THE HEMO LINK
a newsletter for the bleeding disorders community and friends
SUMMER 2021

KURT AND DANIELLE SCHWAGER AT THE INAUGURAL SCHWAGER FAMILY GOLF OUTING ON JULY 19, 2021 AT PINE HILLS GOLF CLUB

NOHF MISSION

TO ENHANCE THE QUALITY OF LIFE FOR PEOPLE WITH BLEEDING DISORDERS AND THEIR FAMILIES, THROUGH ADVOCACY, EDUCATION, RESEARCH AND OTHER CONSTITUENCY SERVICES.

Youth Golf - It's a Wrap!

Thank you to everyone that made our Summer Youth Golf program a success this year. Special thanks to Akron Children's 340b program for sponsoring PT Debbie to attend each week to stretch out our kids and make sure they safely played each week. Coach Rick, Kurt S, Randi and the Parent Volunteers made sure each participant had a great time learning the sport.

Coach Rick put together a great final week event with competition for the youth, so they could show off their skills to their parents.

Ryan started off the competition winning the chipping shot with a close placement! Colin who went first in pitching was super close and held strong until Cameron stepped up last and got a little bit closer. Then on the putting green Carmelo sunk a great hole in one early in the competition, AND then something that has never happened to Coach Rick, Christian also sunk another hole in one! Two holes in one in one competition. It was the perfect ending to a great season.

Inaugural Schwager Family Golf Outing

Monday, July 19, 2021
Pine Hills Golf Club

It was a beautiful day for the Inaugural Schwager Family Golf Outing benefitting the Northern Ohio Hemophilia Foundation! My family and I have been involved with the chapter for several years. After considering many ways in which we could give back to the chapter and community, we thought continuing the tradition of a golf outing – but at a new location – was something we wanted to try.

Golfers came out swinging, and the day included raffles, prizes and a few contests around the course. We weren't sure what to expect in an unexpected year, but it was wonderful to see both old and new faces join us for this year's outing.

THANK YOU to all of our golfers, volunteers and sponsors for their support this year, including my parents Kurt & Vickie Schwager. We truly appreciate you! Special thanks to our 2021 sponsors: Akron Children's Hospital, Bayer and Octapharma.

We look forward to seeing you at next year's outing – SAVE THE DATE: Monday, July 18, 2022.

Sincerely,

Danielle Schwager

SAY HELLO TO JAMES

He has hemophilia A and has gone through two major surgeries while keeping to his factor regimen with the support of his hemophilia care team

"RECOVERY WAS TOUGH, BUT I LEARNED I HAD MORE SUPPORT THAN *I THOUGHT POSSIBLE.*"

HELLO FACTOR

Read stories like James' in *Hello Factor* magazine:
BleedingDisorders.com

Takeda

It's Almost Time to WALK!

We are SO excited to welcome our walkers back to the AKRON ZOO on Saturday, September 11th, 2021! We are incorporating a virtual option for those who wish to walk in their neighborhood or park and still feel part of this magical day.

Registration begins at 8:00a with our walk kicking off at 9:45a. We will have awards, raffles and fun for kids of ALL ages! You'll also be able to visit with our Industry partners. Gift cards for lunch at the zoo are graciously sponsored by Akron Children's Hospital. We truly thank them for their support. Participants raising $25 or more, will receive a Unite for Bleeding Disorders Walk shirt. Parking is FREE.

Your admission ticket to the zoo is free, your donation is PRICELESS. The NOHF relies on these donations to keep our mission alive.

You are welcome to stay and enjoy the beauty of the Akron Zoo until their close at 5p. New in 2021: Wild Asia! The Akron Zoo has added their newest exhibit which includes Sumatran Tigers, Red Pandas and Gibbons. It's going to be a WILD TIME!

Finally, this year's Top Fundraising Team Captain will receive their very own Blood Drop Converse shoes. I mean seriously, how cool is that??

Thanks to all our 2021 National and Local Sponsors: Hemophilia Alliance, Takeda, BioMarin, Pfizer, Sanofi, Ascella Health, Bayer, Grifols, Optum Infusion Pharmacy, Akron Children's Hospital, BioMatrix, InfuCareRx and Novo Nordisk.

Visit our website, www.nohf.org, to register as an individual or a team. Questions? Contact Dawn, dawn@nohf.org or 216.834.0051

Unite for Bleeding Disorders

NOHF

Save the Date

Saturday, September 11, 2021

akron zoo®

Registration: 8:00am
Walk Begins: 9:30am

Walk with us individually or as part of a team!
Register today @ www.nohf.org

The 340B Factor Program

Specialty Pharmacy & Homecare Service

Exceptional comprehensive care for all bleeding disorders.

Akron Children's Hospital

For more information, call JD at 330-543-3513
or toll-free 1-800-262-0333, ext. 33513
akronchildrens.org/departments/Hemostasis-and-Thrombosis-Center

Tyler's Story

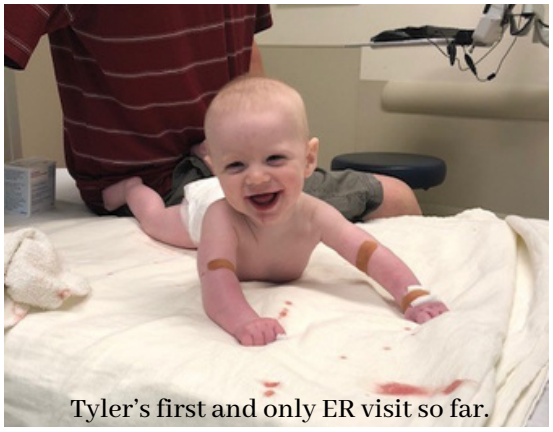
by Brittany Selby

We are so excited to be participating in the 2021 Unite for Bleeding Disorders walk. Our son Tyler is the Hemo Hero in our house! He was born February 25, 2020 and is our perfect, handsome, happy little man. As we have discovered, our storyline is a common one among the hemophilia community- Tyler experienced bleeding issues from day one, with his heel sticks in the hospital along with some birth trauma and bruising. We had a follow-up visit with our pediatrician when Tyler was 5 days old- we told him our concerns and although he was certain it was a long shot since it's such a rare condition, he suggested a bleeding time test. From there things happened very fast - we received the call that we would need to head to Akron Children's Hospital and visit with Hematology. We arrived and met the team: Dr Fargo, Julia and Irene couldn't have been kinder as we navigated our emotions, questions, concerns and general shock at the Severe Hemophilia A diagnosis we had just received. With no family history, we had no idea what this diagnosis meant for our beautiful boy and the future of his health. The team took us through the history of Hemophilia, the medical advances that have been made and the treatment options available for Tyler today. We have continued with genetic testing on me, which determined I am a carrier of Hemophilia. We have not yet continued testing to determine if the mutation started with me, or if it unknowingly goes back further in my family.

As soon as we received Tyler's diagnosis, the computer became our best friend. We immediately started researching and joining social media media groups for Hemophilia families and of course sought out NOHF as recommended by the team at Akron Children's. The more we learned, the more involved we wanted to be!

Those who have come before us have paved the way for Tyler to be able to be the active, fun loving little boy he is destined to be with minimal impact by his bleeding disorder and we are so thankful for that. Now we will do what we can to support and be there for those who come after us.

We cannot wait to meet other local Hemophilia families in person this year at the Akron Zoo.



Tyler's first and only ER visit so far.

Calendar

OF EVENTS

September

Saturday, September 11th - *Unite for Bleeding Disorders WALK*
LIVE at the Akron Zoo

September 24th through 26th - *Family Camp/ Transition Workshop*
VIRTUAL

October

Thursday, October 7th - *Black and Blue Ball*
VIRTUAL

Tuesday, October 26th - *Harvest Hootenanny Pumpkin Carving*
VIRTUAL

November

November 5th and 6th - *Annual Meeting*
Virtual

December

Saturday, December 4th - *Holiday Party*
LIVE at Cleveland Metroparks Zoo/Rainforest

Some events listed as LIVE may go VIRTUAL based on local guidlelines and recommendations for safe gatherings.

Advocacy Update

Dear Fellow Bleeding Disorders Community Members,

It is awesome being back in my role as a patient advocate. I missed working with you all. The Ohio Bleeding Disorders Council had a great first quarter of the 134th General Assembly (GA). It was a very busy spring session at the Statehouse. We had three community members step up to testify on bills in the House and a lot of members that wrote to and called on their lawmakers! Thank you! We advocated and raised awareness for bleeding disorders in a huge way.

Here's a quick run down of the issues:

In the State Budget, we were able to advocate for increasing the age of the Children with Medical Handicaps Treatment Program up to age 23. HB212 when passed will increase the age all the way to 26, to mirror coverage on parents insurance, for the treatment program.

HB185 which will designate March as Bleeding Disorders Awareness Month, passed the House and is in the Senate awaiting hearings.

HB153 will ban the practice of non-medical switching. This legislation was re-introduced and aims to stop plans from being allowed to change drug coverage mid-year.

HB135 is the legislation we are advocating and raising awareness on the most. Copay Accumulators are now impacting 9 out of 10 plans sold in the commercial market in Ohio. OBDC is leading the patient community to educate our lawmakers on what Copay Accumulator Programs are and how they impact access to care.

If you have any questions on any of these bills or are interested in advocating for any of these issues, please email me at randi@nohf.org.

Thanks
Randi Clites
OBDC State Policy Director

CASCADE
HEMOPHILIA CONSORTIUM
SINCE 1994

A Trusted Partner in Your Circle of Care

- Non-profit pharmacy dedicated to respond to the needs of persons affected by bleeding disorders
- Governed by a volunteer board of directors from the bleeding disorders community
- A 340B covered entity offering among the lowest prices for factor available
- Returns all excess revenues to the community for support of patient services and HTC programs

For more information visit us at cascadehc.org

HTC CORNER Akron Children's Hospital

By Irene Beohlefeld and Julia Golden

To keep all of us safe, but especially to protect our most vulnerable patients, Akron Children's Hospital (ACH) will continue to rely on the proven safety protocols that slow the spread of COVID-19. These include screening all patients and visitors upon entering our facilities, requiring face masks for everyone over age 2 and medically able, promoting social distancing and hand washing, and encouraging those who are eligible, to get the vaccine. Vaccines are available by appointment only at Akron Children's Hospital Urgent Care Centers and Primary Care Clinics for anyone 12 years and older. Visit https://www.akronchildrens.org/pages/2019-Novel-Coronavirus-Frequently-Asked-Questions.html for more information on where and how to schedule an appointment.

ACH HTC will continue to offer virtual visits as an alternative to in-person visits when possible. Virtual visits can reduce the burden of getting to an in-office visit and reduce time needed, in addition to limiting contact. MyChart is required to have a virtual visit. Virtual visits are ideal for annual visits, follow-up after a bleed or injury or to develop a treatment plan. HTC team members provide exams, assessments, and education during typical office hours, while patients access care from home or a location most convenient for them. All charges are billed the same as in-person visits and are submitted through insurance. During your visit, whether it is in-person or virtual, HTC team members will continue to focus on education to prepare patients 11-21 years old to eventually transition from pediatric care to adult focused care. The bleeding disorders specific readiness assessment tool is used to help us determine what our patients already know about their bleeding disorder and what topics we need to provide more education about. Many patients and families gave input about the tool to make it comprehensive, acceptable, and relevant. The tool is designed to be completed by the patient without the help of the parent. This will provide the best picture of what the patient knows. Thank you, to all patients ages 11-20, who have been completing the assessment and providing valuable feedback. In the future, we hope to expand this program to include all our patients, since the learning process for transition truly begins at diagnosis.

In addition to the Readiness Assessment Tool, patients ages 12-17, are asked to complete a Patient Experience Survey. This is a national survey asking patients if their HTC has talked to them about Transition. This survey is available in paper form and online. Your responses are confidential and sent directly to a third party. We will continue to collect this information through 2022. Your feedback is helpful!

Another way patients and families of any age can help, is to take the National HTC Patient Satisfaction Survey. Hemophilia Treatment Centers (HTCs) across the United States are participating in the 2021 National HTC Patient Satisfaction Survey! If you, or someone you care for, had contact with our HTC (444) in 2020, we want to hear from you! You can take the survey online at www.htcsurvey.com, or fill out the paper survey we sent in the mail several months ago. The survey closes on August 31, 2021.

This survey is a follow up to the surveys done in 2015 and 2018. The information from these surveys helps our HTC identify areas where we are doing well and those areas we need to improve. Your voice can again help our HTC learn and improve. Please go to www.htcsurvey.com to take the survey, it only takes a few minutes of your time! Thank you for your valuable input!

Patient and family participation in all these initiatives is important to us and helps us serve you best. Thank you to our HTC families for partnering with us to provide the best care.

Black & Blue Ball

We know it's been quite a year and we are excited to announce plans for this year's Black and Blue Ball.

This past spring as our committee began planning for an October 2021 in-person gala, things were unclear how quickly the vaccines would be available and if we would be able to provide a safe event for all our guests. The chapter learned the longer we waited to make a decision to either move forward in-person or to switch back to a virtual event, the more expensive our cancellation fee would be. After surveying sponsors and table hosts, our board made the difficult but thoughtful decision to host our Black and Blue Ball virtually in 2021.

We hope you'll mark your calendars for Thursday, October 7th from 7:00p-8:00p. Grab your favorite device of choice, don your most dapper black and blue garb, raise a glass and let's have some fun helping those in the bleeding disorders community.

We will have raffles, games, an online auction and Bob Hale will return for our LIVE Fund-a-Need portion of the evening. Gala baskets with plenty of delicious appetizers and wine will once again be delivered directly to your home. We look forward to "seeing" you in October.

While you're marking your calendars for our virtual event in 2021 please also mark - Friday, April 29th, 2022 at the Renaissance Hotel in downtown Cleveland. We are going to have a SUPER celebration once we are together again!

Visit our website, www.nohf.org, to purchase Individual, Couple or Table Host tickets.
Questions? Contact Dawn, dawn@nohf.org or 216.834.0051

Northern Ohio Hemophilia Foundation presents

BLACK AND BLUE BALL

Thursday, October 7, 2021
7:00p-8:00p

Grab your device of choice, don your best black and blue attire,
and join us for a special one-hour VIRTUAL celebration.

Evening includes: online silent auction,
interactive "Heads or Tails", raffles, and LIVE Fund-a-Need.

Tickets include: link to Zoom event and gala baskets
containing wine and appetizers shipped directly to your home!

Ticket Prices:
$75 - Individual $150 - Couple
$750 - Enhanced Gala Baskets for Eight
$1,000 - Premium Gala Baskets for Eight

*Enhanced Gala Baskets for Eight includes dessert
*Premium Gala Baskets for Eight includes dessert, linens, and etched wine glasses.

Questions contact:
Dawn Evans - dawn@nohf.org 216-834-0051
Purchase Tickets: www.nohf.org/news-and-events

Gears for Good
Team Resilience Northern Ohio Ride

Saturday, June 19, 2021

The beautiful day brought our riders out in support of Team Resilience and the NOHF's annual Gears for Good, Northern Ohio ride. After grabbing water and snacks, our more "adventurous" riders started their day at 7:00a for a 50-mile ride through the beautiful Ohio & Erie Canalway towpath. The rest of Team Resilience finished their 5-40 mile rides with smiles on their faces.The event ended with everyone receiving a boxed lunch celebrating their accomplishment.

Join us for Team Resilience on June 4, 2022 for this family-friendly event raising money for the NOHF's emergency assistance fund helping those in our community. Funds raised nationally directly support the Hemophilia Federation of America's Helping Hands program, which provides urgent funding for basic living expenses such as housing, transportation and utility bills for families living with bleeding disorders.

Special thanks to our 2021 sponsors: Akron Children's Hospital, Bayer, Octapharma, CSL Behring, Novo Nordisk, Cigna and BioMatrix.

NEW CLINICAL TRIALS UNIT
for HTC Patients at University Hospitals

A possible cure for bleeding disorders has never been as close as it is today! Many novel therapies are currently in development and we are excited to be able to offer them to our community of patients with bleeding disorders. The HTC at University Hospitals and Rainbow Babies & Children's Hospital is happy to announce the creation of a new Pediatric Hematology/Oncology Clinical Trials Unit (PHO CTU). This new unit provides the infrastructure and resources necessary to carry out the latest clinical trials that will bring new and exciting, state-of-the-art therapies to our patients and to those in surrounding HTCs.

We currently have a vast portfolio of trials available in the areas of severe hemophilia A and B, gene therapy, newer factor VIII mimicking agents, von Willebrand Disease, and antithrombin targeting agents for patients with hemophilia and inhibitors.

Please call 216-286-0762 to speak with our research nurse and learn about the clinical trials you may qualify for. We are happy to provide your clinical trial care and coordination while you maintain your standard care with your current HTC medical team. We will work to maintain close communication with your primary hematologist for continuity of care. We look forward to working with you!

esperoct®

antihemophilic factor (recombinant), glycopegylated-exei

Brief Summary information about ESPEROCT® [antihemophilic Factor (recombinant), glycopegylated-exei]

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/esperoct.pdf to obtain FDA-approved product labeling
- Call 1-800-727-6500

Patient Information

ESPEROCT®
[antihemophilic factor (recombinant), glycopegylated-exei]

Read the Patient Information and the Instructions For Use that come with ESPEROCT® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about ESPEROCT® after reading this information, ask your healthcare provider.

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

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

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

What is ESPEROCT®?

ESPEROCT® is an injectable medicine used to replace clotting Factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

ESPEROCT® is used to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A.

Your healthcare provider may give you ESPEROCT® when you have surgery.

Who should not use ESPEROCT®?

You should not use ESPEROCT® if you

- are allergic to Factor VIII or any of the other ingredients of ESPEROCT®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because ESPEROCT® might not be right for you.

What should I tell my healthcare provider before I use ESPEROCT®?

You should tell your healthcare provider if you:

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor VIII.

How should I use ESPEROCT®?

Treatment with ESPEROCT® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A.

ESPEROCT® is given as an infusion into the vein.

You may infuse ESPEROCT® 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 hemophilia treatment center or healthcare provider. Many people with hemophilia A learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much ESPEROCT® to use based on your weight, the severity of your hemophilia A, and where you are bleeding. Your dose will be calculated in international units, IU.

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

If your bleeding is not adequately controlled, it could be due to the development of Factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of ESPEROCT® or even a different product to control bleeding. Do not increase the total dose of ESPEROCT® to control your bleeding without consulting your healthcare provider.

Use in children

ESPEROCT® can be used in children. Your healthcare provider will decide the dose of ESPEROCT® you will receive.

If you forget to use ESPEROCT®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using ESPEROCT®

Do not stop using ESPEROCT® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much ESPEROCT®?

Always take ESPEROCT® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more ESPEROCT® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of ESPEROCT®?

Common Side Effects Include:

- rash or itching
- swelling, pain, rash or redness at the location of infusion

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor VIII products. **Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as:** hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against ESPEROCT®, which may stop ESPEROCT® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all of the possible side effects from ESPEROCT®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

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

What are the ESPEROCT® dosage strengths?

ESPEROCT® comes in five different dosage strengths. The actual number of international units (IU) of Factor VIII in the vial will be imprinted on the label and on the box. The five different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Gray	1500 IU per vial
Yellow	2000 IU per vial
Black	3000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

How should I store ESPEROCT®?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Protect from light. Do not freeze ESPEROCT®.

ESPEROCT® can be stored in refrigeration at 36°F to 46°F (2°C to 8°C) for up to 30 months from the date of manufacture until the expiration date stated on the label.

ESPEROCT® may be stored at room temperature (not to exceed 86°F/30°C), for up to 12 months within the 30-month time period. Record the date when the product was removed from the refrigerator. The total time of storage at room temperature should not exceed 12 months. Do not return the product to the refrigerator.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) ESPEROCT® should appear clear and colorless without visible particles.

The reconstituted ESPEROCT® should be used immediately.

If you cannot use the reconstituted ESPEROCT® immediately, it must be used within 4 hours when stored at or below 86°F (30°C) or within 24 hours when stored in a refrigerator at 36°F to 46°F (2°C to 8°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about ESPEROCT® and hemophilia A?

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

Revised: 02/2019

For Patent Information, refer to: http://novonordisk-us.com/patients/products/product-patents.html

Manufactured by:
Novo Nordisk A/S
Novo Allé
DK-2880 Bagsværd, Denmark

More detailed information is available upon request. Available by prescription only.

For information about ESPEROCT® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA
1-800-727-6500

US19ESP00010 August 2019

novo nordisk®

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

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

Community Voices in Research

NATIONAL HEMOPHILIA FOUNDATION

Community Voices in Research (CVR) is a partnership between the bleeding disorders community and NHF

Community-Powered Registry

360-degree view of living with a bleeding disorder

First-hand experiences directing the future of research

Empowers the community to take active participation in healthcare decisions

Opportunity to participate in patient-reported outcome research

What's in it for me?

- Personalized Dashboard
- Education and resources
- Virtual Advisory Panels—opportunities to share your opinions on specific topics with clinical trial sponsors or investigators before studies are designed.
- Print your personal CVR record

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Enrollment

YOU COMPLETE
Baseline Survey

YOU RECEIVE
Personalized Dashboard

YOU RECEIVE
Virtual Advisory Panel Opportunities

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YOU RECEIVE
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YOU COMPLETE
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Your Voice in Research

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Help researchers understand what it means to live with a bleeding disorder from your perspective and that of your immediate family members.

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