



**NEVADA CHAPTER**  
**NATIONAL HEMOPHILIA FOUNDATION**  
www.hfnv.org

# Staying Connected in Challenging Times

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NEVADA'S ONLY FEDERALLY-DESIGNATED BLEEDING & CLOTTING TREATMENT CENTER FOR CHILDREN & ADULTS.



## Come see us at our new Las Vegas location!

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[www.HTCNV.org](http://www.HTCNV.org)

Services provided:

- Diagnostic testing & screening
- 340B Pharmacy Services
- Physical therapy
- Social work & case management
- Dental assistance
- Patient assistance

**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

222 S. Rainbow Blvd. Suite 203, Las Vegas, NV 89145 | Phone: 702-564-4368 | Fax: 702-446-8134 | www.hfnv.org

**Our Team**



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**Board of Directors**

**Officers**

President: Kim Luong Velasquez  
Vice President: Renee Cotrel Duran  
Treasurer: Miriam Calderon  
Secretary: Stephanie Hrisca- Kennedy

**Directors**

Steve Findlay  
Carlos Reyes

**CALENDAR OF EVENTS**

**BLUE = Online Format**

**BLACK = Continuing as Scheduled**

4/2 **Happy Hour: Quarantine Moming**  
4/9 **Happy Hour: Familia De Sangre**  
4/16 **Happy Hour: Teen Time**  
4/16 **Online Education**  
4/17 **World Hemophilia Day, LV**  
  
5/13 **Online Education**  
5/21 **Ladies Night Out, LV**  
  
6/8-13 **Camp Independent Firefly, CA**  
6/27-28 **Couple's Retreat, LV**  
  
7/11 **Latinos Unidos Luncheon, LV**  
7/11-15 **Teen Camp, CA**  
7/24 **Leaders In Training, Elko**  
7/24-25 **NNV Family Conference, Elko**  
7/25 **Elko Unite For Bleeding Disorders Walk**

8/1 **Renee Paper Picnic, LV**  
8/5-8 **Nat'l Bleeding Disorders Conference, Atlanta**  
  
8/20 **Mother/Daughter Night Out, LV**  
8/22 **Tahoe Family Day, Tahoe**  
8/29 **Bayer Dinner, LV**  
  
9/12 **Reno Unite For Bleeding Disorders Walk**  
9/18-20 **Familia De Sangre, CA**  
9/26 **Las Vegas Unite For Bleeding Disorders Walk**  
  
10/5 **Education Dinner, Elko**  
10/29 **Trunk or Treat, LV**  
  
11/7 **Father/Son Night Out, LV**  
11/11 **Ely Holiday Event, Ely**  
11/21 **Bikes In Your Blood, Henderson**  
  
12/5 **Annual Meeting, LV**  
12/9 **Elko Holiday Event, Elko**  
12/10 **Reno Holiday Event, Reno**

**IMPORTANT DEADLINES**

4/15 **Teen Camp Applications Due**  
5/30 **Travel Grant Requests for National Bleeding Disorders Conference Due**  
6/30 **Travel Grant Requests for Familia De Sangre Due**

*This is a DRAFT Calendar. Dates & topics subject to change. Please check the Chapter website and request an updated calendar periodically.*

## Letter from Our Executive Director / Mensaje de nuestra Directora Ejecutiva

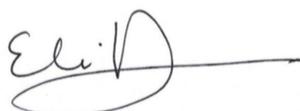
Dear Friends,

A sense of connection is hard to come by these days. As we all Stay Home for Nevada and make drastic changes in our routines to protect the lives of those around us, it is harder than ever to feel connected.

The strength of the bleeding disorders community lies in our deep sense of connection and belonging and our fierce support for one another. I challenge you to find new ways to connect. A phone call, video chat, online program, or even a text can help reduce isolation and could be the thing that keeps a friend afloat.

We know the future is uncertain for many of you. You may be facing loss of a job, loss of insurance or reeling from the loss of a loved one. The Nevada Chapter is here for you – even though we can't be in person, we are still here to help you get through this.

Sincerely,



Chapter Executive Director

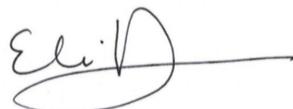
Queridos amigos,

Es difícil llegar a un sentido de conexión en estos días. Como todos nos quedamos en casa para Nevada y hacemos cambios drásticos en nuestras rutinas para proteger las vidas de los que nos rodean, es más difícil que nunca sentirnos conectados.

La fuerza de la comunidad de trastornos de sangre radica en nuestro profundo sentido de conexión y pertenencia, y en nuestro feroz apoyo mutuo. Te ánimo y te desafío a que encuentres nuevas formas de conectarte. Una llamada telefónica, un chat de video, un programa en línea o incluso un mensaje de texto pueden ayudar a reducir el aislamiento y podrían ser lo que mantiene a un amigo a flote.

Sabemos que el futuro es incierto para muchos de ustedes. Puede estar enfrentando la pérdida de un trabajo, la pérdida del seguro médico o la recuperación de la pérdida de un ser querido. El Capítulo de Nevada está aquí para usted, aunque no podemos estar en persona, todavía estamos aquí para ayudarlo a superar esto.

Sinceramente,



Betsy VanDeusen  
Chapter Executive Director



### Meet The Board: Stephanie Hrisca-Kennedy

- Nevada Chapter Board Member Since December 2019
- Board Secretary
- Advocacy Committee

Stephanie is excited to join the board after becoming involved with the chapter after her son's surprised diagnosis with hemophilia A. With no family history, they didn't know where to turn and found the foundation online. After attending Spring Fest for the first time their hope was renewed after seeing other smiling families.

Stephanie is eager to give back to the community that is so important to herself and her family. Stephanie's drive and ambition led to her completing two Masters Degrees in just 18 months and she is looking forward to advocating with the same ferocity for the bleeding disorder community.

## Program Recap: Spring Events

### January 16: Hispanic Leadership Council

We held our first ever Hispanic Community Leadership council meeting where 8 of our community members sharing ideas on how we can be more inclusive with the Hispanic community and how they can be more involved in our chapter.

Sponsored by Takeda

### January 17: Teen Council Meeting, Las Vegas, NV

While building paracord bracelets 8 teen council members discussed the type of events they would like to have throughout the year including a painting workshop and volunteering.



### January 18: Genentech Product Dinner:

10 attendees joined us at Brio Tuscan Grille for a very informative and interactive talk about Hemlibra. Nurse educator and Hemlibra trial member led an educational talk and had participants share stories.

### February 19: Genentech Education Dinner

42 Northern Nevada community members attended this very educational and interactive program on The Science of Optimism presented by Genentech.



### February 20: Ladies Night Out

Our first Ladies Night out of 2020 was a success, 14 incredible women enjoyed some mocktail mojitos, crafting and connecting while having a casual conversation on selfcare.

Sponsored by Octapharma

### February 22: Bowling For Bleeders

STRIKE! Our 2<sup>nd</sup> annual family bowling evening was a success! We had 50 attendees enjoy 2 hours of bowling and pizza at the South Point Casino!



**“The most rewarding part of being in the board has been giving back to a community so important to my family. I have enjoyed helping support other families and advocating for our community.”**

Last year Stephanie attended the State Advocacy Day in Carson City. She and her husband shared their story about barriers they've faced getting Grayson's medication. This year Stephanie and Grayson attended Washington Days. They joined over 400 community members and advocates from across the country in advocating for access to health care and funding for Hemophilia Treatment Centers by meeting with legislatures and members of their office.

Originally from Michigan, Stephanie relocated to Las Vegas her junior year of high school. She is a former high school special education teacher but has taken time off to stay home with her two sons, Grayson (3) and Maddox (1). Stephanie enjoys spending time with her amazing husband, crafting, reading and traveling.

To read Stephanie's full Bio and get to know all of our board members visit <https://hfnv.org/who-we-are/staff.html>

# THE EXTENDED-HALF-LIFE rFVIII WITH PROVEN PROTECTION AND UNIQUE STEP-WISE DOSING<sup>1,2</sup>

For patients  $\geq 12$  years

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

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.



**FEEL EMPOWERED**  
to step up to the challenge  
with Jivi®

Ask your doctor if Jivi® may be right for you. Learn more at [www.jivi.com](http://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](http://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.

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antihemophilic factor  
(recombinant) PEGylated-aucI  
**LET'S GO**

**HIGHLIGHTS OF  
FDA-Approved Patient Labeling  
Patient Information  
Jivi (*J1HV-ee*)  
antihemophilic factor (recombinant), PEGylated-auc1**

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>

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# Winter Wine Fest



## Winter Wine Fest raises \$31,000!

Over 170 attendees came together during a beautiful night on Brio's Tuscan Grille's Patio to raise money for bleeding disorders! Guests enjoyed a two hour wine tasting and Italian tapas while bidding on silent auctions items all to benefit our youth programs!



Thank you to our sponsors, committee, donors, board members & volunteers who made Winter Wine Fest a big success!

### Winter Wine Fest funds raised could:

- Send 42 kids to Camp Independent Firefly
- Provide 62 families with financial assistance when they need it most
- Provide a year of educational programming, peer support, and skill development to 155 individuals affected by bleeding disorders



### Thank you to our Sponsors:

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*We're Listening*



At Pfizer Hemophilia, we have always been deeply committed to you and to listening to what you have to say. Over the years, what you've shared with us has proven invaluable. The events we sponsor, the technology we develop, and the educational materials we create are all designed in response to the requests, needs, and desires of the hemophilia community.

**We are grateful for having the chance to partner with you.**

—Your Pfizer Hemophilia Team

# Managing the Transition From Childhood to Adolescence

## Guiding Preteens With Hemophilia



For more information, visit [b2byourvoice.com](http://b2byourvoice.com) to download *Navigating The Preteen Years*.

This content is brought to you by Pfizer.

Parents of a preteen with hemophilia may have concerns about preparing a child for life with a chronic condition. During the preteen years, children spend time away from family, attend school, and experience additional social influences. This is when children begin to form their own ideas and opinions. Preteens may be exposed to peer pressure to engage in risky behavior and/or forego treatment, making open communication essential.

Preteens are building life experience and taking steps toward independence, and it is important that parents set limits. Preteens may not handle their impulses and desires maturely.<sup>1</sup> Guiding a child to make the right choices can help prepare him or her for the future and the many similar decisions he or she will make. Parents should find a balance between giving a child space to grow and setting boundaries.<sup>1</sup>

Adolescence lasts longer today than in the past; children begin puberty earlier and leave home later. This gives parents and children more time to learn how to negotiate the transition to independence.<sup>2</sup>

### Proactivity is Crucial

Dr. Thomas Truncale ranks proactivity as the most important factor when managing hemophilia. Anticipating needs and putting together a plan ahead of time can have benefits when treating hemophilia, addressing parenting issues, and in seeking education.

Proactively educating children about hemophilia can improve their ability one day to begin managing their own medical care. At a young age, children can gather infusion supplies or even decide on the infusion site. This involvement can help prepare them for self-infusing. Dr. Truncale recommends that families attend summer camps where older children mentor younger children.

“Encourage your child to focus on what he or she can do, not what they can’t do.”

— Thomas Truncale  
DO, MPH

Education helps children living with hemophilia learn to make the right decisions. If a bleed occurs, proper education may help the child identify it as soon as possible so it can be treated early.

Dr. Truncale adds that proactivity should extend to school, church, and community. Create a package of educational information for the school nurse, teachers, church personnel, babysitters, and other families. Ask the hemophilia care team for materials available for this purpose, and don't forget to add relevant personal contact information.

**Reference:** 1. Cassis FRMY. *Psychosocial Care for People With Hemophilia*. Montréal, Québec: World Federation of Hemophilia; 2007. 2. Irish Haemophilia Society. Transition. <https://haemophilia.ie/living-with-haemophilia/parents-of-children-with-bleeding-disorders/the-bridge-of-transition-for-adolescents-with-bleeding-disorders/>. Accessed September 17, 2019.



Patient Affairs Liaisons are Pfizer employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to [hemophiliavillage.com/support/patient-affairs-liaison-finder](http://hemophiliavillage.com/support/patient-affairs-liaison-finder) or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).



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**What is HEMLIBRA?**

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

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

**HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). 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.**

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



**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

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For more information, go to [www.HEMLIBRA.com](http://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



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## COVID-19 Resources

### **Nevada Services & Resources:** <https://hfnv.org/news-events/covid-19-updates.html>

The Nevada Chapter of the National Hemophilia Foundation is compiling information for families in need during the corona virus outbreak and state closures. The page is updated regularly as new information and resources become available. Visit this page for information on:

- Applying for insurance on the state health exchange
- Where to access food
- How to file for unemployment in Nevada
- Utility payment plans
- At home activities

### **National News on Bleeding Disorders:** <https://www.hemophilia.org/Featured-News>

The National Hemophilia Foundation is providing a steady stream of information, articles and updates on topics relevant to the bleeding disorders community. Their news stream regularly has articles such as:

- How to stay healthy during the COVID-10 pandemic
- Insurance Coverage Concerns
- Updates on Product availability

### **Nevada Chapter Financial Assistance:** <https://hfnv.org/support-resources/financial-assistance/>

Nevada households containing a resident with a diagnosed bleeding disorder are eligible to receive up to \$500 per rolling calendar year to help cover essential household expenses and medical bills. Please visit the website for the full policy and eligibility requirements.

## Recursos COVID-19

### **Servicios y recursos de Nevada:** <https://hfnv.org/news-events/covid-19-updates.html>

El Capítulo de Nevada de la Fundación Nacional de Hemofilia está recopilando información para las familias necesitadas durante el brote del virus de la corona y los cierres estatales. La página se actualiza regularmente a medida que hay nueva información y recursos disponibles. Visite esta página para obtener información sobre:

- Solicitud de seguro en el intercambio de salud estatal.
- Dónde acceder a la comida
- Cómo solicitar el desempleo en Nevada
- Planes de pago de servicios públicos
- Actividades en el hogar

### **Noticias nacionales sobre trastornos de sangre:** <https://www.hemophilia.org/Featured-News>

La Fundación Nacional de Hemofilia está proporcionando un flujo constante de información, artículos y actualizaciones sobre temas relevantes para la comunidad de trastornos de sangre. Su flujo de noticias regularmente tiene artículos como:

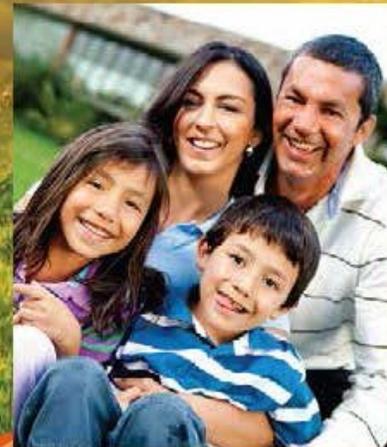
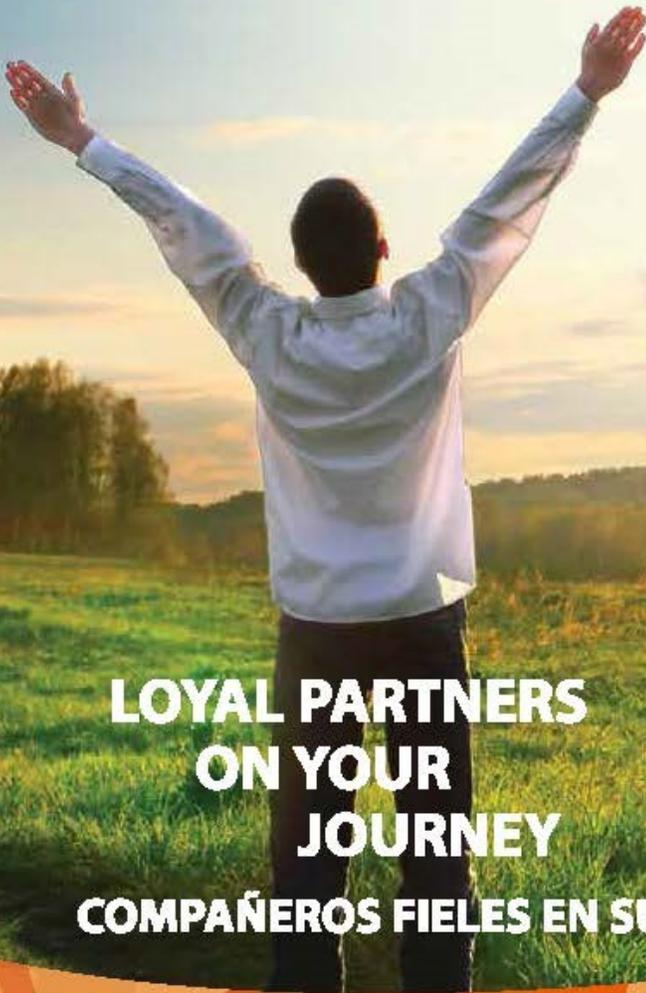
- Cómo mantenerse saludable durante la pandemia de COVID-19
- Preocupaciones de cobertura de seguro
- Actualizaciones sobre disponibilidad de producto

### **Asistencia financiera del Capítulo de Nevada:** <https://hfnv.org/support-resources/financial-assistance/>

Los hogares de Nevada que contienen un residente con un trastorno de sangre diagnosticado son elegibles para recibir hasta \$500 por año calendario móvil para ayudar a cubrir los gastos esenciales del hogar y las facturas médicas. Visite el sitio web para conocer la política completa y los requisitos de elegibilidad.

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based on 2017 patient satisfaction survey  
Datos de la Encuesta de Satisfacción



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# RED TIE CAMPAIGN

FOR ALL BLEEDING DISORDERS

## Existing. Not Pre-Existing

More than 3 million Americans are living with a bleeding disorder, that if left untreated, can be fatal. Access to health care is vital. Advocacy efforts protect the lives of children and families suffering from bleeding disorders.

### 3 Ways to Help during the Red Tie Campaign

**DONATE:** Your generous gift to the 2020 Red Tie Campaign will help those living with bleeding disorders by funding NHFNV's education, peer support and advocacy programs.

**Donate today at <https://hfnv.org/get-involved/red-tie-giving.html>**

**SHARE:** Show support for the bleeding disorders community by taking the Red Tie Challenge. Post a photo of yourself, your family, even your pet wearing their Red Best to tell the world you stand with the bleeding disorders community. Be sure to tag your post with **#RedTieCampaignNV**.

**ADVOCATE:** NHFNV had 12 volunteer advocates meet with all 6 Nevada legislators on Capital Hill in Washington, DC in February. They spoke about the importance of comprehensive health care to Nevada's bleeding disorder community. Help us continue our efforts - become an advocacy ambassador.

**Learn about becoming an advocacy ambassador at <https://hfnv.org/what-we-do/advocacy/red-tie-campaign.html>**