Nevada Chapter Newsletter

Summer 2018

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.hfnv.org

Hemophilia News & Views

HEMOSTASIS
&
THROMBOSIS
CENTER of NEVADA

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

As Nevada's only federally-recognized hemophilia treatment center, our multidisciplinary team is specially trained and certified to provide a comprehensive array of services to our patients. Together, we make up a network of nearly 150 centers to provide care to the bleeding disorder community nationwide.

You or your loved one have a bleeding disorder, but you're not alone.

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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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Features:

In Every Issue:

A Letter from Our Executive Director

Dear Friends,

Summer has always been a great time to connect with friends and family. This issue is full of great opportunities to connect with your bleeding disorders family! Whether you attend an event, organize a walk team, attend a new family play group, or connect on social media – the Nevada Chapter is here to help you stay connected.

Here are a few ways to connect this summer:

- Northern Nevada Education Day & Baseball Family Outing (Pg 5)
- Renee Paper Memorial Picnic & Back To School Event (Pg 6)
- Register Your Walk Team & Recruit Members (Pg 5)
- Summer Social Media Contests (Pg 9)
- Tahoe Family Picnic (Pg 6)

This summer, we are excited to roll out the new brand for the annual walk program: The Unite For Bleeding Disorders Walk & 5K! The new logo and name is inclusive of ALL bleeding disorders, and all of our community members. It's not just a new look – the Walk will have some exciting new components this year including a pinwheel ceremony! I hope to see every member of our bleeding disorders community at the Unite For Bleeding Disorders Walks in Las Vegas on September 15, and Reno on September 22. Together we can kick off the new look with record attendance and record funds raised in support of our bleeding disorders community!

Sincerely,

Betsy VanDeusen
Chapter Executive Director

TOP THREE

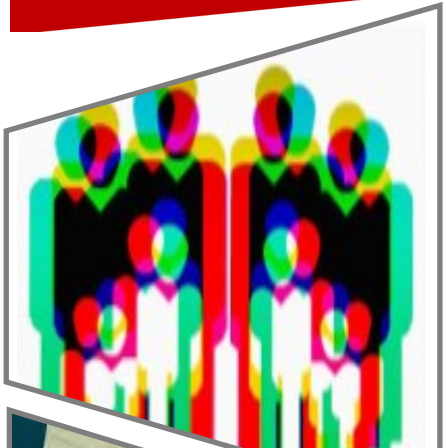
If you only do three things this Summer… try our top three actions for empowerment!

1. Register your walk team and recruit team members. www.uniteforbleedingdisorders.org

2. Call your representative to talk about the importance of essential health benefits. www.commoncause.org

3. Sign-up for a chapter event to connect with your community. www.hfnv.org

Featured Events



Northern Nevada Education Day & Baseball Family Outing
Saturday, July 21, 2018
Harrah's Convention Center, Reno, NV

The Northern Nevada Family Education Day provides families in Northern Nevada, affected by bleeding disorders, an opportunity to bond with their families and peers. Educational programs for the whole family are offered throughout the day, followed by an Education Dinner hosted by Bioverativ and a Family Outing to the Reno Aces Baseball Game!

Travel scholarships and hotel rooms available by applications for families traveling more than 60 miles to the event.

RSVP by June 30th at www.hfnv.org.

Renee Paper Family Picnic & Back To School Event
Saturday, August 4, 2018
Bill & Lillie Heinrich YMCA, Las Vegas, NV

Join us as we remember and honor the Chapter's founder, and an amazing leader for the bleeding disorders community, Renee Paper at a family picnic and swim!

RSVP at www.hfnv.org

New Family Play Group
2nd Saturday of the Month
Various Locations, Las Vegas, NV

Parents of children ages 0-7 are invited to a monthly play group. Connect with other parents, give your littles ones a chance to connect with their peers, and have fun in a safe, family friendly park or play space setting. Check our the Nevada Chapter's facebook for up to date posts on the location and times, or sign-up for the playgroup email list by contacting bvandeusen@hemophilia.org.

Find up-to-date locations at www.facebook.com/NHFNV

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

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

Tuesday, July 10, 2018
Education Dinner
Las Vegas

Saturday, July 21, 2018
Northern Nevada Family Education Day
Reno

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

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

Saturday, August 25, 2018
Women's Retreat
Las Vegas

Saturday, August 25, 2018
Family Picnic
Lake Tahoe

Saturday, September 15, 2018
Las Vegas Walk
Floyd Lamb Park
Saturday, September 22, 2018
Reno Walk
Bartley Ranch Park

Saturday & Sunday, September 22-23, 2018
Women's Retreat
Elko

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

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

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

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

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

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

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

Not getting invitations? Contact us to update your

mmagana@hemophilia.org
702-564-4368

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

Un Mensaje de nuestra Directora Ejecutiva

Queridos amigos,

El verano siempre es un buen tiempo para conectarse con amigos y familiares. ¡En esta edición encontraran grandes oportunidades para juntarse con su familia de trastornos de la coagulación! Ya sea que asista a un evento, organice un equipo para la caminata, asista a un grupo de familias con niños pequeños, o conéctese en las redes sociales, la fundación está aquí para ayudarlo a mantenerse conectado.

Aquí hay algunas maneras de conectarse este verano:

- Día de la Educación del Norte de Nevada y Excursión familiar de béis bol (Pg 5)
- Renee Paper Memorial Picnic y evento de regreso a la escuela (Pg 6)
- Registre su equipo de caminata y Reclute Miembros (Pg 5)
- Concursos de redes sociales de este verano (Pg 9)
- Picnic Familiar en Tahoe (Pg 6)

Este verano, estamos entusiasmados de lanzar la nueva marca para el programa anual de caminatas: ¡la caminata Unite For Bleeding Disorders & 5K! El nuevo logotipo y nombre incluye todos los trastornos hemorrágicos y todos los miembros de nuestra comunidad. No es solo una nueva apariencia: la caminata tendrá algunos componentes nuevos y emocionantes este año, incluida una ceremonia de molinetes.

Espero ver a todos los miembros de nuestra comunidad en el Unite For Bleeding Disorders Walks en Las Vegas (15 de septiembre) y en Reno (22 de septiembre). ¡Juntos podemos iniciar el nuevo aspecto con asistencia de récord y recaudar fondos en apoyo de nuestra comunidad de trastornos de la coagulación!

Sinceramente,

Betsy VanDeusen
Directora Ejecutiva

LOS TRES

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

1. Registre su equipo de caminata y reclute miembros del equipo.

www.uniteforbleedingdisorders.org

2. Llame a su representante para hablar sobre la importancia de los beneficios de salud esenciales.

www.commoncause.org

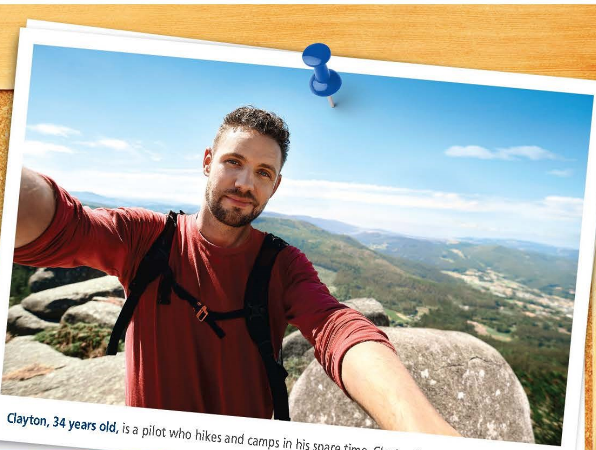
3. Regístrese para un evento de la fundación para conectarse con su comunidad.

www.hfnv.org

In hemophilia B

TAKE CONTROL TO A HIGH LEVEL WITH REBINYN®

NOW AVAILABLE



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

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®
Coagulation Factor IX (Recombinant), GlycoPEGylated

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Coagulation Factor IX (Recombinant), GlycoPEGylated

Brief Summary Information about:
REBINYN® Coagulation Factor IX (Recombinant), GlycoPEGylated

Rx Only

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/REBINYN.pdf to obtain FDA-approved product labeling
- Call 1-844-REB-INYN

Read the Patient Product Information and the Instructions For Use that come with REBINYN® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Product Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about REBINYN® after reading this information, ask your healthcare provider.

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.

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

What is REBINYN®?

REBINYN® is an injectable medicine used to replace clotting Factor IX that is missing in patients with hemophilia B. Hemophilia B is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

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.

Who should not use REBINYN®?

You should not use REBINYN® if you

- are allergic to Factor IX or any of the other ingredients of REBINYN®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because REBINYN® might not be right for you.

What should I tell my healthcare provider before I use REBINYN®?

You should tell your healthcare provider if you

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor IX.

How should I use REBINYN®?

Treatment with REBINYN® should be started by a healthcare provider who is experienced in the care of patients with hemophilia B.

REBINYN® is given as an infusion into the vein.

You may infuse REBINYN® 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 hemophilia treatment center or healthcare provider. Many people with hemophilia B learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much REBINYN® to use based on your weight, the severity of your hemophilia B, and where you are bleeding. Your dose will be calculated in international units, IU.

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

If your bleeding is not adequately controlled, it could be due to the development of Factor IX inhibitors. This should be checked by your healthcare provider. You might need a higher dose of REBINYN® or even a different product to control bleeding. Do not increase the total dose of REBINYN® to control your bleeding without consulting your healthcare provider.

Use in children

REBINYN® can be used in children. Your healthcare provider will decide the dose of REBINYN® you will receive.

If you forget to use REBINYN®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using REBINYN®

Do not stop using REBINYN® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much REBINYN®?

Always take REBINYN® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more REBINYN® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of REBINYN®?

Common Side Effects Include:

- swelling, pain, rash or redness at the location of infusion
- itching

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor IX products. **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.

Your body can also make antibodies called "inhibitors" against REBINYN®, which may stop REBINYN® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

You may be at an increased risk of forming blood clots in your body, especially if you have risk factors for developing blood clots. Call your healthcare provider if you have chest pain, difficulty breathing, leg tenderness or swelling.

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.

These are not all of the possible side effects from REBINYN®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

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

What are the REBINYN® dosage strengths?

REBINYN® comes in three different dosage strengths. The actual number of international units (IU) of Factor IX in the vial will be imprinted on the label and on the box. The three different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Yellow	2000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

How should I store REBINYN®?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Store in original package in order to protect from light. Do not freeze REBINYN®.

REBINYN® vials can be stored in the refrigerator (36-46°F [2°C-8°C]) for up to 24 months until the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not more than 6 months.

If you choose to store REBINYN® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not be more than 6 months. Do not return the product to the refrigerator.
- Do not use after 6 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) REBINYN® should appear clear without visible particles.

The reconstituted REBINYN® should be used immediately.

If you cannot use the reconstituted REBINYN® immediately, it should be used within 4 hours when stored at or below 86°F (30°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about REBINYN® and hemophilia B?

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

More detailed information is available upon request.

Available by prescription only.

For more information about REBINYN®, please call Novo Nordisk at 1-844-REB-INYN.

Revised: 11/2017

REBINYN® is a trademark of Novo Nordisk A/S.

For Patent Information, refer to: http://novonordisk-us.com/patients/products/product-patents.html

Manufactured by:
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Novo Allé, DK-2880 Bagsværd, Denmark

For information about REBINYN® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA

USA17BI003951 12/2017

novo nordisk®

Community Spotlight: Chris Ewing

Meet Chris Ewing.

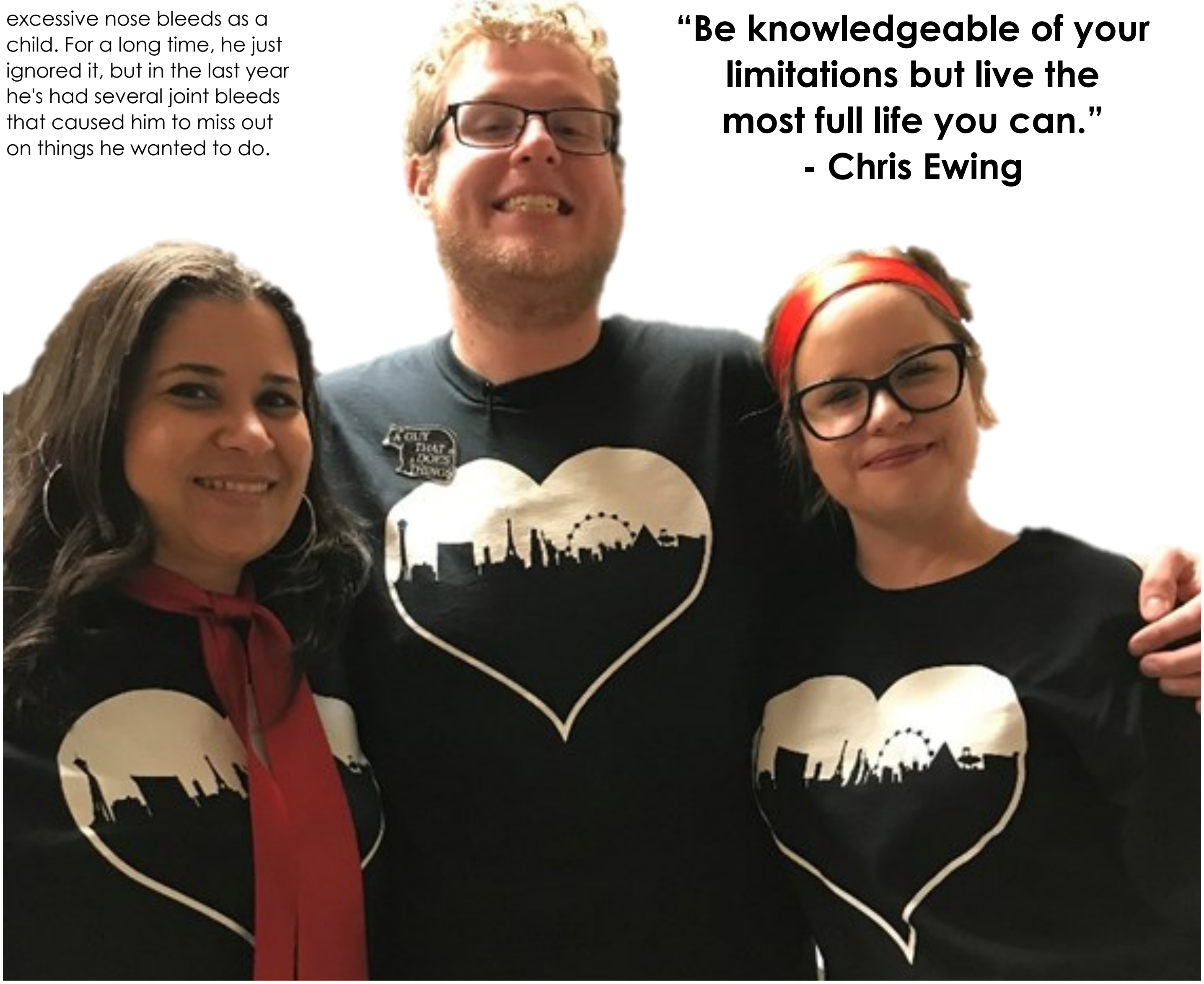
A bleeding disorders community member, Chris called us in February and asked if he could organize a punk festival to benefit our chapter. After he received help to get a much-needed treatment and follow-up care, Chris wanted to give back. We were delighted and honored to be the beneficiary of the first annual Blood Fest, held during Bleeding Disorders Awareness Month and NHF's Red Tie Campaign. Chris did an amazing job and we were so thrilled to get to know him and his big, enthusiastic, caring personality.

Chris has von Willebrand Disease, as do his sister, mother, and grandmother. He was diagnosed in middle school and dealt with excessive nose bleeds as a child. For a long time, he just ignored it, but in the last year he's had several joint bleeds that caused him to miss out on things he wanted to do.

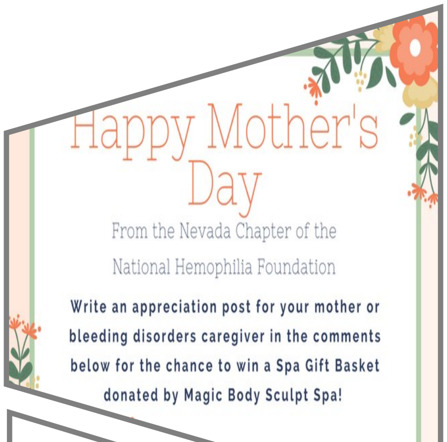
These days, he's more conscious of his limitations but that doesn't mean he lives in a bubble. Chris says, "We all have our limits but a diagnosis is not a sentence to being idle. The most important thing I learned from my HTC doctors and nurses is to be knowledgeable of your limitations but live the most full life you can with those limitations in mind."

Thank you, Chris, for being such a great role model for the bleeding disorders community. We can't wait for Blood Fest 2!

“Be knowledgeable of your limitations but live the most full life you can.”
- Chris Ewing



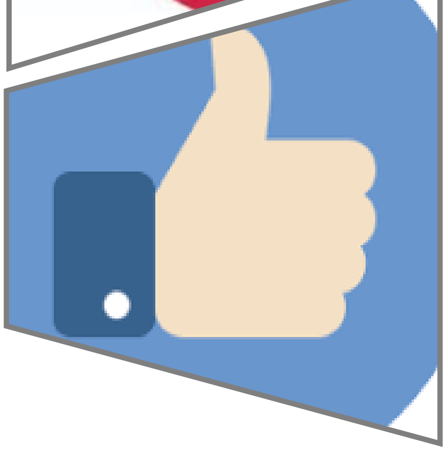
Let's Get Social



Happy Mother's Day

From the Nevada Chapter of the National Hemophilia Foundation

Write an appreciation post for your mother or bleeding disorders caregiver in the comments below for the chance to win a Spa Gift Basket donated by Magic Body Sculpt Spa!



May Social Media Contest Winner:
Jacey Lynn Gonzalez: "For every time I can't find a vein. For every time I'm calling you on the way to the hospital. For every time I wake you up at 3 a.m. because I'm up from anxiety. For every doctor's appointment you hold my hand through. For every time I roll my eyes when you brag. For every hug, kiss, and high five. For being the best mom for 20 years, and to being my best friend now. Happy Mother's Day Mama. I love you, all heart. Kelly Lynn Gonzalez"

Participants:
Josie Clark & Jacey Lynn Gonzalez

Upcoming Contests:

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

JULY: Register for the walk by the end of July and be entered into a drawing.

AUGUST: Share your best tip for talking to teachers about bleeding disorders.

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.

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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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Shire

International Study Group Findings Suggest Prophylaxis Could Reduce Hospitalizations for VWD Patients

Hemophilia.org News Room

Researchers from Sweden and the U.S. recently published an article that focused on potential correlations between patients with von Willebrand disease (VWD), hospitalizations and prophylaxis. The authors conducted a retrospective study of inpatients and outpatients, both with and without VWD. Their objective was to investigate the frequency of hospital admittances and determine whether the implementation of a prophylactic treatment regimen is associated with a reduction in hospitalizations.

The lead author of the article was Elena Holm, MD, Department of Translational Medicine, Lund University, Skåne University Hospital in Lund, Sweden. Holm and her colleagues were joined by Thomas Abshire, BloodCenter of Wisconsin and Departments of Pediatrics and Medicine, Blood Research Institute, Medical College of Wisconsin in Milwaukee.

The authors reviewed patient data from two primary groups. The first group encompassed population-based registers from the National Board of Health and Welfare and Statistics Sweden. Data from these registries were incorporated into Sweden's Congenital Bleeding Disorders study. These registries included 2,790 individuals with a diagnosis of VWD between the year 1987 and 2009. They found that VWD patients were admitted to hospitals at a rate 2.3 times higher than the unaffected control groups, and spent on average, 2.0 times as many days as hospitalized inpatients. The most common impetus for these hospitalizations were gastrointestinal (GI) bleeding, menorrhagia (heavy menstrual bleeding) and epistaxis (nose bleeds). Outpatient visits were also twice as common amongst VWD patients.

For the second segment of their research, investigators tapped the von Willebrand Disease Prophylaxis Network (VWD PN), an international study group established to evaluate the prophylactic regimens of patients with VWD. In all, 105 patients from participating treatment centers in North America and Europe were counted in this study, including individuals with type 3 (52%), type 2A (22%), type 1 (12%), type 2B (9%) and other types (4%). As in the registries, GI bleeding was the most common cause of hospitalization. Of the 122 bleed-related hospitalizations reported, 75 occurred prior to the initiation of prophylaxis and 47 after start of prophylaxis, which translates to 712 and 448 events per 1000 patient years. These findings would indicate that significantly fewer hospitalizations occurred after the initiation of a prophylactic treatment regimen.

The authors cited limitations such as a dearth of data on additional variables that could inform study conclusions and a lack of information that could help remove sources of bias or to investigate outcomes related to VWD type or mode of treatment. On the other hand, a major strength of this type research is that general population data fed by national registries allow investigators access to decades worth of healthy control data to match with affected patients, allowing for long term comparisons.

Holm and her fellow investigators also note the potential positive impact of prophylaxis in VWD patients as demonstrated by the VWD PN.

"The VWD PN enrolled the largest cohort using prophylaxis for the management of VWD, concluded the authors. "Prophylaxis using well defined regimens, as in this study, reduced the need for in- and outpatient visits which should translate to increased quality of life for patients and their families."

The article "Bleeding-related Hospitalization in Patients with von Willebrand disease and the Impact of Prophylaxis: Results from National Registers in Sweden Compared with Normal Controls and Participants in the von Willebrand Disease Prophylaxis Network," was published in the February 2018 edition of the journal Haemophilia.

"Prophylaxis using well defined regimens, as in this study, reduced the need for in- and outpatient visits which should translate to increased quality of life for patients and their families."

Provider Spotlight: Dr. Daisy Cortes, Hemostasis & Thrombosis Center of Nevada

Meet Dr. Daisy Cortes.

Daisy Cortes is a Board Eligible Pediatric Hematologist/ Oncologist and a board certified general Pediatrician. She completed her undergraduate studies at the University of California, Irvine, where she doubled majored in Biological Sciences and Sociology. Daisy then attended medical school at the University of Illinois at Chicago. She returned to Southern California to complete her residency in General Pediatrics at the Children's Hospital of Orange County (CHOC Children's Hospital). During her residency, she rotated through hematology and was fascinated at the delicate balance between what causes bleeding and what can cause clotting. Not only did she see the acute complications that can occur, but she was able to see the chronic care that goes behind bleeding disorders.

She pursued her fellowship in Pediatric Hematology/Oncology at UC Irvine/CHOC Children's under the supervision of Dr. Diane Nugent and Dr. Amit Soni, where she rotated through the Center of Inherited Blood Disorders (CIBD) clinic. During her fellowship training, not only did she see pediatric patients with bleeding disorders, but she was also able to see adults and understand further the complexity of care, as well as the advancements in treatment that would hopefully help the younger generations not have as many chronic joint issues as we see in the older populations. When she would take overnight and weekend call, she was the first line for assisting patients with their emergencies and speaking to the ER docs to give proper treatments.

After working per diem as an oncology physician for CHOC oncology, Daisy moved to Las Vegas to work at the Children's Specialty Center of Nevada, where she was a general pediatric oncologist and hematologist, who rotated through the Hemophilia Treatment Center. She returned to Los Angeles to work at Children's Hospital Los Angeles (CHLA) as a Bone Marrow Transplant hospitalist.

In her free time she enjoys hiking and traveling. She also enjoys kickboxing, dancing, and reading fiction, especially suspenseful crime dramas. She is fluent in Spanish, and some conversational Italian.

She is excited to be part of the Hemostasis and Thrombosis Center of Nevada. Dr. Cortes enjoys educating patients about their disorder and making sure that they not only understand their disorder but understand the importance of proper care. She hopes to work closely with the Nevada bleeding disorders community and with NHF to continue educating and offering the proper resources to make their health a priority.

You can reach Dr. Daisy Cortes at The Hemostasis & Thrombosis Center of Nevada.

6450 MEDICAL CENTER DR.
LAS VEGAS NV 89148

2904 W. HORIZON RIDGE PKWY
HENDERSON NV 89052

P: 702-960-5991

5301 RENO CORPORATE DR. RENO NV 89511

P:775-622-7371

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Golf Gets In Your Blood

Held on April 16, 2018, Golf Gets In Your Blood is an annual golf tournament benefitting the Nevada Chapter of the National Hemophilia Foundation. Funds raised from this event provide programs and services to over 600 families throughout the state of Nevada, with a special focus on supporting children living with bleeding disorders. Our youth programs include Camp Independent Firefly—a medically supervised camp experience, New Family Group—mentoring, support, and education to parents of newly diagnosed children, and our Youth Group—which focuses on creating future leaders.

Total funds raised in support of our mission:
$34,500

These funds could:

- **Send 60 kids to camp**
- **Provide 70 families with financial assistance**
- **Offer 2,000 hours of educational programing**
- **Help 63 teenagers transition to adulthood**

Thank you to our sponsors, volunteers, committee, donors, golfers, and staff who came out for the Golf Gets in Your Blood tournament! It was a super successful and fun event, and we are still feeling the love! We raised enough money to put us in 3rd place nationally for NHF's Red Tie Campaign.

Highlights include the Toby Gallegos Tribute Team; Camp Independent Firefly attendee Andres Manchaca speaking at the reception lunch; and golfer Eric Tippetts winning a Hole in One Cruise!

Thanks to Red Rock Country Club for hosting the event and to our wonderful volunteers!

Special thank you to event chairs John Self & Jeff Griffith.

Golf Gets In Your Blood

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Nevada Chapter
National Hemophilia Foundation
www.hfnv.org

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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.

ADVERTISEMENT

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

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

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:

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

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

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

WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

- Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.
- HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

BEFORE USING HEMLIBRA, TELL YOUR HEALTHCARE PROVIDER ABOUT ALL OF YOUR MEDICAL CONDITIONS, INCLUDING IF YOU:

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

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

HOW SHOULD I USE HEMLIBRA?

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

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

WHAT ARE THE POSSIBLE SIDE EFFECTS OF HEMLIBRA?

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

The most common side effects of HEMLIBRA include:

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

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

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

HOW SHOULD I STORE HEMLIBRA?

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

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

GENERAL INFORMATION ABOUT THE SAFE AND EFFECTIVE USE OF HEMLIBRA.

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

WHAT ARE THE INGREDIENTS IN HEMLIBRA?

Active ingredient: emicizumab

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

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Issued: 11/2017

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

Genentech
A Member of the Roche Group

La nueva prueba de la EvW promete mejores diagnósticos

La nueva prueba de la EvW promete mejores diagnósticos

La tecnología permite medir de forma más precisa el factor de actividad de von Willebrand

Author: Nancy Mann Jackson

Novel Technologies

El trastorno hemorrágico hereditario más común, la enfermedad de von Willebrand (EvW) también ha sido una de las más difíciles de diagnosticar. Pero una nueva prueba diagnóstica desarrollada en BloodCenter de Wisconsin, en Milwaukee, está dando resultados más precisos y confiables que las pruebas tradicionales.

"Al utilizar la nueva prueba, los hematólogos pueden tener más seguridad de que los resultados reflejan de forma precisa el escenario clínico del paciente", señala el Dr. Kenneth Friedman, Director Médico en el BloodCenter de Wisconsin y Director Médico Asociado del Centro Integral de Trastornos Hemorrágicos de BloodCenter (BloodCenter's Comprehensive Center for Bleeding Disorders). "La confianza en el diagnóstico guía de forma más eficiente las decisiones del tratamiento. Cuando se aplican los tratamientos de forma más rápida, la calidad de vida y el resultado de un paciente que padece EvW, y posiblemente el de su familia, mejoran".

Retos del diagnóstico de la EvW

La EvW se debe a deficiencias del factor von Willebrand (FvW), una proteína que se adhiere a las plaquetas, pero cuyas deficiencias pueden variar ampliamente. Por ejemplo, la EvW puede presentarse como de tipo 1 (leve), tipo 2 (moderada) o tipo 3 (grave). Y dentro del tipo 2, hay cuatro subtipos: 2A, 2B, 2M y 2N.

Históricamente, los médicos no han realizado un ensayo definitivo para medir la función del FvW, señala la Dra. Veronica Flood, profesora asociada de hematología y oncología pediátrica en el Colegio Médico de Wisconsin, en Milwaukee. "Es complicado por el hecho de que existen varias funciones diferentes para la proteína FvW", indica.

Una de las funciones principales del FvW es unir las plaquetas, que tradicionalmente se han medido a través de una prueba que no tiene resultados confiables. La prueba se basa en la ristocetina, un antibiótico que se administra para inducir la unión de las plaquetas. Pero debido a las variaciones genéticas, las personas pueden reaccionar de forma diferente a la ristocetina, que es una de las razones por las que los resultados varían. Desafortunadamente, esto a menudo conduce a diagnósticos de la EvW, cuando en realidad el trastorno no está presente, señala Flood.

"La dificultad", indica Friedman, "es que es necesario realizar múltiples pruebas para diagnosticar la EvW de forma precisa. La actividad estándar de la prueba del FvW es sensible e imprecisa. También puede proporcionar resultados bajos falsos en pacientes con una variación genética que es muy común en individuos sanos".

Una nueva forma de analizar el factor von Willebrand

La nueva y más sensible prueba de la actividad del FvW, conocida como la prueba de actividad GPIbM del FvW, está diseñada para descubrir los defectos cualitativos del FvW, para reducir la variabilidad y proporcionar resultados más precisos, confiables y sensibles. Además de mayor precisión, "la nueva prueba tampoco está sujeta a resultados bajos falsos como se ha evidenciado en la prueba estándar actual", indica Friedman.

La nueva prueba utiliza una proteína mutada, desarrollada por los investigadores en el BloodCenter de Wisconsin, para permitir la unión espontánea del FvW a las plaquetas. "Aunque cada prueba tiene una cierta cantidad de variación en las medidas, obtenemos una lectura mejor y más precisa con nuestra nueva prueba", señala Friedman. "La gran confiabilidad de los resultados puede mejorar la interpretación de los mismos, al comparar los múltiples resultados de las pruebas, necesarios para diagnosticar de forma precisa la EvW".

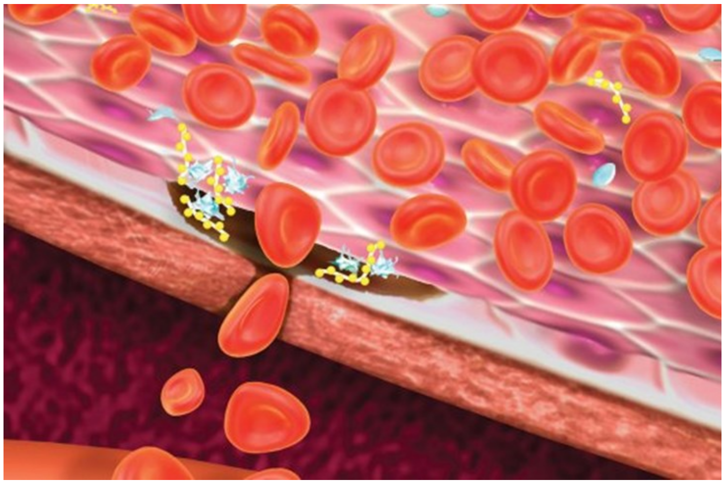
Como el nuevo ensayo no se basa en la ristocetina, "no habrá problemas con las variantes genéticas y los diagnósticos falsos", señala Flood. "La nueva prueba utiliza un GPIb con ganancia de función que une de forma espontánea el FvW, mientras que el antiguo ensayo de la actividad del cofactor de la ristocetina del FvW necesitaba ristocetina para hacer que la interacción ocurriera".

Mirando hacia el futuro

Los médicos creen que la nueva prueba de la enfermedad de von Willerbrand marcará una diferencia en sus pacientes. "A las personas que tienen el FvW bajo se les diagnosticará más fácilmente, ya que serán menos propensas a recibir un nivel tranquilizador falso", indica Flood. "Del mismo modo, los niveles bajos falsos serán menos probables, así que los pacientes serán menos propensos a que se les etiquete con un diagnóstico que no corresponde".

Además de esto, después de un uso y evaluación más clínicos, la nueva prueba puede demostrar ser capaz no solo de determinar si un paciente padece la EvW, sino también de diferenciar a los pacientes que padecen la EvW de tipo 2A o 2B, señala Friedman.

Sin embargo, debido a que el estrés igual puede aumentar los niveles del FvW, las nuevas pruebas no resolverán por completo los problemas de diagnóstico, indica Flood. Ella y otros médicos esperan que las futuras investigaciones continúen mejorando los diagnósticos y planes de tratamiento para las personas que padecen la EvW.



Program Recap: Spring Education Events

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

March 17, 2018
Spring Education Fest

129 community members came together for a day of learning and fun at Circus Circus! Children were treated to a special day at Adventuredome while adults learned about staying active, joint health, navigating insurance, and heard compelling personal stories of community members. The Red Tie Booth gave everyone a chance to show their red tie pride!

Thank you to our gold sponsors for making the event possible: Bayer, Bioverativ, Genentech, Grifols, Hemostasis & Thrombosis Center of Nevada, Novo Nordisk, Octapharma, and Shire

Special thanks to our volunteer chaperones!

April 29, 2018
Education Dinner: Common Connections

Twenty seven community members attended the education dinner at Bonefish Grill in Summerlin to hear from speaker Mary Jane Frey, RN-BC, BSN, CPN, of the Children's Hospital of Michigan.

Thank you to CSL Behring for offering this engaging education dinner.

May 8, 2018
Education Dinner: Inhibitors: Complication of Hemophilia A Treatment

Twenty three community members came together for an engaging evening at Claim Jumpers to learn about Hemophilia A. Speaker Virginia Kraus, RN MSN helped the group understand potential complications of Hemophilia A treatment.

Thank you to Grifols for hosting this education dinner.

May 19, 2018
Hispanic Education Day

Thirty eight members of the Hispanic bleeding disorders community enjoyed a full-day of Spanish language programing at Texas Station. The 3rd Annual Hispanic Education Day offered participants the chance to get to know each other through team building activities, four session focused on health, fitness and advocacy, and finally enjoyed local Mariachi performers in the afternoon.

Thank you to Shire & Hemostasis and Thrombosis Center of Nevada for supporting this event.

Impact Report: Red Tie Campaign

Red Tie Campaign

Our bleeding disorders community shined with creativity and passion during the Red Tie Campaign, ultimately putting Nevada on the map with a 3rd place recognition for most dollars raised, and generating $3,242.61 to support the Nevada bleeding disorders community! Thank you to all of our donors, supporters, and advocates who helped spread the word, generate momentum, and raise much needed funds!

12 individual donors gave online

+$1,497 cash collected during the Golf Tournament "Red Tie Challenge"

+3 local rock shows raised over $1,000 during "Bloodfest"

+3rd Place in the nation for dollars raised!

= $3,242.61 raised!

National Program Spotlight: Steps For Living

STEPS FOR LIVING
Education for all life stages.

10 Things Everyone Should Know About Steps for Living

1. The Steps for Living Web site is a comprehensive online resource that provides information on bleeding disorders for kids, adolescents, adults, parents and health educators to promote healthy living for all life stages.

2. The Steps for Living Web site was launched in 2011 by the National Hemophilia Foundation in collaboration with Pfizer Hemophilia and supported through a collaborative agreement with the Centers for Disease Control and Prevention (CDC).

3. The Steps for Living Web site has four sections: First Step (birth- 8 years old); Next Step (9-15 years old); Step Up (16 to 25 years old); and Step Out (ages 26 and up).

4. The content on the Steps for Living Web site was created by NHF staff, parents, patients and health care professionals from the bleeding disorders community and reviewed by the CDC, medical advisors, and HANDI, NHF’s information resource center.

5. The Steps for Living Web site features videos on a variety of topics including disclosure, sports and siblings.

6. The Steps for Living Web site has fun, interactive videogames including the myth busting “Fact or Fiction” and “Test your Knowledge” about self infusion.

7. The Resources section of the Steps for Living Web site has a variety of downloadable PDFs including: Babysitter Tool Kit, Sample Travel Letter, Sample 504 Accommodation Plan, Quick Facts About Bleeding Disorders, and Questions to Ask at Your Child Care Center Visit.

8. The Steps for Living Web site provides information on treatment and basics of bleeding disorders and addresses the psychosocial and quality of life issues that may be related to living with a bleeding disorder.

9. The Steps for Living Web site content is very easy to share through social media through buttons on the site that allow you to share links to pages through Facebook, LinkedIn, Twitter and E-mail.

10. The Steps for Living Web site is portable – the pages can be printed out and viewed on mobile devices.

STEPSforLIVING.hemophilia.org

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Co-Founder

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

Cadena de Suministro de Factor de Coagulación Segura

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

Monitoreo de Cumplimiento de Normas y Programas de Adhesión

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

Coordinación de Servicios de Enfermería

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

Comprensión de los Beneficios De Seguro

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

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

---

fidelis

specialty pharmacy

(702) 815-0800

www.fidelis-rx.com

Wagner Lemus
Co-Founder

Antonio Rosas
Co-Founder

We Speak Spanish

Serving all of Nevada

24/7 Access to Knowledgeable Pharmacists

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

Secure Pharmaceutical Supply Chain

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

Compliance Monitoring & Adherence Programs

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

Home Nursing Services Coordination

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

Understanding Insurance Benefits

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

"Your preferred specialty pharmacy for the hemophilia community"

ADVERTISEMENT

In the Numbers

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

Quarter 1 2018

social media *SPRING* 2018

WWW.FACEBOOK.COM/NHFNV
41 PAGE LIKES
532 POST LIKES
46 COMMENTS
60 SHARES

TWITTER: @NVHEMOPHILIA
73 LIKES
21 RETWEETS
52 LINK CLICKS
4 REPLIES

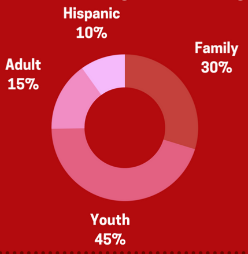
Instagram
@NHFNV
441 LIKES
13 COMMENTS

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

Nevada Chapter
National Hemophilia Foundation
www.hfnv.org

NHF Nevada Program Hours Spring 2018

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



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

YOUTH PROGRAMS
Youth programs accounted for 45% of our Spring programming, including our January Teen Program at Dave & Busters and our Leaders in Training Weekend at Mount Charleston.

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

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

36 PROGRAM HOURS
332 ATTENDEES

NHF NV EVENTS

Spring 2018

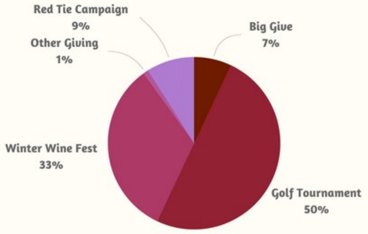
Our fundraising events provide the necessary funds for us to fulfill our mission of improving the lives of all Nevadans with bleeding disorders.

WINTER WINE FEST	GOLF GETS IN YOUR BLOOD
A night to Sip, Shop, and Support our community through wine, pasta, and an exciting silent auction at Brio Tuscan Grille!	Held at Red Rock Country Club, our golf tournament helps to raise funds for Camp Independent Firefly.
130 attendees $16,546 raised	105 attendees $34,500 raised
HIGHLIGHTS	**HIGHLIGHTS**
SNOW! In Las Vegas! Delicious wine Spin the Bottle wine pull	The tribute foursome for the late Toby Gallegos Golfer Eric Tippetts winning a hole-in-one cruise!

LOOKING AHEAD

Upcoming events include our 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!

Individual Donors: Spring 2018



NHF NV had a total of 132 individual donors this Spring!

SHARING OUR IMPACT

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

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

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

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

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

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

Our Target………

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

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

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

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

Nuestra Meta….

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

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

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

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ACT—Access to Care Today
Achieve a CURE Tomorrow

Unite
for Bleeding Disorders

Find your Walk and register at
uniteforbleedingdisorders.org

Las Vegas Unite Walk

Floyd Lamb Park at Tule Springs
September 15, 2018
7 AM Registration / 8 AM Walk

Reno Unite Walk

Bartley Ranch
September 22, 2018
9 AM Registration / 10 AM Walk