!


Actual FEIBA patient.

FEIBA
[anti-inhibitor coagulant complex]

LIVE IN THE BLEED-FREE MOMENT

...with FEIBA® prophylaxis patients can have more bleed-free days as compared to on-demand treatment.

72%
REDUCTION
in median ABR with prophylaxis treatment[3]

Every joint bleed has the potential to do permanent damage[1,2]

Median ABR with prophylaxis vs. on-demand*[3]

28.7 median ABR with **on-demand** treatment[3]

629 bleeding episodes occurred during on-demand treatment[3]

VS

7.9 median ABR with **prophylaxis** treatment[3]

196 bleeding episodes occurred during prophylaxis treatment[3]

NO BLEEDS OCURRED IN 18% (3 out of 17) of patients on FEIBA prophylaxis in a clinical study[1]*

*Based on the results from the FEIBA PROOF clinical study of 36 hemophilia A and B patients with inhibitors receiving FEIBA for prophylaxis or on-demand treatment for 12 months.[3]

†Of those patients who achieved zero bleeding events, 2 out of 3 completed the study.[4]

FEIBA is the ONLY FDA-approved treatment indicated for use in hemophilia A and B patients with inhibitors for routine prophylaxis.[3]

FEIBA [Anti-Inhibitor Coagulant Complex] Indications and Detailed Important Risk Information for Patients

Indications for FEIBA

FEIBA is an Anti-Inhibitor Coagulant Complex approved for use in hemophilia A and B patients with inhibitors for:

- Control and prevention of bleeding episodes
- Use around the time of surgery
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes.

FEIBA is NOT for use in the treatment of bleeding episodes resulting from coagulation factor deficiencies without inhibitors to factor VIII or factor IX.

Detailed Important Risk Information for FEIBA

WARNING: EVENTS INVOLVING CLOTS THAT BLOCK BLOOD VESSELS

- **Blood clots that block blood vessels and their effects have been reported during post-marketing surveillance following infusion of FEIBA, particularly following administration of high doses (above 200 units per kg per day) and/or in patients at risk for forming blood clots.**
- **If you experience any of these side effects, call your doctor right away.**

Who should not use FEIBA?

You should not use FEIBA if:

- You had a previous severe allergic reaction to the product
- You have Disseminated Intravascular Coagulation (DIC), or signs of small blood vessel clots throughout the body
- You have sudden blood vessel clots or blocked blood vessels, (such as, heart attack or stroke)

What other important information should I know about FEIBA?

Events involving blood clots blocking blood vessels (such as blood clot in vein, blood clot in the lung, heart attack, and stroke) can occur with FEIBA, particularly after receiving high doses (above 200 units per kg per day) and/or in patients with risk factors for clotting.

Events of thrombotic microangiopathy (TMA), a condition where blood clots and damage occur in small blood vessels, were reported in an emicizumab (Hemlibra®) clinical trial where patients received FEIBA with emicizumab as part of a treatment plan for breakthrough bleeding. The safety and efficacy of FEIBA for breakthrough bleeding in patients receiving emicizumab has not been established. If you take, or anticipate taking, FEIBA with emicizumab, tell your doctor, since they will need to closely monitor you.

At first sign or symptom of a sudden blood vessel clot or blocked blood vessel (such as chest pain or pressure, shortness of breath, fever, altered consciousness, vision, or speech, limb or abdomen swelling and/or pain), stop FEIBA administration right away and seek immediate emergency medical treatment.

Infusion of FEIBA should not exceed a single dose of 100 units per kg body weight and daily doses of 200 units per kg of body weight. Maximum injection or infusion rate must not exceed 2 units per kg of body weight per minute.

Allergic reactions, including severe, sometimes fatal allergic reactions that can involve the whole body, can occur following the infusion of FEIBA. Stop using FEIBA promptly and call your doctor or get emergency treatment right away if you get a rash, hives or welts, experience itching, tightness of the throat, vomiting, abdominal pain, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Because FEIBA is made from human plasma it may carry a risk of transmitting infectious agents, such as viruses, variant Creutzfeldt-Jakob disease (vCJD) and, theoretically, the Creutzfeldt-Jakob disease (CJD).

What are the possible side effects of FEIBA?

The most common side effects observed during the prophylaxis clinical study were low number of red blood cells, diarrhea, bleeding into a joint, positive test for hepatitis B surface antibodies, nausea, and vomiting.

The serious side effects seen with FEIBA are allergic reactions and clotting events involving blockage of blood vessels, which include stroke, blockage of the main blood vessel to the lung, and deep vein blood clots.

Call your doctor right away about any side effects that bother you during or after you stop taking FEIBA.

What other medications might interact with FEIBA?

Talk with your doctor about the possibility of formation of blood clots when taking drugs that may prevent clot breakdown such as tranexamic acid, and aminocaproic acid. There have not been adequate studies of the use of FEIBA and rFVIIa (NovoSeven®), or emicizumab together, or one after the other. Use of drugs that may prevent clot breakdown within approximately 6 to 12 hours after the administration of FEIBA is not recommended.

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 next page for Important Facts about FEIBA.
Please see accompanying FEIBA full Prescribing Information, including BOXED WARNING on blood clots, and discuss with your doctor.

References: 1. Pergantou H, Matsinos G, Papadopoulos A, Platokouki H, Aronis S. Comparative study of validity of clinical, X-ray and magnetic resonance imaging scores in evaluation and management of haemophilic arthropathy in children. Haemophilia. May 2006;12(3):241-247. **2.** Gringeri A, Ewenstein B, Reininger A. The burden of bleeding in haemophilia: is one bleed too many? Haemophilia. Jul 2014;20(4):459-463. **3.** FEIBA Prescribing Information. **4.** Antunes SV, Tangada S, Stasyshyn O, et al. Randomized comparison of prophylaxis and on-demand regimens with FEIBA NF in the treatment of haemophilia A and B with inhibitors. Haemophilia. 2014;20(1):65-72.

Shire

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Important Facts about FEIBA® (Anti-Inhibitor Coagulant Complex)

What is FEIBA used for?

FEIBA (Anti-Inhibitor Coagulant Complex) is used for people with Hemophilia A and B with Inhibitors to control and prevent bleeding episodes, around surgery, or routinely to prevent or reduce the number of bleeding episodes. It is NOT used to treat bleeding conditions without inhibitors to Factor VIII or Factor IX.

When should I not take FEIBA?

You should not take FEIBA if you have had hypersensitivity or an allergic reaction to FEIBA or any of its components, including factors of the kinin generating system, if you have a condition called Disseminated Intravascular Coagulation (DIC), which is small blood clots in various organs throughout the body, or currently have blood clots or are having a heart attack. Make sure to talk to your healthcare provider about your medical history.

What Warnings should I know about FEIBA?

FEIBA can cause blood clots, including clots in the lungs, heart attack, or stroke, particularly after high doses of FEIBA (above 200 units per kg per day) or in people with a high risk of blood clots. Patients that have a risk of developing blood clots should discuss the risks and benefits of FEIBA with their healthcare provider since FEIBA may cause blood clots. Events of thrombotic microangiopathy (TMA), a condition where blood clots and damage occur in small blood vessels, were reported in an emicizumab (Hemlibra®) clinical trial where patients received FEIBA with emicizumab as part of a treatment regimen for breakthrough bleeding. The safety and efficacy of FEIBA for breakthrough bleeding in patients receiving emicizumab has not been established. If you take, or anticipate taking, FEIBA with emicizumab, tell your doctor, since they will need to closely monitor you. At first sign or symptom of a sudden blood vessel clot or blocked blood vessel (such as chest pain or pressure, shortness of breath, fever, altered consciousness, vision, or speech, limb or abdomen swelling and/or pain), stop FEIBA administration right away and seek immediate emergency medical treatment.

Allergic reactions, including severe, sometimes fatal allergic reactions that can involve the whole body, can occur following the infusion of FEIBA. Stop using FEIBA promptly and call your doctor or get emergency treatment right away if you get a rash, hives or welts, experience itching, tightness of the throat, vomiting, abdominal pain, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Because FEIBA is made from human plasma, it may carry the risk of transmitting infectious agents, for example, viruses, including Creutzfeldt-Jakob disease (CJD) agent, and the variant CJD agent. Although steps have been taken to minimize the risk of virus transmission, there is still a potential risk of virus transmission.

What should I tell my healthcare provider?

Make sure to discuss all health conditions and medications with your healthcare provider. If you are pregnant or are planning to become pregnant, or are a nursing mother, make sure to talk with your healthcare provider for advice on using FEIBA.

What are the side effects of FEIBA?

The most frequent side effects of FEIBA are: low red blood cell count, diarrhea, bleeding into a joint, hepatitis B surface antibody positivity, nausea, and vomiting. The most serious side effects of FEIBA include: hypersensitivity reactions, including anaphylaxis, stroke, blood clots in the lungs, and blood clots in the veins. Always immediately talk with your healthcare provider if you think you are experiencing a side effect.

What other medications might interact with FEIBA?

Talk with your doctor about the possibility of formation of blood clots when taking drugs that may prevent clot breakdown such as tranexamic acid, and aminocaproic acid. There have not been adequate studies of the use of FEIBA and rFVIIa (NovoSeven®), or emicizumab together, or one after the other. Use of drugs that may prevent clot breakdown within approximately 6 to 12 hours after the administration of FEIBA is not recommended. For additional information on potential drug interaction with emicizumab, see the "What Warnings Should I Know about FEIBA?" section above.

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

The risk information provided here is not comprehensive. To learn more, talk about FEIBA with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at

http://www.feiba.com/us/forms/feiba_pi.pdf or by calling 1-800-423-2090 and selecting option 5.

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5 Ways to Foster Independence in Your Teen with a Bleeding Disorder

Author: Donna Behen

Here's how to help your adolescent child take the necessary steps toward becoming an adult

If you have a child with a bleeding disorder, the teen years can be challenging. It's a time when adolescents are naturally looking to separate themselves from their parents and take on more responsibility. But after years of being so involved in managing your child's bleeding disorder, it can be hard to step back and give him or her the freedom and independence teens need as they grow toward adulthood.

How can you help teens with bleeding disorders become more independent and empower them to take charge of their health? Here are some suggestions:

1. Hand over all treatment responsibilities

Ideally, a teenager will have already taken one of the biggest steps toward independence, which is learning how to self-infuse. But in addition to that important milestone, teens should be handling a lot of the other aspects of their treatment, including knowing the details of their medication, being responsible for their own treatment log and eventually taking on the task of ordering their medication.

2. Stay positive

Whether it's helping your child transition to managing his or her medical appointments schedule, recognize the signs of a bleed, or cope with a medical emergency, your attitude can make all the difference.

"Let your child know that you are confident that they can take on these new responsibilities, and that you're there to consult or help in any way that they might need," says Mary Alvord, PhD, a child clinical psychologist in private practice in Rockville and Chevy Chase, Maryland. What's important is not only what you say, says Alvord, but even more so, what you do. "You can model that something is challenging but also problem-solve out loud about how you will approach the issue," she says.

"This approach can counter those 'I can't' thoughts that teens can be susceptible to, and provide the powerful message to your teen that, they can try, and they can do it, with help," says Alvord, author of Conquer Negative Thinking for Teens.

3. Teach teens to advocate for themselves

Encourage your child to start taking a more active role in his or her own healthcare by speaking up and asking questions of hemophilia treatment center (HTC) team members or his or her primary care doctor. Once children are high school-aged, they should be able to make their own doctor's appointments and order their own factor and infusion supplies.

The more people can advocate for themselves and learn to communicate what they need, the more they feel in control of their healthcare, says Alvord. "We also know that being proactive and asking for help are strengths that factor into resilience," she says. According to a recent study, teens who have a medical condition may be better prepared to transition from pediatric care to adult care while taking charge of their own healthcare than teens who don't have a medical issue. When psychologists at the University of Georgia studied 494 older adolescent and young adult patients, they found that those with a chronic condition were more self-supporting in completing health-related tasks and were less reliant on input from their parents.

4. Sign up for camp

A week at overnight camp is when many adolescents with bleeding disorders learn to take a bigger role in managing their own health. Not only do they become more comfortable and confident with self-infusing, they also gain independence by being away from home for several days. Many kids who are active in camp go from being campers to counselors, which teaches them responsibility and leadership skills. There are more than 50 overnight summer camps in 37 states for young people with bleeding disorders, and the cost is usually covered by your local chapter. It's not too early to start planning for next summer. Find a camp near you by contacting your local chapter or HTC, or search NHF's online camp locator< https://www.hemophilia.org/Community-Resources/Locate-a-Camp-Near-You-0>.

5. Encourage your teen to connect with other young adults

Adolescents need role models and mentors, and talking to other teens and young adults who have bleeding disorders can help them feel much more comfortable about their changing role. You can help your child connect with young adults in your area by contacting your local NHF chapterto discover what programs are available. Participation in these events can help teens learn to talk much more openly and appropriately about their disorder with friends, and also be more likely to act responsibly and take ownership of their healthcare.

LifeCare
SPECIALTY PHARMACY
3050 EAST DESERT INN RD., STE. #124
LAS VEGAS, NEVADA 89121
PHONE (702) 697-2105
FAX (702) 697-2107

LifeCare Specialty Pharmacy specializes in dispensing medications used for the treatment of hemophilia at home and other types of bleeding disorders

We deliver our patients care in accordance with pharmaceutical manufacturers, health Insurance plan carriers, physicians, and payers. At LifeCare Specialty Pharmacy, our team is educated and knowledgeable about hemophilia, bleeding disorders and their concomitant therapies at the comfort of the client's home.

LifeCare Specialty Pharmacy Team is dedicated to maintaining long-term relationships with our customers through our mainstream values and mission that every patient is a family and hope has no limits….

Our Target………

- Keeping You Out of the Hospital is Our Main Priority: We arrange skilled nursing with nurses that are experienced in treatment and wound management of our client bleeding disorder.
- Customized Medication & Supply Delivery: We dispense and ship home infusion therapies to your home and customize the order to your specialty needs.
- We are continuously reaching out to our patients with information, research and support with social media.
- Our community liaisons sponsor exercise events for the entire family that promote healthy activities and bonding opportunities.
- We are continually involved in our teens and young adults with bleeding disorders

LifeCare Specialty Pharmacy se especializa en la administración de medicamentos utilizados para el tratamiento de la hemofilia en el hogar y otros tipos de trastornos hemorrágicos.

Entregamos a nuestros pacientes sus cuidados de acuerdo con fabricantes de productos farmacéuticos, proveedores de planes de seguro de salud, médicos y pagadores. En LifeCare Specialty Pharmacy, nuestro equipo está instruido y es conocedor sobre la hemofilia, los trastornos hemorrágicos y terapias concomitantes en la comodidad del hogar de cada paciente.

El equipo de LifeCare Specialty Pharmacy está dedicado a mantener relaciones de largo plazo con nuestros clientes a través de nuestros valores y misión principal: que cada paciente es familia y la esperanza no tiene límites….

Nuestra Meta….

- Nuestra principal prioridad es mantenerlo alejado del hospital: coordinamos enfermería especializada con enfermeras con experiencia en el tratamiento y manejo de heridas de trastorno hemorrágico de cada uno de nuestros clientes.
- Suministro personalizado de medicamentos y entrega de suministros: dispensamos y enviamos terapias de infusión a domicilio a su hogar y personalizamos el pedido según sus necesidades especiales.
- Estamos continuamente acercándonos a nuestros pacientes con información, investigación y apoyo con las redes sociales
- Nuestros enlaces comunitarios patrocinan eventos de ejercicios para la familia entera que promueven actividades saludables y oportunidades de vinculación.
- Estamos continuamente involucrados en nuestros adolescentes y adultos jóvenes con trastornos hemorrágicos.
- Proporcionamos descargas gratuitas de aplicaciones trimestrales, educación nutricional, recetas saludables y videos de ejercicios con nuestras entregas medicamentos.

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Camp Independent Firefly

Held in June in Big Bear, California, Camp Independent Firefly is a medically supervised overnight camp that for many of our campers is the first time they are away from their parents. More than just recreation, the skills and education gained at camp is a crucial step to reaching an independent future. In 2018, 72 children attended Camp. Over 50 volunteers served over 2,000 hours to make Camp possible this year!

Thank you to our sponsors for making a difference and supporting Camp Independent Firefly!

Engelstad Family Foundation
Grand Lodge Independent Order of Odd Fellows of Nevada
Hemostasis & Thrombosis Center of Nevada

Bayer
Bioverativ
CVS Health
Eric Tippetts
John Lynch
Kevin Shaughnessy
Novo Nordisk
Pfizer
Quality Home Infusion

Robert Brown
Shane Victorino
Shire
The Siegel Company
Soleo Health
Specialty Care Rx
Speedway Children's Charities
Stephen Chiang

Unite For Bleeding Disorders Walk & 5K

Unite
for Bleeding Disorders

Our Nevada Unite For Bleeding Disorders Walks raised a total of $64,000!

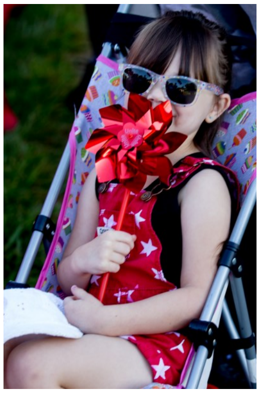
Thank you to all of our donors, team captains, fundraisers, volunteers, walkers, runners & sponsors who helped make our first Unite for Bleeding Disorders Walk & 5K a huge success!

Special Thanks to our Award Winners who went above and beyond in their fundraising efforts!

Las Vegas:
Top Individual and Top Youth Fundraiser – Aliyah Christmas, $2,350
Top Team – Team Nightwing, $7,958
Top Corporate Team - Team Briova, $5,261

Reno:
Top Individual - Amanda Bradhurst, $735
Top Team & Top Corporate Team: Team Genentech, $995
Top Youth Fundraiser: Jacey Gonzalez, $70

THANK YOU!



A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

Discover **HEMLIBRA.com**

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 with hemophilia A with factor VIII inhibitors.

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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 signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **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 the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

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.

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

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.

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 OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

The most common side effects of HEMLIBRA include: redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

ADVERTISEMENT

Medication Guide Brief Summary
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. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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.

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 with hemophilia A with 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.
- 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.
- 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 before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose 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 7 days at 86°F (30°C) or below.
- 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

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

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
Issued: 11/2017

HEMLIBRA
emicizumab-kxwh 150 mg/mL
Injection for subcutaneous use

Genentech
A Member of the Roche Group

Los jóvenes defensores de los trastornos hemorrágicos hacen la diferencia

Los Días de Washington de la Fundación Nacional de Hemofilia brindan oportunidades para conectarse con legisladores y aprender lecciones de vida

Del 7 al 9 de marzo de 2018, cientos de personas de todo el país se reunieron en Washington, DC, para los Días de Washington de la Fundación Nacional de Hemofilia (National Hemophilia Foundation, NHF). El evento de defensa que dura tres días reúne a las personas afectadas por los trastornos hemorrágicos cara a cara con sus representantes en el Congreso para que aboguen por el apoyo federal en asuntos críticos. Es un foro impactante que deja una impresión duradera tanto en los legisladores como en los defensores.

Para Jacey Gonzalez de 19 años y estudiante de la Universidad de Nevada, Reno, los Días de Washington son una confusión feliz. “Es la mejor experiencia de su vida, pero después tendrá que recordarlo todo porque pasan muchas cosas en tan poco tiempo”, afirma.

Antes de invadir Capitol Hill, todos los defensores voluntarios reciben capacitación sobre cómo comunicarse con claridad sobre los trastornos hemorrágicos y los expertos en políticas detallan los mensajes esenciales del evento y “les piden” que los transmitan a los legisladores. En el mismo Hill, se llevan a cabo numerosas reuniones con representantes, senadores y miembros del personal, una oportunidad para que los defensores cuenten sus historias y personalicen los problemas.

“Los Días de Washington son un paso importante para cualquiera que desee involucrarse más con la comunidad de trastornos hemorrágicos”, afirma Gonzalez, quien padece la enfermedad de von Willebrand y la deficiencia de almacenamiento del pool plaquetario, un trastorno de la función plaquetaria. El evento de 2015 la presentó al Instituto Nacional del Liderazgo para la Juventud (National Youth Leadership Institute, NYLI) de la NHF, un programa de tres años para jóvenes adultos de entre 18 y 24 años que ofrece capacitación en liderazgo y oportunidades para facilitar talleres y programas educativos. Gonzalez se encuentra ahora en su último año del programa y durante los últimos dos años ha participado en la especialidad del NYLI centrada en la defensa (los otros dos temas del NYLI son divulgación y desarrollo sin fines de lucro).

El poder en los números

Matthew Delaney de 20 años de edad y estudiante de tercer año en la Universidad Estatal de Nueva York en New Paltz, describe los Días de Washington como una experiencia “transformadora”. “Todos tienen su propia historia que aportar. Pero necesitamos que todos vengan y hagan oír su voz. Porque cuantas más voces tengamos, más poder tendremos”, afirma.”

Delaney, que padece la enfermedad de von Willebrand y la trombastenia de Glanzmann, un trastorno de la agregación plaquetaria, también está en su tercer año en el programa del NYLI y es miembro de la sección de defensa. Tanto él como Gonzalez opinan que eventos como los Días de Washington generan confianza personal y conexiones con la comunidad.

“Asistir a los Días de Washington e involucrarse y rodearse de un grupo de miembros de la comunidad de apoyo realmente permite llegar a ese punto en el que confía en ser una persona independiente con un trastorno hemorrágico”, afirma Gonzalez.

Más allá de los Días de Washington: El papel fundamental de defensa del estado

Si bien los Días de Washington pueden ser el principal evento del calendario nacional de defensa de los trastornos hemorrágicos, no todos pueden realizar el viaje a Washington, DC. Además, involucrarse más cerca de casa puede tener un impacto aún mayor. “De hecho, gran parte de la política de atención médica se implementa a nivel estatal”, afirma Brendan Hayes, especialista en relaciones gubernamentales de la NHF que administra la sección de defensa del NYLI.

Jacey Gonzalez, miembro de sección de defensa del NYLI y participante en los Días de Nevada en el capitolio estatal en Carson City, afirma que los días de la legislatura estatal “por lo general, son un ambiente más relajado”. Gonzalez afirma que las conversaciones más largas con representantes pueden sentar las bases para un diálogo continuo.

En Albany, Nueva York, el miembro del NYLI Matthew Delaney señala que es más fácil establecer relaciones con los legisladores estatales en comparación con los miembros del Congreso y que la formulación de políticas es a menudo mucho más rápida que en Washington.

Póngase en contacto con su sede local para obtener más información sobre los días de defensa en su estado.

Program Recap: Summer Education Events

Check out the great education programs and events that took place this Summer!

July 10, 2018
Bayer Education Dinner

32 members of the bleeding disorder community came together at Gordon Biersch to meet other members of the community, hear about their experiences and learn more about KOVALTRY.

Hosted by Bayer.

August 15, 2018
Pfizer Education Dinner (Spanish)

24 community members attended the dinner presentation to learn tips and tricks to overcome challenges. Presented by Angelica Flores at the Twisted Fork in Reno, the event was offered in Spanish.

Hosted by Pfizer.

July 21 & 22, 2018
Northern Nevada Family Education Weekend

56 attendees participated in seven education sessions covering fitness, back to school, advocacy, pain management, and personal empowerment, while kids attended science based workshops offered by Accredo.

25 kids were equipped for school with supplies and backpacks, and everyone enjoyed an evening at the ball pack watching the Reno Aces & Las Vegas 51's.

August 4, 2018
Renee Paper Memorial Picnic & Back To School BBQ

83 attendees came out for an afternoon to hear Becki Berkowitz, RN speak about school programs (504 Plans and IEP's) and enjoy a family swim and BBQ at the YMCA pool.

60 kids received backpacks stuffed with school supplies to get them ready for school!

Sponsored by the HTCNV & CVS

August 16, 2018
Young Hope Society Mixer

The Young Hope Society hosted a fun, networking, summer mixer at Sammy's Woodfired Pizza. Attendees had a chance to meet other young professionals connected to the bleeding disorders community and give back through their monthly gift. The next mixer will be December 13th at the Downtown Grand. Join YHS at www.hemophilia.org.

August 25, 2018
Las Vegas Women's Retreat

25 women enjoyed a day full of relaxation, learning, laughs, and a few tears. Hosted by Brothers Healthcare & CSL Behring, topics covered Depression and Anxiety, Girl Talk, How to Laugh Through Stress, and an opportunity to connect with Daisy Cortes, MD, from the HTCNV. The day culminated with Planting an Intentional Garden-Succulent Terrarium.

Thanks to CSL Behring, Brothers Healthcare, & HTCNV for sponsoring this event.

Program Recap: Summer Education Events

July & August
New Family Playgroup

Families with kids age 0-7 have enjoyed our summer play groups. Held at the splash pad at Charlies Frias Park, and playground at the Gardens Park, kids have received build-a-bears, and bubble toys while parents connect.

Keep an eye on Facebook for our fall playgroups!

Thanks to the HTCNV for sponsoring these events.

August 25, 2018
Tahoe Education Day

40 members of the Northern Nevada community came together to learn about dealing with chronic pain from presenters Myles Ganley and Amber Federizo, APRN, FNP-BC.

Everyone enjoyed a picnic lunch on the beach at Zephyr Cove on Lake Tahoe and tried out paddle boarding and kayaking.

Thanks to Aptevo & Soleo for sponsoring the event.

In the Numbers

QUARTER 2 - 2018

Check out the impact your support is making in the Nevada bleeding disorders community:

social media *through summer* 2018

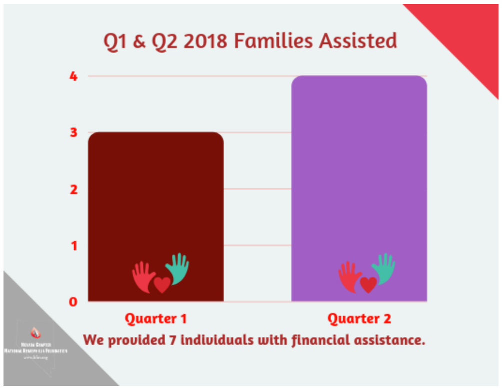
WWW.FACEBOOK.COM/NHFNV
55 PAGE LIKES
613 POST LIKES
47 COMMENTS
65 SHARES

TWITTER: @NVHEMOPHILIA
123 LIKES
44 RETWEETS
71 LINK CLICKS
5 REPLIES

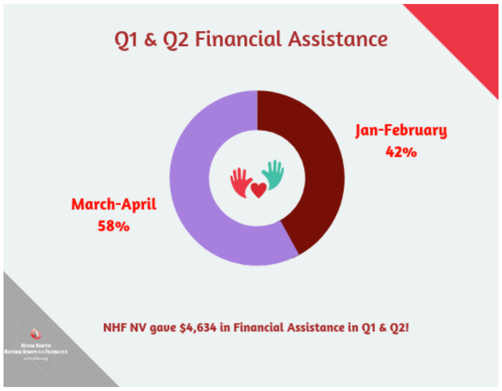
Instagram
@NHFNV
521 LIKES
18 COMMENTS

Here at the chapter, we love it when you engage with us online. Be on the lookout for our monthly social media challenges and community spotlights for fun giveaways and recognition!

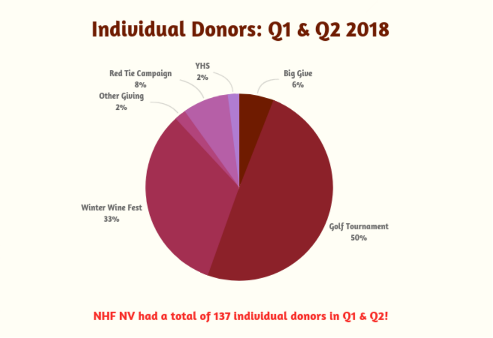
Nevada Chapter
National Hemophilia Foundation
www.hfnv.org



We provided 7 individuals with financial assistance.



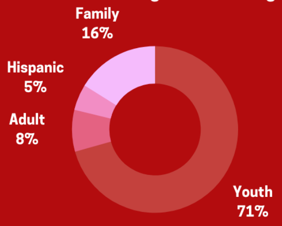
NHF NV gave $4,634 in Financial Assistance in Q1 & Q2!



NHF NV had a total of 137 individual donors in Q1 & Q2!

NHF Nevada Program Hours Q1 & Q2 2018

As a leader in the bleeding disorders community, we offer programs and services to make a difference for people and families living with bleeding disorders.



FAMILY PROGRAMS
We offered four education dinners, as well as our annual Spring Education Fest at Circus Circus Convention Center!

YOUTH PROGRAMS
Youth programs accounted for 70% of our Q1&2 programming, including our medically supervised summer camp, Camp Independent Firefly.

ADULT PROGRAMS
Our Reno Women's Wellness Retreat took place on February 24th and included yoga, terrarium building, and a support group session.

HISPANIC PROGRAMS
Hispanic Education Day took place on May 19th at Texas Station. Shire and HTC sponsored the event which featured Desert Pines High School's Mariachi Band!

74 PROGRAM HOURS
420 ATTENDEES

SHARING OUR IMPACT

The Nevada Chapter offers programs, services, education, and support to the Nevada bleeding disorders community. We take our mission seriously and think it's important to be transparent on our progress. This section of the Newsletter offers you insight into our progress and accomplishments. It is our hope that our readers will be inspired to action by these updates—whether that be to reach out to help us where we may be falling short, or celebrate our accomplishments when we deliver!

The chapter is only as strong as its community—we look forward to your partnership to help us continue to pursue the highest quality of life and quality of care for every member of our bleeding disorders community.

Sirviendo a todo Nevada

fidelis

specialty pharmacy

(702) 815-0800

www.fidelis-rx.com


Wagner Lemus
Co-Founder


Antonio Rosas
Co-Founder

Hablamos Español

Acceso 24/7 a Farmacéuticos con Experencia

Nuestros farmacistas son especializados en el tratamiento de Hemofilia y estan disponibles para contestar sus preguntas 24 horas al día, 7 días por la semana.

Cadena de Suministro de Factor de Coagulación Segura

Nuestras farmacias solo obtienen el factor de Coagulación de los mayores distribuidores farmacéuticos, exclusivamente de Centros de Distribución de clase Mundial. La calidad e Integridad de su producto está garantizado.

Monitoreo de Cumplimiento de Normas y Programas de Adhesión

Nos mantenemos en contacto regular con usted para apoyar la adherencia a la terapia prescrita. Personal de la farmacia siempre confirmará la cantidad de medicamentos y suministros que usted tiene en la mano antes de programar su próximo envío.

Coordinación de Servicios de Enfermería

Pacientes con Hemofilia requieren coordinación y atención de alta calidad y apoyo. Vamos a coordinar los servicios de enfermería de salud a domicilio si es requerido por su médico.

Comprensión de los Beneficios De Seguro

Le ayudamos a comprender cómo obtener el máximo provecho de sus beneficios de seguro y reducir los costos de su propio bolsillo lo más bajo posible. Ofrecemos la confirmación inicial de cobertura, incluyendo beneficios de farmacia y médica.

99%

Datos de encuesta de satisfacción del 2017

"Su farmacia preferida especializada en hemofilia para la comunidad latina"

Serving all of Nevada

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Wagner Lemus
Co-Founder


Antonio Rosas
Co-Founder

We Speak Spanish

24/7 Access to Knowledgeable Pharmacists

Our pharmacists are specialty trained in hemophilia treatment and are available to answer your questions 24 hours a day, 7 days a week.

Secure Pharmaceutical Supply Chain

Our pharmacies only source blood clotting factors from the top pharmaceutical distributors, each with world-class distribution centers. The quality and security of your drug product is guaranteed.

Compliance Monitoring & Adherence Programs

We stay in regular contact with you to support adherence to your prescribed therapy. Pharmacy staff will always confirm the amount of medication and supplies you have on hand before scheduling your next shipment.

Home Nursing Services Coordination

Hemophilia patients require high-quality care coordination and support. We will coordinate home health nursing services if required by your prescriber.

Understanding Insurance Benefits

We help you understand how to get the most out of your insurance benefits and make out-of-pocket costs as low as possible. We'll provide upfront confirmation of coverage, including pharmacy and medical benefits.

99%

2017 Patient Satisfaction Survey Data

"Your preferred specialty pharmacy for the hemophilia community"

National Hemophilia Foundation
Nevada Chapter
222 S. Rainbow Blvd Suite 203
Las Vegas, NV 89145

Phone: 702-564-4368
Fax: 702-446-8134
www.hfnv.org

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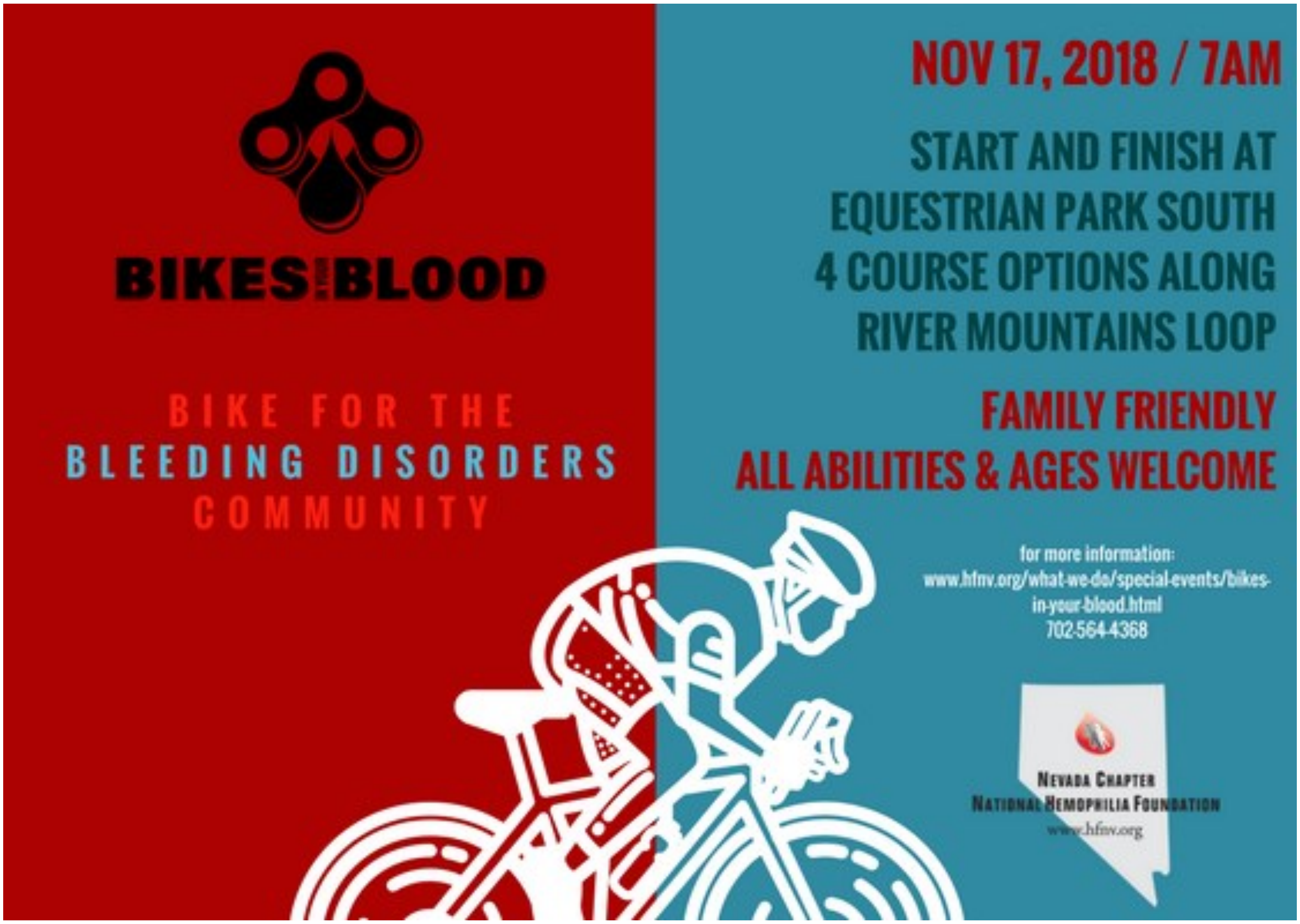

BIKES [illegible] BLOOD

BIKE FOR THE
BLEEDING DISORDERS
COMMUNITY

NOV 17, 2018 / 7AM

START AND FINISH AT
EQUESTRIAN PARK SOUTH
4 COURSE OPTIONS ALONG
RIVER MOUNTAINS LOOP

FAMILY FRIENDLY
ALL ABILITIES & AGES WELCOME

for more information:
www.hfnv.org/what-we-do/special-events/bikes-in-your-blood.html
702-564-4368

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.hfnv.org