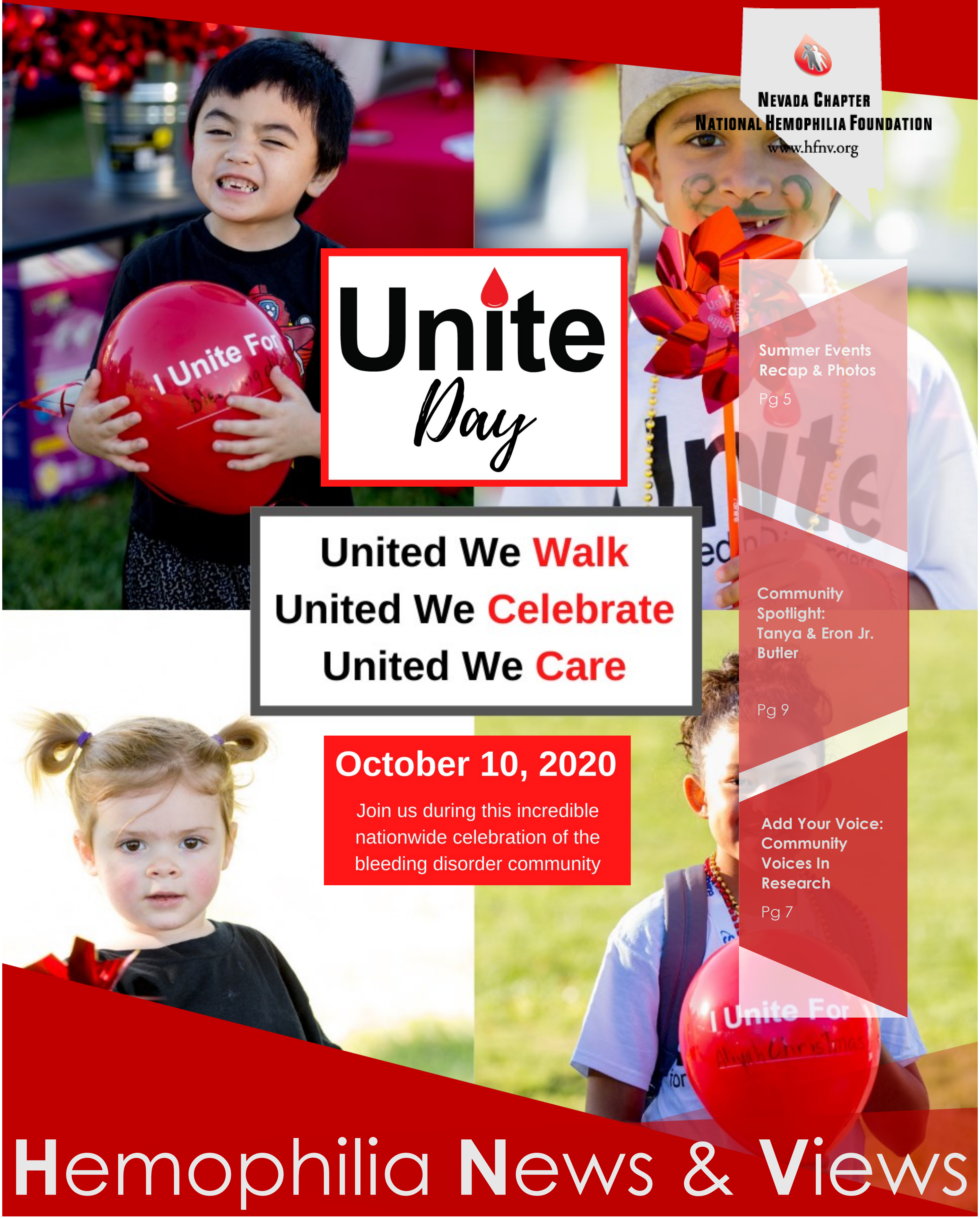
Nevada Chapter Newsletter

Fall 2020

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.hfnv.org



Unite Day

United We Walk
United We Celebrate
United We Care

October 10, 2020

Join us during this incredible nationwide celebration of the bleeding disorder community

Hemophilia News & Views

Make sure your vote will count in the November 3rd, 2020 General Election

Visit www.RegisterToVoteNV.gov
to register to vote or update your registration online.

IMPORTANT DEADLINES

- Deadline to register online to vote is Thursday, October 29, 2020
- Deadline for registering by mail to vote is Tuesday, October 6, 2020
- Early voting period runs from October 17—October 30th
- You can register to vote when you vote early in person or at the polls on Election Day.

VOTE BY MAIL

- Nevada will mail all active, registered voters a blank ballot in the mail in late September/early October.
- When your ballot arrives, read it carefully and follow the instructions to complete it and return it by dropping it off in person by November 3, 2020 or postmarked in the mail by November 3, 2020.

NEVADA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

HEMOSTASIS
&
THROMBOSIS
CENTER of NEVADA

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

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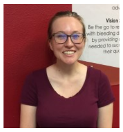

Kaley Dingeman
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Phone: 702-564-4368 x 102
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Board of Directors

Officers

President: Kim Luong Velasquez
Vice President: Renee Cotrel Duran
Treasurer: Miriam Calderon
Secretary: Stephanie Hrisca– Kennedy

Directors

Steve Findlay
Carlos Reyes

CALENDAR OF EVENTS

Event Safety during COVID-19

The Nevada Chapter is committed to maintain the health and safety of our community members, volunteers, staff and supporters. There are still a number of unknowns, but we are committed to communicating updates through email, phone, website, and social media as events change. Please contact us if you have any questions.

- The Nevada Chapter Team

This is a DRAFT Calendar. Dates & topics subject to change. Please check the Chapter website and request an updated calendar periodically.

All Events to be Held Virtually through March 31, 2021

10/10	**Unite Day Nationwide**
10/17	**CVR Education Program**
10/29	**Women's Retreat**
11/14	**Father/Son Night In**
11/21	**Bikes In Your Blood**
11/30—12/5	**Annual Meeting & Holiday Celebrations**

Visit www.hfnv.org for details and to register

Letter from Our Executive Director / Mensaje de nuestra Directora Ejecutiva

Dear Friends,

I am continually impressed with the resilience of the Nevada bleeding disorders community. Even in the midst of a global pandemic our families are finding ways to connect, raise awareness, and give back to one another. The support everyone has shown for the Unite For Bleeding Disorders Virtual Walk program is inspirational. The ongoing willingness to offer peer support to each other through virtual experiences is motivational.

I want to thank each member of the Nevada bleeding disorders community for doing their part to reach out to those who are struggling, lift each other up, and work together to overcome the everyday challenges faced by the bleeding disorders community that are exacerbated by the social isolation of the pandemic closures.

2020 is an election year. **Please vote.** Your voice in the local, state, and national elections is important to making sure patients can continue to receive lifesaving medications and the care they need to survive and thrive. Visit www.nvsos.gov/elections to check your voter registration status, register to vote, information on mail in ballots, and your representatives.

Betsy VanDeusen
Chapter Executive Director

Queridos amigos,

Estoy continuamente impresionada con la resistencia de la comunidad de trastornos de la sangre de Nevada. Incluso en medio de una pandemia mundial, nuestras familias están encontrando formas de conectarse, crear conciencia y retribuirse mutuamente. El apoyo que todos han mostrado al programa de la Caminata Virtual "Unidos por los Trastornos de la Hemorragia" es inspirador. La continua voluntad de ofrecer apoyo mutuo a través de experiencias virtuales es motivadora.

Quiero agradecer a cada miembro de la comunidad de trastornos de la coagulación de Nevada por hacer su parte para llegar a los que están luchando, levantarse unos a otros y trabajar juntos para superar los desafíos diarios que enfrenta la comunidad de trastornos de la coagulación que se ven exacerbados por el aislamiento social de los cierres pandémicos.

El año 2020 es un año de elecciones. **Por favor, voten.** Su voz en las elecciones locales, estatales y nacionales es importante para asegurarse de que los pacientes puedan seguir recibiendo los medicamentos que salvan vidas y la atención que necesitan para sobrevivir y prosperar. Visite www.nvsos.gov/elections para comprobar el estado de su registro de votantes, inscribirse para votar, información sobre el correo en las boletas y sus representantes.

Betsy VanDeusen
Chapter Executive Director

Meet The Board: Renee Duran

- *Nevada Chapter Board Member Since 2018*
- *Board Vice President*
- *Governance Committee*

A native Las Vegan, Renee has worked for Station Casinos for 6 years. Previously she worked for a nonprofit for 10 years and really missed it. NHFNV was something she really wanted to be involved in and she wants to help the bleeding disorders community in anyway she can.

“The most rewarding part of joining the board so far is being able to meet some amazing people. The yearly walk was really eye-opening for me. It was the first time I was able to meet this community. Seeing all the hard work each team put in to help raise funding was heartwarming.”

Renee and her husband Jose have two small dogs: Yogi and Astro and she used to be a race car driver.

Program Recap: Summer Events

July 8: Latinos Unidos En las Red
Six families joined us for a chat about staying fit and eating healthier options with "Move It! Staying Active & Healthy presented by Takeda. Attendees enjoyed a virtual scavenger hunt games and fun raffle prizes.

Sponsored by Takeda

July 15: Media Training
In this intensive training, 6 participants learned from Stacey Escalante, PR Consultant and former News Personality on how to best share their story and advocate for the bleeding disorders community while speaking to the Media.

July 20-22: Teen Camp Dragonfly
9 Nevada Teens joined teens from San Diego for three days of adventure, learning and fun. They learned how to purify water, build a fire, make pancakes, and make a shelter. The teens also worked on self-reflection and defining their identify.

Hosted by GutMonkey

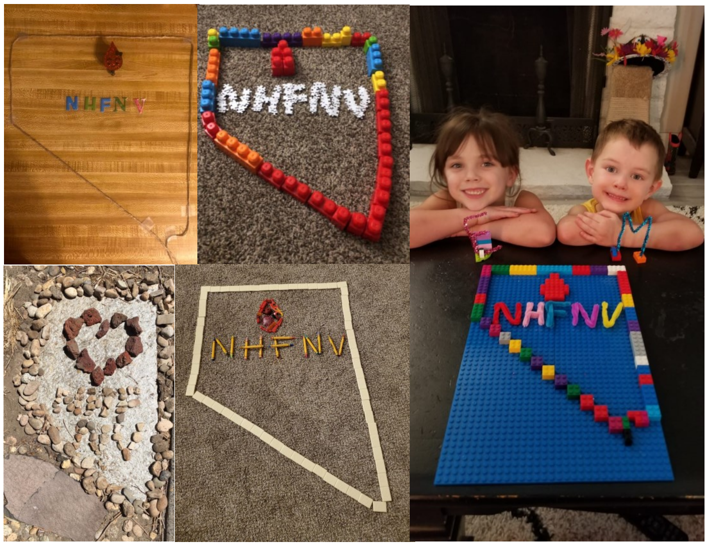
August 1: Back To School Virtual Family Conference
65 community members from across the state joined us to learn about being prepared for school with sessions for parents on mental health, kids on virtual learning, and teens on advocating for yourself. We also celebrated our 30th year Anniversary as a Chapter with a wonderful memorial of our founder, Renee Paper. Families enjoyed participating in the daily family challenges shared the week of the event!

August 20: Mother Daughter Night In
Seven women came together for an engaging chat about sexuality and relationships with bleeding disorders led by Amber Federizo. The night finished off with a fun game of taboo. All attendees received a special gift box subscription for 3 months full of items to help support stressed moms.

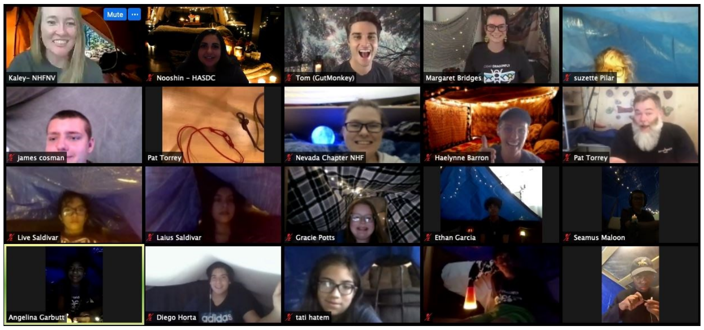
Sponsored by Octapharma

August 29th: Medexus Education Program—Rebuilding the Body with Diet
21 community members joined us for a talk with speaker Myles Ganley as he helped share the components of food to help balance not only a plate, but an entire day's nutrition. All attendees were nourished with a pizza delivery to their homes.

Hosted by Medexus.

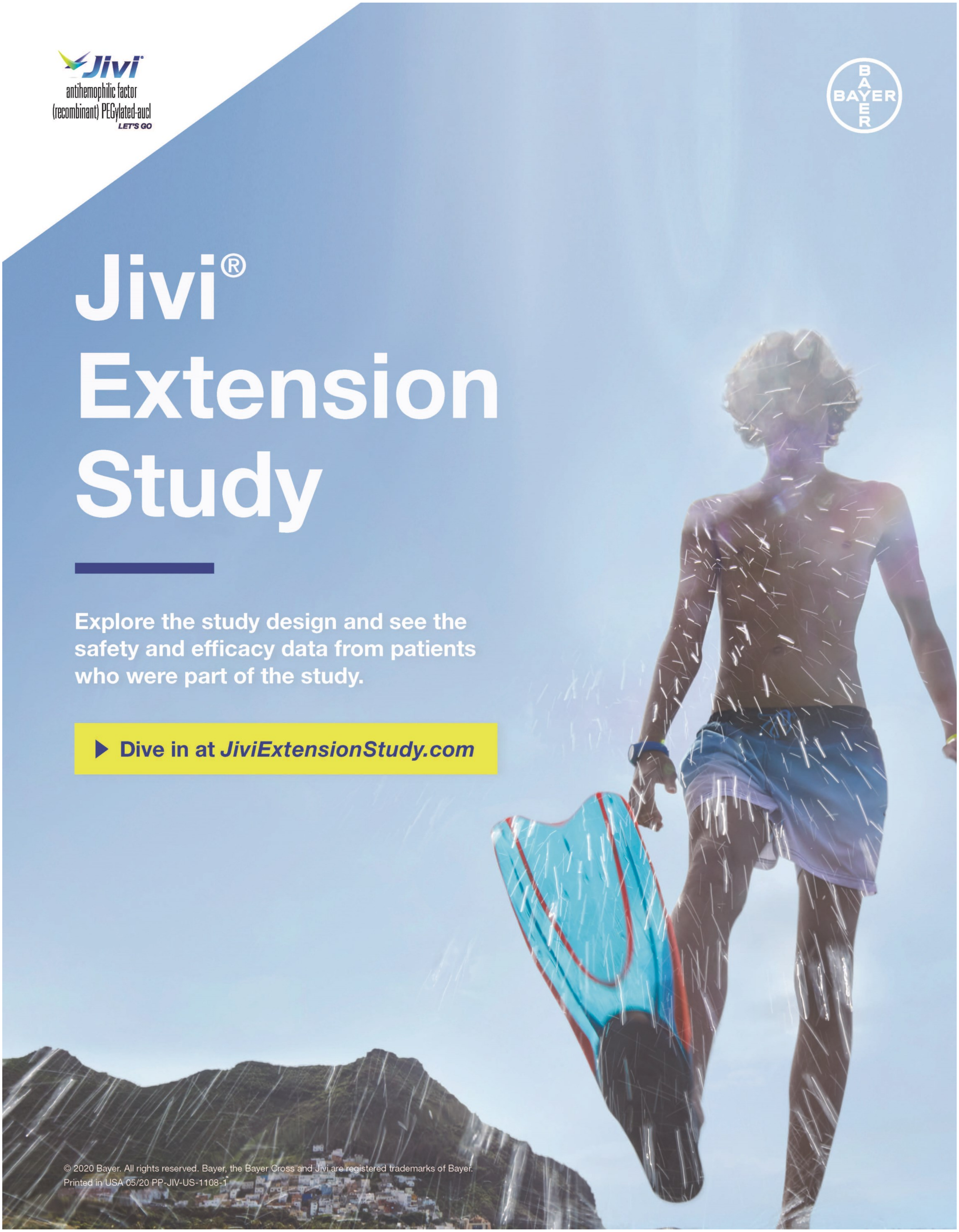


Creative submissions for the Back To School Family Challenge: Recreate the NHFNV Logo!



Teens showing off their shelters on Day 3 of Teen Camp Dragonfly!

Wear Your Red Best Challenge for the Back To School Family Conference



Community Voices in Research: Add Your Voice

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Community Voices in Research

What is CVR?

Community Voices in Research *(CVR)* formally known as *MyBDC*, is a community-powered registry but most importantly it is a partnership between the bleeding disorders community *and* NHF. When enrolling in CVR you are adding *your* voice and *your* experience which in turn helps to determine the direction of research for our community!

The Power of Data

Your voice turns into deidentified aggregated data which provides necessary useful information! For example; collected data from your local chapter community can highlight the possible need for additional women's programming and provide the required data to apply for grants to fulfill that need.

Call to Action!

Have you registered for CVR **and** taken your baseline survey already? If not, we are talking to *you*, your Nevada Chapter needs *you*! When you enroll in CVR **and** complete your baseline survey you are providing immediate valuable deidentified aggregated data for your community!

Enroll Now!

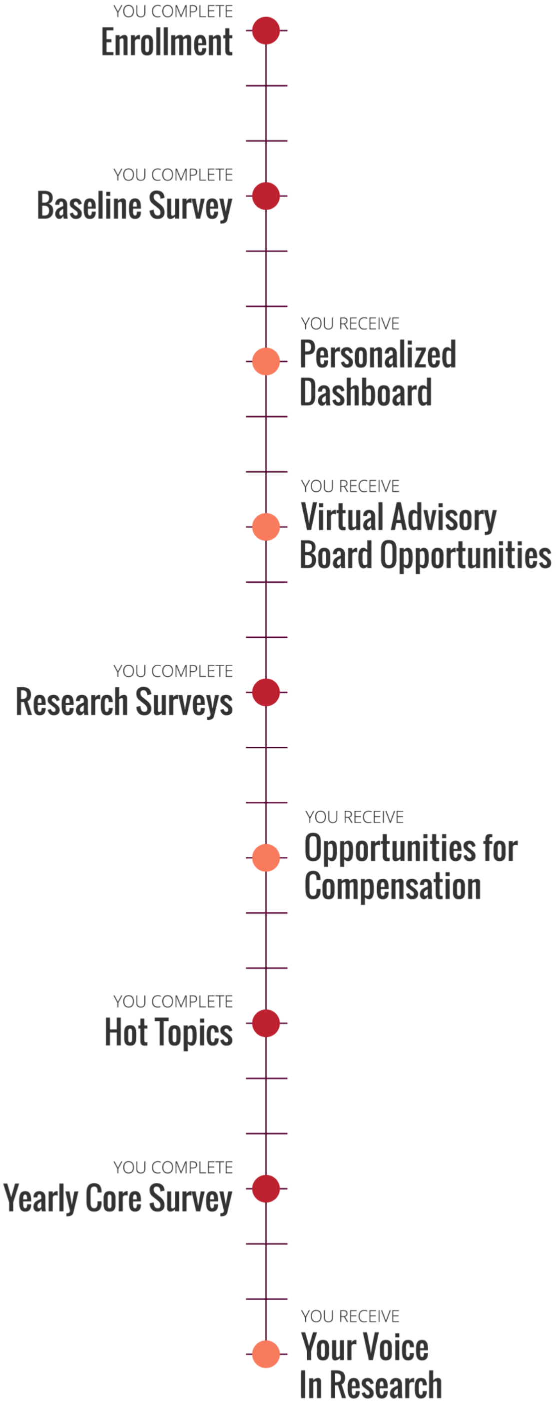
Step 1: **Take enrollment survey** (2 minutes). Answer a few questions about you and how bleeding disorders affect you.

Step 2: **Take baseline survey** (20-30 minutes) by following the link sent to your email. It will ask you more detailed questions about living with a bleeding disorder. You don't have to complete it all in one sitting.

Step 3: **Access your CVR Dashboard**. Now you have access to everything CVR has to offer!

Ready to get started?

www.hemophilia.org/cvr



How People with Bleeding Disorders Can Safely Get Back to Exercise

Advice from experts about resuming physical activity at home after a break

Author: Donna Behen

Has the COVID-19 pandemic disrupted your normal exercise routine? Maybe your gym closed down. Or your favorite hiking trail suddenly got a lot more crowded, so you stayed away for fear of catching the virus. Or, like a lot of people these days, maybe stress and anxiety has made you lose your motivation to work out.

Whatever the reason, lots of people who were physically active before the pandemic have found themselves increasingly more sedentary over the last four or five months. But staying physically active has a number of well-documented benefits. In addition to improving cardiovascular health, bone health, muscle flexibility and strength, regular exercise can also lower the risk of falls, reduce pain and contribute to maintaining a healthy weight. Exercise also causes biochemical changes that can improve mood and increase energy level.

What can people with bleeding disorders do to get back to regular exercise at home after a few months (or more) of sitting on the couch? For answers, we consulted two physical therapists who work at hemophilia treatment centers (HTCs). Here's what they recommend:

Consult Your HTC Physical Therapist

Especially for people with bleeding disorders, no "one size" exercise fits all, says Sherry Herman-Hilker, PT, MS, physical therapist at the University of Michigan's Hemophilia and Coagulation Disorders Program. "Every person with a bleeding disorder is different and has unique considerations that need to be taken into account when developing an exercise program," she says. People need to consider the activity they are interested in, the condition of their joints and muscles, their current fitness level, and what resources are available to them at home, Herman-Hilker says.

Start Slowly

Don't make the mistake of thinking that you can pick up where you left off, says Cindy Bailey, PT, DPT, OCS, SCS, ATC, director of Physical and Occupational Therapy at the Orthopaedic Hemophilia Treatment Center of the Orthopaedic Institute for Children in Los Angeles. "If you have been doing nothing, then you are at a much lower fitness level than you were when you left the gym or your workouts back in March," she says.

Begin with Walking

"Walking is the first form of exercise we suggest for those who have not been exercising," Bailey says. "Your first day, do about a quarter-mile warmup walk, then stop and stretch your lower body: buttocks, front of the hips, hamstrings, quads and calves. Then continue your walk for 20 minutes at a minimum."

As you get used to walking, you can increase either your time or your intensity level, but never increase both time and intensity at the same time or you'll risk doing too much too soon. You can also add in upper body (shoulders and trunk) stretches.

Add in Strength Training to Your Fitness Plan

"Once you're used to a walking workout and having no problems, you may begin some calisthenic-type exercise with light weights, your body weight or resistance bands," Bailey says. The same rule applies for increasing a weight or resistance band program. Either increase your amount of weight or resistance, or increase your number or repetitions. Never increase both variables at the same time. "If you get soreness or pain, you won't know what caused it if multiple variables were changed," Bailey says.

Protect Your Joints

People with bleeding disorders who have joints that have been damaged by bleeding need to carefully select exercises that will not aggravate their existing issues, Herman-Hilker says. "Think about which joints are problematic for you and consider activities that keep the joints moving but without high impact," she says. In addition to walking, other good choices include swimming and biking. A general rule of thumb is to avoid activities that cause you pain.

Community Spotlight: Tanya & Eron Jr Butler

Meet Tanya

Why did you join the Board in the past and what was the best part of your board service?
I felt it would be a great opportunity to be part of an organization that I could personally relate to as my husband and youngest son have von Willebrand disease. The best part of being on the board was the planning and making decisions for the events that would directly benefit the bleeding disorders community.

What do you hope your son learns from being on the Teen Council?
I hope Eron Jr learns team building skills. I believe that is important especially during these times. Often, we get in the mode, "I am by myself and I have to figure things out by myself," especially teens who want and need to be independent. During these times Eron Jr can learn the benefits of working along with his peers, while creating opportunities for our community.

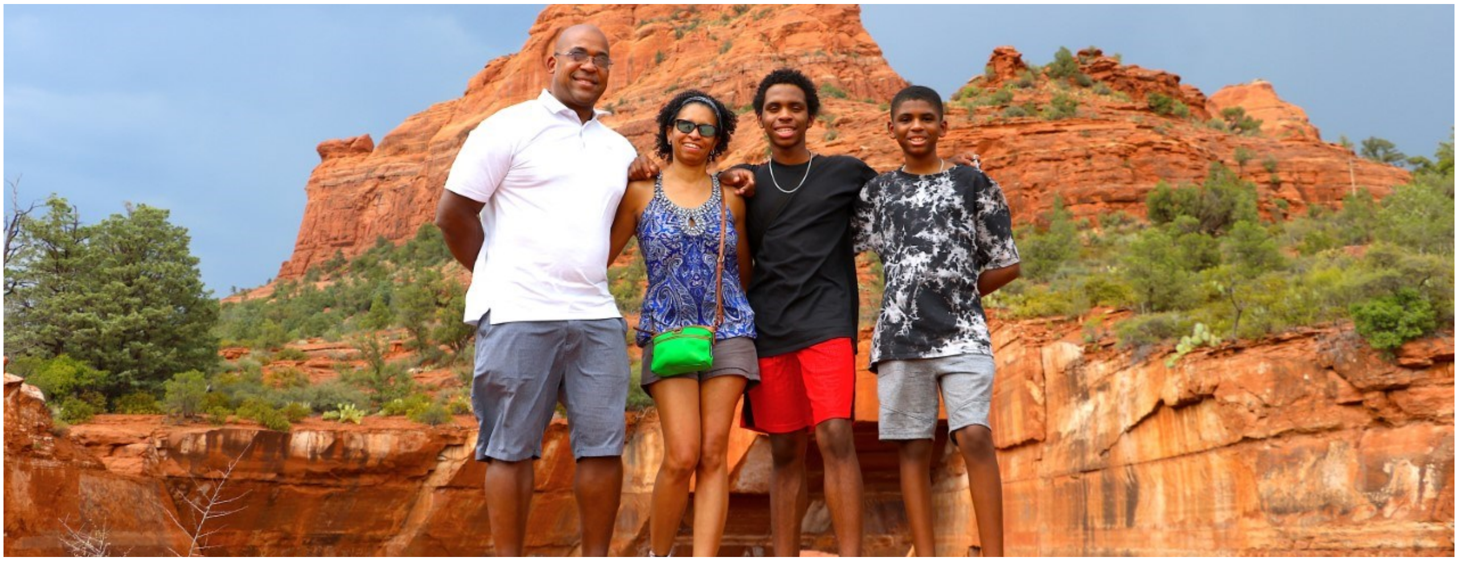
What advice do you have for new families looking to get involved with the chapter?
I would encourage families to get involved by attending events, even the virtual ones, because I don't want families to be discouraged and not get involved. Being involved with the chapter has helped our family tremendously. You can talk to people that understand some the challenges your family might be having, and you can get advice and receive resources that helps your family deal with everyday life.

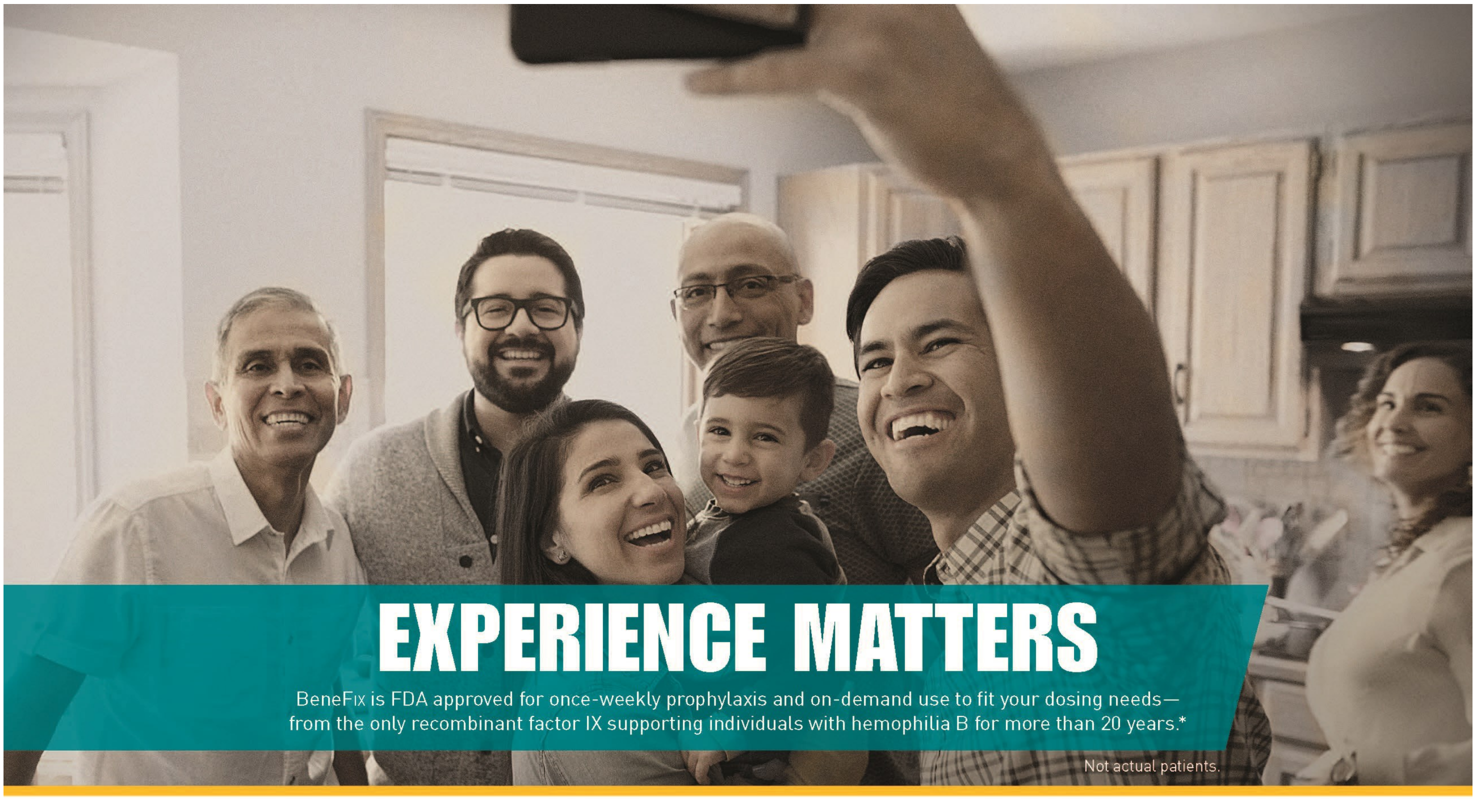
Meet Eron Jr

Why did you join the Teen Council and what has been the best part of the Council so far?
I knew I would be able to make decisions that would make a difference in many people's lives and I wanted to join a community I took pride in. The best part of being on the teen council is being a leader with the people around me. On the Teen council you always have a chance to be a leader with many other people.

How did your mom's past experience with the board influence your decision to join the Teen Council?
Seeing how my mom's past decisions make an impact made me feel comfortable joining the council, especially as a blood relative. Her impactful decisions made me feel like I could make impactful decisions too.

What advice do you have for teens and young people looking to get involved with the chapter?
I would say do not hold back on your slightest belief in your own leadership. The chapter will give you the chance to be a leader. I would encourage others to aim high and not cut yourself short on your ambitions because all your goals will give you a sense of leadership.



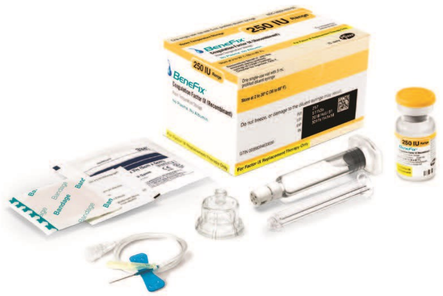


EXPERIENCE MATTERS

BeneFix is FDA approved for once-weekly prophylaxis and on-demand use to fit your dosing needs—from the only recombinant factor IX supporting individuals with hemophilia B for more than 20 years.*

Not actual patients.

- **More than 20 years* of experience—**the first recombinant treatment for individuals with hemophilia B
- **Dosing options to meet your needs—**for once-weekly prophylaxis and on-demand use
- Designed with viral safety in mind. More than 150 quality control tests are done on each batch of BeneFix
- The convenience of the BeneFix Rapid Reconstitution (R2) Kit with a range of vial sizes



ASK YOUR DOCTOR WHICH BENEFIX DOSING OPTIONS MAY BE RIGHT FOR YOU

What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.

YOUR EXPERIENCE 20+ YEARS* MATTERS

BeneFix®
Coagulation Factor IX (Recombinant)
Room Temperature Storage

*BeneFix was approved February 11, 1997.

PP-BEN-USA-0471 July 2020

Pfizer

ADVERTISEMENT

BeneFix®

Coagulation Factor IX (Recombinant)

Room Temperature Storage

Rx only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

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

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

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

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

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

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

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

How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

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

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-12.0, revised June 2020.

PP-BEN-USA-0470 July 2020

Pfizer

Cómo pueden hacer las personas con trastornos hemorrágicos para volver a hacer ejercicio de forma segura

Consejos de especialistas sobre cómo retomar la actividad física en casa después de una pausa

Author: Donna Behen

¿La pandemia de COVID-19 ha interrumpido su rutina normal de ejercicios? Quizás su gimnasio cerró. O su sendero favorito de repente se llenó de gente y usted se mantuvo alejado por miedo a contagiarse el virus. O, como muchas personas en la actualidad, quizás perdió la motivación por estrés o ansiedad.

Cualquiera sea el motivo, mucha gente que era físicamente activa antes de la pandemia se ha vuelto cada vez más sedentaria en los últimos cuatro o cinco meses. Pero mantenerse físicamente activo tiene diversos beneficios comprobados. Además de mejorar la salud cardiovascular y de los huesos, y la flexibilidad y fuerza muscular, hacer ejercicio con regularidad también puede reducir el riesgo de caídas y el dolor, y contribuir a mantener un peso saludable. El ejercicio también genera cambios bioquímicos que pueden mejorar el estado de ánimo y aumentar el nivel de energía.

¿Qué pueden hacer las personas con trastornos hemorrágicos para volver a hacer ejercicio con regularidad en el hogar después de meses (o incluso más tiempo) de estar sentadas en el sofá? Para obtener respuestas, consultamos a dos fisioterapeutas que trabajan en centros de tratamiento de la hemofilia (Hemophilia Treatment Center, HTC). Esto es lo que recomiendan:

Consulte al fisioterapeuta de su HTC

Especialmente en el caso de personas con trastornos hemorrágicos, no hay un solo tipo de ejercicio que se adapte a todas las personas, dice Sherry Herman-Hilker, fisioterapeuta (Physical Therapist, PT) y máster en Cirugía (Master of Surgery, MS), fisioterapeuta del Programa de hemofilia y trastornos de la coagulación de la Universidad de Michigan. “Cada persona con un trastorno hemorrágico es diferente y tiene consideraciones únicas que deben tenerse en cuenta cuando se diseña un plan de ejercicios”, dice. Las personas tienen que pensar en la actividad que les interesa, el estado de las articulaciones y los músculos, el nivel de estado físico actual y qué recursos tienen en la casa, dice Herman-Hilker.

Comience de a poco

“No cometa el error de pensar que puede retomar desde donde dejó”, dice Cindy Bailey, fisioterapeuta (PT), doctora en Fisioterapia (Doctor of Physical Therapy, DPT), especialista en Ortopedia Clínica (Orthopedic Clinical Specialist, OCS), especialista en fortalecimiento y acondicionamiento físico (Strength and Conditioning Specialist, SCS), preparadora física certificada (Athletic Trainer, Certified, ATC) y directora de Fisioterapia y Terapia Ocupacional del Centro de Tratamiento Ortopédico de la Hemofilia del Instituto Ortopédico para Niños de Los Ángeles. “Si no ha hecho nada, entonces tiene un nivel de estado físico muy inferior a cuando dejó el gimnasio o el entrenamiento en marzo”, dice.

Comience caminando

“Caminar es la primera forma de ejercicio que sugerimos a quienes no se han ejercitado”, dice Bailey. “El primer día, entre en calor caminando durante un cuarto de milla aproximadamente, luego deténgase y elongue la parte inferior del cuerpo: los glúteos, la cadera, los músculos isquiotibiales, los cuádriceps y las pantorrillas. Luego, siga caminando como mínimo durante 20 minutos”.

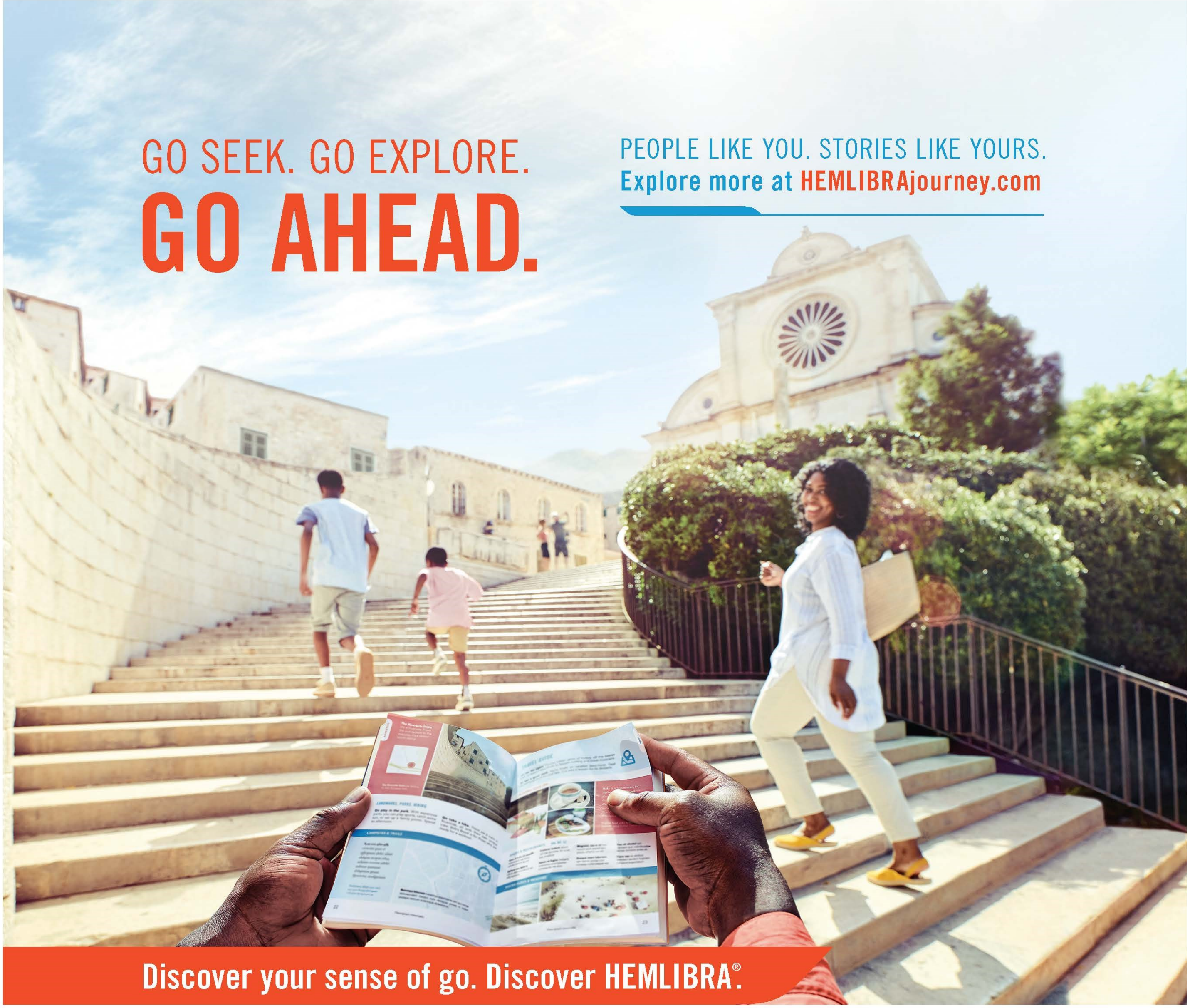
A medida que se acostumbra a caminar, puede aumentar el tiempo o el nivel de intensidad, pero nunca aumente ambos al mismo tiempo o correrá el riesgo de hacer demasiado ejercicio demasiado pronto. También puede añadir elongación de la parte superior del cuerpo (hombros y torso).

Añada entrenamiento de fuerza a su plan de actividad física

“Una vez que se acostumbre a ejercitarse caminando y no tenga problemas, puede comenzar a hacer ejercicios de calistenia con pesas livianas, su peso corporal o bandas de resistencia”, dice Bailey. La misma regla se aplica para intensificar un programa con pesas o bandas de resistencia. Aumente ya sea la cantidad de peso o la resistencia o bien aumente la cantidad o las repeticiones. Nunca aumente ambas variables al mismo tiempo. “Si siente dolor, no va a saber qué lo causó si cambió múltiples variables”, dice Bailey.

Proteja las articulaciones

Las personas con trastornos hemorrágicos que tienen articulaciones dañadas por las hemorragias tienen que seleccionar cuidadosamente ejercicios que no agraven los problemas existentes, dice Herman-Hilker. “Piense qué articulaciones le causan problemas y considere las actividades que las hagan moverse, pero sin mucho impacto”, dice. Además de caminar, otras buenas opciones incluyen nadar y andar en bicicleta. La regla de oro general es evitar actividades que le causen dolor.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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.

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

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Nevada Chapter
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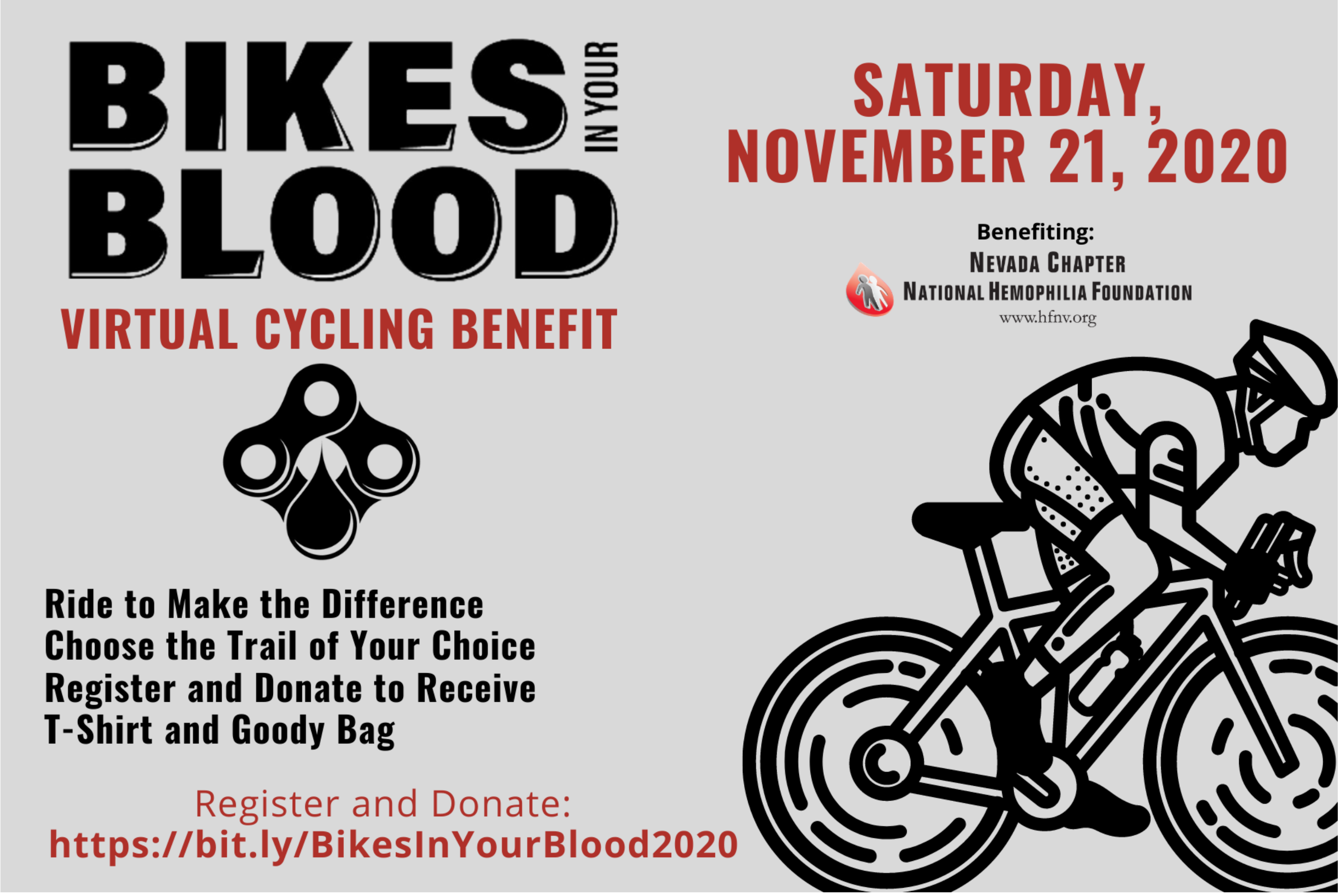

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