Nevada Chapter Newsletter
Fall 2019

Nevada Chapter
National Hemophilia Foundation
www.hfnv.org

BIKES IN YOUR BLOOD

November 16 2019
River Mountain Loop Course
Henderson/Boulder City

3 COURSE OPTIONS:
36 MILES - 14 MILES - 7 MILES

REGISTER AT HFNV.ORG

Check out the featured events this Fall!
Pg 5

Check out our community spotlight:
The Wolff Family
Pg 16

Unite Walks Raise $70,000 across the State!
Pg 9

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

Betsy VanDeusen
Executive Director
Phone: 702-564-4368 x100
bvandeusen@hemophilia.org

Maureen Magana-Salazar
Chapter Bilingual Program Manager
Phone: 702-564-4368 x101
mmagana@hemophilia.org

Kaley Dingeman
Development Manager
Phone: 702-564-4368 x 102
kdingeman@hemophilia.org

Board of Directors

Officers

President: Kim Luong Velasquez
Vice President: Lupe Torres
Treasurer: Miriam Calderon
Secretary: Renee Cotrell Duran

Directors

Sarah Hoover

2019 CALENDAR OF EVENTS

Oct 2-5	**National Bleeding Disorders Conference, Anaheim, CA**
Oct 11	**Teen Leadership Council, Las Vegas**
Oct 12-13	**Reno Women's Retreat, Reno**
Oct 19	**Product Round Robin Dinner, Las Vegas**
Oct 28	**Trunk or Treat at HTCNV, Las Vegas**
Nov 4	**Legislative Summit, Las Vegas**
Nov 6	**Sanofi Education Talk: Navigating Insurance, Reno**
Nov 6	**Takeda Product Dinner: VWD, Las Vegas**
Nov 8-10	**PEP, Las Vegas**
Nov 15	**Adulting 101—Teen Program, 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**

2020 CALENDAR OF EVENTS

Feb 7	**Winter Wine Fest**
Feb 26-27	**Washington Days, DC**
Mar 21	**LIT Training for Camp, Las Vegas**
Mar 28	**Spring Fest, Las Vegas**
Apr 17	**World Hemophilia Day**
Apr 25	**Latinos Unidos, Las Vegas**
May 2	**Golf Gets In Your Blood**
Jun 9-13	**Camp Independent Firefly**
Jul 10-15	**Teen Rafting Camp**
Jul 24	**LIT Training, Elko**
Jul 24-25	**Northern Nevada Family Camp, Elko**
Jul 25	**Elko Unite For Bleeding Disorders Walk**
Aug 5-7	**Bleeding Disorders Conference, Atlanta**
Sep 12	**Reno Unite for Bleeding Disorders Walk**
Sep 19	**Las Vegas Unite for Bleeding Disorders Walk**
Sep 26	**Latinos Unidos Luncheon, Las Vegas**
Nov 21	**Bikes In Your Blood**
Dec 5	**Annual Meeting, Las Vegas**
Dec 9	**Elko Holiday Event**
Dec 10	**Reno Holiday Event**

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,

I am so inspired at how our community embraced the Walk Program this year. Your support as team captains, volunteers, donors, and walkers made it possible to raise $70,000 across the State! Congratulations and thank you. Your support will make it possible for the Nevada Chapter to continue to provide the same level of support, programs and assistance you've come to expect.

This Fall, I hope you will consider supporting the Nevada Chapter as a volunteer! We have open positions for community members on the board of directors, programs committee and advocacy committee. Please reach out to me if you are interested. We depend on the input and perspective of community members to drive our programs and services.

I am pleased to welcome Kaley Dingeman, Development Manager to our Nevada Chapter Team. You may have met her during the Walks. She joins us with a warm and outgoing personality and a background in communications, customer service and fundraising.

I look forward to seeing you at one of our upcoming events this Fall and hope to see many of the great leaders in our community stepping up to fill the leadership roles in our organization!

Sincerely,

Betsy VanDeusen
Chapter Executive Director

Queridos amigos,

Estoy tan inspirada en cómo nuestra comunidad se dedicó a la caminata este año. ¡Su apoyo como capitanes de equipo, voluntarios, donantes y caminantes hizo posible recaudar $70,000 en todo el estado! Felicidades y gracias. Su apoyo hará posible que el Capítulo de Nevada continúe proporcionando el mismo nivel de apoyo, programas y asistencia que usted espera.

¡Este otoño, espero que consideren apoyar al Capítulo de Nevada como voluntario! Tenemos puestos vacantes para los miembros de la comunidad en la junta directiva, comité de programas y comité de abogacía. Comuníquese conmigo si está interesado. Dependemos de la opinión y la perspectiva de los miembros de la comunidad para impulsar nuestros programas y servicios.

Me complace dar la bienvenida a Kaley Dingeman, Gerente de Desarrollo a nuestro Equipo. Es posible que la hayas conocido durante las caminatas. Ella se une a nosotros con una personalidad cálida y extrovertida y una experiencia en comunicaciones, servicio al cliente y recaudación de fondos.

Espero verlos en uno de nuestros próximos eventos este otoño y espero ver a muchos de los grandes líderes en nuestra comunidad dar un paso adelante para llenar los roles de liderazgo en nuestra organización!

Sinceramente,

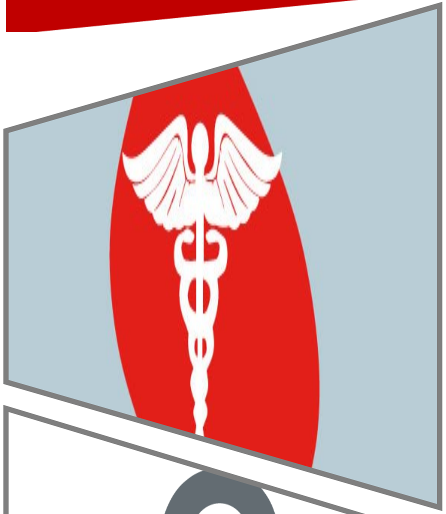
Betsy VanDeusen
Chapter Executive Director

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



Product Dinner Round Robin
October 19, 2019
The Orleans Convention Center, Las Vegas NV

RSVP by Oct 10, 2019

Wondering about products available to treat bleeding disorders? Get all your questions answered at this interactive, progressive dinner style round robin event.

2-5 pm: Rare Bleeding Disorders (Hemophilia B, Platelet Disorders, Inhibitors)
Visit with Manufacturers while sampling different appetizers.
5-7 pm: Networking, Exhibits & Dinner
7-9 pm: Hemophilia A & VWD Session
Visit with Manufacturers while sampling different desserts

Register online at www.hfnv.org

Bikes In Your Blood
Saturday, November 16, 2019
Equestrian Park South, Henderson NV

The cycling fundraiser offers three courses 6.5, 14.4 & 36.6 miles to engage all levels of riders. Registration is FREE but donations are encouraged! If you donate at least $25 get an exclusive Bikes In Your Blood t-shirt! Prizes for the top fundraising team!

Register online at www.hfnv.org

Annual Meeting & Holiday Celebration
Saturday, December 7, 2019: 10 am—5 pm
Orleans Convention Center, Las Vegas NV

Please join us for a day of fun, education, food and holiday cheer! The Annual Family Conference is taking place at a new location this year: The Orleans Convention Center. There will be a photo booth and a visit with Santa! We have some fabulous speakers that will be presenting topics in both English and Spanish for all ages. We will also have our annual raffle with proceeds benefiting our youth programs including Camp Independent Firefly!

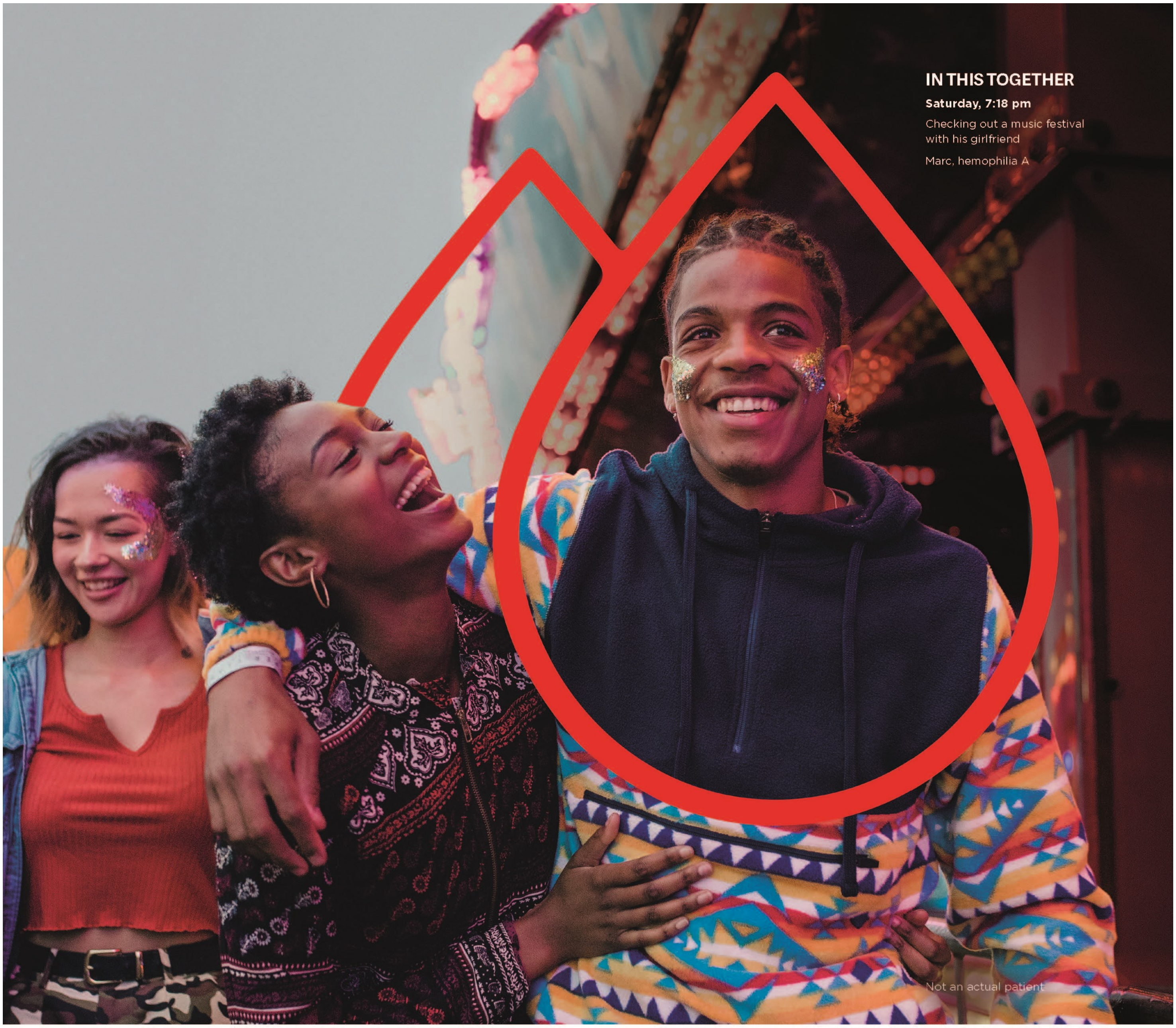
Register at www.hfnv.org

Centerpeice Contest—$50 gift card for the winner!
Donations: We are seeking donated presents, gift cards, and raffle prizes!

Elko Holiday Celebration
Wednesday, Dec 11, 2019
Hilton Garden Inn, Elko NV
6:30—8 pm

Reno Holiday Celebration
Thursday, Dec 12, 2019
Hunsberger Elementary, Reno NV
6:30—8 PM

Join us for a Holiday Celebration with the Bleeding Disorders Community and a visit from Santa. Please bring raffle prizes! Register at www.hfnv.org.


IN THIS TOGETHER
Saturday, 7:18 pm
Checking out a music festival with his girlfriend
Marc, hemophilia A
Not an actual patient

¿Qué es MyBDC?

MyBDC
BLEEDING DISORDERS COMMUNITY
Experiences Impacting the Future
NATIONAL HEMOPHILIA FOUNDATION

¿Qué es MyBDC?

My Bleeding Disorders Community or *MyBDC (por sus iniciales en ingles)* es un registro impulsado por pacientes para personas con trastornos hemorrágicos hereditarios y sus familiares. Esta iniciativa comunitaria capturará una visión de 360 -grados de vivir con un trastorno hemorrágico, directamente de las personas afectadas y sus familiares. Estas experiencias compartidas apoyarán y mejorarán la capacidad de los investigadores para mejorar los tratamientos actuales, descubrir terapias transformacionales y, lo más importante, contribuir a encontrar una cura.

¿Cómo va a funcionar?

Los participantes toman solo 2-3 minutos para inscribirse (proporcionar información demográfica básica y establecer un portal). En unas pocas semanas, los participantes recibirán una encuesta de referencia (la encuesta más larga) seguida de encuestas anuales "básicas". Las encuestas centrales pedirán información similar cada año para que se puedan observar patrones y tendencias. Periódicamente, los participantes pueden esperar recibir encuestas más cortas durante todo el año para ayudarnos a comprender los problemas que les interesan. Nuestro objetivo es mantener siempre la mayoría de las encuestas en menos de 15 minutos para completar. *Los participantes pueden optar por entrar y salir de las encuestas en cualquier momento **

- **Todas las encuestas son confidenciales.** Personal muy limitado tendrá acceso a los datos a nivel del paciente, y se accederá estrictamente según sea necesario. Cualquier acceso se documentará electrónicamente y se seguirá de forma similar a cómo se controlan los registros médicos. Las posibles razones para que el personal de NHF acceda a los datos a nivel del paciente incluirían: resolver consultas (por ejemplo, un hombre dice que tiene problemas con sus períodos o está embarazada), asistencia con contraseña, etc.
- **Informes**. ¡Cuantos más participantes estén inscritos, mejores serán los datos, para ellos personalmente, la comunidad en su conjunto, NHF, investigadores y capítulos! La información recopilada siempre se informará de manera agrupada y desidentificada; esto se hace para que nadie pueda ser identificado personalmente.

¿Quién es elegible para participar?

Esta iniciativa está abierta a personas afectadas con un trastorno hemorrágico y sus familiares inmediatos no afectados (padres, esposo/a, hermanos, abuelos, etc.).

¿Cuáles son los beneficios de participar?

Algunos beneficios para los participantes incluyen:

- Acceso a un panel de instrumentos personalizado para seguir las tendencias y comparar los cambios a lo largo del tiempo.
- Acceso a recursos educativos y información de tendencias.
- CareLinks – una herramienta para enviar información seleccionada a una persona o entidad específica (guardería / escuela / proveedor) durante un período de tiempo elegido (ej .: septiembre-junio)

Algunos beneficios del Capítulo incluyen:

- Acceso a un panel personalizado del Capítulo que contiene datos generales, agregados y no identificados de los participantes de MyBDC dentro del área de captación geográfica del Capítulo.
- Capacidad de enviar detalles de eventos de manera confidencial a los participantes de MyBDC que viven en el área de captación geográfica del Capítulo, ya sea que estén registrados en un Capítulo o no.
- Estadísticas instantáneas y completas para utilizar en la escritura de concesión, el desarrollo de recursos y la programación educativa.

¿Cómo puedo inscribirme o animar a otros a inscribirse?

Inscríbase si está afectado por un trastorno hemorrágico o un miembro de su familia. Anime a otros miembros del Capítulo y amigos a apoyar esta iniciativa y comenzar a inscribirse.

Apoye a la comunidad difundiendo la palabra.
Inscribirte AQUI. ¡Solo toma 2-3 minutos! Para obtener más información, vaya a MyBDC.hemophilia.org
*Si ya se ha inscrito en MyBDC, **¡GRACIAS!***


LOYAL PARTNERS
ON YOUR
JOURNEY
99%
Patient
Satisfaction
Survey Data
Based on 2017 patient satisfaction survey

Unite For Bleeding Disorders

2019 Unite For Bleeding Disorders raises $70,000!

Nevadans across the state came together to pledge support for bleeding disorders through three events held in Elko, Reno & Las Vegas! The funds raised go directly back into the community to support Nevadans living with bleeding disorders by funding our youth and family programs, advocacy efforts, and financial assistance offered to the over 500 Nevadans living with bleeding disorders.

Thank you to our sponsors, committee, donors, walkers, and team captains who made the 2019 Unite for Bleeding Disorders Walk Program successful!

Thank You to Our Local Sponsors!

GOLD SPONSORS

Hemostasis & Thrombosis Center of Nevada

novo nordisk®

Genentech
A Member of the Roche Group

SILVER SPONSOR

CSL Behring
Biotherapies for Life®

BRONZE SPONSORS

Diplomat Specialty Infusion Group

octapharma

Las Vegas Party Rentals

Soleo Health
Innovators in Specialty Infusion

Brothers Healthcare

LifeCare Specialty Pharmacy

CVS specialty

Unite for Bleeding Disorders

briova Rx

Thank You to Our National Sponsors!

Bayer

Pfizer

accredo
Specialty Pharmacy

Takeda

Grifols

Sanofi Genzyme

Photo Credit: Kayla Faasse & Jose Tabares


GO SEEK. GO EXPLORE.
GO AHEAD.
PEOPLE LIKE YOU. STORIES LIKE YOURS.
Explore more at HEMLIBRAjourney.com
Discover your sense of go. Discover HEMLIBRA®.

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

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

Genentech
A Member of the Roche Group

Program Recap: Summer Events

June 5: Bayer Education Dinner—Maintain Joint Health Through Exercise: Get Up and Move! Las Vegas, NV
26 community members enjoyed an Italian dinner at Maggiano's Little Italy while learning from Jeff Kallberg, PT, DPT, about how their body moves and how to strengthen their joints.

June 19: Pfizer Education Talk: Empoderando: herramientas para la auto abogacia, Reno, NV
21 people attended the dinner to learn about self advocacy. Presented in Spanish, the dinner helped the attendees learn how to make sure their voice is heard and needs are met.

June 29: Couples Retreat, Las Vegas, NV
8 couples attended two sessions on communicating with their partner and finding intimacy, followed by a dinner theater performance of Marriage Can Be Murder and a stay at the D Hotel on Fremont Street.

July 13: Takeda Education Talk—Understanding Von Willebrand Disease, Las Vegas, NV
42 people came together to learn about Von Willebrand Disease. The session offered in English and Spanish at Maggiano's in Downtown Summerlin gave an in-depth understanding of VWD.

July 18: Leaders In Training—Northern Nevada, Reno, NV
4 young adults attended the training at the Whitney Peak Hotel in Reno and then traveled to Elko to lead the children through a mini camp and support the family conference.

July 19-21: Northern Nevada Family Camp, Elko, NV
85 people from the Elko, Owyhee, Winnemucca and Reno community came together for a fun-filled, highly interactive conference that spanned three days with a mini-camp for kids, family challenges, and backpacks full of school supplies for all of the children.

July 27: Latinos Unidos, Las Vegas, NV
25 people attending the mini conference offered completely in Spanish with two education presentations, games, lunch and prizes. Sponsored by Takeda & the Hemostasis & Thrombosis Center of Nevada.

August 3: Renee Paper Family Picnic, Las Vegas, NV
114 community members came to the YMCA for a session on IEPs & 504s. The children played water games led by teen volunteers and everyone enjoyed an evening at the pool with BBQ. All kids left with backpacks for school.

August 3: Teen Leadership Retreat, Las Vegas, NV
12 teens participated in the leadership games, set goals, and learned skills for reaching independence. Led by Gut Monkey.


Takeda VWD Dinner, July 2019, Las Vegas


Northern Nevada Leaders In Training, July 2019, Elko


Northern Nevada Kids Camp, July 2019, Elko


Renee Paper Picnic "Water Games", August 2019, Las Vegas

Program Recap: Summer Events

August 21: Pfizer Education Talk—Balancing Emotional Wellness, Las Vegas, NV

22 individuals attended the educational presentation held at the Twisted Fork in Reno.

August 24: Tahoe Family Education Day, Lake Tahoe, NV

18 community members joined us on Lake Tahoe to learn about bleeding disorders with women and girls and enjoy a fun day kayaking on the lake. Sponsored by Aptevo and Factor Support Network.

September 10: Novo Nordisk Education Talk: Food & Fitness, Las Vegas, NV

29 individuals learned about Food & Fitness basics at the Bonefish Grill.

September 28: Latino Unidos Almuerzo, Las Vegas, NV

40 individuals learned about VWD, shared information about Familia De Sangre, and discussed ideas for Hispanic Programming in the future at Allure Gardens. Sponsored by Takeda & HTCNV.

Tahoe Family Day, August 2019, Lake Tahoe

Camp 2019

This summer 70 children ages 7-17 attended the 5 day, 4 night Camp in Big Bear, CA. Campers learned important communication, team work, problem solving and coping skills while doing camp activities such horseback riding, archery, water wars, and more. Campers received one Big Stick Awards, 6 Gold Bells, and 32 Silver Bells for learning how to self-infuse!

Thank you to our Camp Independent Firefly Sponsors:

Engelstad Family Foundation
Grand Lodge Independent Order of Odd Fellows of Nevada
Hemostasis and Thrombosis Center of Nevada
Bayer
Boyd Gaming Corporation
Brothers Healthcare
CSL Behring
CVS Health
Grifols
Novo Nordisk
Octapharma
Quality Home Infusion
Sanofi
Soleo Health
Speedway Children's Charities
Takeda
The Vegas Golden Knights Foundation

Teen Rafting Camp

Five teens joined us for our first teen camp experience. Together with the Hemophilia Association of San Diego County, Nevada Teens spent three exciting days on the river in Class II and III rapids. Teens gained independence skills by setting up their own tents and hammocks, cooking all of the meals, and learning water safety.

What is MyBDC?

MyBDC
BLEEDING DISORDERS COMMUNITY
Experiences Impacting the Future
NATIONAL HEMOPHILIA FOUNDATION

What is MyBDC?

My Bleeding Disorders Community or *MyBDC is* a patient-powered registry for people with any inherited bleeding disorders and their family members. This community-based initiative will capture a 360-degree view of living with a bleeding disorder, directly from affected persons *and their relatives*. These shared experiences will support and enhance the ability of researchers to improve current treatments, discover transformational therapies, and most importantly, contribute to finding a cure.

How will it work?

Participants take only 2-3 minutes to enroll (provide basic demographic information and establish a portal). Within a few weeks, participants will receive a baseline survey (the longest survey) followed by annual "core" surveys. The core surveys will ask similar information every year so that patterns and trends can be noted. Periodically, participants can expect to receive shorter surveys throughout the year to help us understand issues of interest to them. Our goal is to always keep most surveys under 15 minutes for completion. *Participants can opt in & out of surveys at any time**

- ***All surveys are confidential.*** Very limited staff will have access to patient level data, and it will be strictly accessed on a need-to-know basis. Any access will be electronically documented and followed similar to how medical records are monitored. Possible reasons for NHF staff to access patient level data would include: resolve queries (ex: a man states he is having problems with his periods or is pregnant), password assistance, etc.
- ***Reporting.*** *The more participants who are enrolled the better the data – for them personally, the community as a whole, NHF, researchers, and Chapters!!* Information gathered will always be reported in a grouped and de-identified manner -this is done so that no one can ever be personally identified.

Who is eligible to participate?

This initiative is open to persons affected with a bleeding disorder *and* their unaffected immediate family members (parents, spouses, siblings, grand-parents, etc.).

What are the benefits to participating?

Some participant benefits include:

- Access to a personalized dashboard to follow trends and compare changes over time
- Access to educational resources and trending information
- CareLinks – a tool to send selected information to a specific person or entity (daycare/latchkey/school/provider) for a chosen period of time (ex: Sept-June)

Some Chapter benefits include:

- Access to a Chapter personalized dashboard containing general, aggregate and de-identified data from MyBDC participants within the Chapter's geographic catchment area.
- Ability to confidentially push out events to MyBDC participants that live in the Chapter's geographic catchment area - whether they are registered in a Chapter or not
- Instant and comprehensive statistics to utilize for grant writing, resource development, and educational programming

How can I enroll or encourage others to enroll?

Please enroll if you are affected with a bleeding disorder or a family member. Encourage other Chapter members and friends to support this initiative and begin enrolling.

Support the Community by spreading the word.
You can enroll HERE. It only takes 2-3 minutes! For more information go to MyBDC.hemophilia.org
*If you have already enrolled in MyBDC, **THANK YOU!***

Community Spotlight: The Wolff Family

Meet Emily, Jeff, Ethan & Samantha.

What is your family's diagnosis story?

Due to family medical history, Ethan was tested before his circumcision, and our pediatrician came back with a scary diagnosis…they said Ethan had a severe bleeding disorder and only 14 years to live. It was terrifying to hear. Sam, Ethan's older sister, was only 7 and she just wanted her brother to be healthy. We were sent to Dr Bernstein. Dr Bernstein diagnosed Ethan with VWD, which is less severe. I then called my father and found out that not only did VWD run in the family, but several other family members had it. Even with the less severe diagnosis, we were blindsided. The circumcision procedure was nerve-wracking because you worry that the doctors won't know how to deal with bleeding disorder complications, but the procedure was short and everything ended up being fine, which was a huge relief.

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

Ethan is a firecracker of a child. He's very active. When he started preschool, before he got his helmet, he hit his head on concrete two times in one week! These instances helped me to be proactive and advocate for my children. I am on a first-name basis with the school nurses. One time he fell and a teacher's assistant carried him and ran with him through the school to the nurse. This urgency and care from the school is exactly what a parent with a bleeding disorder could hope for. Sam also has VWD but it's less severe and she has taken more of a caretaker role, which has been really sweet and helpful.

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

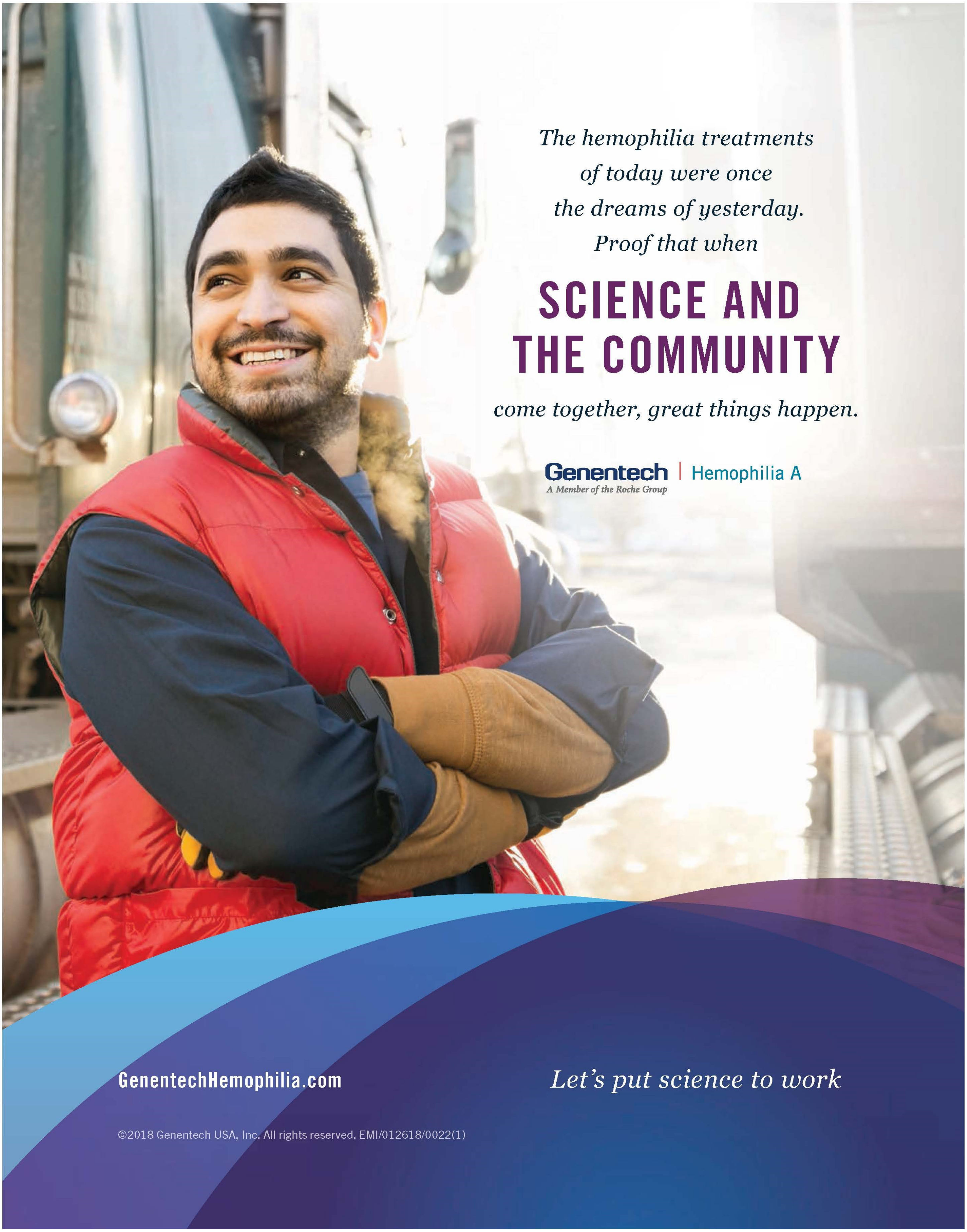
Remember that you're the parent and if for some reason you don't trust what's happening, get a second opinion. Look up networks of people who are going through the same thing, and go to their events, because it's a place to breathe. Socializing at events has helped our kids learn things like empathy and gratitude.

Please share a little about your involvement with the chapter.

We show up to chapter events and represent. We've gone to Women's Retreats, Couples Retreats, PEP, Spring Fest, Family Days, the Annual Meeting and Holiday Parties, Camp Independent Firefly, and more. Sometimes it's hard to go out but it's always worthwhile to connect. We like to welcome new families because we remember how good it felt when Kelly Gonzalez welcomed us. Being involved in a community takes away the fear of being alone.

Samantha, Ethan & Jeff Wolff

> **We like to welcome new families because we remember how good it felt when Kelly Gonzalez welcomed us. Being involved in a community takes away the fear of being alone.**
>
> **- Emily Wolff**
> **(Not pictured)**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JUDY PADILLA | PATIENT ADVOCATE
jpadilla@aspcares.com | (702)292- 5760

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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 Two In Review

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

Q2 2019 Fundraising:

Red Tie Campaign—

$2,119

Supporting Advocacy.

Golf Gets In Your Blood—

$29,783

Supporting youth programs.

NHFNV Programs —Q2 2019

Our mission is to improve the quality of care and quality of life for those living with inherited bleeding disorders through peer support, education and advocacy.

13 Peer Support & Community Building Hours

44 Education & Program Hours

200 Individuals Served

7 Events Offered

Communications Q2 2019:

www.hfnv.org

Average of **484** unique visitors per month.

Social Media

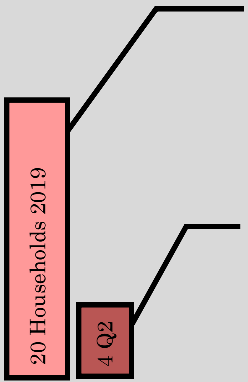
1873 followers

- Facebook—792
- Instagram—371
- Twitter—710

1584

Consumers in our database. Consumer is someone affected by a bleeding disorder or an immediate family member.

Financial Assistance - Q2 2019



$7,900
Distributed in 2019

$1403
Distributed in Q2

Q2 2019 Volunteers:

104

Volunteers

1800

Hours

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.

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

Phone: 702-564-4368
Fax: 702-446-8134
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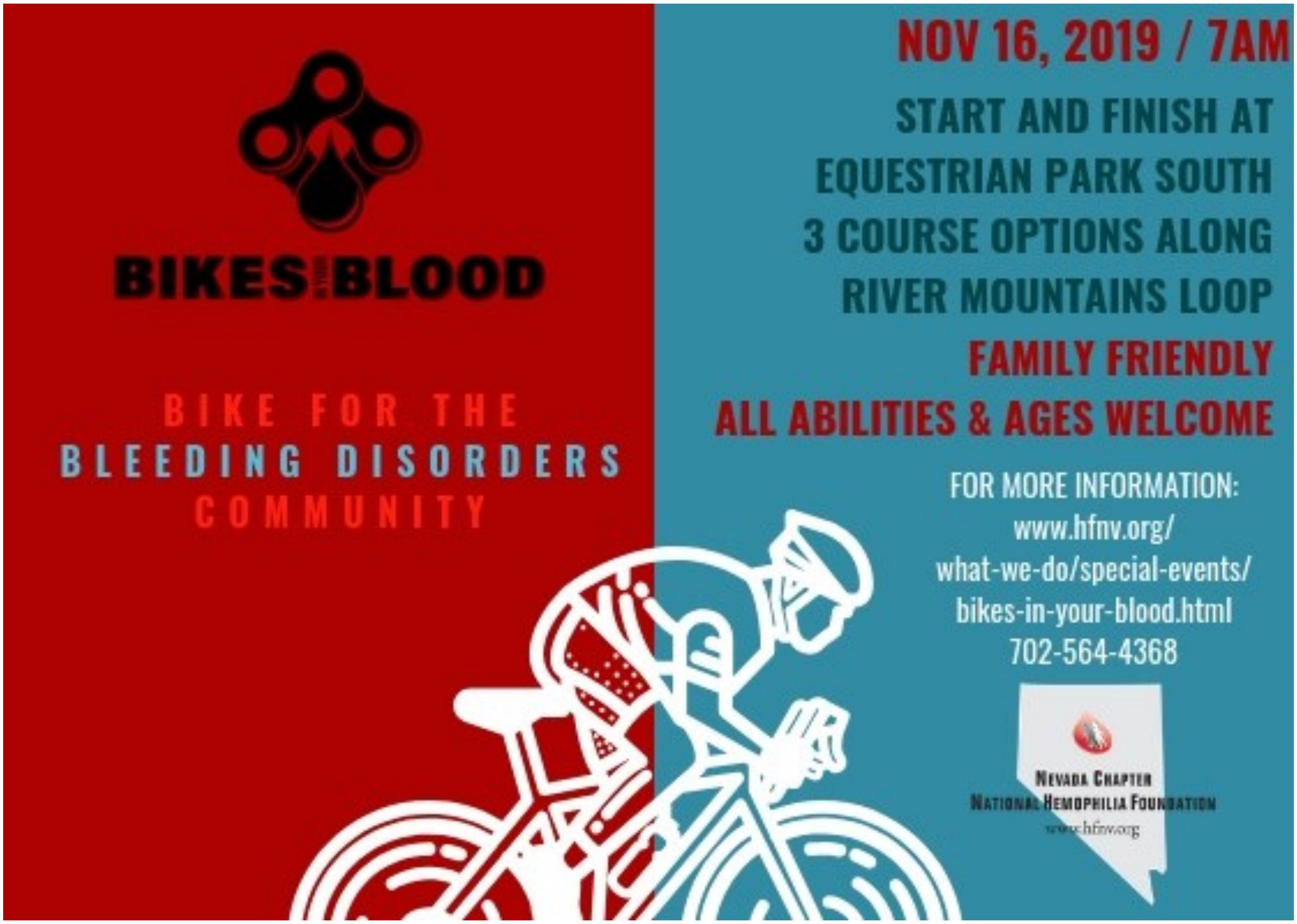

NOV 16, 2019 / 7AM

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