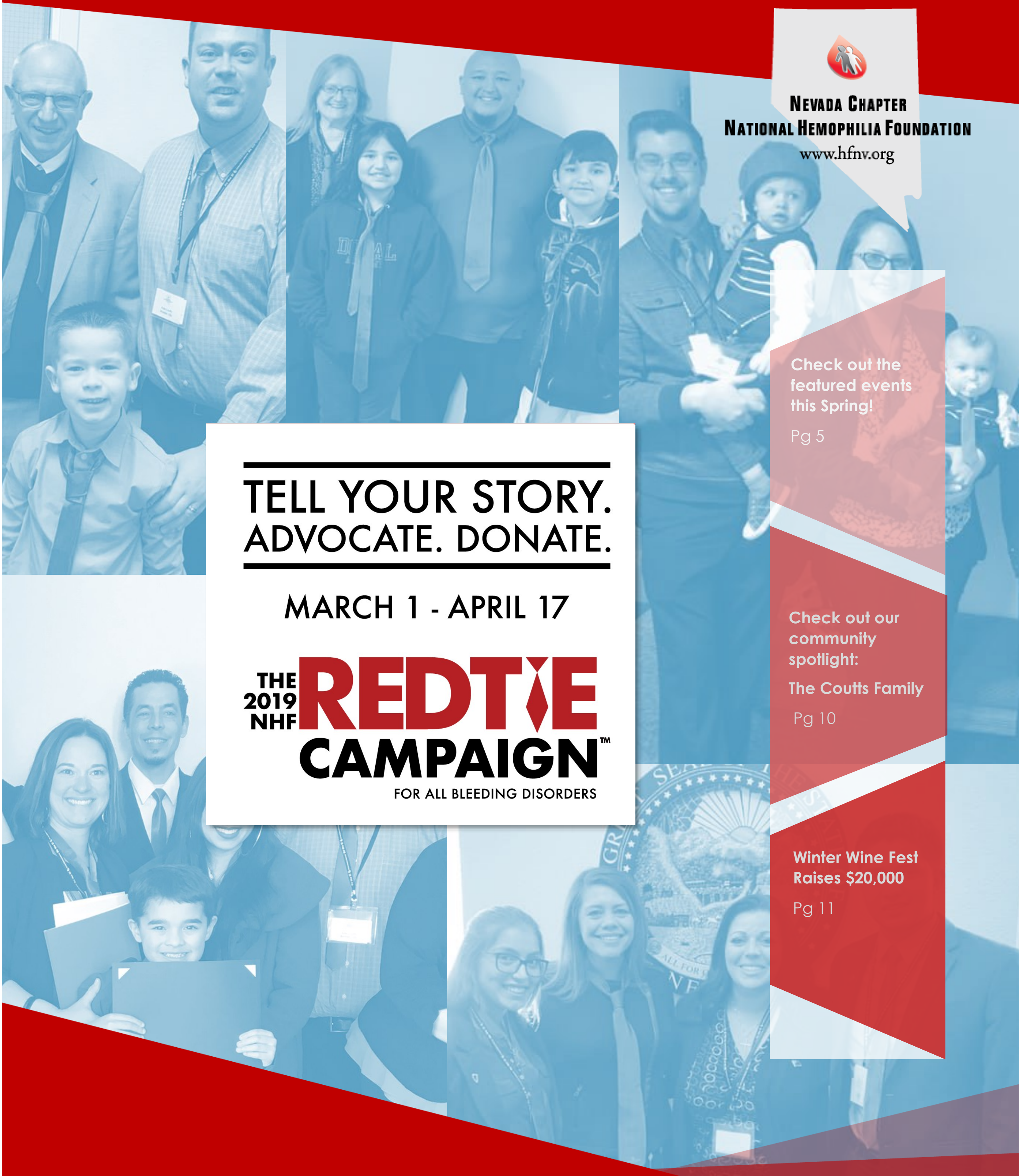
Nevada Chapter Newsletter
Spring 2019

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.hfnv.org



TELL YOUR STORY. ADVOCATE. DONATE.

MARCH 1 - APRIL 17

THE 2019 NHF REDTIE CAMPAIGN™
FOR ALL BLEEDING DISORDERS

Check out the featured events this Spring!
Pg 5

Check out our community spotlight:
The Coutts Family
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Winter Wine Fest Raises $20,000
Pg 11

Hemophilia News & Views

ADVERTISEMENT

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.

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
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Our Team

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

ADVERTISEMENT

Letter from Our Executive Director / Mensaje de nuestra Directora Ejecutiva

Dear Friends,

It’s time to put on your red ties again and join us for the **2019 Red Tie Campaign!** This March, during Bleeding Disorders Awareness Month, the Nevada Chapter along with NHF and chapters across the country, will raise funds and awareness to support the bleeding disorders community.

To participate in the 2019 Red Tie Campaign, you can:

- **Give:** Our collective goal is to raise $30,000 across all chapters and NHF during the Red Tie Campaign. If you donate to NHF NV, NHF will match that donation up to $750! Give today to double your support of your local bleeding disorders community.
- **Share:** Be a part of the movement! Put on your red tie and share why Bleeding Disorders Awareness Month and NHF NV are important to you. Follow #RedTieCampaign on Twitter, Facebook and Instagram, and share your story to raise awareness within your personal network.
- **Advocate:** We’ll be heading to Washington DC for NHF’s Washington Days event March 27-29, 2019. Follow us on social media as we advocate for access to healthcare.

To learn more about the Red Tie Campaign, visit RedTieCampaign.org. For more information on bleeding disorders and our chapter, please visit hfnv.org.

Sincerely,

Betsy VanDeusen
Chapter Executive Director

Queridos amigos,

¡Es hora de volver a ponerse la corbata roja y unirse a nosotros para la Campaña Red Tie del 2019! Este mes de marzo, durante el Mes de Concientización sobre los Trastornos Sangrantes, el Capítulo de Nevada, junto con NHF y los capítulos de todo el país, recaudarán fondos y crearán conciencia para apoyar a la comunidad de trastornos de la coagulación.

Para participar en la campaña Red Tie 2019, puedes:

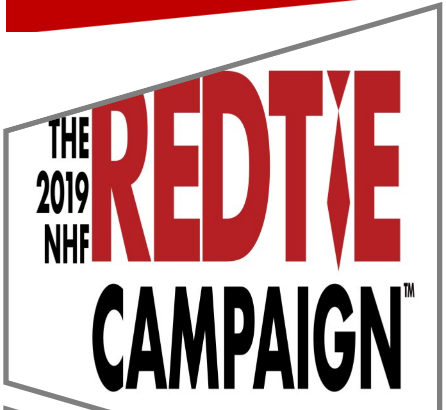
- **Donar:** Nuestro objetivo colectivo es recaudar $ 30,000 en escala nacional durante la Campaña de Red Tie. ¡Si realiza una donación a NHF NV, NHF igualará esa donación hasta $ 750! Da hoy para duplicar tu apoyo a tu comunidad local de trastornos de la coagulación.
- **Compartir:** ¡Sé parte del movimiento! Póngase su corbata roja y comparta por qué el Mes de Concientización sobre los desórdenes de sangre y NHF NV son importantes para usted. Siga #RedTieCampaign en Twitter, Facebook e Instagram, y comparta su historia para crear conciencia dentro de su red personal.
- **Abogacia:** Nos dirigiremos a Washington DC para el evento de los Días de Washington del NHF del 27 al 29 de marzo de 2019. Síganos en las redes sociales mientras abogamos por el acceso a la atención médica.

Para obtener más información sobre la Campaña Red Tie, visite RedTieCampaign.org. Para obtener más información sobre los trastornos de la coagulación y nuestro capítulo, visite hfnv.org.

Sinceramente,

Betsy VanDeusen
Chapter Executive Director

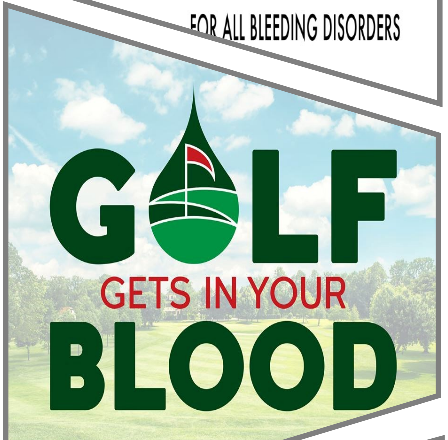
2019 Featured Events



Red Tie Campaign
March 1—April 17th, 2019
www.redtiecampaign.org

This March, during Bleeding Disorders Awareness Month, the Nevada Chapter along with NHF and chapters across the country, will raise funds and awareness to support the bleeding disorders community.

The Nevada Chapter has a goal of raising $3,000 for the red tie campaign. All donations will be matched up to $750! Every little bit helps!



Golf Gets In Your Blood
Monday, April 15, 2019
Red Rock Country Club—Mountain Course

Funds raised from the golf event on the private mountain course at the picturesque Red Rock Country Club will support children with bleeding disorders. With space up to 144 golfers, the event is a one of a kind golfing experience.
Register online at www.hfnv.org

Rest, Relax & Recharge Retreat
Saturday, April 27th—April 28th
Boulder City, NV

Join us for a retreat focused on women's needs in the bleeding disorders community. Whether you are affected or a caregiver, learn about how to take care of yourself during this weekend of rest, relaxation, learning and recharging.

Register at www.hfnv.org

Sponsored by Octapharma, Factor Support Network, Aptevo & HTCNV

May Family Event—Morning Out at Lake Las Vegas
Saturday, May 11th, 2019
Lake Las Vegas

Join the Bleeding Disorders community at Lake Las Vegas for a fun morning out, getting to know other families, taking turns kayaking on the lake and window shopping! Register at www.hfnv.org.

2019 Calendar of Events

March 16	**Spring Fest, Las Vegas**
March 27-29	**Washington Days, Washington DC**
April 13	**Play Group, Las Vegas, NV**
April 15	**Golf Gets In Your Blood, Las Vegas**
April 17	**World Hemophilia Day**
April 27	**Spring Mini Education Day: Focused on Women, Las Vegas**
May 11	**Family Event: Kayaking at Lake Las Vegas**
June 8	**Play Group, Las Vegas, NV**
June 10-15	**Camp Independent Firefly, Big Bear CA**
June 29	**Couples Retreat, Las Vegas**
July 6-10	**Teen Rafting Camp, Sacramento**
July 13	**Play Group, Las Vegas, NV**
July 18	**LIT Training, Reno**
July 19-21	**Northern Nevada Family Camp, Elko**
July 20	**Elko Unite for Bleeding Disorders Walk, Elko**
July 27	**Summer Mini Education Day: Spanish, Las Vegas**
August 3	**Renee Paper Picnic, Las Vegas**
	Teen Leadership Training, Las Vegas, NV
August 9-11	**PEP, Las Vegas**
August 24	**Tahoe Family Education**
September 6-8	**Familia De Sangre, Anaheim, CA**
September 14	**Reno Unite For Bleeding Disorders Walk, Reno**
September 21	**Las Vegas Unite for Bleeding Disorders Walk, Las Vegas**
October 2-5	**National Bleeding Disorders Conference, Anaheim, CA**
October 12	**Play Group, Las Vegas, NV**
October 19	**Product Dinner Round Table, Las Vegas, NV**
November 19	**Play Group, Las Vegas, NV**
November 16	**Bikes In Your Blood, Henderson**
November 20	**Ely Patient Appreciation Dinner/Clinic**
December 7	**Annual Meeting & Holiday Party, Las Vegas**
December 11	**Elko Holiday Party**
December 12	**Reno Holiday Party**
December 19	**Volunteer & Donor Appreciation Reception, Las Vegas**

This is a DRAFT Calendar. Dates & topics subject to change. Please check the Chapter website periodically. To RSVP for an event, please visit www.hfnv.org.

Tips & Tricks for Accessing Problem Veins

It's not always easy, but there are ways to help make bleeding disorder infusions smoother.

No two people's veins are exactly alike. And while nobody enjoys being stuck, some people have relatively little trouble accessing veins to infuse clotting factor, while for others it's a seemingly constant struggle. No matter what type of veins you or your child has, it helps to know these tricks when you find it difficult to access a vein:

Get warm

When the body is warm, blood flow increases, dilating the veins and making them easier to find and stick. Try the following methods to see what works best for you:

- Apply a hot washcloth to the area you plan to infuse for several minutes before the infusion.
- Soak the hand or arm in warm water or run it under the faucet for five minutes.
- Take a hot shower or bath before the infusion.
- Gently massage the area over the chosen site. Do not slap the skin to help raise the vein—you may see it on TV, but it doesn't work.
- Do some short, vigorous exercise, such as push-ups or jumping jacks.

Use gravity

Increase blood flow to your arm and hand by letting gravity do the work.

- Lie on a bed or sofa and let the arm you plan to infuse hang down. Slowly making a fist or squeezing a ball and releasing it over and over will also increase blood flow to the area.
- Swing the arm around several times like a windmill. Centrifugal force ensures blood will enter the arm, dilating the vein, and have a harder time leaving.

Hydrate

When the body is properly hydrated, veins become more dilated. Try to take in extra fluids the day before an infusion. If kids don't want to drink water, a sports drink or juice is fine. Avoid trying to drink a lot of fluid the night before an infusion to make up for a lack of hydration earlier—you're likely to end up with disrupted sleep from having to go to the bathroom a lot overnight.

Relax

Sure, it's easier said than done when you're about to stick a needle in your vein, but tension can further constrict veins, making infusion even more difficult. Put on some relaxing music, breathe in and out calmly and don't be hard on yourself if you have difficulty—you can do this.

Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

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

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

What is HEMLIBRA?

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

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048
HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised : 10/2018

Community Spotlight: The Coutts Family

Meet Jamie & Kyle.

What is your family's diagnosis story?

When Connor was 14 months old, he got a cold and we took him into the pediatrician to have him checked out. He got his ears cleaned and later that day, we noticed he had blood coming out of his ear. We had no idea why. We took him to the ER and the ER referred us to see the ENT. At 2 years old, another cold, another ear cleaning and another ear bleed. When we went in for a check-up, our head doctor asked if he bled at his circumcision. We said yes, and she ran a blood test on him. The results came back as a factor 8 deficiency, and we were referred to a hematologist, which was Amber. He was diagnosed with Hemophilia A at 2 years old. We have learned SO much in so little time! After more tests, we've learned that I am a carrier for hemophilia and myself and my 3-year-old daughter have mild hemophilia A.

How did the diagnosis impact you & your family's everyday life?

At first, Connor received treatment only when needed as we had Amicar on hand. At 4 years old, we decided it would be best for Connor to receive weekly treatment as he is an active little boy in Pre-k. After receiving 5 weeks of training to learn the infusion process, I am now able to give my brave little boy weekly infusions in the comfort of our own home. I can honestly say that he does very well with these infusions and doesn't cry which makes me a very proud parent as he is only 5 years old. He likes to help mommy get all the supplies ready and open everything up.

This has affected our lives in countless ways and one way in particular that has given us the most stress in going down to a one-person income. Before Connor was diagnosed, I was able to work and help my family financially. My husband and I were working to pay off some debt and save up for a house and a more reliable car. Since Medicaid and insurance have such strict polices; I had to become a stay at home mom in order for Connor to receive the required medicine and treatment to live a somewhat normal life.

Now you may ask yourself if we are able to survive on one income and the answer is yes, to an extent. We are grateful to have a roof over our heads, food in our refrigerator and are generally in good health, but I would be lying if I said that our life was perfect. There are absolutely some hard days and nights that we go through. Being on one income has made it extremely difficult to envision now what we were planning on having some years ago such as our own home.

What advice would you give to someone newly diagnosed with a bleeding disorder?

My advice for parents and children who just found out about their bleeding disorder is to honestly take it one day at a time. The support system surrounding bleeding disorders is INCREDIBLE. There are support groups on social media that I have joined, and they have so much advice. It is so hard learning about your child having a chronic disease. You, as a parent, just want to take all the pain of infusions away and make it all better. It does get better with time and easier to manage. Learn all that you can, and never stop! ADVOCATE! My family recently went to Carson City, NV to advocate for bleeding disorders and meeting with the Senators and District Assembly Members, is something I will NEVER forget. They listened to our stories and understood what we wanted. We are also going to be attending the National Hemophilia Washington days in DC, and we cannot wait to advocate there! Make your voice heard!

"Learn all that you can, and never stop! ADVOCATE! Make your voice heard!"

2019 Winter Wine Fest

2019 Winter Wine Fest

Our 4th annual Winter Wine Fest was held on Friday, February 8, 2019 at Brio Tuscan Grille in Tivoli Village. The annual wine tasting and silent auction raises funds for the Nevada bleeding disorders community. 100% of the proceeds stay in Nevada and support our programs and services improving the quality of life and care of families living with bleeding disorders.

Over 170 people attended the event, enjoyed delicious wine and pasta, a Spin the Bottle Wine Pull, and bid on dozens of exciting auction prizes, including a Vegas Golden Knights luxury suite, a Lake Tahoe townhouse rental, a Coyote Springs foursome, and show tickets to Cirque de Soleil, Absinthe, Opium, and more!

Total amount raised: $20,400

These funds could send 35 kids to camp
or provide 60 families with financial assistance!

Special thank you to event chair Kelly Gonzalez, our board, and our generous sponsors and volunteers.

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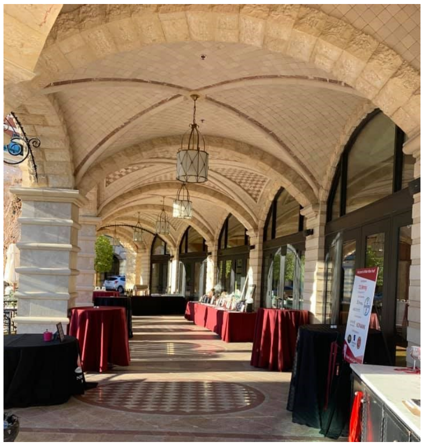


Not actual patients.

EXPERIENCE MATTERS

BeneFIX: The only recombinant factor IX supporting individuals with hemophilia for more than 20 years.*

More than 20 years* of experience—you've been at the heart of all we do

- The first recombinant treatment indicated for bleed control and prevention in individuals with hemophilia B
- Designed with viral safety in mind
- More than 150 quality control tests are done on each batch of BeneFIX
- The flexibility to infuse on demand or preventively based on your physical activity
- The convenience of the BeneFIX Rapid Reconstitution (R2) Kit with a range of vial sizes

What Is BeneFIX?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

Visit BeneFIX.com to learn more

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash or hives.
- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

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 the Brief Summary for BeneFIX on the next page.

PP-BEN-USA-0340-01

Printed in USA/September 2018

BeneFix®
Coagulation Factor IX (Recombinant)
Room Temperature Storage

R_x only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing
difficulty breathing
chest tightness
turning blue
(look at lips and gums)
fast heartbeat
swelling of the face
faintness
rash
hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE BeneFix. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

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

If you would like more information, talk to your doctor. You can ask your doctor for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-10.0, revised June 2017.

PP-BEN-USA-0338

Printed in USA/August 2018

Pfizer

Program Recap: Winter Events

January 12, 2019
January Play Group, Las Vegas, NV

12 community members came together to play at the Bill Briare Park. The monthly play groups are a chance for families with kids age 0-7 to get together, connect with other parents and help the kids get to know their peers in the bleeding disorders community.

January 26, 2019
Advocacy Boot Camp, Las Vegas, NV

27 community members attended a half day program to learn about advocacy. The training included sessions on crafting a persuasive story, understanding the legislative process, current legislative issues and a kids session all about self efficacy.

Sponsored by Shire, Sanofi, and CSL Behring

February 9, 2019
Bowling For Bleeders—Family Event, Las Vegas, NV

41 community members came together for a fun family event at the Orleans Bowling Center. Families got a chance to get to know each other, children had a chance to connect with their peers and show off their bowling skills! Quarterly family events are an opportunity to build a sense of community and peer connections through fun, networking focused, family events.

Sponsored by Quality Home Infusion, Bayer and HTCNV

February 17-18, 2019
Carson City Advocacy Day, Carson City, NV

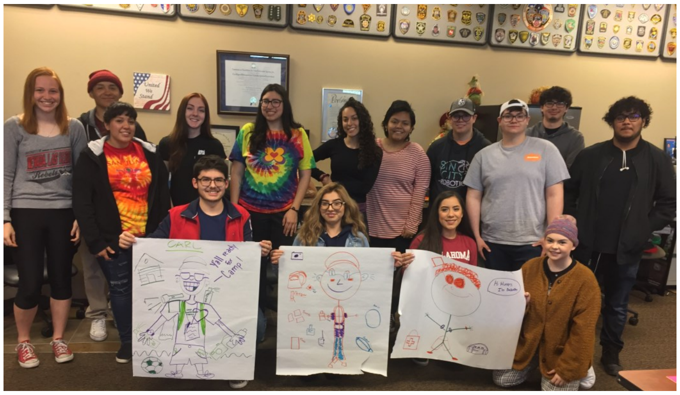
35 individuals from across Nevada came together to advocate for access to healthcare for the Nevada bleeding disorders community, Participants attended an extensive training on Sunday evening, collectively made 30 meetings with legislatures and attended the Senate proclamation declaring March as Bleeding Disorders month.

March 2, 2019
Junior Counselor Training, Las Vegas, NV

14 young adults attended the intensive all-day session teaching skills on communication, leadership, team work and the nuts and bolts of transition from a camper to a counselor.

Bowling For Bleeders Family Event, February 9, 2019

Carson City Advocacy Training, February 17, 2019



Junior Counselor Training, March 2, 2019

5 aspectos fundamentales sobre la infusión casera para tratar el trastorno hemorrágico

5 aspectos fundamentales sobre la infusión casera para tratar el trastorno hemorrágico
Repase los aspectos básicos para estar seguro
Tratar un trastorno hemorrágico en casa a través de autoinfusiones es práctico, seguro y efectivo si presta mucha atención al correcto almacenamiento de los productos de factor y desecha correctamente artículos como agujas y jeringas.

Siga los siguientes aspectos básicos de la terapia en casa para asegurarse de que su rutina sea segura y confiable

1. Mantenga un registro del factor y de los suministros
Conocer la cantidad de factor y suministros para la infusión que tiene a la mano le garantizará saber cuándo necesita ordenar más, sin preocuparse de que se le agoten. Cada vez que llegue un envío de factor, verifique su contenido y asegúrese de que el orden sea el correcto y que no haya nada roto o que falte algo. Escriba la fecha de vencimiento del nuevo suministro de factor en su registro de infusiones.

2. Almacene el factor correctamente
Si el factor se almacena incorrectamente o se encuentra vencido puede no tratar ni evitar las hemorragias como se espera. Para garantizar que el factor pueda hacer su trabajo correctamente, siga todas las instrucciones de almacenamiento que se incluyen en sus medicinas. (cada medicamento puede tener instrucciones ligeramente diferentes). Si tiene dudas, llame a su centro para el tratamiento de hemofilia (Hemophilia Treatment Center, HTC) o al número gratuito de ayuda al paciente del fabricante de su factor, el cual se encuentra en el material impreso que viene con el factor. La mayoría de los productos de factor se conservan estables a temperatura ambiente por un tiempo limitado, por lo que normalmente el factor requiere refrigeración. El método más seguro es almacenar el factor en un refrigerador específicamente destinado para ello. Si no es posible hacerlo, coloque el medicamento en un recipiente cubierto o en una bolsa de plástico que pueda sellar y guárdelo en el centro del refrigerador (no lo ponga en la puerta). Mantenga la etiqueta del factor y las instrucciones en la bolsa o en el recipiente junto a la medicina para que siempre esté a la mano.

Recuerde: Una vez retire el factor del refrigerador y lo deje a temperatura ambiente para hacerse la infusión, no podrá volver a guardarlo en la nevera. Planifique sus infusiones de tal forma que el factor se use cuando esté listo.

3. Siga las precauciones de seguridad
Para evitar infecciones, mantenga limpia el área donde se va a realizar la infusión. Lávese las manos y los brazos usando agua tibia y jabón o algún limpiador a base de alcohol antes de comenzar la infusión. Use guantes durante todo el procedimiento de infusión y también al desechar los suministros después de la infusión.

4. Deseche de manera segura los suministros
Si almacena correctamente el factor, no tendrá que desecharlo. Si su factor está dañado o vencido, contacte a su farmacia local para saber cómo desecharlo correctamente (las leyes para desechar medicamentos varían de acuerdo con cada estado y comunidad).

Al terminar la infusión, ponga los suministros (el factor vacío y las ampollas con diluyente, la jeringa, los tubos y la aguja de la vía intravenosa) en un recipiente exclusivo para objetos afilados. Cuando el recipiente esté lleno, confirme con la agencia de recolección de desechos de su comunidad la manera de desecharlo correctamente.

5. Al viajar…
El factor no debe estar expuesto a cambios de temperatura extremos por lo que, generalmente, la mejor manera de garantizar que esté seguro es guardándolo en un bolso térmico con compresas frías para mantenerlo refrigerado. Al viajar en avión, el factor y los suministros de la infusión deben ir siempre en su equipaje de mano en lugar de su equipaje registrado. Verifique con su hematólogo o con el personal de su HTC cuál es la mejor manera de almacenar correctamente sus productos de factor para su transporte durante el viaje.

YOUNG HOPE SOCIETY
NATIONAL HEMOPHILIA FOUNDATION

The Young Hope Society is a young professionals group that was created to inspire the next generation of young philanthropic supporting the bleeding disorders community. The Young Hope Society recognizes individuals between the ages of 21-40 who make annual gifts of at least $5 a month. With the annual commitment, members play a critical role in fueling the mission of NHF and supporting the bleeding disorders community. Through the Young Hope Society, you also have the opportunity to build a young professional network in your area with national networking opportunities!

Join Today at https://www.hemophilia.org/How-You-Can-Help/Join-the-Young-Hope-Society

THE EXTENDED-HALF-LIFE rFVIII WITH PROVEN PROTECTION AND UNIQUE STEP-WISE DOSING[1,2]

For patients ≥12 years

Start simply	TWICE **WEEKLY**	**For all prophylaxis patients:** Recommended starting regimen is Jivi **twice weekly** (30-40 IU/kg)[1]
Step up	EVERY **5 DAYS**	**Based on bleeding episodes:** Less frequent dosing of Jivi **every 5 days** (45-60 IU/kg) can be used[1]
Fine tune	⇅	**Based on bleeding episodes:** The dosing frequency may be further **adjusted up or down**[1]

IU, international units; kg, kilograms; rFVIII, recombinant Factor VIII.

INDICATIONS

- Jivi is an injectable medicine used to replace clotting factor (Factor VIII or antihemophilic factor) that is missing in people with hemophilia A.
- Jivi is used to treat and control bleeding in previously treated adults and adolescents (12 years of age and older) with hemophilia A. Your healthcare provider may also give you Jivi when you have surgery. Jivi can reduce the number of bleeding episodes in adults and adolescents with hemophilia A when used regularly (prophylaxis).
- Jivi is not for use in children below 12 years of age or in previously untreated patients.
- Jivi is not used to treat von Willebrand disease.

IMPORTANT SAFETY INFORMATION

- You should not use Jivi if you are allergic to rodents (like mice and hamsters) or to any ingredients in Jivi.
- Tell your healthcare provider about all of your medical conditions that you have or had.
- Tell your healthcare provider if you have been told that you have inhibitors to Factor VIII.
- Allergic reactions may occur with Jivi. Call your healthcare provider right away and stop treatment if you get tightness of the chest or throat, dizziness, decrease in blood pressure, or nausea.
- Allergic reactions to polyethylene glycol (PEG), a component of Jivi, are possible.
- Your body can also make antibodies, called “inhibitors,” against Jivi, which may stop Jivi from working properly. Consult your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

Ask your doctor if Jivi® may be right for you. Learn more at www.jivi.com.

IMPORTANT SAFETY INFORMATION (CONT'D)

- If your bleeding is not being controlled with your usual dose of Jivi, consult your doctor immediately. You may have developed Factor VIII inhibitors or antibodies to PEG and your doctor may carry out tests to confirm this.
- The common side effects of Jivi are headache, cough, nausea, and fever.
- These are not all the possible side effects with Jivi. Tell your healthcare provider about any side effect that bothers you or that does not go away.

For additional important risk and use information, please see the Brief Summary on the following page.

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

References: 1. Jivi® Prescribing Information. Whippany, NJ: Bayer LLC; 2018.
2. Data on file. Tx Review 0918. Bayer; 2018.

Jivi®
antihemophilic factor
(recombinant) PEGylated-aucl
LET'S GO

HIGHLIGHTS OF
FDA-Approved Patient Labeling

Patient Information

Jivi (*JIHV-ee*)
antihemophilic factor (recombinant), PEGylated-aucl

This leaflet summarizes important information about Jivi with vial adapter. 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 Jivi. If you have any questions after reading this, ask your healthcare provider.

Do not attempt to self-infuse, unless your healthcare provider or hemophilia center has taught you how to self-infuse.

What is Jivi?

Jivi is an injectable medicine used to replace clotting factor (Factor VIII or antihemophilic factor) that is missing in people with hemophilia A (congenital Factor VIII deficiency).

Jivi is used to treat and control bleeding in previously treated adults and adolescents (12 years of age and older) with hemophilia A. Your healthcare provider may also give you Jivi when you have surgery. Jivi can reduce the number of bleeding episodes in adults and adolescents with hemophilia A when used regularly (prophylaxis).

Jivi is not for use in children < 12 years of age or in previously untreated patients.

Jivi is not used to treat von Willebrand disease.

Who should not use Jivi?

You should not use Jivi if you

- are allergic to rodents (like mice and hamsters).
- are allergic to any ingredients in Jivi.

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

Tell your healthcare provider about:

- All of your medical conditions that you have or had.
- All of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.
- Pregnancy or planning to become pregnant. It is not known if Jivi may harm your unborn baby.
- Breastfeeding. It is not known if Jivi passes into the milk.
- Whether you have been told that you have inhibitors to Factor VIII.

What are the possible side effects of Jivi?

The common side effects of Jivi are headache, cough, nausea and fever.

Allergic reactions may occur with Jivi. Call your healthcare provider right away and stop treatment if you get tightness of the chest or throat, dizziness, decrease in blood pressure, or nausea. Allergic reactions to polyethylene glycol (PEG), a component of Jivi, are possible.

Your body can also make antibodies, called "inhibitors", against Jivi, which may stop Jivi 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.

If your bleeding is not being controlled with your usual dose of Jivi, consult your doctor immediately. You may have developed Factor VIII inhibitors or antibodies to PEG and your doctor may carry out tests to confirm this.

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

Tell your healthcare provider about any side effect that bothers you or that does not go away.

How do I store Jivi?

Do not freeze Jivi.

Store Jivi at +2°C to +8°C (36°F to 46°F) for up to 24 months from the date of manufacture. Within this period, Jivi may be stored for a period of up to 6 months at temperatures up to +25°C or 77°F.

Record the starting date of room temperature storage clearly on the unopened product carton. Once stored at room temperature, do not return the product to the refrigerator. The product then expires after storage at room temperature for 6 months, or after the expiration date on the product vial, whichever is earlier. Store vials in their original carton and protect them from extreme exposure to light.

Administer reconstituted Jivi as soon as possible. If not, store at room temperature for no longer than 3 hours.

Throw away any unused Jivi after the expiration date.

Do not use reconstituted Jivi if it is not clear.

What else should I know about Jivi and hemophilia A?

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

This leaflet summarizes the most important information about Jivi that was written for healthcare professionals.

Resources at Bayer available to the patient:

For Adverse Reaction Reporting, contact Bayer Medical Communications 1-888-84-BAYER (1-888-842-2937)

To receive more product information, contact Jivi Customer Service 1-888-606-3780

Bayer Reimbursement HELPline 1-800-288-8374

For more information, visit http://www.Jivi.com

Bayer HealthCare LLC
Whippany, NJ 07981 USA
U.S. License No. 0008

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In The Numbers

2018 Year In Review

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

NHF NV EVENTS

2018

Our fundraising events provide the necessary funds for us to fulfill our mission of improving the lives of all Nevadans with bleeding disorders.

WINTER WINE FEST

130 attendees
$18,454 raised
14 volunteers

GOLF GETS IN YOUR BLOOD

105 participants
$34,479 raised
17 volunteers

UNITE WALK LAS VEGAS

421 participants
$54,900 raised
31 volunteers

UNITE WALK RENO

102 participants
$10,236 raised
9 volunteers

BIKES IN YOUR BLOOD

60 participants
$14,000 raised
12 volunteers

social media 2018

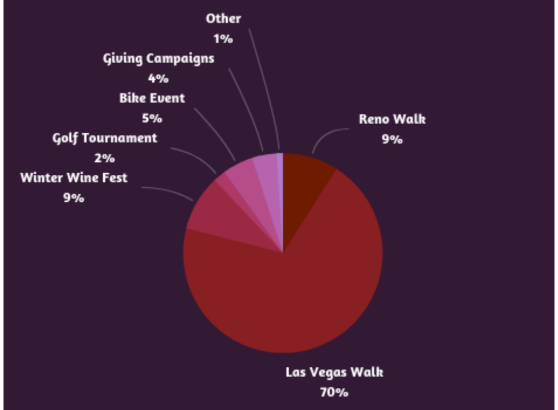
WWW.FACEBOOK.COM/NHFNV
100 PAGE LIKES
159 POSTS
2,891 LIKES, COMMENTS, SHARES

TWITTER: @NEVADANHF
231 LIKES
80 RETWEETS
119 LINK CLICKS
4 REPLIES

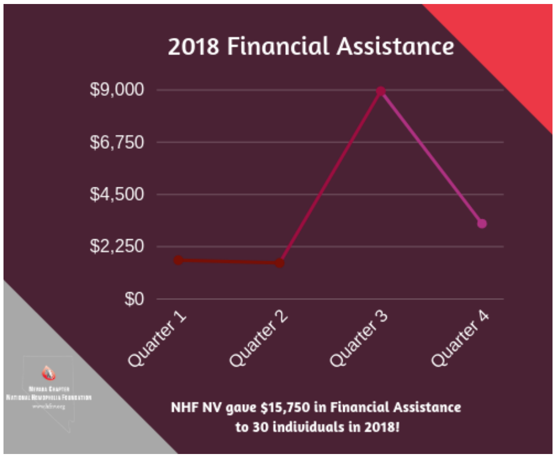
Instagram
@NEVADANHF
41 POSTS
735 LIKES
24 COMMENTS

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

2018 Donors



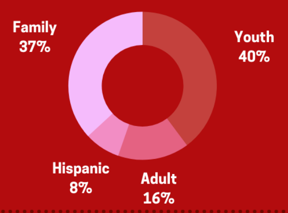
NHF NV had a total of 663 individual donors in 2018!



NHF NV gave $15,750 in Financial Assistance to 30 individuals in 2018!

NHF Nevada Program Hours 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

Our family programs include education dinners, education fests in the Spring and Fall, and our Annual Meeting & Holiday celebration.

YOUTH PROGRAMS

This includes our Teen Leadership Program, Camp Independent Firefly, and our New Family Playgroup.

ADULT PROGRAMS

Includes our Men's, Women's, and Couple's Retreats.

HISPANIC PROGRAMS

We offered a Hispanic Education Day and 2 Spanish Education Dinners.

147 PROGRAM HOURS
1124 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.

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

**ACT—Access to Care Today
Achieve a CURE Tomorrow**

NON-PROFIT ORG.
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LAS VEGAS, NV
PERMIT NO. 447

Golf Gets in Your Blood

Monday, April 15, 2019
Mountain Course at Red Rock Country Club
Registration | 8 AM   Shotgun Start | 9:30 AM

Register by March 29th. Sign-Up Online at www.hfnv.org. Support NHFNV.