Nevada Chapter Newsletter
Spring 2018

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.hfnv.org

March is Bleeding Disorders Awareness Month. See what you can do to spread the word!
Pg 17

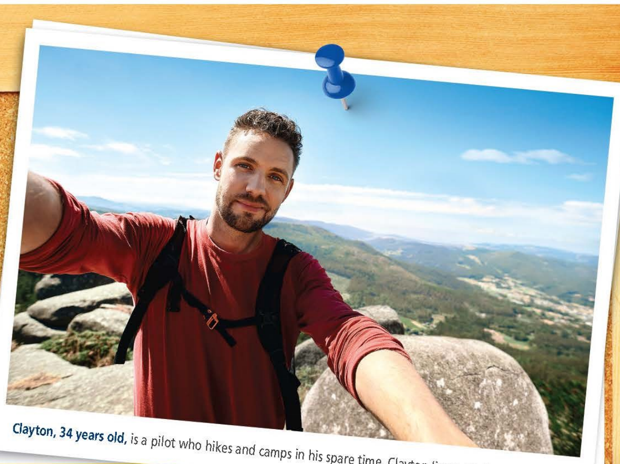
Congratulations to our social media contest winner! Check-out upcoming contests.
Pg 11

Thank you for a successful Winter Wine Fest
Pg 16

Hemophilia News & Views

In hemophilia B

TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®



Clayton, 34 years old, is a pilot who hikes and camps in his spare time. Clayton lives with hemophilia B.

NOW AVAILABLE

Rebinyn® elevates factor levels above normal levels[a]

+94% **Factor IX (FIX) levels achieved** immediately after an infusion[b]

17% **FIX levels sustained** after 7 days[a]

With a single dose of Rebinyn® 40 IU/kg in adults with ≤2% FIX levels[a]

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[a] In two phase 3 studies, factor levels were evaluated for 1 week after the first dose of Rebinyn® 40 IU/kg. The average levels after 7 days were 16.8% in 6 adults, 14.6% in 3 adolescents, 10.9% in 13 children ages 7 to 12 years, and 8.4% in 12 children up to age 6 years.

[b] Based upon a 2.34% increase in factor levels per IU/kg infused in adults.

Image of hemophilia B patient shown is for illustrative purposes only.

INDICATIONS AND USAGE

What is Rebinyn® Coagulation Factor IX (Recombinant), GlycoPEGylated?

Rebinyn® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Rebinyn® is used to treat and control bleeding in people with hemophilia B. Your healthcare provider may give you Rebinyn® when you have surgery. Rebinyn® is not used for routine prophylaxis or for immune tolerance therapy.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about Rebinyn®?

- **Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center.** Carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing Rebinyn®.

Who should not use Rebinyn®?

Do not use Rebinyn® if you:

- are allergic to Factor IX or any of the other ingredients of Rebinyn®.
- are allergic to hamster proteins.

What should I tell my health care provider before using Rebinyn®?

Tell your health care provider if you:

- have or have had any medical conditions.
- take any medicines, including non-prescription medicines and dietary supplements.
- are nursing, pregnant, or plan to become pregnant.
- have been told you have inhibitors to Factor IX.

How should I use Rebinyn®?

- Rebinyn® is given as an infusion into the vein.
- **Call your healthcare provider right away if your bleeding does not stop after taking Rebinyn®.**
- Do not stop using Rebinyn® without consulting your healthcare provider.

What are the possible side effects of Rebinyn®?

- **Common side effects include** swelling, pain, rash or redness at the location of the infusion, and itching.
- **Call your healthcare provider right away or get emergency treatment right away if you get any of the following signs of an allergic reaction:** hives, chest tightness, wheezing, difficulty breathing, and/or swelling of the face.
- **Tell your healthcare provider about any side effect that bothers you or that does not go away.**
- Animals given repeat doses of Rebinyn® showed Polyethylene Glycol (PEG) inside cells lining blood vessels in the choroid plexus, which makes the fluid that cushions the brain. The potential human implications of these animal tests are unknown.

Please see Brief Summary of Prescribing Information on the following page.

Rebinyn® is a prescription medication.

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.

Learn more at rebinyn.com

novo nordisk®

Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

Rebinyn® is a registered trademark of Novo Nordisk Health Care AG.
Novo Nordisk is a registered trademark of Novo Nordisk A/S.

USA17BIO02796 February 2018

rebinyn®
Coagulation Factor IX (Recombinant), GlycoPEGylated

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

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www.hfnv.org

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Board of Directors

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Vice President:
Treasurer:
Secretary: Tanya Butler

Directors

Jacey Gonzalez
Kim Luong Velazquez
Lupe Torres

Features:

In Every Issue:

A Letter from Our Executive Director

Dear Friends,

I hope this issue of the Nevada Chapter News & Views Newsletter encourages you to let your voice be heard. Sharing your story takes courage, but now more than ever, your story can change the world. Raising awareness can help influence policies that affect everyone living with a bleeding disorder, connect an undiagnosed individual with appropriate treatment, and bring someone out of isolation who might think they are struggling alone. March is Bleeding Disorders Awareness Month and this Spring we have a number of ways for you to help raise awareness.

- Join the Red Tie Campaign nationwide movement to raise awareness (pg 17)
- Make a donation during Nevada's Big Give to support the Chapter's Programs and Services (pg 5)
- Register a team for the newly rebranded "Unite for Bleeding Disorders" Walk & 5K (Pg 5)
- Participate in the Spring social media challenges (pg 11)

You may have noticed our new look for the Nevada Chapter's Hemophilia News & Views. Along with an updated design we have some new regular features. Our hope is that the newsletter will be a resource for you to get to know the Nevada bleeding disorders community better with our "Social Media Contest Winners", and "Community Spotlight". The new content is designed to help you understand the impact of the Chapter's programs and activities with "In The Numbers", and provide a little more guidance on how you can connect with the Chapter in "Featured Events" and "Event Calendar."

Thank you for your ongoing support and courage in sharing your story. Together we can reach a high quality of care and quality of life for everyone living with a bleeding disorder.

With Gratitude & Warm Regards,

Betsy VanDeusen
Chapter Executive Director

Featured Events

Nevada's Big Give
Thursday, March 22, 2018
www.nvbiggive.org

Nevada's Big Give is an opportunity to give where you live and take part in a statewide philanthropy day. It doesn't matter how much you give. You can donate to the Nevada Chapter during the Big Give and help us be eligible for special prizes and contests throughout the day...generating even more funds for Nevada's only nonprofit focused on bleeding disorders.

Golf Gets In Your Blood
Monday, April 16, 2018
Red Rock Country Club, Mountain Course, Las Vegas, NV
8:00 am Registration—9:30 am Shotgun Start

All proceeds benefit the Nevada bleeding disorders community!

RSVP by April 30th at www.hfnv.org

Camp Independent Firefly
Saturday June 12-16, 2018
Camp Whittle, Fawnskin, CA

This year's theme is Time Travel! Campers must be 7 years old by June 13th 2017. Applications must be completed by March 31st. Space is limited. You will be notified if your camper is accepted by April 15th. Camp Independent Firefly is a 5 day 4 night sleep over camp for youth 7 thru 17 years of age. Activities will include horseback riding, swimming, arts & crafts and a rock wall, along with other fun activities.

Register online at www.hfnv.org

Unite for Bleeding Disorders Walk & 5K
Las Vegas Walk: Saturday, September 15, 2018
Floyd Lamb Park

Reno Walk: Saturday September 22, 2018
Bartley Ranch Park

Register your team today at www.uniteforbleedingdisorders.org

2018 Calendar of Events

Monday, April 16, 2018
Golf Gets In Your Blood
Golf Tournament
Red Rock Country Club

Saturday July 21, 2018
Northern Nevada Family Education Weekend
Reno

Unite for Bleeding Disorders

Saturday, September 15, 2018
Las Vegas Walk
Floyd Lamb Park

Saturday September 22, 2018
Reno Walk
Bartley Ranch Park

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

Hispanic Family Education Day

Saturday May 19, 2018
Hispanic Heritage Event
Las Vegas

Saturday August 4, 2018
Renee Paper Memorial Picnic & Back To School Event
Las Vegas

70th NHF Bleeding Disorders Conference ORLANDO • 2018

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

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

CAMP INDEPENDENT FIREFLY EST. 2013

June 12 –16, 2018
Camp Independent Firefly
Camp Whittle, CA

NEVADA PEP
Strengthening Families *with* Education • Empowerment • Encouragement

Saturday August 17-19, 2018
Parents Empowering Parents
Las Vegas

October 21 & 22, 2018
Fall Fam Jam
Las Vegas

Thursday December 5, 2018
Consumer Meeting & Holiday Party
Reno

Saturday, July 14, 2018
Women's Retreat
Las Vegas, NV

Saturday August 25, 2018
New Family Group
Las Vegas

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

Espero que esta edición del boletín informativo de el Nevada Chapter News & Views lo anime a que deje que se escuche su voz. Compartir su historia requiere valor, pero ahora más que nunca su historia puede cambiar el mundo. Asiendo consiencia puede ayudar a influir en las políticas que afectan a todas las personas que viven con un trastorno de la sangre, conectar a una persona no diagnosticada con el tratamiento adecuado y sacar a alguien del aislamiento que podría pensar que está luchando solo. Marzo es el Mes de Concientización sobre los Trastornos de Sangre y esta primavera tenemos varias formas para ayudarlo a crear conciencia.

- Únase al movimiento nacional de la Campaña Corbata Roja (Red Tie) para crear conciencia (pg 17
- Haga su donación a Nevada's Big Give para apoyar los Programas y Servicios del Capítulo (pg 5)
- Registre un equipo para la recién renombrada caminata "Unidos por trastornos de la sangre" for Bleeding Disorder" Walk& 5K (pg 5)
- Participe en los concursos de nuestras redes sociales (pg 11)

Es posible que haya notado nuestro nuevo aspecto de boletín informativo del Nevada Chapter-Hemophilia News &Views. Junto con un diseño actualizado, tenemos algunas características regulares nuevas. Esperamos que el boletín sea un recurso para que conozcan mejor a la comunidad de trastornos de la sangre de Nevada con nuestros "ganadores del concurso de redes sociales" y "Community Spotlight". El nuevo contenido está diseñado para ayudarlo a comprender el impacto de los programas y actividades del Capítulo con "In The Numbers", y brindarle un poco más de orientación sobre cómo puede conectarse con el Capítulo en "Eventos destacados" y "Calendario de eventos".

Gracias por su continuo apoyo y valor al compartir su historia. Juntos podemos alcanzar una alta calidad de atención y calidad de vida para todas las personas que viven con un trastorno de la sangre.

Con agradecimiento y cordial saludo,

Betsy VanDeusen
Chapter Executive Director

xyntha® solofuse®

Antihemophilic Factor (Recombinant)

We all have something that drives us

WHAT'S YOUR IT?

Reach out to your local Patient Affairs Liaison to learn more about Pfizer Hemophilia's products, resources, and support.

Patty Eastin
480-734-4011
Patricia.D.Eastin@Pfizer.com

DON'T WING IT. BRING IT.

Visit XYNTHA.com to watch the video and find out how XYNTHA SOLOFUSE can help prepare you to live actively.

Talk to your doctor about the activities that are right for you.

What is XYNTHA?

XYNTHA® Antihemophilic Factor (Recombinant) is indicated in adults and children for the control and prevention of bleeding episodes in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia) and for the prevention of bleeding during surgery in patients with hemophilia A.

XYNTHA does not contain von Willebrand factor and, therefore, is not indicated for von Willebrand's disease.

Important Safety Information for XYNTHA

- Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction: wheezing, difficulty breathing, chest tightness, turning blue (look at lips and gums), fast heartbeat, swelling of the face, faintness, rash, low blood pressure, or hives. XYNTHA contains trace amounts of hamster protein. You may develop an allergic reaction to these proteins. Tell your healthcare provider if you have had an allergic reaction to hamster protein
- Call your healthcare provider right away if bleeding is not controlled after using XYNTHA; this may be a sign of an inhibitor, an antibody that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests to monitor for inhibitors
- Across all clinical studies, the most common side effects (10% or more) with XYNTHA in adult and pediatric previously treated patients (PTPs) were headache (26% of subjects), joint pain (25%), fever (21%), and cough (11%). Other side effects reported in 5% or more of patients were: diarrhea, vomiting, weakness, and nausea
- XYNTHA is an injectable medicine administered by intravenous (IV) infusion. You may experience local irritation when infusing XYNTHA after reconstitution in XYNTHA® SOLOFUSE®.

Please see the Brief Summary for XYNTHA SOLOFUSE on the next page.

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.

Printed in USA/July 2017 Marketed by Pfizer Inc.

xyntha® xyntha® solofuse®

Antihemophilic Factor (Recombinant) **Antihemophilic Factor (Recombinant)**

Rx only

Brief Summary

See package insert for full Prescribing Information, including patient labeling. For further product information and current patient labeling, please visit XYNTHA.com or call Pfizer Inc toll-free at 1-800-879-3477.

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

What is XYNTHA?

XYNTHA is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia A. Hemophilia A is also called classic hemophilia. Your healthcare provider may give you XYNTHA when you have surgery.

XYNTHA is not used to treat von Willebrand's disease.

What should I tell my healthcare provider before using XYNTHA?

Tell your healthcare provider about all your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if XYNTHA may harm your unborn baby.
- are breastfeeding. It is not known if XYNTHA passes into your milk and if it can harm your baby.

Tell your healthcare provider 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.

How should I infuse XYNTHA?

Step-by-step instructions for infusing with XYNTHA are provided at the end of the complete Patient Information leaflet. The steps listed below are general guidelines for using XYNTHA. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedures, please call your healthcare provider before using.

Call your healthcare provider right away if bleeding is not controlled after using XYNTHA. Your body can also make antibodies against XYNTHA (called "inhibitors") that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests from time to time to monitor for inhibitors.

Call your healthcare provider right away if you take more than the dose you should take.

Talk to your healthcare provider before traveling. Plan to bring enough XYNTHA for your treatment during this time.

What are the possible side effects of XYNTHA?

Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction:

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

Common side effects of XYNTHA are

- headache
- fever
- nausea
- vomiting
- diarrhea
- weakness

Talk to your healthcare provider about any side effect that bothers you or that does not go away. You may report side effects to FDA at 1-800-FDA-1088.

How should I store XYNTHA?

Do not freeze.

Protect from light.

XYNTHA Vials

Store XYNTHA in the refrigerator at 36° to 46°F (2° to 8°C). Store the diluent syringe at 36° to 77°F (2° to 25°C).

XYNTHA can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA at room temperature, carefully write down the date you put XYNTHA at room temperature, so you will know when to either put it back in the refrigerator, use it immediately, or throw it away. There is a space on the carton for you to write the date.

If stored at room temperature, XYNTHA can be returned one time to the refrigerator until the expiration date. Do not store at room temperature and return it to the refrigerator more than once. Throw away any unused XYNTHA after the expiration date.

Infuse XYNTHA within 3 hours of reconstitution. You can keep the reconstituted solution at room temperature before infusion, but if you have not used it in 3 hours, throw it away.

Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

XYNTHA SOLOFUSE

Store in the refrigerator at 36° to 46°F (2° to 8°C).

XYNTHA SOLOFUSE can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA SOLOFUSE at room temperature, carefully write down the date you put XYNTHA SOLOFUSE at room temperature, so you will know when to throw it away. There is a space on the carton for you to write the date.

Throw away any unused XYNTHA SOLOFUSE after the expiration date.

Infuse within 3 hours after reconstitution or after removal of the grey rubber tip cap from the prefilled dual-chamber syringe. You can keep the reconstituted solution at room temperature before infusion, but if it is not used in 3 hours, throw it away.

Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

What else should I know about XYNTHA?

Medicines are sometimes prescribed for purposes other than those listed here. Talk to your healthcare provider if you have any concerns. You can ask your healthcare provider for information about XYNTHA that was written for healthcare professionals.

Do not share XYNTHA with other people, even if they have the same symptoms that you have.

This brief summary is based on the Xyntha® [Antihemophilic Factor (Recombinant)] Prescribing Information LAB-0516-5.0, revised 10/14, and LAB-0500-9.0, revised 10/14.

RUS706211 December 2014 Pfizer U.S. Pharmaceuticals

Community Spotlight: Tanya Butler

Meet Tanya Butler.

Tanya's husband and son have von Willebrand Disease. When they were first diagnosed, Tanya found comfort in accepting that the diagnosis was out of their control, while realizing that they needed to do all they could to understand the disease in order to live good lives. Tanya is very active at the chapter, where she serves on the Board of Directors and several event committees. Our experience working with Tanya is always enormously positive. She is reliable, supportive, kind, and a great role model for caregivers of people with bleeding disorders.

Who in your family has a bleeding disorder and what is their diagnosis story?

Eron Sr. (husband) and Tyler(son) have von Willebrand disease. We actually found out when Tyler had several nosebleeds that would not stop like normal nosebleeds. I told his pediatrician at the time I thought it was odd to have nosebleeds that do not stop after 15 minutes. I was told it was that the nosebleeds were frequent and took longer to stop because we lived in the desert. However, I still thought something was not right because we even started going to the ER for the nosebleeds. Finally, we changed pediatricians and the new doctor said she wanted to have Tyler checked. And sure enough an ENT told us he was going to test for von Willebrand disease based on the symptoms we told him Tyler was having.

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

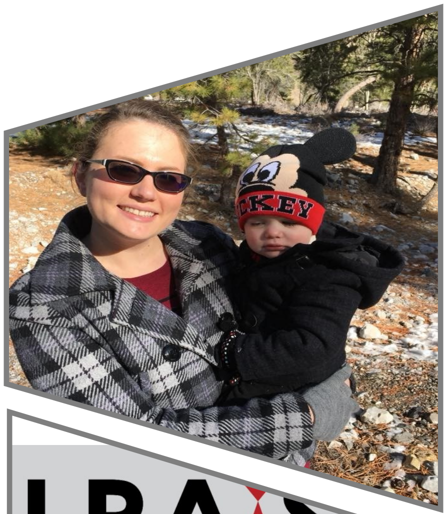
Of course you never want to hear your child or spouse has a disease or disorder. But, it is something out of your control. For us it was like, now we know what the diagnosis is so now we need to find ways to deal with it. First, we were given plans on how to handle bleeding which included RICE (rest, ice, compression, and elevation), oral and nasal Amicar, and von Willebrand factor. Some things may seem simple or common sense, but it was actually helpful, because things changed from how we were told to handle bleeds years ago. Right after the diagnosis we were not comfortable going out to eat, movies, and enrolling in activities because were concerned something may happen. Now we do things as family like going out, playing tennis, bike riding, golf, and swimming. We were told being active also is helpful to von Willebrand disease. There are some things that we do not participate in like football, soccer, or wrestling.

What advice would you give to newly diagnosed families?

I would tell newly diagnosed families to reach out to their treatment center, Nevada Hemophilia Foundation, and the community. We share our story not to gain sympathy, but to promote awareness. And we have found other families that are dealing with bleeding disorders. The resources and programs provide families with the support that is needed to live a healthy and happy lifestyle for the entire family. Because even though my older son EJ and I do not have von Willebrand disease we are still impacted by it.

"We share our story not to gain sympathy, but to promote awareness."

Let's Get Social



February Social Media Contest:
Who adds love to your life? Here at the Chapter we love our amazing bleeding disorders community and everyone who supports them!

Share a picture of who adds love to your life in a comment by February 20th, and be entered for a chance to win two tickets to the Winter Wine Fest on February 23rd! xoxo

Winner:
Logan Kennedy, "Don't know what I would do without these two! They are my everything!"

Participants:
Betsy VanDeusen, Christine Bettis, Nohemi Ramirez, Tiffani Kelly, Brandi Dawkins, Stephanie Hrisca-Kennedy, Sue Hrisca, Katrina Goodman, The Giving Water.

March Social Media Contest:
Support the 2018 Red Tie Campaign and Bleeding Disorders Awareness Month by taking a picture of yourself in your Red Tie. Show your creativity by the most unique way to put on that tie. Don't have a red tie? No problem. Check out redtiecampaign.org and visit the virtual photo booth where you can add a red tie to your picture. Anyone who posts a picture with a red tie, tags the chapter, and uses #RedTieCampaign during the month of March will be entered into a drawing for a $50 gift card.

Upcoming Contests:

APRIL: What's one thing you'd want people to know about living life with a bleeding disorder? Comment with your answer in this post for a chance to win a $50 gift card!

MAY: Tribute to Mothers and Caregivers of people with bleeding disorders. Post a photo or comment in honor of a mother or caregiver in your life and be entered into a giveaway!

JUNE: Active summer fun! Post a picture in the comments of you being active to be entered into a giveaway!

Follow us on Social Media!

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

ADYNOVATE

[Antihemophilic Factor (Recombinant), PEGylated]

ADYNOVATE® is FDA approved for patients of all ages with Hemophilia A

PROVEN PROPHYLAXIS +
SIMPLE,* TWICE-WEEKLY DOSING SCHEDULE =

moments YOUR WAY

*ADYNOVATE allows you to infuse on the same 2 days every week.

The pediatric study of children <12 years of age (N=66) evaluated the immunogenicity, efficacy, PK (as compared to ADVATE® [Antihemophilic Factor (Recombinant)]), and safety of ADYNOVATE twice-weekly prophylaxis (40-60 IU/kg) and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.[1,2]

The pivotal trial of children and adults ≥12 years (N=137) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis (40-50 IU/kg) vs on-demand (10-60 IU/kg) treatment, and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.[1]

- Children (<12 years) experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds[1,3]
- 38% (n=25) of children (<12 years) experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds[1]

Talk to your doctor and visit ADYNOVATE.com

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

Indications

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADYNOVATE if you:
- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

You should tell your healthcare provider if you:
- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE 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.

You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

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 following page for ADYNOVATE Important Facts.

For full Prescribing Information, visit www.ADYNOVATE.com.

References: 1. ADYNOVATE Prescribing Information. **2.** Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2016 Nov 27. doi: 10.1111/hae.13119 [Epub ahead of print]. **3.** Data on file.

S31486 05/17

Shire

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

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

What is the most important information I need to know about ADYNOVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

How should I use ADYNOVATE? (cont'd)

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

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

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

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

What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.shirecontent.com/PI/PDFs/ADYNOVATE_USA_ENG.pdf or 855-4-ADYNOVATE.

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

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NHF 70th: A Revolution in Therapy Has Begun

Steven Pipe, MD

NHF 70th: A Revolution in Therapy Has Begun

January 10, 2018

Recently, when I was asked to describe the current state of bleeding disorders therapy in just one word, the word "revolutionary" came to mind. I chose that word because we are in the midst of a sudden, radical change in how hemophilia is treated as compared to the past.

In the last few years alone, we've seen steady advances that have reduced the burden of traditional factor replacement. This has been achieved primarily through extended half-life factors. But the more dramatic changes have been the recently approved non-factor replacement therapies that offer a completely new way of doing prophylaxis. They feature a unique mechanism of action and for the most part, involve subcutaneous administration. For several of these new therapies, dosing could be as infrequent as once a month, which is revolutionary for individuals who have needed IV infusions every other day since they were infants. More recently, in just the last two months of 2017, you probably read about two separate clinical trials that found that just one infusion of each of the novel gene therapies being studied eliminated or nearly eliminated the need for preventive infusions of clotting factor. Moreover, these effects lasted for a year and a year and a half, respectively.

The potential for gene therapy in treating bleeding disorders didn't spring up overnight, but rather is the result of the hard work of many investigators around the world for the past 25 years. And it was 25 years ago that I began my career in research—when the recombinant era in therapy had just begun. Looking back, I remember that it didn't take long for scientists to conclude that recombinant DNA technology held the promise of unlocking novel therapies. And they were right.

Current gene therapy technologies are still grounded in replacement therapy. All that we've done is shift recombinant expression from the pharmaceutical manufacturing plant, where cells are grown in big vats, to the patient's own "production facility" —their own liver—through gene transfer. This is a very important step toward a cure.

This is an exciting time for bleeding disorders research, but there is still so much to be done. As healthcare providers, we're going to have to adjust and learn as these revolutionary therapies become available. The new gene therapies are not without some risk, so we must continue to maintain proper oversite and management.

For 70 years, NHF has been a catalyst for much of this innovation. If you were to look at which researchers and clinicians have impacted this field of study, you would find that many of them have received support through NHF's Clinical Fellowship program, or their research was helped by the Judith Graham Poole and Career Development Awards. All of these people have contributed, whether on the clinical or basic science side, to take us to the place we are today.

But it's not only the training of clinicians and the grant opportunities that are part of NHF's 70-year legacy. It is the message to the community that innovation is achievable. It is giving people a reason to dream about what may have once seemed impossible. Children today born with hemophilia are being born into an era where, due to these groundbreaking therapies, they should in all respects be able to live their lives to their fullest potential.

Steven Pipe, MD
Chair
NHF Medical and Scientific Advisory Council (MASAC)

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.

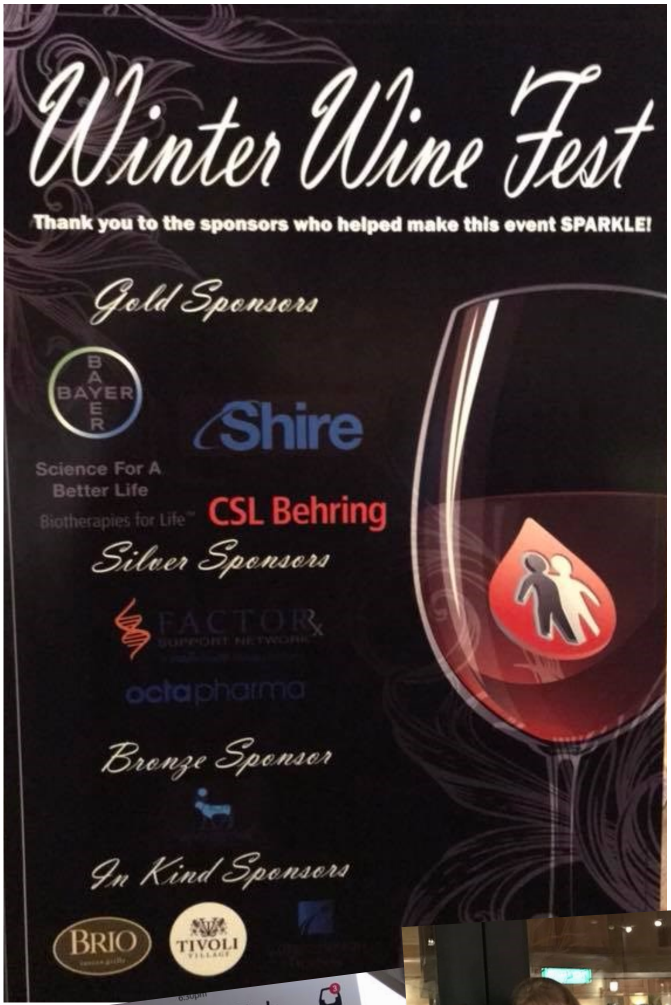
El equipo de LifeCare Specialty Pharmacy está dedicado a mantener relaciones de largo plazo con nuestros clientes a través de nuestros valores y misión principal: que cada paciente es familia y la esperanza no tiene límites….

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.

ADVERTISEMENT

Winter Wine Fest



Held on February 23, 2018, the Winter Wine Fest is an annual wine tasting event hosted by the Nevada Chapter of the National Hemophilia Foundation to raise 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.

Total funds raised in support of our mission:

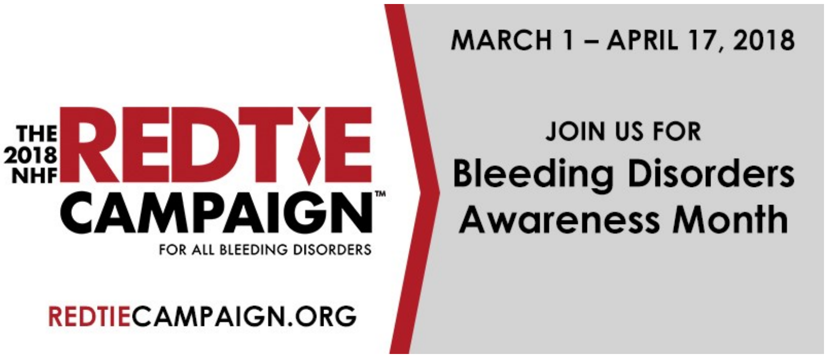
$16,546

These funds could send 30 kids to camp or provide 55 families with financial assistance!

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

National Program Spotlight: Red Tie Campaign

NHF Nevada Launches the 2018 Red Tie Campaign



In March 2016, hundreds of Nevadans and thousands of Americans nationwide participated in the first-ever Red Tie Challenge during the first-ever Bleeding Disorders Awareness Month.

Last year, we added a fundraising component to the campaign, and together with chapters across the country, we raised $20,000 to support National Hemophilia Foundation's (NHF) advocacy, education, and research initiatives.

Now, it's time to put on your red ties again and join us for the 2018 Red Tie Campaign!

This year, we're building upon the success of the fundraising goal from last year's Red Tie Challenge to launch a new campaign that celebrates our advocacy and awareness-raising efforts and challenges our community to raise $25,000 to fight bleeding disorders.

"For years, as the largest nongovernment funder of research awards, fellowships and grants, NHF has been the leading fight against bleeding disorders. In partnership with NHF, we have advanced the standard of care and the quality of life for our community," said Betsy VanDeusen, Chapter Executive Director. "We aim to raise an increased level of funds and do even more to build awareness to support our research, education and advocacy initiatives in Nevada and across the country."

To participate in the 2018 Red Tie Campaign, you can:

- **Sign:** Join the fight to protect access to quality healthcare for people with bleeding disorders and for all Americans by signing our open letter.
- **Give:** Make a donation to support NHF's innovative research, critical advocacy, and education programs.
- **Share:** Follow #RedTieCampaign on Twitter, Facebook and Instagram, and create your own red tie style with our customizable photo booth.

To learn more about the Red Tie Campaign, visit RedTieCampaign.org. For more information on bleeding disorders and the Nevada Chapter of the National Hemophilia Foundation please visit hfnv.org.

Donations made online at RedTieCampaign.org to support the Nevada Chapter will be matched up to $500—directing much needed resources to the Nevada bleeding disorders community.

Now Approved

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 | 150 mg/mL
injection for subcutaneous use

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**.

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
Injection for subcutaneous use | 150 mg/mL

Genentech
A Member of the Roche Group

Todavía está a tiempo de protegerse de la gripe, y sí, ¡aún puede vacunarse!

Todavía está a tiempo de protegerse de la gripe, y sí, ¡aún puede vacunarse!

Los adultos y los niños con trastornos hemorrágicos pueden y deben vacunarse contra la gripe

Si no se siente tan bien, y tiene fiebre y dolores musculares, puede que se haya unido a los millones de personas víctimas del impacto del virus de la influenza de esta temporada. Y no es por asustarlo si ahora se siente bien, pero puede que la gripe dure hasta mayo, así que vale la pena protegerse. ¿Sigue pensando en qué puede hacer para evitar enfermarse? A continuación, se presentan algunas respuestas a preguntas comunes relacionadas con la gripe:

¿Es muy tarde para que me administren la vacuna contra la gripe?
¡No! Si bien es mejor vacunarse antes del inicio de la temporada de gripe en otoño, hacerlo puede ofrecer cierta protección en caso de que no se haya vacunado contra la gripe aún. La temporada de gripe generalmente tiene su auge en los meses de enero y febrero, pero a veces se extiende hasta abril y mayo. Los Centros para el Control y la Prevención de Enfermedades (Centers for Disease Control and Prevention, CDC) indican que el cuerpo toma dos semanas para desarrollar anticuerpos resistentes a la gripe, así que no lo retrase.

¿Las personas con trastornos hemorrágicos deberían vacunarse contra la gripe? ¿Y el nebulizador nasal para la gripe?
El Consejo Asesor Médico y Científico (Medical and Scientific Asvisory Council, MASAC) de la Fundación Nacional de Hemofilia recomienda en el documento nro. 252 del MASAC que las personas con trastornos hemorrágicos sigan las recomendaciones sobre vacunas de la Academia Estadounidense de Pediatría y de los CDC. En el caso de la gripe, esto quiere decir que todas las personas, a partir de 6 meses de edad, deben vacunarse.

El MASAC indica que se deberían evitar las inyecciones intramusculares, pero de administrarse, deben precederlas una terapia de factores. Las vacunas contra la gripe intradérmicas, administradas bajo la piel en vez de en un músculo, son otra opción. Consulte con su hematólogo y con el equipo de atención médica de su centro de tratamiento de hemofilia (Hemophilia Treatment Center, HTC) sobre cuál es el mejor método de vacunación para usted y para su hijo.

Sin embargo, algo es seguro: no pueden evitarse las vacunas por completo. A partir de la temporada de gripe 2016-2017, los CDC dejaron de recomendar la versión de aerosol nasal de la vacuna contra la gripe al indicar que no era efectiva.

¿Cómo sé si tengo gripe?
Como un resfriado, la gripe puede causar dolor de garganta, estornudos, congestión nasal y tos. Pero los síntomas de la gripe a menudo son más graves y pueden incluir fiebre, dolores y escalofríos. Dichos síntomas también suelen presentarse rápidamente.

¿Qué puedo hacer para sentirme mejor?
Descanse mucho y beba agua y otros líquidos para evitar la deshidratación. Dado que la gripe es muy contagiosa, las personas que piensan que la tienen deberían quedarse en casa hasta que se sientan mejor o al menos durante 24 horas luego de pasar la fiebre.

¿Cuándo necesito llamar al doctor?
La mayoría de las personas no necesitan atención médica para recuperarse. Sin embargo, la gripe puede generar neumonía, bronquitis, sinusitis e infección de oído, y puede empeorar problemas de salud crónicos, como el asma.

Esté atento a estos síntomas de complicaciones:
- Falta de aire o dificultad para respirar
- Dolor u opresión de pecho
- Mareo o confusión repentina
- Vómito grave o persistente
- Síntomas que pueden desaparecer y luego volver con fiebre o tos

En los niños, esté atento a:
- Piel azulada
- Apatía o comportamiento inusualmente irritable
- Fiebre con erupción

En bebés, esté atento a:
- Dificultad para respirar
- Incapacidad para comer
- Señales de deshidratación, como ausencia de lágrimas al llorar o menos pañales húmedos de lo normal

¿Qué puedo hacer para evitar la gripe?
Lavarse las manos e intentar mantenerse lejos de quienes están enfermos puede prevenir la transmisión de gérmenes. ¡Y vacúnese contra la gripe!

Article from HEMAWARE Spanish

Program Recap: Spring Education Events

Check out the great education programs and events that have already taken place in 2018!

These events and learning opportunities are made possible through the generous support of sponsors and donors of the Nevada Chapter.

January 24, 2018
Education Dinner: Step It Up! Being More Active with Hemophilia

Twenty community members attended the presentation shared by Patty Eastin on ways patients can stay active and reach their personal goals while being protected, as well as reviews ways to communicate by having constructive conversations.

Thank you to Pfizer for hosting the education dinner.

January 27, 2018
Teen Leadership: Transition Ignition & Break Out Group Discussions

Seventeen teens attended the four hour program at Dave & Busters. Transition Ignition presented by Bayer was an interacive program engineered for honest open discussion that encouraged young adults engaging in their treatment and health.

The second half of the meeting was split into boys and girls. The boys had an open forum discussion led by Johnson Shao about what's next and careers, while the girls had a great talk about their developing bodies assisted by Amber Federizo.

Thank you to Bayer, HTCNV, and Hemophilia Alliance Foundation for your support of this program.

February 10, 2018
Education Dinner: No Sweat

Forty community members attended the two hour education dinner at Maggiano's Restaurant. Speaker Kristine Pearl guided a very interesting and engaging talk about physical activity and the benefits of staying active through sports and exercise in our daily lives.

Thank you to Shire for hosting this education dinner.

February 24, 2018
Women's Wellness Retreat

Sixteen women came together in Reno for a full day of learning, relaxation, and wellness. The day began with a yoga and meditation session, followed by engaging and interactive presentations: "Factor Fiction" and "Tools in the Toolkit." After lunch participants connected during a support group and created terrariums to take home and remember their wellness intention.

Thank you to Bioverativ, Brothers Healthcare, and HTCNV for your support.

Program Recap: Washington Days

TOP THREE

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

1. Register Your Walk Team.
2. Call Your Representative.
3. Sign-Up to Volunteer with the Chapter.

March 7-9, 2018
Washington Days

Five Nevada community members and Chapter Staff met with Nevada's U.S. Representatives and Senators to advocate for access to quality care. On Thursday, March 8th our community members met with Senator Dean Heller and staff members of U.S Representative Dina Titus, Senator Catherine Cortez Masto, Representative Mark Amodei, and Representative Jacky Rosen.

Important messages were shared on maintaining the essential health benefits—especially no life time caps and pre-existing condition exclusions.

In addition, the importance of the HTCs to the overall health and quality of care for bleeding disorders patients was shared with a request to maintain federal funding for these important programs.

Thank you to donors to the Nevada Chapter of the National Hemophilia Foundation that made this trip possible.

Interested in Advocacy? The Nevada Chapter is seeking volunteers for the Advocacy Committee that will help advocate at the state and federal level in the future. Contact Betsy at bvandeusen@hemophilia.org to learn more.

You can still support the effort! Visit www.redtiecampaign.org for ways to support by signing, posting, and donating.

- Keep spreading the word by posting your Red Tie pictures with #RedTieCampaign.
- Donate to the Nevada Chapter at www.redtiecampaign.org/donate to help us reach our $500 goal.
- Add your name to our letter of asking for protecting of access to quality healthcare.

In the Numbers

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

a year in *SOCIAL MEDIA* 2017

WWW.FACEBOOK.COM/NHFNV

93 PAGE LIKES
369 POST LIKES
149 COMMENTS
217 SHARES

TWITTER: @NVHEMOPHILIA

82 LIKES
32 RETWEETS
45 LINK CLICKS
6 REPLIES

Instagram

@NHFNV

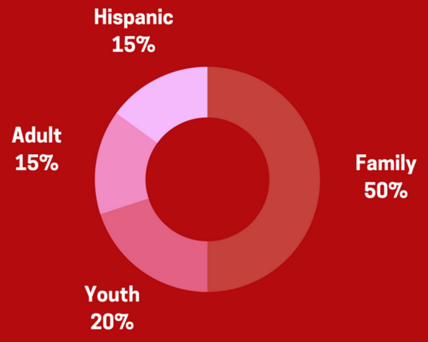
156 LIKES
5 COMMENTS

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

Nevada Chapter
National Hemophilia Foundation
www.hfnv.org

NHF Nevada Program Hours 2017

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 current family programs include Spring Fest Education Day, Northern Nevada Family Weekend, Annual Education Meeting, Family Picnic, Holiday Parties, Education Dinner, and Fall Fam Jam -- 50% of all our programming!

YOUTH PROGRAMS

Youth programs account for 20% of our programming, including Youth Group, Leaders in Training Weekend, & our Back to School Event.

ADULT PROGRAMS

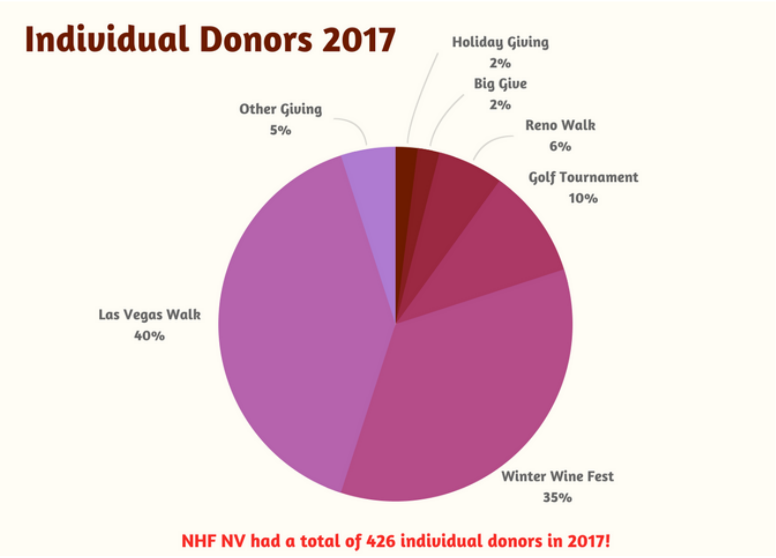
15% of our programs are Adult Programs include our Couples' Retreat, Las Vegas and Reno Women's Retreats, and our Men's Group.

HISPANIC PROGRAMS

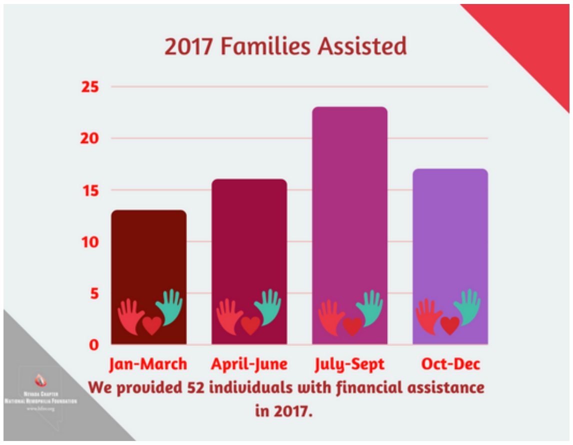
15% of our programs are dedicated to serving the Hispanic bleeding disorders community, which includes Hispanic Educations Days, Educational Dinners, and Hispanic Social Events.

WE OFFERED A TOTAL OF 98 PROGRAM HOURS IN 2017!

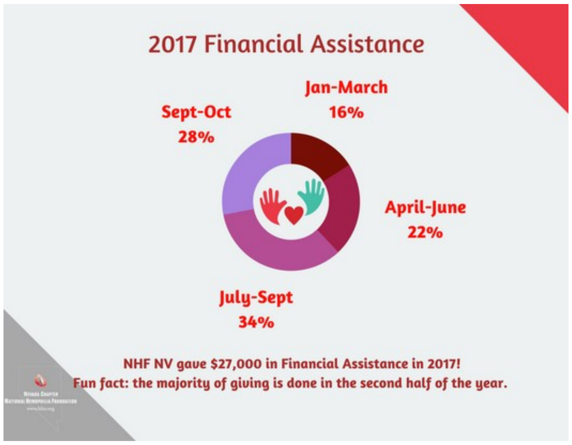
In The Numbers



NHF NV had a total of 426 individual donors in 2017!



We provided 52 individuals with financial assistance in 2017.



NHF NV gave $27,000 in Financial Assistance in 2017!
Fun fact: the majority of giving is done in the second half of the year.

NHF NV EVENTS

2017

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

WINTER WINE FEST

Our Winter Wine Fest had 187 attendees and raised $33,000!

GOLF TOURNAMENT

Our Golf Tournament had 133 participants and raised $63,000!

RENO WALK

Our Reno Hemophilia Walk had 57 participants and raised $8,300!

LAS VEGAS WALK

Our LV Hemophilia Walk had 476 participants and raised $55,000!

TOTAL EVENTS HELD

4

TOTAL DOLLARS RAISED

$159,300

LOOKING AHEAD

For 2018 we have 5 wonderful events planned! Winter Wine fest, Golf Gets in Your Blood: NHF NV Golf Tournament, The Unite for Bleeding Disorders Walks in Las Vegas & Reno, and new to our calendar this year: Bikes in Your Blood. Join us & make a difference today!


simplify
home infusion therapy

HEMOSTASIS & THROMBOSIS CENTER of NEVADA

Wherever you are in the Silver State and beyond, we're here for you.

The Hemostasis & Thrombosis Center is Nevada's only federally-designated hemophilia and bleeding disorder treatment center.

Our team is excited to see you!


Amber Federizo
MEDICAL DIRECTOR & NURSE PRACTITIONER


Ariana Stanley
ADMINISTRATIVE ASSISTANT


Becki Berkowitz
PROGRAM CO-DIRECTOR/ NURSE COORDINATOR


Danielle Serrano
PHYSICAL THERAPIST


Jennifer Roberts
PATIENT & COMPLIANCE COORDINATOR


Johnson Shao
SOCIAL WORKER


JR Dyer
REGISTERED NURSE


Lisa Cervantes
ADMINISTRATIVE ASSISTANT


Maria Reyes
ADMINISTRATIVE ASSISTANT


Ofelia Barrera
ADMINISTRATIVE ASSISTANT


Michael Usgaard
EXECUTIVE DIRECTOR

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JUNE 12-16
CAMP INDEPENDENT FIREFLY

CAMPER APPLICATIONS DUE 3/31

APPLY ONLINE ONLY

Go to hfnv.org
News & Events/Event Calendar for application link

This year's theme is Time Travel!
What fun we have in store for our campers!

Campers must be 7 years old by June 13th 2017

Applications must be completed by March 31st. Space is limited. You will be notified if your camper is accepted by April 15th.

Camp Independent Firefly is a 5 day 4 night sleep over camp for youth 7 thru 17* years of age. Activities will include horseback riding, swimming, arts & crafts and a rock wall, along with other fun activities.