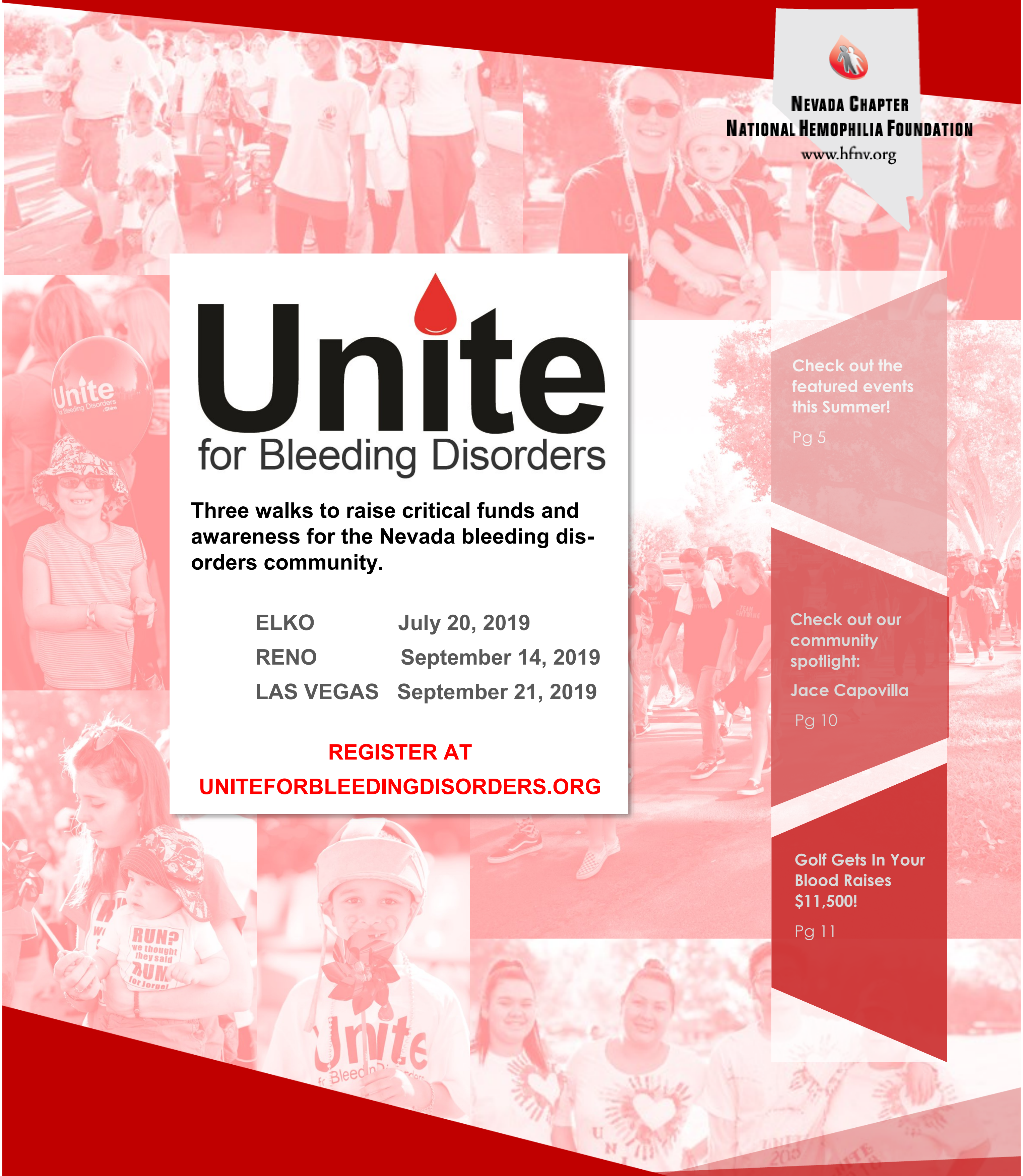
Nevada Chapter Newsletter
Summer 2019

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.hfnv.org



Unite
for Bleeding Disorders

Three walks to raise critical funds and awareness for the Nevada bleeding disorders community.

ELKO	July 20, 2019
RENO	September 14, 2019
LAS VEGAS	September 21, 2019

REGISTER AT
UNITEFORBLEEDINGDISORDERS.ORG

Hemophilia News & Views

Mission

The Nevada Chapter of the National Hemophilia Foundation's mission is to improve the quality of care and life for people with hemophilia, von Willebrand disease and other inherited bleeding disorders through education, peer support and advocacy.

The National Hemophilia Foundation is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy and research. "Coming together is a beginning. Keeping together is progress. Working together is success."

Contact Us

Nevada Chapter of the National Hemophilia Foundation
222 S. Rainbow Blvd. Suite 203, Las Vegas, NV 89145 I Phone: 702-564-4368 I Fax: 702-446-8134 I www.hfnv.org

Our Team

Staff

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The Nevada Chapter is hiring a Development Manager. We look forward to welcoming a new member of our team soon!

Board of Directors

Officers

President: Kim Luong Velasquez
Vice President: Lupe Torres
Treasurer: Miriam Calderon
Secretary: Open

Directors

Sarah Hoover
Joel Bousley
Renee Cotrell Duran

2019 CALENDAR OF EVENTS

Jun 10-15	**Camp Independent Firefly, Big Bear CA**
Jun 19	**Pfizer Education Talk: Spanish, Reno**
Jun 29	**Couples Retreat, Las Vegas**
Jul 6-10	**Teen Rafting Camp, Sacramento**
Jul 13	**Play Group, Las Vegas, NV**
Jul 18	**LIT Training, Reno**
Jul 19-21	**Northern Nevada Family Camp, Elko**
Jul 20	**Elko Unite for Bleeding Disorders Walk**
Jul 27	**Latinos Unidos, Las Vegas**
Aug 3	**Renee Paper Picnic, Las Vegas**
	Teen Leadership Training, Las Vegas
Aug 10	**Play Group Infusion Class, Las Vegas**
Aug 16-18	**PEP, Las Vegas**
Aug 24	**Tahoe Family Education**
	Pfizer Education Talk: Balancing Emotional Wellness, Las Vegas
Sept 6-8	**Familia De Sangre, Anaheim, CA**
Sept 10	**Novo Nordisk Education Talk: Food & Fitness, Las Vegas**
Sept 14	**Reno Unite For Bleeding Disorders Walk**
Sept 21	**Las Vegas Unite for Bleeding Disorders Walk**
Sept 28	**Hispanic Community Education Dinner, Las Vegas**
Oct 2-5	**National Bleeding Disorders Conference, Anaheim, CA**
Oct 12	**Play Group—Dental Health Lunch, Las Vegas**
Oct 12-13	**Reno Women's Retreat, Reno**
Oct 19	**Product Dinner Round Table, Las Vegas**
Nov 6	**Sanofi Education Talk: Navigating Insurance, Reno**
Nov 9	**Play Group, Las Vegas**
Nov 15	**Teen Etiquette & Insurance Dinner, Las Vegas**
Nov 16	**Bikes In Your Blood, Henderson**
Nov 20	**Ely Patient Appreciation Dinner/Clinic**
Dec 7	**Annual Meeting & Holiday Party, Las Vegas**
Dec 11	**Elko Holiday Party**
Dec 12	**Reno Holiday Party**
Dec 19	**Volunteer & Donor Appreciation Reception, Las Vegas**

Dates & topics subject to change. Please check the Chapter website periodically. To RSVP for an event visit www.hfnv.org

Letter from Our Executive Director / Mensaje de nuestra Directora Ejecutiva

Dear Friends,

Summer is here and it's time to connect with your bleeding disorders family! As the weather heats up, I hope you will join us at one of our summer events. We have something for everyone no matter where you are in Nevada.

The Nevada Chapter offers over 30 programs annually to the Nevada bleeding disorders community. These programs are offered free of charge so that everyone living with a bleeding disorder can benefit from education, support, and skill development.

This summer, I hope you will consider making a donation to support the Nevada Chapter's programs. **$200 sponsors one person for a whole year and gives them the opportunity to learn, grow, and connect so that they can reach their highest quality of life and quality of care possible.** You can sign up for a $16.50 monthly gift to provide much needed funding the Chapter and become a Chapter Champion. Please visit https://hfnv.org/get-involved/chapter-champion.html to register today.

I hope you will consider getting connected and giving back this summer.

Sincerely,

Betsy VanDeusen
Chapter Executive Director

Queridos amigos,

¡El verano está aquí y es hora de conectar con su familia de trastornos de sangre! A medida que el clima se calienta, espero que nos acompañe en uno de nuestros eventos de verano. Tenemos algo para todos, sin importar dónde se encuentre en Nevada:

El Capítulo de Nevada ofrece más de 30 programas anuales a la comunidad de trastornos de sangrado de Nevada. Estos programas se ofrecen de forma gratuita para que todas las personas que viven con un trastorno de sangre puedan beneficiarse de la educación, el apoyo y el desarrollo de habilidades.

Este verano, espero que consideren hacer una donación para apoyar los programas del Capítulo de Nevada. **$200 patrocina a una persona por un año entero y les brinda la oportunidad de aprender, crecer y conectarse para que puedan alcanzar la mejor calidad de vida y la mejor atención posible.** Puedes inscribirte para dar un regalo mensual de $16.50 para proporcionar el financiamiento del Capítulo y convertirte en un Campeón del Capítulo. Visite https://hfnv.org/get-involved/chapter-champion.html para registrarse hoy.

Espero que consideren conectarse y retribuir este verano.

Sinceramente,

Betsy VanDeusen
Chapter Executive Director

CHAPTER CHAMPION

Supporting the Nevada Chapter of the National Hemophilia Foundation

$16.50/month gives 30+ educational programs, peer support, and assistance to an individual affected by bleeding disorders. Sign-up for your monthly gift and become a Chapter Champion at www.hfnv.org/get-involved/chapter-champion.org.

2019 Featured Events

Couples Retreat
June 29-30, 2019
The D Las Vegas

RSVP by June 14, 2019

10 couples will come together for an amazing afternoon and evening. The workshops will explore different type of intimacy to help couples build strong relationships. Presenters will offer communication tools and practical ideas to cultivate a rewarding, enjoyable connection with a partner. Following the workshops, couples will be treated to "Marriage Can Be Murder" dinner theater performance and enjoy a one night stay at the D Las Vegas.

Register online at www.hfnv.org

Latinos Unidos
Saturday, July 27, 2019
Texas Station

Latinos Unidos is an educational conference offered completely in Spanish. Sessions will cover the topics of mindfulness and self advocacy. The program will include Lunch, entertainment, and a special activity.

Register online at www.hfnv.org

Northern Nevada Family Education Weekend
Friday, July 19—Sunday, July 21, 2019
Elko Convention Center, Elko, NV

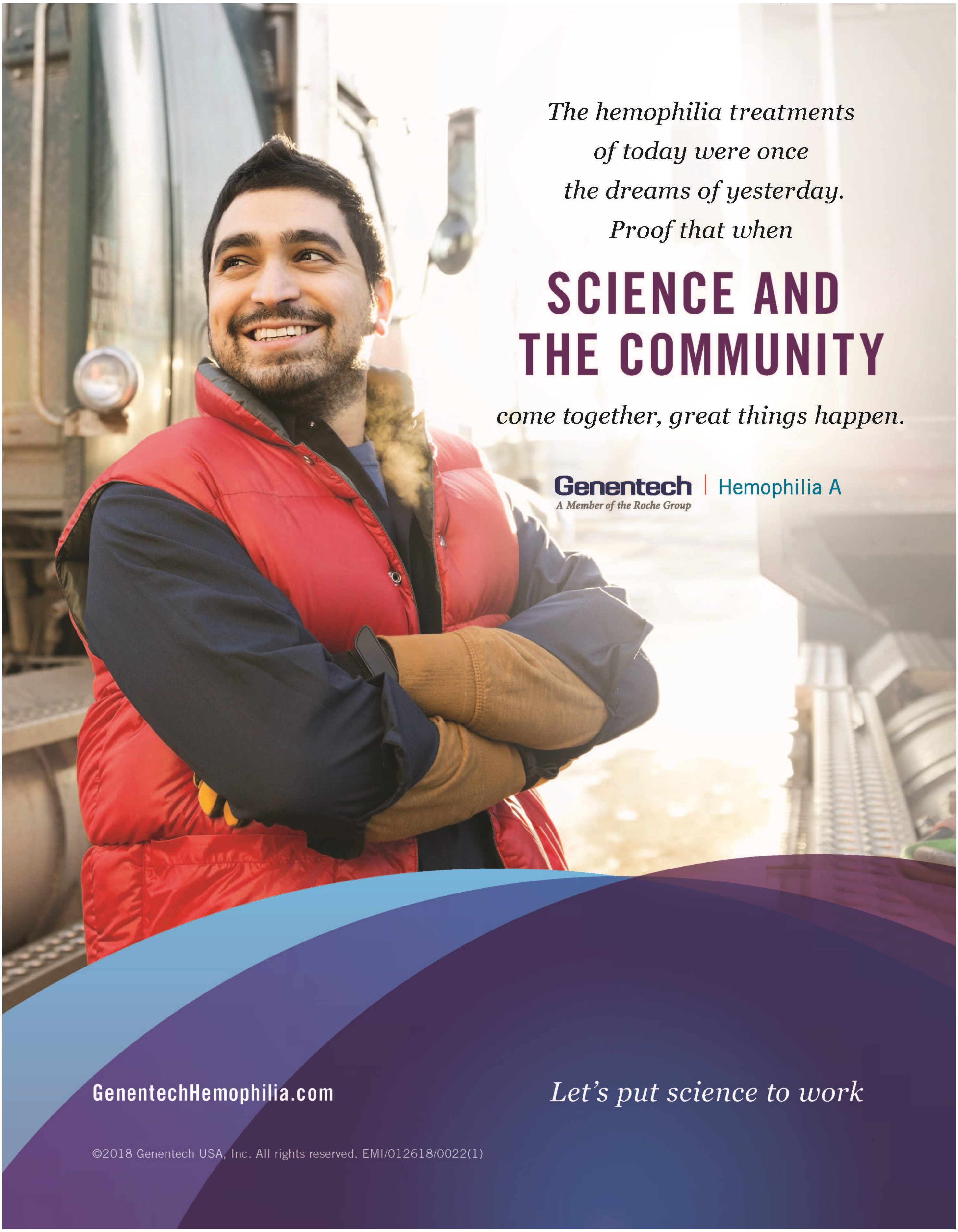
Join us in Elko for a Family Education Weekend from Friday evening– Sunday morning. Take "Family Camp Challenges" throughout the weekend for a chance for your family to win a prize. Education sessions on setting educational expectations, parenting children with bleeding disorders, tools for self-advocacy, self-infusion workshops, and more. Special day camp for kids ages 5-14 on Friday & Saturday. Family Swim, Bingo, Bowling & BBQ!

Register at www.hfnv.org

Those traveling 50+ miles to the convention center are eligible for a travel grant gas card and hotel room. Register by 6/21/2019 and submit travel grant request on registration.

Teen Leadership Retreat
Saturday, August 3, 2019—Springs Preserve, Las Vegas, NV

30 teens will be selected for this adventure-education based retreat. Gain leadership and independence skills through a series of games, challenges, reflection and activities. Held the same day as the Renee Paper Picnic - join your family in the evening for open swim, BBQ and fully loaded backpack. Registration will open in June. Space is limited. Register at www.hfnv.org.


The hemophilia treatments
of today were once
the dreams of yesterday.
Proof that when
SCIENCE AND
THE COMMUNITY
come together, great things happen.
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Let's put science to work
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6 Ways for Young Adults to Make Adherence Easier

Following through with your treatment protocol isn't always easy, but it's essential for your health

Author: Beth Levine

"I wish I could go back and tell my younger self to take my hemophilia more seriously," says Sean Jeffrey, now 28, of Missoula, Montana. As a middle schooler, his adherence to his treatment protocol was hit or miss. "Sometimes I just wouldn't infuse and then I'd go play tackle football at recess."

Jeffrey says he didn't start to make adherence more of a priority until he was 16. "I got more mature, and my joints started to get worse," he says. "I really wanted to keep playing sports, so I kept infusing regularly so I could allow myself to do those things."

Taking responsibility for your own care is an important milestone for anyone with a bleeding disorder, but it can often be challenging when you're also being bombarded with the physical, psychological and social changes that come with young adulthood.

Research shows that many young adults are likely to struggle with adherence issues. One 2016 study by researchers at the Northern Regional Bleeding Disorder Center in Michigan revealed that while 17% of study participants between ages 13 and 17 were nonadherent to their prescribed treatment regimens, that number jumped to 47% for participants ages 18 to 25.

"We will see kids who have been treated all their lives at hemophilia treatment centers, but as teens learn to treat themselves. With this independence, teens may skip a dose," says Lisa Littner, MSW, LISW-S, hemophilia grants manager and a former social worker at the hemophilia treatment center at Cincinnati Children's Hospital. "If there is no bad result, they think, 'I don't need this, I'm OK skipping once in a while.' But other times, they can have a severe bleed." Missing doses increases the chance of bleeding and thus long-lasting joint damage.

Neglecting treatment may even have insurance implications, says Marla Feinstein, senior policy and healthcare analyst at the National Hemophilia Foundation. "Insurance companies request infusion logs because they know the long-term costs to patients who don't follow their regime," Feinstein says. "Those bleeds you get when you don't stay on track will add up to increased costs down the road."

How to Get Back on Board

If you have trouble staying compliant with your recommended treatment routine, try these tips:

- Remind yourself: Post notes around your home that remind you to infuse.
- Use technology: Set up calendar alerts, or get an app that helps you track your doses and bleeds.
- Find an infusion buddy: "Is there someone you can check in with and say, 'Hey, I did my factor today; did you do it too?'" says Sean Jeffrey, of Missoula, Montana, who has hemophilia.
- Educate yourself: Learn why you need to adhere to your protocol. "I know your treatment team can be annoying and frustrating, especially when they are telling you that you can't play a sport, but know that they are doing it for a reason, that they have your best health in mind," Jeffrey says.
- Connect with peers: Others in the bleeding disorders community can share advice about how they stay compliant. Jeffrey, for example, went to bleeding disorders camp. "I think it's the most beneficial thing kids with hemophilia can do. You become independent, learn to take care of yourself, find other kids like you and know you are not alone," he says.
- Connect with elders: At chapter events or camp, talk to slightly older people who have a bleeding disorder. Hearing what they have gone through can be eye-opening.

Elko Walk
Saturday, July 20, 2019
Main City Park, Area 8
5 PM Registration, 6 PM start

Reno Walk
Saturday, Sept 14, 2019
Bartley Ranch Park
9 AM Registration, 10 AM start

Las Vegas Walk
Saturday, Sept 21, 2019
Floyd Lamb Park
8 AM Registration, 9 AM start

FIND YOUR WALK AND REGISTER AT UNITEFORBLEEDINGDISORDERS.ORG

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

ADYNOVATE® is FDA approved for children and adults 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. Work with your doctor to determine an infusion schedule that is appropriate for you.

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 to see if ADYNOVATE treatment may be right for you and visit ADYNOVATE.com

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

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 (HCP) 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

Who should not use ADYNOVATE?

Do 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 HCP if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

What should I tell my HCP before using ADYNOVATE?

Tell your HCP 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 or 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).

DETAILED IMPORTANT RISK INFORMATION (cont'd)

What important information do I need to know about 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.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

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. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADYNOVATE?

- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP 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 Important Facts about ADYNOVATE on the following page and discuss with your HCP.

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*. 2017;23(2):238-246. **3.** Data on file; Shire US Inc.

Shire

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

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

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

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

What is ADYNOVATE?

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

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

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

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

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

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

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

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

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

How should I use ADYNOVATE? (cont'd)

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

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

You should tell your healthcare provider if you:

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

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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.ADYNOVATE.com or 1-877-825-3327.

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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S47033

Community Spotlight: Jace Capovilla

Meet Jace.

Jace went into surgery at 18 months of age to remove his adenoids. After recovery and once home, Jace continued to bleed internally for the next 6 hours. We had no idea that he was still bleeding until it was quite visible. He underwent emergency surgery. The doctor was able to stop the bleeding and ultimately saved Jace's life. This was the moment that changed our lives forever.

The next day, a hematologist from California flew to Nevada to meet with us in the hospital. This meeting was quite emotional from not only what occurred the day before, but also to be learning that our son had a bleeding disorder. We did not know anything about bleeding disorders. **Will Jace be okay? What does this mean? What will this look like? What do we need to do now and in the future?** We had so many questions and as some were answered more questions arose. Each test provided another layer to the complex diagnosis of hemophilia.

For months and months, 2 year old Jace underwent a multitude of blood tests and doctor visits. Each time, it left us exhausted and disheartened. Having to wrestle and hold your baby down for what seemed like hours because they couldn't get any blood or not enough blood, and watching your child endure this treatment on a monthly basis was excruciating. All the while trying to convince yourself that your little boy has to go through this to get answers. Luckily, we had a wonderful hematologist that spent time educating us. We were trying to learn all we could while still trying to comprehend that Jace had a bleeding disorder and that our lives would never be the same again.

After all of the tests, we learned that Jace had Hemophilia A. It was quite shocking to learn that merely 400 babies are born with hemophilia each year in the United States. Most importantly, we learned what to do if Jace had an injury, which was quite common being that he was a two year old boy in preschool. Although we learned what to do it never prepares you for when it happens, even if it happens a lot. You do panic! You do freak out!

Jace is 10 years old now and the panic and freaking out has subsided. Fortunately, he doesn't get hurt as often. When he does our hearts will still race and adrenaline rushes through our bodies, but we feel prepared and ready for anything that may occur. This preparedness is only because of the Hemostasis and Thrombosis Center of Nevada (HTC) and the Nevada Chapter.

Our lives have changed, and we are so fortunate to have such a wonderful young boy! Jace is in the 4th grade now and participates in sports. His favorite is swimming and soccer. The HTC has taught us so much about living life with Hemophilia. They have taught us about physical activity, teacher and school preparedness, medication, factor infusions, and the disease in general. Through the Chapter, Jace has had the opportunity to meet peers with bleeding disorders and has made some lifelong friends.

I would recommend anyone newly diagnosed with a bleeding disorder to get information as soon as possible. Knowledge is power! Our knowledge grows with every event and meeting. We are very involved with the chapter. We have participated in almost all of the northern Nevada events as well as some of the southern Nevada events. These events include walks, dinners, information events, advocacy days as well as a summer camp for the kiddos. **The partnership that our family has formed with the HTC and the Chapter has afforded us empowerment to advocate for our son.** I truly believe that once you have found a support system that works for you and your family then your child will be encouraged and empowered as well.

2019 Golf Gets In Your Blood

Held on April 15, 2019, 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.

Total funds raised in support of our mission: $11,489

These funds could:

- **Send 20 kids to camp**
- **Provide 20 families with financial assistance**
- **Provide educational programs for 57 adults for the year**

Thank you to our sponsors, committee, donors, golfers, and staff who came out for our tournament! It was a super successful and fun event, and we are grateful for all the support! Highlights include the Toby Gallegos Tribute Team; Campers speaking at the reception; and the Bloody Mary bar!

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

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GOLF GETS IN YOUR BLOOD

Nevada Chapter
National Hemophilia Foundation
www.hfnv.org

Thank You to Our Sponsors

Program Recap: Spring Events

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

132 community members attended educational talks on Resilience, Mindfulness, Navigating Insurance Benefits and connected with Chapter Programs while the kids enjoyed a trip to Adventuredome, chaperoned by our generous volunteers!

March 27-29, 2019
Washington Days, Washington DC

9 Nevadans traveled to Washington DC to advocate for access to care with our national legislatures. Attendees met with 7+ representatives and senators and attended trainings on how to build advocacy at the State level.

Washington Days, March 2019

April 13, 2019
Play Group at Kangamoo, Las Vegas, NV

15 people enjoyed a play date at Kangamoo. Parents had a chance to connect with the kids played on the indoor playground.

April 27, 2019
Women's Retreat, Boulder City, NV

19 women came together for an amazing weekend of reflection, relaxation, and sharing. Held in Boulder City, NV the women had a chance to connect with each other and their personal goals.

Sponsored by Octapharma, Factor Support Network, Aptevo & HTCNV

Women's Retreat, April 2019

May 11, 2019
Family Day at Lake Las Vegas, Henderson, NV

44 people attended our first Lake Las Vegas Family Day. After enjoying bagels and coffee, everyone had a chance to explore the lake on electric boats for a beautiful day on the water.

Family Day at Lake Las Vegas, May 2019

OUR GOAL IN CARING FOR PATIENTS WITH BLEEDING DISORDERS IS MORE THAN PROVIDING FACTOR AND SUPPLIES.

We provide drug utilization management, patient education and patient services that promote adherence to therapies which result in improved outcomes.

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Antonio Rosas
Co-Founder

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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.

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Satiscacción del Paciente
99%
Datos de encuesta de satisfacción del 2017

La Próxima Generación de Investigadores Médicos

Los ganadores del Programa Clínico de Becas de la Fundación Nacional de Hemofilia (National Hemophilia Foundation, NHF)-Shire están comprometidos con la atención e investigación médica de trastornos hemorrágicos.

Desde 2003, 36 médicos han participado en este programa. El prestigioso programa, financiado a través del generoso apoyo de Shire, se desarrolló para atraer nuevos médicos al campo de la hematología no maligna y apoyar su desarrollo como investigadores clínicos. La meta es aumentar la cantidad de médicos comprometidos con carreras en el campo de los trastornos hemorrágicos, al brindarles capacitación de alta calidad. Los becarios son nominados por directores del programa provenientes de 23 centros de tratamiento destacados académicamente en Estados Unidos. El premio brinda hasta $100,000 anuales para apoyar dos años de capacitación en la institución becaria.

En octubre, la NHF anunció a los dos últimos ganadores de la beca: Hanny Al-Samkari, MD, del Boston Hemophilia Center/Massachusetts General Hospital y la Universidad de Harvard; y Michel H. White, MD, de la Universidad Emory y el Children's Healthcare of Atlanta.

Hanny Al-Samkari, MD
Al-Samkari obtuvo su título universitario en la Universidad de Washington, en St. Louis. Realizó su residencia en medicina interna en el hospital de la Universidad de Pensilvania, y su beca en hematología y oncología médica en el programa combinado del Instituto de Cáncer Dana-Farber del Massachusetts General Hospital (MGH). Durante su beca, su pasión por la hematología clásica aumentó bajo la tutela principal del David Kuter, MD, en el MGH. La investigación de su beca se centraba en indicaciones novedosas sobre los receptores agonistas de trombopoyetina.

Como becario de NFH-Shire, Al-Samjari obtendrá experiencia clínica y en investigación, relacionada con la hemofilia y los trastornos hemorrágicos poco comunes, bajo la tutela de Stacy Croteau, MD, en el Boston Children's Hospital; y Eric Grabowski, MD, y Larissa Bornikova, MD, en el MGH.

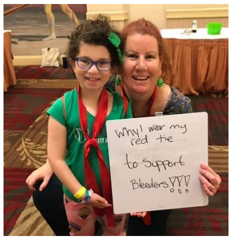
También liderará la clínica de telangiectasia hemorrágica hereditaria en el MGH, bajo la tutela de Kuter. Al-Samkari es un educador médico dedicado y miembro de la iniciativa del Programa de Hematología Benigna de la Sociedad Americana de Hematología. Mientras fue becario, impartió clases y se desempeñó como profesor de varios cursos y continúa enseñando a estudiantes de medicina, residentes, asistentes médicos y estudiantes de asistentes médicos.

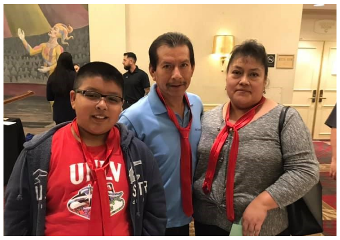
Michael H. White, MD
White es un hematólogo pediátrico y becario de oncología en la Universidad de Emory/Children's Healthcare of Atlanta (CHOA). Obtuvo su título universitario en la Facultad de Medicina de la Universidad del Suroeste de Texas y realizó su residencia de pediatría general en la Universidad de Vanderbilt. Está inscrito en el programa de la Maestría en Ciencias de la Investigación Clínica en la Universidad Emory y se le otorgaron fondos a través de una beca de capacitación del Instituto Nacional de Salud TL1, debido a su enfoque en ciencia multidisciplinaria clínica y traslacional. White es el presidente electo de la Red de Becarios de la Sociedad de Investigación de la Trombosis y es miembro de la junta de la Fundación Internacional de Atención Médica.

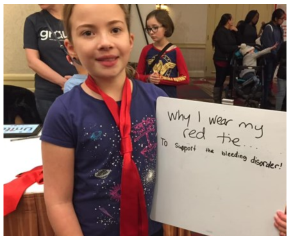
Como un becario del programa de NHF-Shire, White recibirá capacitación clínica especializada, en la Clínica Integral de Trastornos Hemorrágicos y la Clínica de Hemorragias para Mujeres y Niños en el CHOA, bajo la tutela del Robert Sidonio, MD, y Shannon Meeks, MD. Además de su enfoque clínico para tratar pacientes, la investigación clínica de White se basará en caracterizar el control y los resultados del sangrado menstrual abundante en adolescentes con trastornos hemorrágicos y en aquellas que tomen medicamentos anticoagulantes o antiplaquetarios.

THE 2019 NHF REDTIE CAMPAIGN™
FOR ALL BLEEDING DISORDERS

Thank you to our entire community for a successful 2019 Red Tie Campaign. Through your support and hard work we raised amazing awareness for bleeding disorders and generated over $2,000 to support our Nevada advocacy efforts.





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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.

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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

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injection for subcutaneous use
150 mg/mL

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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

ADVERTISEMENT

In The Numbers

2019 Quarter One In Review

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

NHF NV EVENTS

Q1 2019 Events

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

170 ATTENDEES	**$18,555 RAISED**

social media Q1 2019

WWW.FACEBOOK.COM/NHFNV
9 NEW PAGE LIKES
51 POSTS
558 LIKES

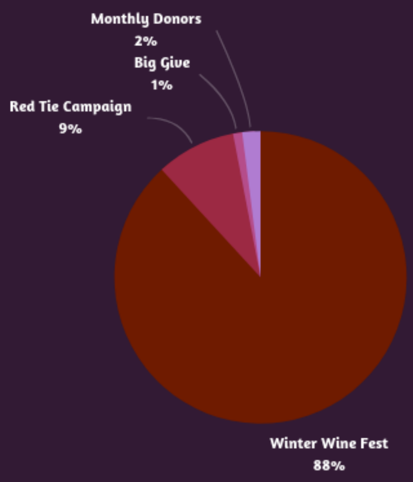
TWITTER: @NEVADANHF
99 TWEETS
88 LIKES
12 RETWEETS
38 NEW FOLLOWERS

Instagram
@NEVADANHF
7 POSTS
145 LIKES
34 NEW FOLLOWERS

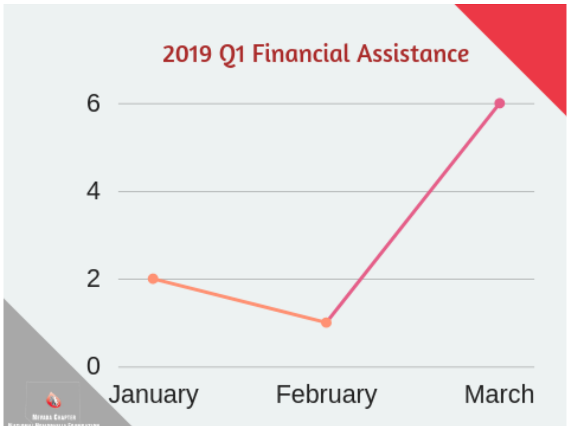
Here at the chapter, we love it when you engage with us online. Be on the lookout for our photos, FB events, and community spotlights!

Nevada Chapter
National Hemophilia Foundation
www.hfnv.org

Q1 2019 Donors



NHF NV had a total of 80 individual donors in Q1!



NHF NV gave $4,877.23 in Financial Assistance in Q1!

NHF Nevada Program Hours Q1 2019

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.

30 PROGRAM HOURS
249 ATTENDEES

FAMILY PROGRAMS

These include our education days and dinners. Our annual Spring Fest took place March 16th at Circus Circus with 132 attendees!

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

Our retreats help the men and women of our community to cope and thrive with their bleeding disorder.

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.

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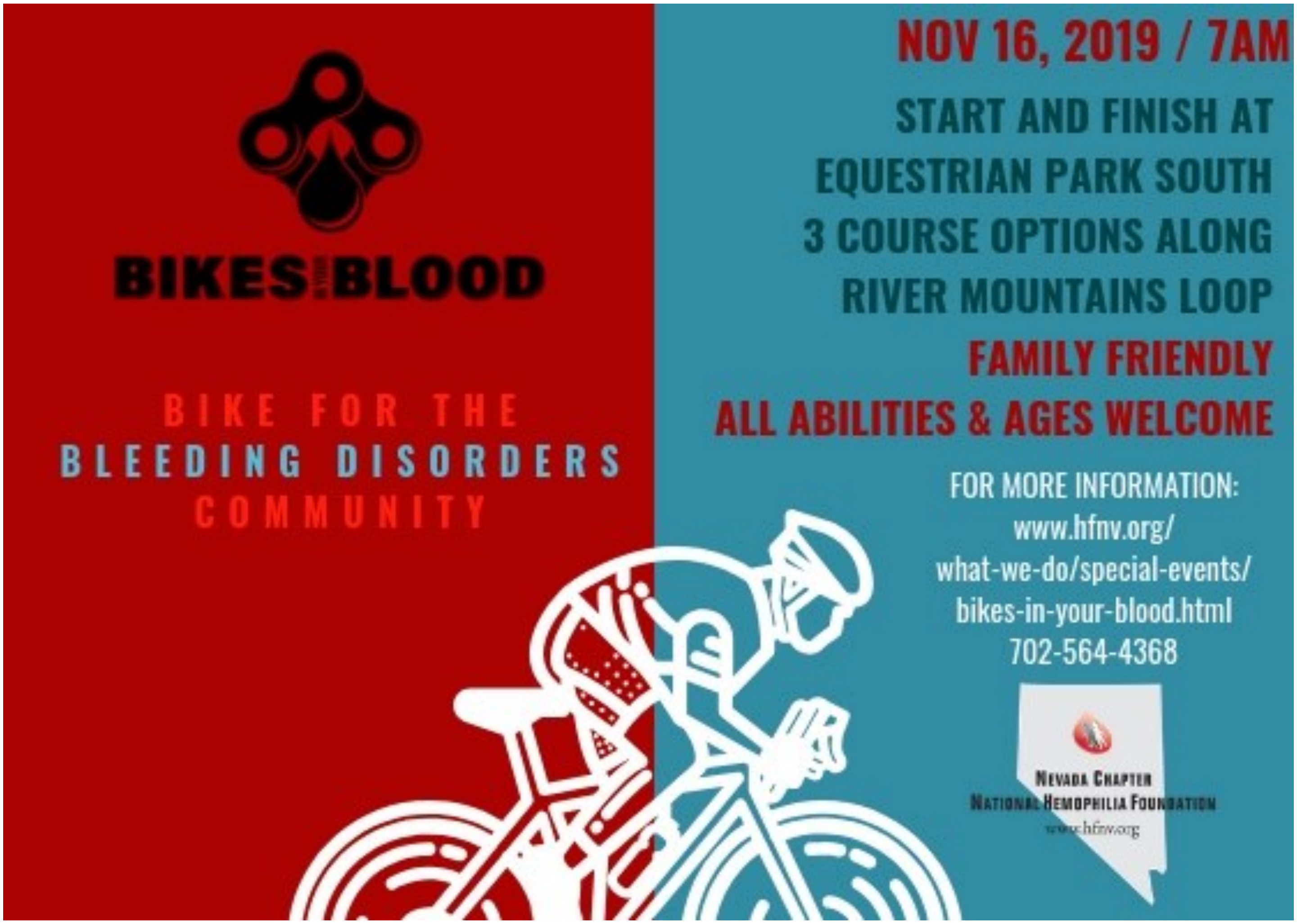

NOV 16, 2019 / 7AM

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