Nevada Chapter Newsletter

Winter 2018

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.hfnv.org

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Your donation supports people affected by bleeding disorders from birth to adulthood - helping them reach a productive, pain-free, and independent adulthood.
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Hemophilia News & Views

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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,

I want to extend a heartfelt thank you to everyone who made 2018 a success. We have a had a year of constant changes, new challenges, and amazing success stories.

The resilience, perseverance, and dedication of our Nevada bleeding disorders community continues to inspire me to find new ways to meet our mission of finding the highest quality of care and quality of life through peer support, education, and advocacy for those affected by bleeding disorders.

Watching a community of support grow for bleeding disorders is amazing – as new donors, supporters and volunteers join our dedicated community working to make a difference every day.

Thank you. It is through your support that we are able to look forward to 2019 with a sense of possibility as we work to make positive change for the bleeding disorders community.

Here are just a few of the highlights from this year that you helped accomplish:

- Improved access to care by advocating for extended prior authorization cycle.
- Raised awareness for undiagnosed women with bleeding disorders with over 10,000 people reached in our online campaign.
- Held 32 events offering over 149 hours of educational programing.
- Helped 30 families when they needed it most with emergency financial assistance.

I have one final request for 2018. **Will you make a brighter future possible by making a year-end gift?** Your donation supports people affected by bleeding disorders from birth to adulthood – helping them reach a productive, pain-free, and independent future. Please donate now through December 31 to make a brighter future possible!

With warmest regards and heartfelt thanks,

Sincerely,

Betsy VanDeusen
Chapter Executive Director

TOP THREE

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

1.Give the gift of a bright future. Make a year end donation to NHFNV. www.hfnv.org

2. Shop, Sip & Support at the Winter Wine Fest on February 8th. www.hfnv.org

3. Get out your calendar and save the dates for the 2019 Program Events.

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2019 Featured Events

Winter Wine Fest
Friday, February 8, 2019
Brio at Tivoli Village
6:00-8:00 pm

Join the Nevada Chapter for an evening of wine tasting to raise funds for the Nevada Chapter programs serving youth and young adults. Ticket price $30 in advance, $35 at the door. Purchase your tickets online at www.hfnv.org.

We are seeking sponsors, silent auction donations, and volunteers for the Winter Wine Fest. Contact Christine at cbettis@hemophilia.org to get involved.

Advocacy Events
Sunday, February 17: Advocacy Training in Carson City.
Monday, February 18: State Advocacy Day at the State Capitol
March 27—March 29: Washington Days, Washington DC

To be considered to participate in each of these events, please complete a registration form by December 15th. Candidates will be selected by December 20th, 2018 for participation in the state events.

Spring Education Fest
Saturday, March 16, 2019
Circus Circus, Las Vegas NV

Join us for the Annual Spring Education Fest at Circus Circus. Kids will enjoy an outing to Adventuredome while parents attend education sessions. Everyone will rejoin for lunch in the ballroom.

Register at www.hfnv.org

We are seeking volunteers to chaperone the kids through Adventuredome. Please contact Maureen at mmagana@hemophilia.org to sign-up.

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

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

2019 Calendar of Events

January 26	**Winter Mini Education Day: Advocacy Boot Camp**
February 8	**Winter Wine Fest, Las Vegas**
February 9	**Family Event: Rex Center, Las Vegas**
February 17-18	**State Advocacy Day, Carson City**
March 2-3	**LIT Training, Las Vegas**
March 16	**Spring Fest, Las Vegas**
March 27-29	**Washington Days, Washington DC**
April 15	**Golf Gets In Your Blood, Las Vegas**
April 27	**Spring Mini Education Day: Focused on Women, Las Vegas**
May 11	**Family Event: Bowling, Las Vegas**
June 10-15	**Camp Independent Firefly, Big Bear CA**
June 29	**Couples Retreat, Las Vegas**
July 6-10	**Teen Camp, Sacramento**
July 18	**LIT Training, Reno**
July 19-21	**Northern Nevada Family Camp, Elko**
July 20	**Elko Unite for Bleeding Disorders Walk, Elko**
July 27	**Summer Mini Education Day: Spanish, Las Vegas**
August 3	**Renee Paper Picnic, Las Vegas**
August 9-11	**PEP, Las Vegas**
August 24	**Tahoe Family Education**
September 14	**Reno Unite For Bleeding Disorders Walk, Reno**
September 21	**Las Vegas Unite for Bleeding Disorders Walk, Las Vegas**
October 2-5	**National Bleeding Disorders Conference, Anaheim, CA**
October 19	**Fall Mini Education Day, Las Vegas**
November 16	**Bikes In Your Blood, Henderson**
November 20	**Ely Patient Appreciation Dinner/Clinic**
December 7	**Annual Meeting & Holiday Party, Las Vegas**
December 11	**Elko Holiday Party**
December 12	**Reno Holiday Party**
December 19	**Volunteer & Donor Appreciation Reception, Las Vegas**

Key: **Southern Nevada-Red** **Out of State—Purple**
Northern Nevada—Blue **Northeastern Nevada—Green**

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

Un Mensaje de nuestra Directora Ejecutiva

Queridos amigos,

Quiero extender mi sincero agradecimiento a todos los que hicieron del 2018 un éxito. Hemos tenido un año con muchos cambios, nuevos desafíos e increíbles historias de éxito.

La adaptabilidad, la perseverancia y la dedicación de nuestra comunidad de trastornos de la coagulación de Nevada continúan inspirándome a encontrar nuevas formas de cumplir con nuestra misión de encontrar la más alta calidad de atención médica y calidad de vida a través del apoyo de la comunidad, la educación y la abogacía para los afectados.

Ver a una comunidad de apoyo crecer para los trastornos de la coagulación es increíble, con nuevos donantes, colaboradores y voluntarios uniéndose a nuestra comunidad dedicada de colaboradores para marcar la diferencia cada día.

Gracias. Es por su apoyo que podemos esperar el 2019 con un sentido de esperanza mientras trabajamos para lograr un cambio positivo para la comunidad de trastornos de la coagulación.

Estos son solo algunos de los puntos destacados de este año que usted ayudó a lograr:

- Mejoramos el acceso al cuidado médico por abogacía para extender la autorización previa.
- Aumentamos el conocimiento de las mujeres no diagnosticadas con trastornos de la coagulación con más de 10,000 personas contactadas por nuestra campaña por internet.
- Celebramos 32 eventos ofreciendo más de 149 horas de programación educativa.
- Ayudamos a 30 familias cuando más lo necesitaban con asistencia financiera de emergencia

Tengo una última solicitud para el 2018. **¿Podrías hacer el futuro más brillante al hacer un regalo de fin de año?** Su donación apoya a las personas afectadas por trastornos hemorrágicos desde el nacimiento hasta la edad adulta, ayudándoles a alcanzar un futuro productivo, sin dolor e independiente. ¡Done ahora hasta el 31 de diciembre para hacer posible un futuro más brillante!

Con un cordial saludo y un sincero agradecimiento,

Betsy VanDeusen
Directora Ejecutiva

LOS TRES

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

1. Da el regalo de un futuro brillante. Haga una donación de fin de año a NHFNV.
www.hfnv.org

2. Compre, tome y apoye en el Winter Winefest el 8 de febrero.
www.hfnv.org

3. Saque su calendario y guarde las fechas para los Eventos del a 2019.
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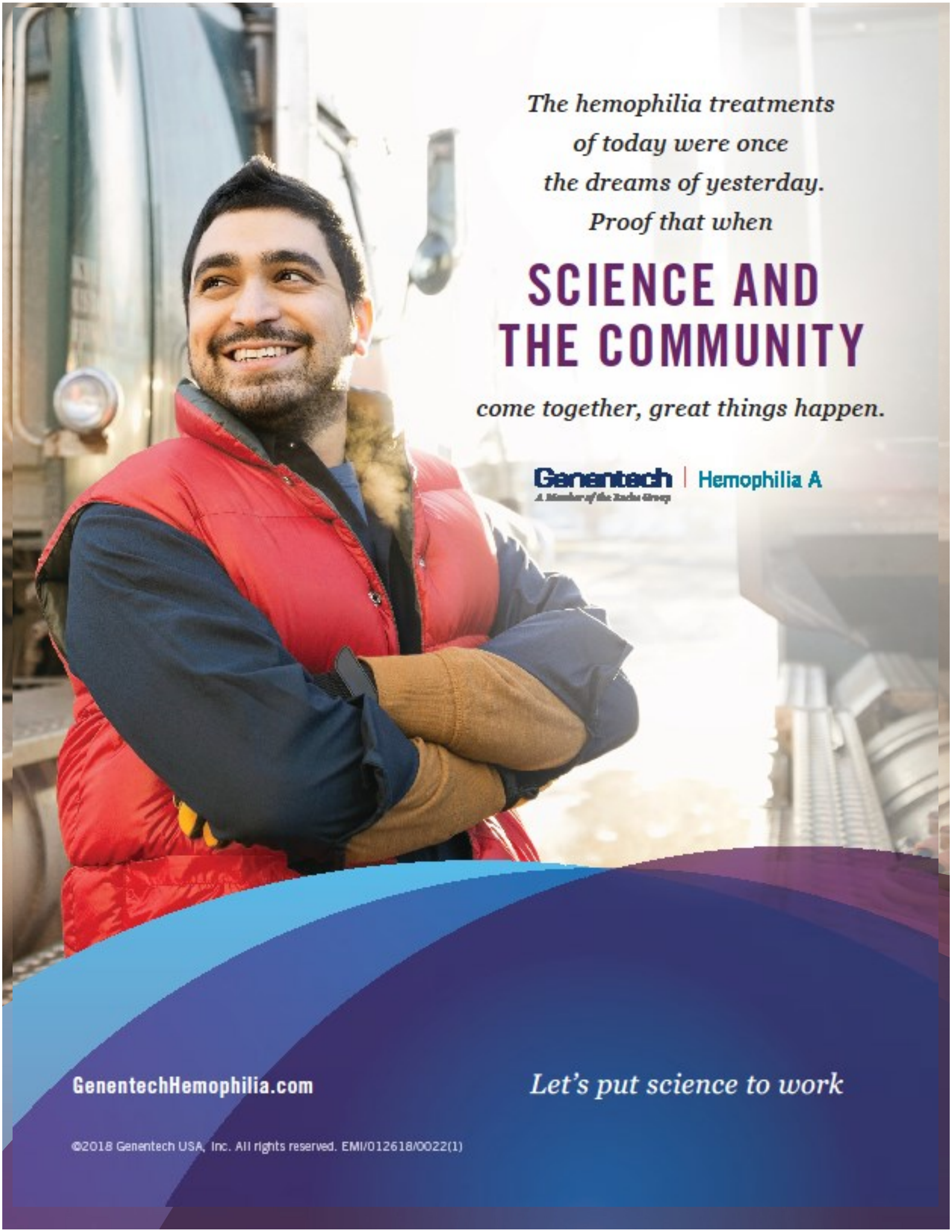


National Program Spotlight: Online Education

NHF's online education provides free quality education on issues that matter to all members of the bleeding disorders community, from moms of young children to adults with inhibitors. These webinars and webcasts bring the experience of expert providers and your peers directly to you. Whether you need help figuring out insurance issues or are wondering how to tell your boss about your bleeding disorder, NHF's online education brings you the information you need.

Over twenty archived topics include:

- Technology & Fitness: Using Technology as Part of Your Fitness Routine
- What to Know: Parenting with a Baby and a Bleeding Disorder
- The Advantage of Prophylaxis for Adults with Joint Issues
- Skills for Coping with Anxiety and Depression
- Communicating in the Workplace
- To Reveal of Conceal: Navigating Disclosure of a Bleeding Disorder
- The Art of Speaking Up
- Is Hemophilia a Secret? Disclosure in a World Filled with Technology
- Getting Unstuck: Overcoming Roadblocks to Intimacy and Relationships
- Learning to Let Go: Fostering Independence

View webinars at https://www.hemophilia.org/Events-Educational-Programs/Online-Education

Community Spotlight: Jesus Lopez

Meet Jesus.

What is your diagnosis story?

One day when I was younger I was playing in the front yard when suddenly I got my foot stuck in a hole in the grass. I fell with my foot still being stuck in the hole and it caused my knee to bend sideways. My knee later swelled up a great amount. My parents took me to many doctors to see what was happening inside my knee because a week after the injury the swelling was still there. No doctor could give me a proper diagnosis and eventually the swelling went away with the help of home remedies and no walking. It wasn't until a while later that I began to have frequent nose bleeds that my mom decided to take me to the doctor once again. There the doctor sent me to go get tested for Hemophilia and that is when, at the age of six, I was diagnosed.

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

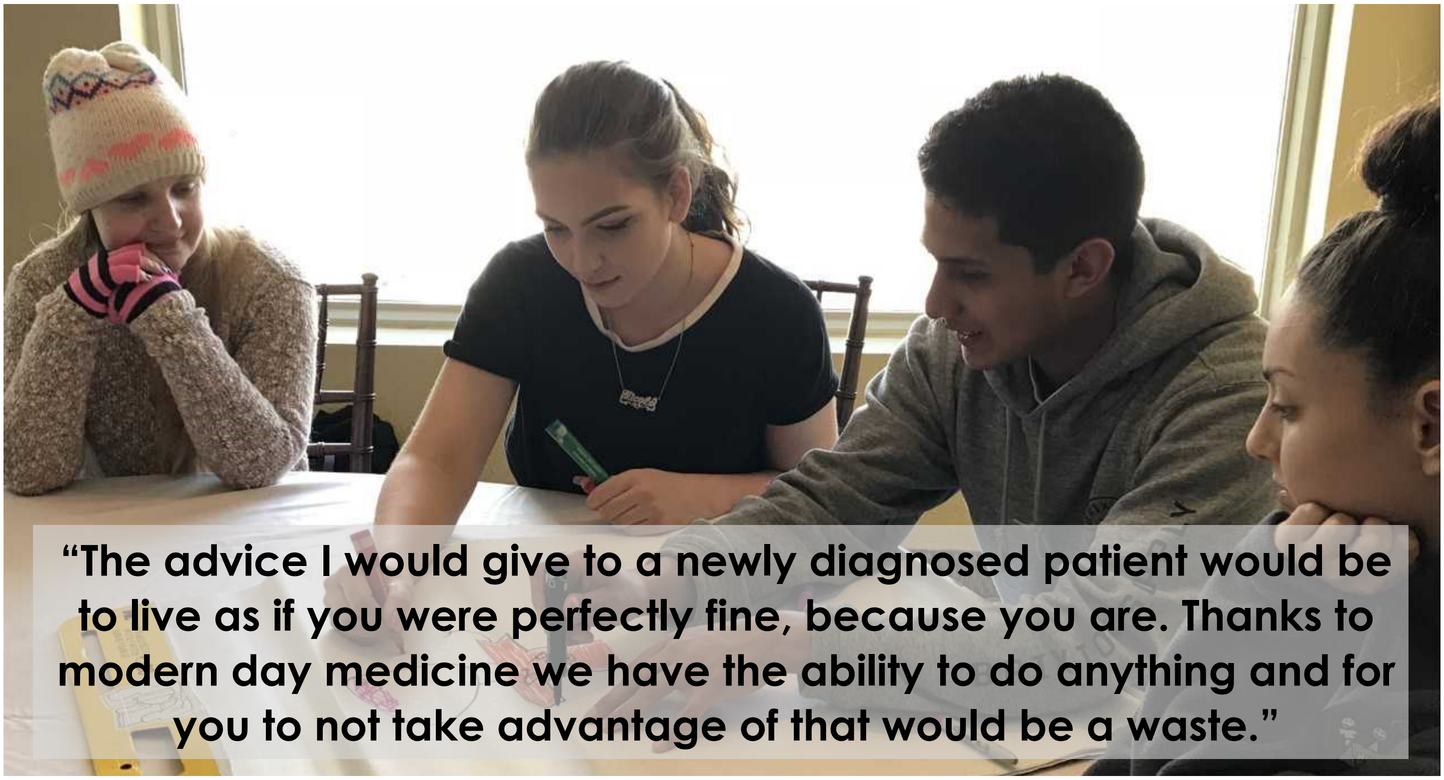
My family had to learn how to care for me properly to make sure that I was as healthy as I could be. They would check up on me more frequently, when I played outside. They always told me to be extra careful and the fridge was now stuffed with factor.

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

The advice I would give to a newly diagnosed patient would be to live as if you were perfectly fine, because you are. Thanks to modern day medicine we have the ability to do anything and for you to not take advantage of that would be a waste. Other people who aren't familiar with the disorder may still treat you differently but it shouldn't affect you because you know who you are what you are capable of. Do you and keep on keeping on.

Talk about your involvement with the chapter.

I've been involved with the community since my diagnosis, I try to make every event that is held. I've been going to camp since I was 7 or 8 and now I am a counselor. I just recently went to my first conference in Orlando. I saw many people who went through the challenges of hemophilia without access to the medicine we have today. This motivated me to continue to take care of myself so that I am able to enjoy all that life has to offer.



> **"The advice I would give to a newly diagnosed patient would be to live as if you were perfectly fine, because you are. Thanks to modern day medicine we have the ability to do anything and for you to not take advantage of that would be a waste."**

We're in this together.

Estamos en esto juntos.

NCHS ha estado sirviendo a pacientes con hemofilia y trastornos hemorrágicos desde el año 2000. Debido a nuestra experiencia en trastornos hemorrágicos, sabemos de primera mano que la situación de cada paciente es única. En cada interacción, usted encontrará personal experimentado y dedicado dispuesto a escuchar y comprender cómo podemos satisfacer mejor sus necesidades específicas. Ya sea que usted sea nuevo en el tratamiento, un veterano de los trastornos hemorrágicos o que esté transitando por la vida en algún punto intermedio, su equipo en NCHS está con usted en cada paso del camino.

nchs | DE PUERTA A PUERTA + MUCHO MÁS

¡Nos encantaría saber de usted!
Llámenos al **877.616.6247** o visite
NCHSwecare.com para obtener más información.

NCHS has been serving hemophilia and bleeding disorder patients since 2000. Because of our expertise in bleeding disorders, we know firsthand that every patient's situation is unique. In every interaction, you'll encounter experienced, dedicated staff ready to listen and understand how we can best meet your specific needs. Whether you're new to treatment, a bleeding disorder veteran, or navigating life somewhere in between, your team at NCHS is with you every step of the way.

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We'd love to hear from you! To learn more,
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Potential Gene Therapy for Hemophilia A, AMT-180, May Treat Patients Regardless of Inhibitor Status, uniQure Says.

NOVEMBER 26, 2018
JOSE MARQUES LOPES, PHD
from Hemophilia News Today

Potential Gene Therapy for Hemophilia A, AMT-180, May Treat Patients Regardless of Inhibitor Status, uniQure Says

A gene therapy from uniQure in early testing, called AMT-180, has the potential to treat all hemophilia A patients, including those with inhibitors, according to the company.

Hemophilia A is caused by missing or defective factor VIII (FVIII), a clotting protein. About 30% of patients with severe hemophilia A develop inhibitors, or antibodies, that neutralize FVIII activity.

AMT-180 is designed for one-time intravenous (IV) delivery and uses a type of viral vector called adeno-associated virus 5 (AAV5). The potential therapy contains a modified factor IX gene known as Super9, which has shown an ability to bypass inhibitors to FVIII in preclinical studies, suggesting it may be beneficial for a patient population previously excluded from gene therapy approaches.

A proof-of-concept study in mice also demonstrated that Super9 had clinically relevant activity mimicking FVIII, and was not associated with exaggerated blood clotting.

In primates, a single AMT-180 dose led to expression levels corresponding to FVIII activity likely to be clinically relevant in hemophilia A patients with or without inhibitors, the company said. These findings were supported by Super9-induced activation of the blood clotting protein thrombin in FVIII-depleted human blood with or without inhibitors.

Results suggest long-term prevention of bleeds in hemophilia A patients treated with AMT-180, the company said.

uniQure also recently issued a company update on ongoing patient enrollment in its open-label Phase 3 trial (NCT03569891) of a potential gene therapy for hemophilia B, called AMT-061. More information on participation is available here.

And it announced that three patients taking part in a Phase 2b study (NCT03489291) of AMT-061, which is also still enrolling eligible patients, have already been treated. Information for this trial is available here.

At its Research & Development (R&D) Day, held on Nov. 19 in New York City, uniQure also announced the development of other one-time AAV approaches to possibly treat Fabry disease and spinocerebellar ataxia type 3 (SCA3).

For Fabry disease, uniQure is advancing AMT-190. This therapy is intended to evade anti-GLA protein antibodies found in most male patients, so as to be a more effective and longer-lasting therapy.

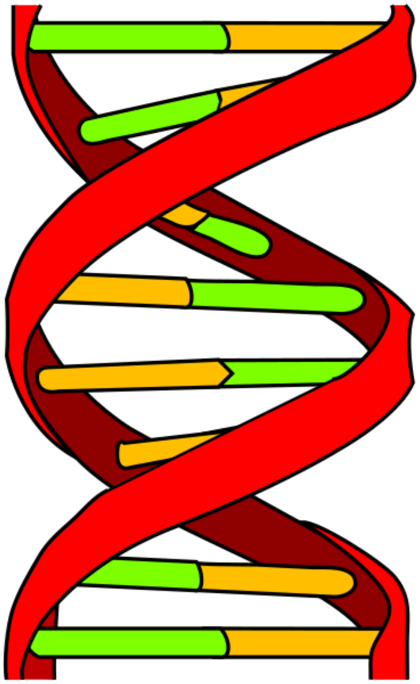
For SCA3, also known as Machado-Joseph disease, uniQure is developing AMT-150, which uses the company's new miQURE technology to halt ataxia — a lack of voluntary coordination of muscle movements — in patients with early disease symptoms.

"We are very proud of the progress the Company has made to deliver extensive preclinical data for these new gene therapy programs that expand our pipeline and further validate uniQure's potential best-in-class vector delivery platform," Sander van Deventer, MD, PhD, uniQure's chief scientific officer, said in a press release.

The new gene therapy candidates represent a step forward "towards uniQure's goal of delivering transformational medicine to patients suffering from genetic diseases. We look forward to advancing these programs closer to the clinic in 2019," van Deventer added.

uniQure also presented advancements in technology and manufacturing, topped by miQURE, a technology platform designed to safely degrade disease-causing genes. miQURE is intended to induce long-lasting gene silencing of the entire target organ. Improved tissue specificity and more pronounced gene expression lowering were seen in preclinical studies. Besides AMT-150, miQURE has been incorporated into AMT-130, a Huntington's disease treatment candidate.

The company also showed data on a novel promoter — the DNA portion that initiates gene expression — for liver-directed gene therapies, indicating up to 40-fold greater protein expression compared to the referenced alternative. This promoter will be incorporated in AMT-180.



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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Bikes In Your Blood

BIKES IN YOUR BLOOD

The first Bikes In Your Blood fundraising ride was a big success with over 60 cyclists and over $14,000 raised in support of the bleeding disorders community

Thank you to our sponsors for making a difference and supporting Bikes In Your Blood!

Presenting Sponsors:

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HEMOSTASIS & THROMBOSIS CENTER of NEVADA

Event Sponsors

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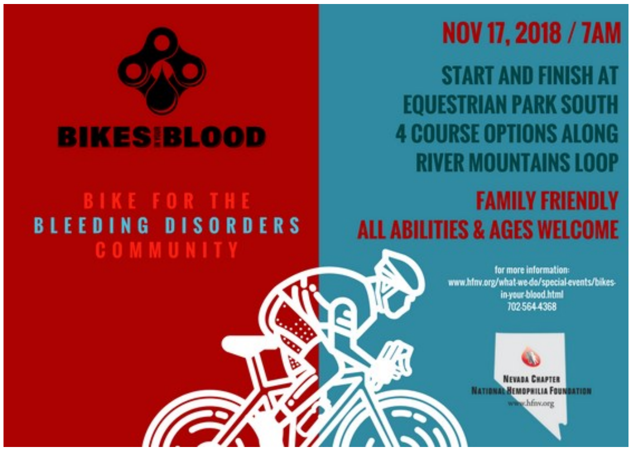

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NOV 17, 2018 / 7AM

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www.hfnv.org/what-we-do/special-events/bikes-in-your-blood.html
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Nevada Chapter
National Hemophilia Foundation
www.hfnv.org

5 formas de fomentar la independencia en su adolescente con un trastorno hemorrágico

He aquí cómo ayudar a su hijo adolescente a tomar las medidas necesarias para convertirse en adulto

Author: Donna Behen

Family Matters

Si usted tiene un hijo con un trastorno hemorrágico, los años de la adolescencia pueden ser difíciles. Es una época en la que los adolescentes buscan naturalmente separarse de sus padres y asumir más responsabilidad. Pero después de años de estar tan involucrado en el manejo del trastorno hemorrágico de su hijo, puede ser difícil dar un paso atrás y darle la libertad e independencia que los adolescentes necesitan a medida que crecen hacia la edad adulta.

¿Cómo puede ayudar a los adolescentes con trastornos hemorrágicos a ser más independientes y capacitarlos para que se hagan cargo de su salud? Aquí tiene algunas sugerencias:

1. Entregue todas las responsabilidades del tratamiento

Lo ideal es que un adolescente ya haya dado uno de los pasos más importantes hacia la independencia, que es aprender a inyectarse a sí mismo. Pero además de ese importante hito, los adolescentes deben manejar muchos de los otros aspectos de su tratamiento, incluyendo conocer los detalles de sus medicamentos, ser responsables de su propio registro de tratamiento y, finalmente, asumir la tarea de pedir sus medicamentos.

2. Manténgase positivo

Ya sea que se trate de ayudar a su hijo a hacer la transición para manejar su horario de citas médicas, reconocer los signos de sangrado o hacer frente a una emergencia médica, su actitud puede hacer toda la diferencia.

"Hágale saber a su hijo que usted está seguro de que puede asumir estas nuevas responsabilidades, y que usted está ahí para asesorarlo o ayudarlo de cualquier manera que pueda necesitar", dice la Dra. Mary Alvord, una psicóloga clínica infantil en un consultorio privado en Rockville y Chevy Chase, Maryland.

"Lo importante no es solo lo que usted dice", sugiere Alvord, "sino aún más, lo que hace". "Usted puede demostrar que algo es desafiante pero también expresar en voz alta sobre cómo abordará el tema".

"Este enfoque puede contrarrestar esos pensamientos *negativos* a los que los adolescentes pueden ser susceptibles, y proporcionar el poderoso mensaje a su adolescente de que *puede* intentarlo, y *puede* lograrlo, con ayuda" dice Alvord, autora de Conquistar los pensamientos negativos para adolescentes.

3. Enséñele al adolescente a abogar por sí mismo

Anime a su hijo a que empiece a desempeñar un papel más activo en su propia atención médica hablando y haciendo preguntas a los miembros del equipo del centro de tratamiento de la hemofilia (hemophilia treatment center, HTC) o a su médico de atención primaria. Una vez que los niños están en edad de asistir a la escuela secundaria, deben poder hacer sus propias citas con el médico y pedir sus deben poder hacer sus propias citas con el médico y pedir sus propios suministros de factor y de infusión.

Mientras más personas puedan abogar por sí mismas y aprender a comunicar lo que necesitan, más se sentirán en control de su atención médica, dice Alvord. "También sabemos que ser proactivos y pedir ayuda son fortalezas que influyen en la resiliencia".

Según un estudio reciente, los adolescentes que tienen una afección médica pueden estar mejor preparados para pasar de la atención pediátrica a la atención de adultos mientras se hacen cargo de su propia atención médica que los adolescentes que no tienen un problema médico. Cuando los psicólogos de la Universidad de Georgia estudiaron a 494 pacientes adolescentes mayores y adultos jóvenes, encontraron que los que tenían una afección crónica eran más autosuficientes para completar las tareas relacionadas con la salud y dependían menos de los aportes de sus padres.

4. Inscríbase en un campamento

Una semana en un campamento para pasar la noche es cuando muchos adolescentes con trastornos hemorrágicos aprenden a desempeñar un papel más importante en el control de su propia salud. No solo se sienten más cómodos y seguros con inyectarse a sí mismos, sino que también ganan independencia al estar fuera de casa durante varios días. Muchos de los niños que participan activamente en el campamento pasan de ser campistas a consejeros, lo que les enseña responsabilidad y habilidades de liderazgo. Hay más de 50 campamentos de verano en 37 estados para jóvenes con trastornos hemorrágicos, y el costo por lo general lo cubre su delegación local. No es demasiado pronto para empezar a planear para el próximo verano. Encuentre un campamento cerca de usted poniéndose en contacto con su delegación local o HTC, o busque en el localizador de campamentos en la web de la NHF< https://www.hemophilia.org/Community-Resources/Locate-a-Camp-Near-You-0>.

5. Anime a su adolescente a conectarse con otros adultos jóvenes

Los adolescentes necesitan modelos de conducta y mentores, y hablar con otros adolescentes y adultos jóvenes que tienen trastornos hemorrágicos puede ayudarles a sentirse mucho más cómodos acerca de su papel cambiante. Usted puede ayudar a su hijo a conectarse con adultos jóvenes en su área comunicándose con su delegación local de la NHF para descubrir qué programas están disponibles. La participación en estos eventos puede ayudar a los adolescentes a aprender a hablar de manera mucho más abierta y adecuada sobre su trastorno con sus amigos, y también es más probable que actúen de manera responsable y se apropien de su atención médica.

Program Recap: Annual Meeting & Holiday Celebrations

December 1, 2018
Annual Meeting & Holiday Celebration, Las Vegas

170 community members joined together for our Annual Consumer Meeting and Holiday Gathering at the East Las Vegas Community Center, we had amazing sessions on The ABCs (A=Advocate, B=Believe, C= Create), Understanding VWD, Let's talk about Anxiety and Depression, and two great programs for the kids, My Amazing Blood, and Jr. Scientist where kids learned about clotting and got to recreated how a blood clot forms.

Thank you to our Sponsors::

Presenting: Hemostasis & Thrombosis Center of Nevada

Gold: Bayer, Bioverativ, CSL Behring,
Genentech, Grifols, Novo Nordisk, Shire

Silver: CVS Health, Octapharma, Soleo Health

December 5, 2018
Annual Meeting & Holiday Celebration, Elko

65 community members came together for a dinner at the Hilton Garden Inn. Bioverativ shared an engaging presentation on Highlighting Unaffected Siblings that helped attendees learn new ways to connect with the entire family. Santa visited bringing stockings donated by the Las Vegas little helpers and a gift for all the children.

Sponsored by Bioverativ, Factor Support Network, Soleo, and Octapharma

Program Recap: Annual Meeting & Holiday Celebrations

December 6, 2018
Annual Meeting & Holiday Celebration, Reno NV

60 members of the Reno and Carson community came together for a fun evening featuring an engaging talk about family communication offered by Bioverativ, crafts, raffle, and of course a visit from Santa!

Sponsored by Bioverativ, Factor Support Network, Soleo, and Octapharma

Program Recap: Fall Events

September 12, 2018
Bioverativ Education Dinner, Reno, NV

28 community members attended the dinner presentation in Reno to learn about how DNA works and the relationship between DNA and Hemophilia.

Hosted by Bioverativ

September 22, 2018
Elko Women's Retreat

10 women joined some of our amazing community leaders at our Elko Women's Retreat to discuss great topics like Women Bleeders, Finding your Voice, To Treat or Not to Treat. Event concluded with a trip to the Spa for a relaxing manicure and pedicure.

Sponsored by Octapharma, Factor Support Network and the Hemostasis & Thrombosis Center of Nevada.

October 6, 2018
Shire Education Talk—Spanish, Las Vegas, NV

17 Spanish community members attended Shire's Hello Talk about Resilience. Managing stress is an important aspect of our lives, of every day. This presentation discussed some of the causes of stress and provides examples of how best to adapt and manage adversity.

Hosted by Shire.

October 8, 2018
Shire Education Talk, Winnemucca, NV

Our Winnemucca families gathered for an intimate dinner and discussion about types of Von Willenbrand and how to recognize potential treatment options, and learn how emotional and community support systems can help those living with this bleeding disorder.

Hosted by Shire

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

During the two-day educational event 44 community members attended various sessions including Advocacy Bootcamp, Couples Day Retreat, Powering Through Keynote by Patrick James Lynch, New Family Infusion Class, Teen Leadership, and TIPs to improve Communications with Healthcare Providers (Spanish).

November 7, 2018
Shire Education Talk, Reno, NV

26 community members of our Northern Nevada community attended Shire's Hello Talk about Resilience in Reno. The presentation shared important causes of stress and gave examples of how to work through challenges.

Hosted by Shire.

Jacey Gonzalez, Speaker, welcoming women to the Elko Retreat.

Families listening to Binh Le, Speaker, at the Las Vegas Shire Talk in Spanish.

Families gathering and connecting during lunch at the Fall Fam Jam.

Program Recap: Fall Events

November 11, 2018
Men's Event at Top Golf, Las Vegas, NV

The event included time for our 18 participants in TOPGOLF's plush hitting Bays and an informal golf clinic with Perry Parker, a PGA professional with a bleeding disorder. Perry led skill-building activities, explained how he found the strength to overcome the challenges of his disorder to achieve his dream, and educated participants on the importance of leading a happy, healthy and active lifestyle.

Sponsored by CSL Behring and Quality Home Infusion

November 16, 2018
Bayer Education Dinner

20 community members attended our Bayer – Pain In Hemophilia Dinner, where Judy Kaufman led a discussion on the importance of people with bleeding disorders understanding that pain is a journey, and shared skills on how to describe their pain experience to their healthcare provider.

Presented by Bayer.

Men's Event participants posing with Perry Parker.

What is HEMLIBRA?

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

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

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

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

HEMLIBRA
emicizumab-kxwh

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

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

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

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

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

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

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

What is HEMLIBRA?

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

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

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

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

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

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

How should I use HEMLIBRA?

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

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

What are the possible side effects of HEMLIBRA?

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

The most common side effects of HEMLIBRA include:

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

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

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

How should I store HEMLIBRA?

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

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

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

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

ADVERTISEMENT

In the Numbers

QUARTER 3 - 2018

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

social media
Q3
2018

WWW.FACEBOOK.COM/NHFNV
27 PAGE LIKES
446 POST LIKES
36 COMMENTS
101 SHARES

TWITTER: @NVHEMOPHILIA
50 LIKES
16 RETWEETS
25 LINK CLICKS

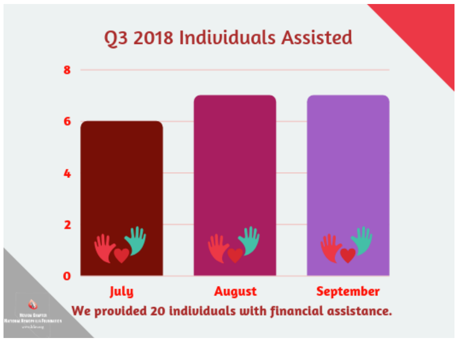
Instagram
@NHFNV
63 LIKES
3 COMMENTS

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

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.


Q3 2018 Individuals Assisted

We provided 20 individuals with financial assistance.

NHF NV EVENTS

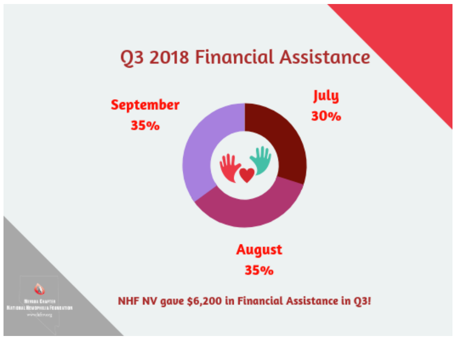
Q3 Events

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

LAS VEGAS UNITE FOR BLEEDING DISORDERS WALK	RENO UNITE FOR BLEEDING DISORDERS WALK
421 registrants **$54,370 raised**	**102 registrants** **$10,186 raised**
HIGHLIGHTS Beautiful weather Alison Bartko speaking during the Pinwheel Ceremony Team Nightwing wins top team!	**HIGHLIGHTS** Record turnout and amount raised! Delicious cookout Team Genentech wins top team!

LOOKING AHEAD

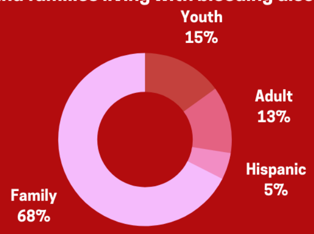
Register for our fourth annual Winter Wine Fest happening Friday, February 8, 2019! Join us & make a difference today!


Q3 2018 Financial Assistance

NHF NV gave $6,200 in Financial Assistance in Q3!

NHF Nevada Program Hours Q3 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, as well as our annual Northern NV Family Day, Tahoe Family Day, and our Renee Paper Memorial Picnic and Back to School event!

YOUTH PROGRAMS

Our New Family Playgroup meets on the second Saturday of every month at a new, fun location! Look for the event on our FB page to RSVP.

ADULT PROGRAMS

In August, CSL Behring, Brothers Healthcare, and HTCNV sponsored our Las Vegas Women's Retreat. 25 women attended and enjoyed yoga, planting an intentional garden, and education sessions.

HISPANIC PROGRAMS

Pfizer sponsored a Spanish Education DInner in Reno in August at The Twisted Fork which focused on topics like how to deal with chronic illness, medical finances, and the importance of staying active.

40 PROGRAM HOURS
319 ATTENDEES

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Wagner Lemus
Co-Founder

Antonio Rosas
Co-Founder

Hablamos Español

Acceso 24/7 a Farmacéuticos con Experencia

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

Cadena de Suministro de Factor de Coagulación Segura

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

Monitoreo de Cumplimiento de Normas y Programas de Adhesión

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

Coordinación de Servicios de Enfermería

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

Comprensión de los Beneficios De Seguro

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

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

Serving all of Nevada

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www.fidelis-rx.com

Wagner Lemus
Co-Founder

Antonio Rosas
Co-Founder

We Speak Spanish

24/7 Access to Knowledgeable Pharmacists

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

Secure Pharmaceutical Supply Chain

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

Compliance Monitoring & Adherence Programs

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

Home Nursing Services Coordination

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

Understanding Insurance Benefits

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

"Your preferred specialty pharmacy for the hemophilia community"

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

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

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ACT—Access to Care Today
Achieve a CURE Tomorrow

YOU CAN SUPPORT A

Bright Future

Your donation supports people affected by bleeding disorders from birth to adulthood - helping them reach a productive, pain-free, and independent adulthood.

Donate now through December 31 at
https://bitly.com/
or hfnv.org