Nevada Chapter Newsletter

Summer 2020

Nevada Chapter
National Hemophilia Foundation
www.hfnv.org

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Hemophilia News & Views

HTCNV
HEMOSTASIS & THROMBOSIS CENTER OF NEVADA

NEVADA'S ONLY FEDERALLY-DESIGNATED BLEEDING &
CLOTTING TREATMENT CENTER FOR CHILDREN & ADULTS.

Dear HTCNV family,

In accordance with Phase II of Nevada's reopening process, the HTCNV will begin scheduling routine visits by appointment only. The following measures have been implemented to ensure minimal risk of COVID-19 transmission:

- No walk-ins are allowed at this time. All visits are by appointment only.
- Please arrive promptly for your scheduled appointment, as we are trying our best to ensure our waiting room remains clear and patients are seen immediately. Failure to make your appointment time may result in cancellation or rescheduling or your appointment.
- All who enter the clinic will be screened with a series of questions and have their temperature taken by a HTCNV staff member.
- All who enter and remain in the clinic are required to don a mask and other PPE as recommended by HTCNV staff.
- All who enter will be required to wash their hands or sanitize them with hand sanitizer.
- People in the waiting room must maintain 6 feet of distance from one another. An additional waiting room across the hall will be made available. People are also encouraged to wait in their vehicle if it is safe to do so.
- If you are feeling ill or have symptoms associated with COVID-19, please call the HTCNV IN ADVANCE of your appointment. Our providers will advise on whether or not to keep the appointment or reschedule.
- Guidelines from Phase I, i.e. handwashing, social distancing of 6 feet or more, and mask/PPE use, are required.

The HTCNV and SCCNV now offers telehealth services. Please consult with your provider.

We appreciate the patience and diligence of our community. For any questions, please do not hesitate to call us during business hours. Thank you.

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P: 702-330-0555 F: 702-832-1128
6880 S. MCCARRAN BLVD., STE. 4 RENO NV 89509
P: 775-622-7371 F: 775-800-5748

www.HTCNV.org

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MISSION

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

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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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.

BLUE = Online Format
BLACK = Continuing as Scheduled

7/8	**Latinos Unidos**
7/20-22	**Teen Camp, CA**
8/1	**Back To School Family Conference**
8/1-8	**Nat'l Bleeding Disorders Conference**
8/20	**Mother/Daughter Night Out, LV**
8/22	**Tahoe Family Day, Tahoe**
8/29	**Bayer Dinner, LV**
9/12	**Reno Unite For Bleeding Disorders Walk**
	Elko Unite For Bleeding Disorders Walk
9/18-20	**Familia De Sangre, CA**
9/26	**Las Vegas Unite For Bleeding Disorders Walk**
10/5	**Education Dinner, Elko**
10/29	**Trunk or Treat, LV**
11/7	**Father/Son Night Out, LV**
11/11	**Ely Holiday Event, Ely**
11/21	**Bikes In Your Blood, Henderson**

Letter from Our Executive Director / Mensaje de nuestra Directora Ejecutiva

Dear Friends,

The past months have been emotionally turbulent and we are still facing an overwhelming amount of unknowns looking at the future.

Now, more than ever we need to lean on each other. While the Nevada Chapter's Events will continue to be virtual through the summer, we are still very much here for you. If you are struggling, need financial assistance, help navigating this new normal, or just someone to talk to, we are here for you.

2020 marks the 30th anniversary of the Nevada Chapter. We thought we would be celebrating this milestone year differently. But to foster the sense of community that drove Renee Paper to found the chapter in 1990, we are introducing **29 Apart. 30 Together**. This summer we are challenging everyone to take 29 one-mile walks on your own. In September at the Unite Walk, we hope to walk our 30th mile together as a community in celebration of the Chapter's 30 years.

Take selfies, post your progress, and offer support to others as they walk. This is one more creative way to connect with others as we continue to navigate these uncertain times.

Betsy VanDeusen
Chapter Executive Director

Queridos amigos,

Los últimos meses han sido emocionalmente turbulentos y todavía nos enfrentamos a una cantidad abrumadora de incógnitas mirando al futuro.

Ahora, más que nunca necesitamos apoyarnos el uno en el otro. Mientras que los Eventos del Capítulo de Nevada van a seguir siendo virtuales durante el verano, todavía estamos aquí para ayudarlos. Si tiene dificultades, necesita asistencia financiera, ayuda para navegar en esta nueva normalidad o simplemente alguien con quien hablar, estamos aquí para ayudarlo.

2020 marca el 30 aniversario del Capítulo de Nevada. Pensamos que celebraríamos este año histórico de manera diferente. Pero para fomentar el sentido de comunidad que llevó a Renee Paper a fundar el capítulo en 1990, presentamos **29 Separados. 30 Juntos.** Este verano estamos desafiando a todos a realizar 29 caminatas de una milla por su cuenta. En septiembre en nuestro Unite Walk, esperamos caminar nuestra 30 milla como comunidad para celebrar los 30 años del Capítulo.

Tomese selfies, publique su progreso y ofrezca apoyo a otros mientras caminan. Esta es una forma más creativa de conectarse con otros a medida que continuamos navegando estos tiempos inciertos.

Betsy VanDeusen
Chapter Executive Director

Meet The Board: Carlos Reyes

- *Nevada Chapter Board Member Since December 2019*
- *Board Vice President*
- *Advocacy Committee*

Carlos joined the board because he has a son and a wife both with a bleeding disorder. He is excited to have the opportunity to be part of the board because he is very committed to giving back to the community.

Carlos was born in Los Angeles, CA and moved to Las Vegas in 2008. He's a husband and father of three boys. He enjoys spending time with his family going bowling, camping, going to the movies, and he loves going to the beach.

"The most rewarding part of serving as a board member is to work with our staff and participate in events with the Chapter as well as being able to work more with our community."

Program Recap: Spring Events

Virtual Happy Hours
Throughout April & May, we hosted six Virtual Happy Hours to help everyone adjust to the new normal at home and let off some steam. With themes of Quarantine Parenting, Viviendo en Cuarentena, Teen Netflix & Chill, Ladies Chat, Noche de Juegos & Virtual Birthday Party, we engaged 31 community members.

April 16: My Journey to Jivi Virtual Education Evening
Community members joined an online program to learn from a patient about their experience with Jivi.

Sponsored by Bayer

April 17: World Hemophilia Day
We challenged our community to post selfies wearing red to help raise awareness and everyone delivered including our Teen Leadership Council! #AllInRed

April 22: Teen Gut Monkey Experience
10 teens were guided through virtual brain teaser games and working together challenges that promoted good communication, creativity and leadership skills.

May 13: Gene Therapy Virtual Education Evening
Community members joined an online program to learn about Gene Therapy and how it can be used to treat genetic conditions.

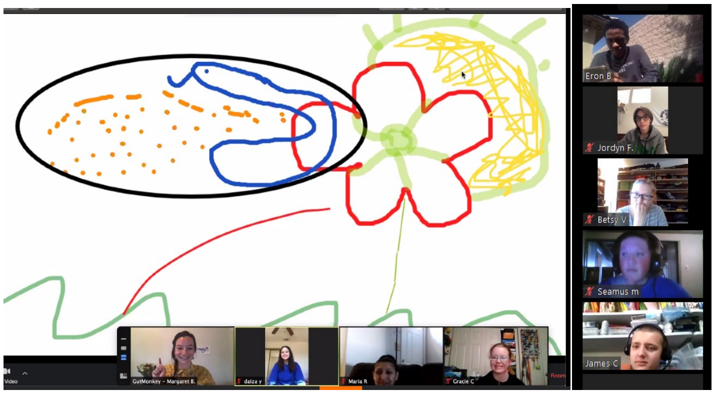
Sponsored by BioMarin

May 19: Ladies Night Out
23 amazing ladies joined us for our Virtual Women's Mini-Retreat. We discussed advocacy, celebrate the legacy of one of our community members, and set goals for self advocacy.

Sponsored by Octapharma

May 27: Walk Rally
9 Team Captains jumped on a zoom meeting to offer support for each other, learn new ideas, and get pumped up for the Unite Walks!

June 5-11: Camp Independent Firefly
51 campers got to experience a little bit of the magic at home with a camper box delivered to their house, at-home videos recorded by camp counselors and volunteers, and live video chats with their cabins complete with silly camp activities that helped them grow. Over 14 hours of programming was offered for Virtual Camp.



Collaborative Drawing during the Teen Gut Monkey Experience

Wear Red Photo Challenge for World Hemophilia Day

Cabin Time in the Big Village at Camp

What is HEMLIBRA?

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

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

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

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

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

ADVERTISEMENT

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 | 150 mg/mL
injection for subcutaneous use

Genentech
A Member of the Roche Group

We Stand With You.

Dear NHF Community,

Over the past weeks, our country has been overwhelmed with emotion—shock, grief, horror, rage, and more—amid the news reports and video footage showing harassment of, and violence against Black Americans. At a time when the world is already wearied by the COVID-19 pandemic, we are once again confronted by a crisis that has been a shameful part of our nation's history. We care deeply about this issue and are prepared to do everything in our power to drive positive change.

The deaths of George Floyd in Minnesota, Ahmaud Arbery in Georgia, and Breonna Taylor in Kentucky, as well as the weaponized racism against Christian Cooper in New York, are only the most recent and visible reminders of how far we, as a society are from eliminating racial injustices and disparities.

NHF rejects and condemns injustice, racism, and harassment in all its forms. We are committed to an inclusive workplace and community where we all can share our authentic selves. To us, inclusion and diversity are not just organizational buzzwords, but personal imperatives. For Black employees and community members who today don't feel safe to leave their homes, or who live each day with apprehension for their own safety or the safety of their loved ones: We see you. We stand with you. We may never be perfect, but we are going to do better every day.

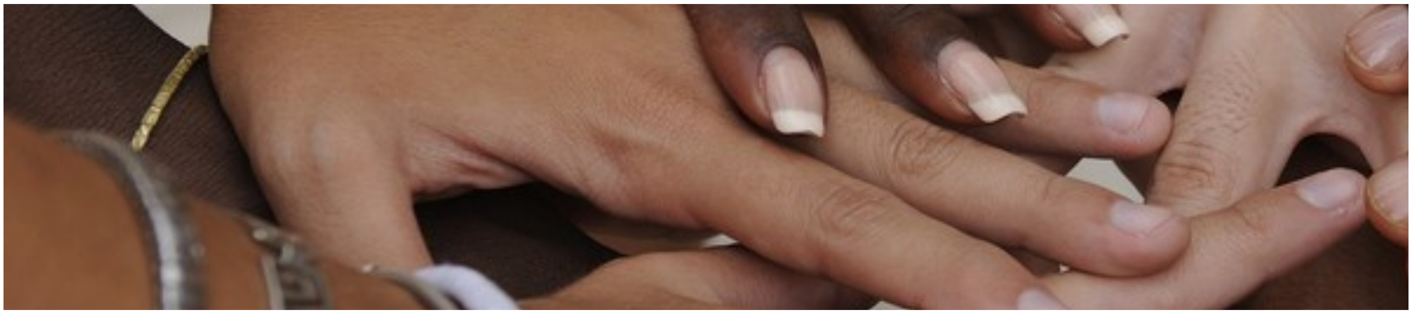
At NHF, we define diversity and inclusion as part of our inherited mission; to serve those affected by all inheritable bleeding disorders. We are committed to our employees as well as those we serve. To do so, NHF seeks and values those qualities, both visible and invisible, that makes individuals unique. We strive to be a safe place where regardless of age, color, disability, gender, gender identity, gender expression, family status, national origin, race, ethnicity, or sexual orientation, you are heard, empowered and valued because we truly believe that every person brings a unique perspective and experience to advance our mission.

Dr. Martin Luther King Jr. reminded us and called on all Americans to fulfill the promise that all of us—of every race, skin tone, language, ability, sexual orientation, gender, religion, background and talent—rely on one another to be allies, to stand up together, and to share strength. And that is the promise and commitment I reaffirm today: to reject violence, discrimination, and harassment, and to create equitable and safe spaces that acknowledge and foster the mental and physical wellness of all of our community.

I will end by letting you know that NHF is here for you, ALL our community members. But today, we are here particularly for our Black American community members. We acknowledge our responsibility to be part of the solution. We are committed to doing our part.

Sincerely,

Leonard A. Valentino, M.D.
President & Chief Executive Officer
National Hemophilia Foundation



Estamos Con Ustedes.

Estimada comunidad de NHF,

En las últimas semanas, nuestro país ha estado abrumado por la emoción (conmoción, dolor, horror, rabia y más) en medio de los informes de noticias y videos que muestran el acoso y la violencia contra los afroamericanos. En un momento en que el mundo ya está cansado por la pandemia de COVID-19, una vez más nos enfrentamos a una crisis que ha sido una parte vergonzosa de la historia de nuestra nación. Nos preocupamos profundamente por este problema y estamos preparados para hacer todo lo que esté a nuestro alcance para impulsar un cambio positivo.

Las muertes de George Floyd en Minnesota, Ahmaud Arbery en Georgia y Breonna Taylor en Kentucky, así como el racismo armado contra Christian Cooper en Nueva York, son solo los recordatorios más recientes y visibles de lo lejos que estamos, como sociedad, de eliminando injusticias raciales y disparidades.

NHF rechaza y condena la injusticia, el racismo y el acoso en todas sus formas. Estamos comprometidos con un lugar de trabajo y una comunidad inclusivos donde todos podamos compartir nuestro ser auténtico. Para nosotros, la inclusión y la diversidad no son solo palabras de moda organizacionales, sino imperativos personales. Para los empleados negros y los miembros de la comunidad que hoy en día no se sienten seguros al abandonar sus hogares, o que viven cada día con aprensión por su propia seguridad o la seguridad de sus seres queridos: los vemos. Estamos con ustedes. Puede que nunca seamos perfectos, pero lo haremos mejor cada día.

En NHF, definimos diversidad e inclusión como parte de nuestra misión heredada; para servir a los afectados por todos los trastornos hemorrágicos hereditarios. Estamos comprometidos con nuestros empleados y con aquellos a quienes servimos. Para hacerlo, NHF busca y valora esas cualidades, tanto visibles como invisibles, que hacen que los individuos sean únicos. Nos esforzamos por ser un lugar seguro donde, independientemente de la edad, el color, la discapacidad, el género, la identidad de género, la expresión de género, el estado familiar, el origen nacional, la raza, el origen étnico o la orientación sexual, sean escuchados, empoderados y valorados porque realmente creemos que cada persona aporta una perspectiva y experiencia únicas para avanzar en nuestra misión.

El Dr. Martin Luther King Jr. nos recordó y exhortó a todos los estadounidenses a cumplir la promesa de que todos nosotros, de cada raza, tono de piel, idioma, habilidad, orientación sexual, género, religión, antecedentes y talento, dependemos unos de otros para ser aliados, para estar juntos y compartir fuerzas. Y esa es la promesa y el compromiso que reafirmo hoy: rechazar la violencia, la discriminación y el acoso, y crear espacios equitativos y seguros que reconozcan y fomenten el bienestar mental y físico de toda nuestra comunidad.

Terminaré informándoles que NHF está aquí para ustedes, TODOS los miembros de nuestra comunidad. Pero hoy, estamos aquí particularmente para los miembros de nuestra comunidad afroamericana. Reconocemos nuestra responsabilidad de ser parte de la solución. Estamos comprometidos a hacer nuestra parte.

Sinceramente,

Leonard A. Valentino, M.D.
President & Chief Executive Officer
National Hemophilia Foundation

*In clinical trials, ADVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

Not an actual patient.

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.[1]

ADVATE
[Antihemophilic Factor (Recombinant)]
REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

Prophylaxis with ADVATE prevented bleeds[1]

- ADVATE was proven in a pivotal clinical trial to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)
- The efficacy of ADVATE was studied in a multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe to moderately severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20–40 IU/kg every 48 hours, or pharmacokinetic-driven, 20–80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis
  - 98% reduction in median annualized bleeding rate (ABR) from 44 to 1 when 53 patients in the clinical study switched from on-demand to prophylaxis
  - 0 bleeds in 42% (22/53) of patients during 1 year on prophylaxis

ADVATE Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your HCP if you are pregnant or breastfeeding because ADVATE may not be right for you.

What should I tell my HCP before using ADVATE?

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 ADVATE passes into your milk and if it can harm your baby.

What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP 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 ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE 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 ADVATE 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 ADVATE?

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

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 ADVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.ADVATE.com.

Reference: 1. ADVATE Prescribing Information.

Takeda

ADVERTISEMENT

ADVATE
[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. 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 ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

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 ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

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

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE 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 ADVATE by themselves or with the help of a family member.

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

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

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

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

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 ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

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.

Side effects that have been reported with ADVATE include:

cough
sore throat
unusual taste
abdominal pain
diarrhea
nausea/vomiting
headache
fever
dizziness
hot flashes
chills
sweating
joint swelling/aching
itching
hematoma
swelling of legs
runny nose/congestion
rash

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 ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE 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 ADVATE 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 ADVATE for a condition for which it is not prescribed. Do not share ADVATE 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 ADVATE. The FDA-approved product labeling can be found at www.ADVATE.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.

Patented: see https://www.shire.com/legal-notice/product-patents

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S47030

Community Spotlight: Joli McAnany

Meet Jolie.

What is you and your family's diagnosis story?

I was not diagnosed until after my daughter was born. Due to a variety of complications with the birth and recovery, my wonderful OB/Gyn was the one who originally suspected von Willebrand. He referred me for testing, and things went from there. The diagnosis solved the mystery of a number of issues I had experienced throughout my history! It's a bit amazing to think it took so long for someone to think of it. My grandmother had quite serious bleeding issues, but at that time, no one had ever mentioned the chance that it may be hereditary. Because of my diagnosis, both of my children were diagnosed at a young age.

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

Honestly, when I was first diagnosed, there was a fair amount of fear. We questioned whether we should try for another child and worried a lot about what we should be doing to manage my newly known condition. But I don't believe in living my life from a place of fear, nor do I want that for my kids. So, with some education and reassurances, we learned that most of the time, it doesn't need to affect our daily life. We are lucky, in that none of us have daily bleeds or need infusions on a regular basis. So far, I have more symptoms than either of the kids do. Of course, we chose soccer over football for my son, and we all know that there are certain activities that are risky for us, but we choose to move forward with that information and live fully. When I have a bleed, I contact the HTC and follow proper protocols. With the other medical issues I have had, my hematology team is always involved, but in my daily life, I live just like anyone else.

"...getting involved in the bleeding disorders community really helps put your mind at ease, helps you not to feel alone in this and give you a place to turn when something new is going on or when you are afraid or unsure about something."

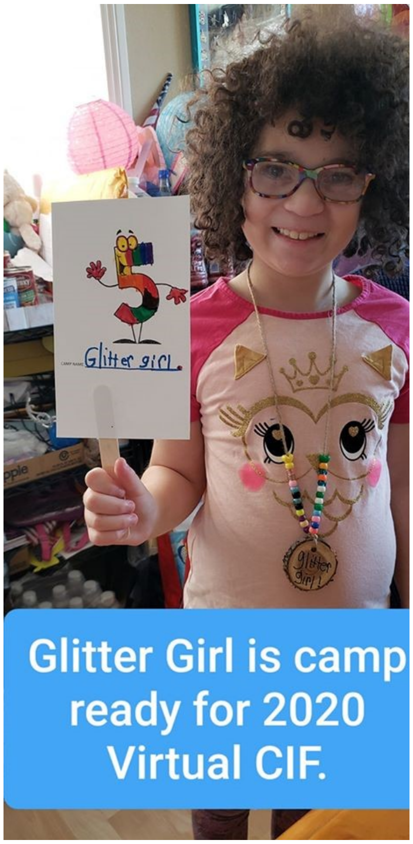
What advice would you give to someone newly diagnosed with a bleeding disorder?

Educate yourself! And, use the resources available to you. The people at NHF and HTC are a wealth of knowledge and a wonderful support system. It took me a while to really understand what great resources we have here in Nevada to support our bleeding disorder community. Using those resources and getting involved in the bleeding disorders community really helps to put your mind at ease, helps you not to feel alone in this, and gives you a place to turn when something new is going on or when you are afraid or unsure about something.

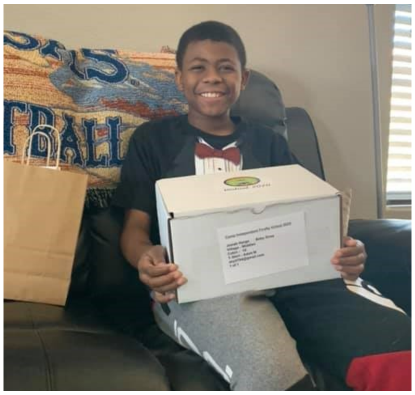
Please share a little about your involvement with the chapter.

Honestly, I was pretty slow to get involved with the chapter. I just didn't realize what NHF was all about. Since I started paying attention, I have tried to be as involved as I can be. I have never been able to make it to the Unite Walk in Reno, but have heard such great things about it. I also like to try to participate in some type of volunteer opportunity at least once per month. I participate with a variety of organizations, but none of them have the personal tie to my heart like NHF does. So, a couple of years ago, when an NHF staff member was asking what suggestions I had for community involvement, I told them I thought we should have a walk in Elko. We have an interesting cluster of bleeding disorder patients here in Northern Nevada, and I was hoping to be able to raise some money for NHF and help the local bleeding disorder community to come together. Last year was the first Elko walk. It was a little last minute, but I tried to help as much as I could, and I think it was pretty nice for a first try! I am so hoping that post COVID-19 we can get a bigger crowd this year! I can't wait to see what happens! I've got my walking shoes on already!

Camp Independent Firefly Virtual 2020



Glitter Girl is camp ready for 2020 Virtual CIF.



Thank You Camp Sponsors

51 children attended virtual camp experiencing over 14 hours of programming including building a social connection during live video chats with counselors and cabin mates, doing at home activities and crafts, and participating in camp challenges by submitting videos of themselves lip syncing, water wars, and dancing.

While virtual camp can never replace Camp Independent Firefly our kids felt a little big of the magic, got to smile, grow and connect in ways that wouldn't be possible without the generous support of our sponsors.

We invite you to watch the camp video by going to https://vimeo.com/428352012

Hemostasis & Thrombosis Center of Nevada I Running Bull Productions
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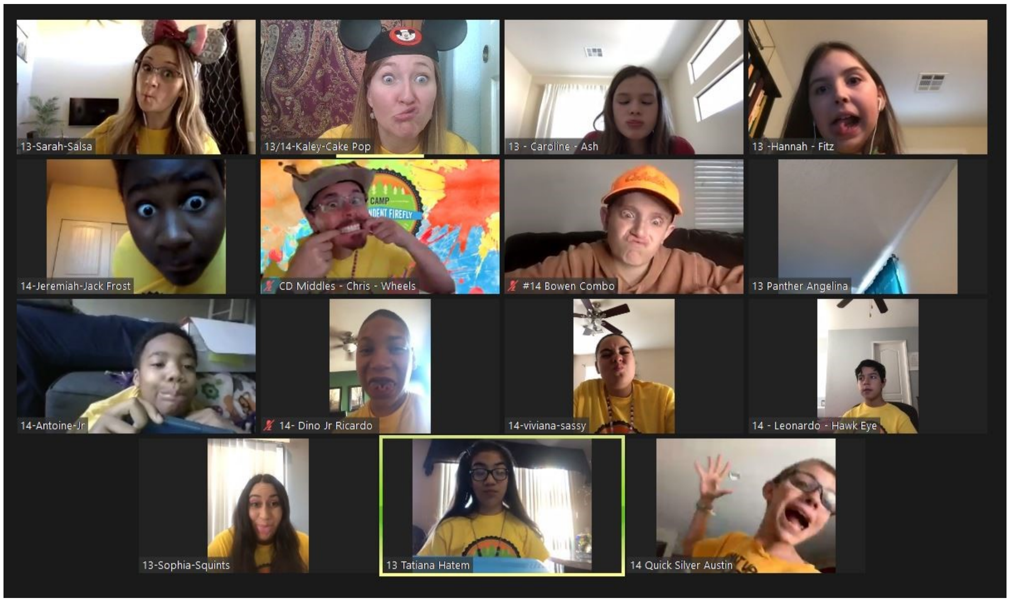

BeneFix®
Coagulation Factor IX (Recombinant)
Room Temperature Storage
*BeneFix was approved February 11, 1997.

Not actual patients.

EXPERIENCE MATTERS

BeneFix: The only recombinant factor IX supporting individuals with hemophilia for more than 20 years.*

More than 20 years* of experience—you've been at the heart of all we do

- The first recombinant treatment indicated for bleed control and prevention in individuals with hemophilia B
- Designed with viral safety in mind
- More than 150 quality control tests are done on each batch of BeneFix
- The flexibility to infuse on demand or preventively based on your physical activity
- The convenience of the BeneFix Rapid Reconstitution (R2) Kit with a range of vial sizes

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. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

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

Visit BeneFix.com to learn more

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 nausea, injection site reaction, injection site pain, headache, dizziness and rash.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

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

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Pfizer

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BeneFix®

Coagulation Factor IX (Recombinant)

Room Temperature Storage

R_x 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.

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 remedies.

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

- 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 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 BeneFix. 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 to your doctor. You can ask your doctor for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-10.0, revised June 2017.

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Pfizer

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for Bleeding Disorders

ELKO WALK
- **Saturday, September 12th | Walk - 10:00 am**
- **VIRTUAL WALK**
    - Register online and join us virtually!

RENO WALK
- **Saturday, September 12th |** Walk - 10:00 am
- Bartley Ranch Park
    - 6000 Bartley Ranch Rd, Reno, NV 89511

LAS VEGAS WALK
- **Saturday, September 26th** | Walk - 9:00 am
- Floyd Lamb Park at Tule Springs
    - 9200 Tule Springs Rd, Las Vegas, NV 89131

Contact Kaley Dingeman for more details at
kdingeman@hemophilia.org | 702.564.4368 ext 102

REGISTER TODAY AT www.uniteforbleedingdisorders.org