BIG RED FACTOR

2019—Issue II

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NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

Nebraska Chapter News

It's hard to believe that we are already half way through the year. The first six months of the year have had wonderful programming with a new advocacy workshop and VWD Education Day. We did a lot of advocacy work, had a super informational and interactive Family Education Weekend and New Parent Group.

We all know how busy summer is for families and it's no exception for the chapter! We are working hard on raising funds for our year round programming through our Bloody Mary Mix off and gearing up for Walk. These two events are how we are able to provide staff and programming for the Chapter. We need you to help spread the word and awareness for the bleeding disorder community here in Nebraska. Every dollar we raise stays here to support your community through education, advocacy and support for the Nebraska Bleeding Disorder Community.

We look forward to seeing you at Family Camp, at Kearney Education Day and especially at Walk! Misti and I are so proud to serve this community, share your message and your stories and continue to advocate for you locally and across the State of Nebraska.

Have a safe and fun summer! We hope to see a lot of you in the coming months. As always, we appreciate your ongoing support and participation in keeping this organization dynamic and the place to call home for those with bleeding disorders.

-Maureen Grace, Executive Director

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

Our Mission:

The National Hemophilia Foundation—Nebraska Chapter is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy & research.

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The material in this newsletter is provided for your general information only. The Nebraska Chapter does not give medical advice or engage in the practice of medicine. NHF-NE does not recommend particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

2019
Third Quarter Events

July

July 13-14 2019
Women's Retreat with HOI
Des Moines, IA
July 21, 2019
Infusion: Bloody Mary Mix-Off

August

August 9-11, 2019
Family Camp
August 25-26, 2019
Kearney Outreach

September

September 21, 2019
Unite for Bleeding Disorders Walk

Unite for Bleeding Disorders

2019 Save the Dates

October 19, 2019

Harvest Festival
Roca Berry Farms

November 9, 2019

Industry Symposium

A Proud Member of

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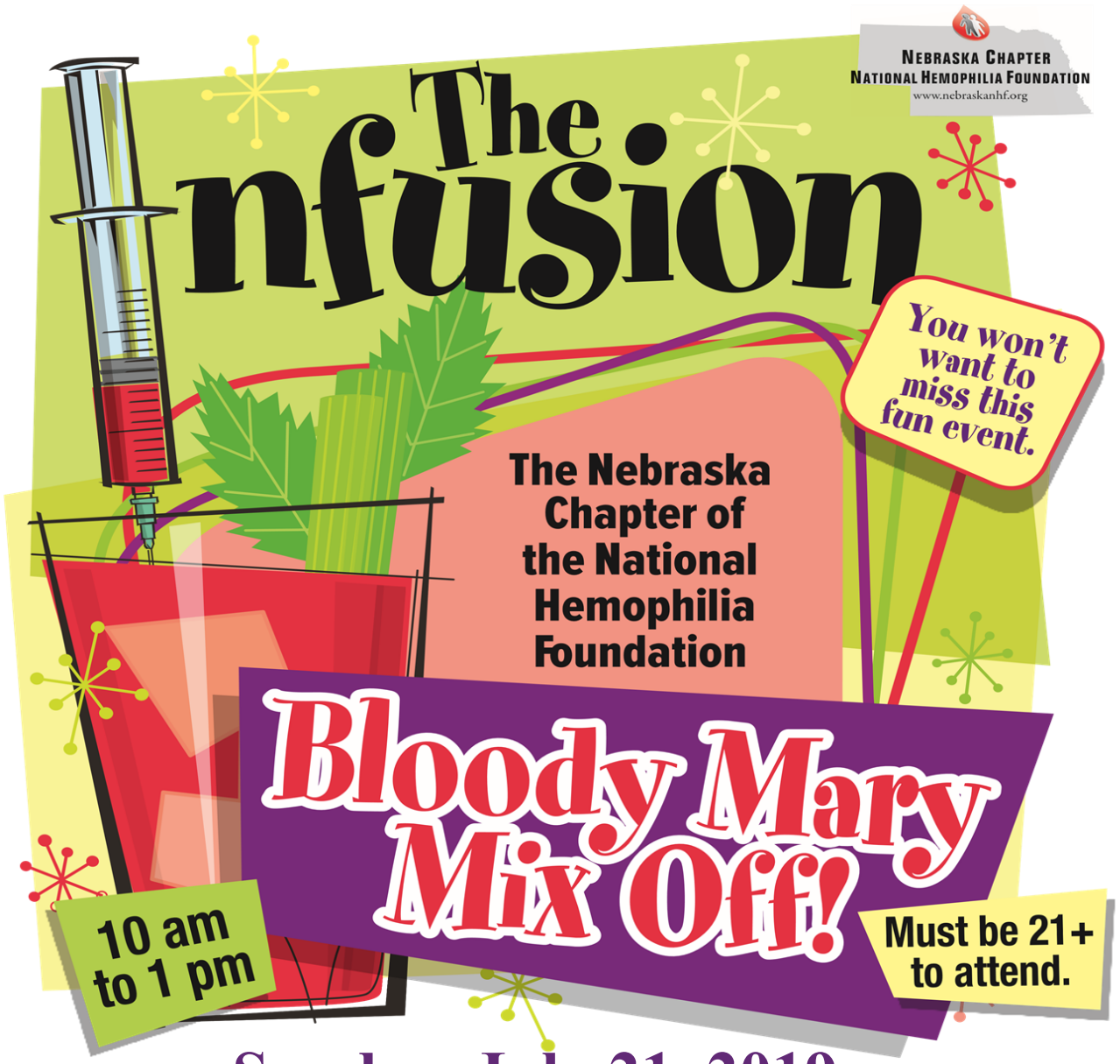

Sunday, July 21, 2019

Founders One-Nine • 1915 Jackson St. Omaha, NE

Guests enjoy bloody marys from every bar, a catered brunch and the chance to vote for their favorite Bloody in Omaha.

Prizes will be awarded: Best Overall Bloody, Most Like a Meal, Most Inventive and Best Garnish.

Sponsored by:

Tito's Handmade Vodka Austin Texas

novo nordisk®

Participating bars for the event

Tracks Lounge World's Best Chicken · BeyondGolf Bar + Kitchen · Krug Park · Spirit World Est. 1974 · Bald Brothers Catering

AND More!!

Tickets available on: Eventbrite www.nebraskanhf.org

Family Education Weekend 2019

On April 27-28, we welcomed over individuals and families to the Embassy Suites in downtown Lincoln, for the Nebraska Chapter's annual Family Education Weekend. Saturday morning, we opened with introductions, announcements and an HTC Update from Dr. James Harper, pediatrician of hematology at Children's Hospital & Medical Center in Omaha, NE. Throughout the weekend, adults attended sessions on managing stress and wellness, women's health, sibling support and vWD. The young ones played, went to Paint Yourself Silly and had some child friendly education from Accredo. Meanwhile ages 12-20 enjoyed programming from Gut Monkey, a company that provides adventure education for people with chronic medical conditions. We wrapped up programming with an infusion clinic where kids and adults of all ages got to work on their self infusion skills, some for the very first time. Self infusion is one of the most important life skills we can impart on our members and it's great to see everyone improve and become more confident with their infusions and taking control of their health.

Our Saturday evening activity was a community service project in which we made care packages for the Children's Hospital in Omaha. Care packages consisted of coloring books, Kleenex, toys, candy and handmade cards of encouragement for hospital residents which were donated to the 6th Med/Surg floor which specializes in hematology and oncology.

Sunday morning, the conference concluded with a fun and interactive group exercise from CVS's Juli Mason, updates from the chapter and a kickboxing session from CKO Kickboxing in Lincoln, NE.

Thank you to all who attended!

Save the date for next year's FEW on May 16-17, 2020 in Omaha!


Welcom
Making Cha


VLX Series

You Be the Judge

When I share with people that my son has hemophilia, I often hear comments like these: "Hemophilia, what?" "Are you kidding me?" "Does it affect his brain, his learning?" "Is it contagious?" "But your son was just limping yesterday, and not today." "But I can't see the disability." I am mother to Omar, a 14-year-old with severe hemophilia, and his disorder is not always apparent. Handling these comments from others can be tough when it comes to a chronic disorder like hemophilia. It's especially challenging when the disorder doesn't have consistent visible symptoms, and you are often confronted with more questions.

Parenting a child with a chronic disorder has a whole new set of challenges and worries. Hemophilia is unpredictable, inconsistent, and some sometimes invisible. One time when we lived in south Florida, my son received a handicap decal for our car because he was unable to walk due to his ankle bleed. We received stares in the parking lot of our local grocery store. A woman questioned, "Why the decal? You both look fine. Do you have that handicap card illegally?" I was floored. But I responded politely, "We are okay, and have a nice day, ma'am."

Some chronic conditions are not always obvious, and many patients are limited in their work or daily activities; sometimes they're labeled lazy, overdramatic, or even a liar. Many patients try to explain their disability after hearing, "But you look so good." It's crucial that we spread awareness about invisible disorders to everyone we encounter and dispel any judgment calls.

Here are three incidents our family experienced with our invisible disorder—hemophilia:

Story 1. Omar was in fifth grade when he had a little sprain in his ankle, which happens to be his target joint. Just to be safe, my husband and I took Omar to the hemophilia treatment center (HTC) to get examined. The very next day, Omar went to school with crutches to avoid permanent damage. With high levels of factor in him, Omar decided not to use crutches at school for the next three days. He was fine, walking normally. Judging started right away. When Omar returned home, he said that his teacher and friends had called him a liar, and had assumed that all of this was made up. The next day, I visited school and clearly explained again about Omar's bleeding condition, distributed additional information, and stated that this invisible illness is something to take seriously.

Story 2. In the fall of 2015, I was assigned to teach at a special needs school in Livingston, New Jersey. I was so excited to teach this population and wanted to take up the challenge. At the time, it was my 15th year teaching special needs, ranging from age six months to 72 years. But I too judged someone, something I had never done in 15 years of teaching. I judged one of my students because he was not in a wheelchair; all of my students were in wheelchairs. I assumed that he didn't have an intellectual disability. I thought, "Why is he in this school? He looks perfectly fine, and he is walking well." I then discovered that this student had a major visual problem and indeed did have an intellectual disability. He was 14, and was learning at a third-grade level. This was a reminder to not judge others, even as a parent of a child with a chronic disorder. It was a learning moment for me.

Story 3. Omar's wish was granted by the Make-A-Wish Foundation in 2014 to attend WrestleMania 30 in New Orleans, Louisiana, at the Mercedes-Benz Superdome. On the third day of the trip, we were invited to attend one of the six WWE WrestleMania Axxess sessions at the Moral Convention Center. At the session, there was a replica of the WWE stage, complete with music and video screen. All of the Make-A-Wish children lined up to make their special appearances on stage as if they were wrestlers. Omar decided he would walk in with the music and video of wrestler John Cena. As we approached the beginning of the line, an attendant stopped us and said, "He can't go in." I quickly responded, "And why not?" The attendant continued to stare at our son and at us. He said, "This line is for the Make-A-Wish kids only, and he is not in a wheelchair." I replied, "Oh, you don't see his illness, but can you see his badge that says 'Make-A-Wish.'" I finished by saying, "He is making his entrance."

As a parent and teacher, I have learned that some disabilities are invisible. And just as we can't assume that a child or young adult in a wheelchair has limited intellectual abilities, we can't assume that a child or young adult who is walking normally doesn't have a chronic disorder like hemophilia.

I work closely with my students and take inventory of their strengths, weaknesses, likes, and dislikes—whether visible or not. At times, our disorders may be invisible, but we need to speak up and dispel any misconceptions and misunderstandings by sharing our knowledge. Folks, continue to advocate for yourself, for your children, and for others. Knowledge is power and empowering!

Mily Cepeda *lives in New Jersey. She is a special education teacher and motivational speaker. Mily has an MA in special education and a BA in psychology. She is currently a doctoral student in education, dedicating her degree to her son and her father.*

Omaha Gives! 2019

On Wednesday, May 22, the Nebraska Chapter of the National Hemophilia Foundation joined other area nonprofits on this annual community-wide day of giving, asking for your donations to support the work we are doing for the bleeding disorders community in the state of Nebraska.

NHF-NE has continued to make a difference in the lives of those with bleeding disorders with the generosity of donors like you!

We are dedicated to finding better treatments and cures for inheritable bleeding disorders and preventing the complications of these disorders through education, advocacy and research.

Thank you for your support!

Goal: $750 **Raised: $1,060**

Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever. **Let's make today brilliant.**

bleedingdisorders.com

Takeda

BAXALTA AND SHIRE ARE NOW PART OF TAKEDA

Where Does Your Factor Come From?

Laurie Kelley

You may know the brand name of the factor concentrate your child or other loved one uses to treat bleeds. And you may have chosen the brand with the help of your hematologist. But where do get your factor? Who provides it? Is your current brand the best way to meet your personal needs? Do you have choice of provider?

Pharmaceutical companies develop and manufacture factor. Then they sell the factor to a licensed pharmacy—a factor provider. You can't buy factor directly from the manufacturer, just as you can't buy a car directly from General Motors, or diapers from Kimberly-Clark. And you can't get factor from your local drug store. Your hematologist supplies a prescription to a factor provider, who delivers it to you. Who are factor providers?

Hospital Pharmacies

You want a factor provider that can meet your personal needs; this usually means being cost-effective and speedy, and supplying factor in the correct assay sizes with all the ancillaries (such as needles and syringes) you require. Unless you are a member of a health maintenance organization (HMO) and are required to buy factor from the hospital pharmacy, or your hospital runs a 340B program (see p. 18), obtaining your factor through a hospital pharmacy is usually not a good option. Why not? Hospital pharmacies are the least cost-effective factor provider, and often mark up the cost of factor several hundred percent to cover the high overhead costs of running the hospital. Also, hospital pharmacies are not set up for home delivery and unlike specialty pharmacies, do not offer any additional services, such as a home nurse. Factor is already very expensive without the hospital markup! You'll want a long-term solution, with a factor provider that ships to your home.

Specialty Pharmacies

Specialty pharmacies are one of the chief factor providers in the US. If your insurance payer approves a specialty pharmacy based on your physician's prescription, you make a phone call, order your factor, and receive the order at your home within 24 to 48 hours, along with all necessary ancillaries and supplies. Reimbursement specialists handle your insurance paperwork. Specialty pharmacies stock most brands of factor, and usually can provide a size or assay that closely mirrors what you need for your child's infusions. Some specialty pharmacies will send a nurse to your home to perform or assist in the infusion process. There are many specialty pharmacies and home care companies that service hemophilia, and some are devoted only to hemophilia.

Your HTC

Did you know your hemophilia treatment center might sell factor? There are about 140 HTCs in America as of this writing, and over 100 participate in the 340B program; all are licensed distributors of factor. So you also have the option—if your payer permits—to purchase factor from your HTC. Why and when would you consider buying from your HTC? Federally funded HTCs can take advantage of the federal Public Health Service (PHS) Act known as the 340B Drug Pricing Program. The PHS Act allows certain federally funded entities and public hospitals to purchase prescription outpatient drugs (including factor) at steeply discounted prices. So federally funded HTCs can buy factor from pharmaceutical companies at rock-bottom prices, and then sell it to you and make a profit.

In theory, 340B pricing is beneficial. It offers competition to help keep prices down, reduces costs for the government, and generates funds for the HTC to use for staff positions or overhead—which is truly needed. But not every eligible HTC uses the 340B program. And even when an HTC does offer factor through 340B, not all the HTC's hemophilia consumers take advantage of this. Why? Sometimes, 340B pricing doesn't guarantee lower prices to the consumer: some HTCs charge the same price per unit as specialty pharmacies. And some consumers simply prefer the personal relationship they have with their specialty pharmacy reps.

Where Does Your Factor Come From?, cont'd.

PBM Pharmacies

Pharmacy benefit managers (PBMs) are powerful, multi-billion-dollar companies hired by insurance companies to manage the insurance benefits and prescription drug plans of private-sector entities, such as employers and labor unions. PBMs help determine the formulary—a limited list of preferred drugs that the payer will reimburse. PBMs also negotiate and manage contracts with pharmaceutical companies to buy the drugs needed by plan beneficiaries like you. The main function of a PBM is to keep prescription drug costs low for the insurance company.

PBMs are able to make high-volume drug purchases to receive substantial discounts from pharmaceutical companies. With their vast resources and negotiating skills, PBMs such as Express Scripts and CVS Health now serve most of the hemophilia patients in the US. Some PBMs have started their own specialty pharmacies to sell factor; and because they have a direct line to the payer, these PBMs are able to switch families from the factor provider of their choice to the PBM's specialty pharmacy. They have incredible power over pricing, product availability, and your payer.

Based on this, can you even choose a factor provider? Unfortunately, your healthcare payer—insurance company or government program—often chooses for you. Find out if your insurance company reimburses for specialty pharmacy services. Then, learn which companies are in-network for you. Your choices might be limited, because for the payer, working with a single factor provider is one way to lower costs. More and more often, choice is being restricted. You may face a struggle when choosing a preferred factor provider.

If you can choose, use this list of questions to ask your factor provider to make sure your personal needs are met:

- Which brands of factor concentrate do you provide?
- How much product will you provide at one time?
- How are products delivered to me?
- Do you ship during emergencies?
- Do you supply the assay size I need as a single dose?
- How much will I pay per unit of product?
- Do you (the HTC) offer 340B pricing?
- Are you recognized as an in-network provider by my insurance company?
- What are your hours of operation?
- Are a pharmacist and registered nurse available 24/7?
- Can I use your regular HTC services even if I choose to use a specialty pharmacy as my factor provider?
- Do you supply ancillaries: needles, syringes, and bandages?
- Do you provide needle disposal containers?
- Do you contract with local home nursing services?
- Is home nursing service included in the cost of product or billed separately?

Even though choice is being limited, you are not limited! Learn all you can about who supplies your factor, and continue to safeguard your needs. Ask questions, and get the answers that will help you make effective decisions.

Publication: PEN 5.19

Column: YOU, Sponsored by Takeda

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

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

CAMP TAP-A-VEIN-A-DAY-A

Nebraska Chapter NHF

August 9th-11th, 2019

Eastern Nebraska 4-H Center

Please join us for NE NHF's Family Camp!
Open to all ages and every kind of family.
The fun starts Friday night at 5 pm and goes through Sunday morning at 10 am.
Enjoy camp activities like the zip line, canoeing, archery, camp fires, crafts and water games.

Education and Infusion clinic will be part of the fun!

Includes all meals and accommodations (cabins with twin bunk beds and private bathrooms).

Family Registration: $35
Individual Registration: $25
Register online at www.nebraskanhf.org

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

Family Camp FAQs!

Q: Who can go to Family Camp? Do I have to have an affected kid to go?

A: ANYONE in the bleeding disorder community in Nebraska can come. It doesn't matter if you are 3, 33 or 63, we want you to come have fun at camp. If you have a direct family member with a bleeding disorder, family camp is for you. This means if you are affected and your kids aren't, COME! If you are a carrier or affected and have no kids, COME! If you are part of a family with a bleeding disorder, COME!

Q: I'm not outdoorsy and love air conditioning. Will I hate camp?

A: No! Our staff is also not very outdoorsy and would never sleep in a tent and you won't have to either. All the cabins are air conditioned with plumbing and real bunk beds. We won't expose you to the creepy crawlies of camp unless you seek them out yourself! All the buildings are air conditioned and I promise to not let you over heat out our account.

Q: What do we even DO at family camp?

A: Family camp is a mix of games, activities, outdoor fun with a little education and an infusion clinic mixed in. We want everyone to get the camp experience and get kids ready for the opportunity to go away to hemophilia camp. We tie dye, make smores, zip line, have water fights, do fun interactive activities and so much more. It's a fun filled weekend in nature without TOO MUCH nature.

Q: How do I sign up?

A: Go online to www.nebraskanhf.org and register by August 1st to hold your spot at camp!

Summer PING



On summer's hottest day of the year, families gathered at Mahoney State Park for our summer Parent Information and Networking Group (PING) for an interactive conversation about what it's like to be an unaffected sibling to someone with a bleeding disorder. There are many challenges to having a sibling who needs more medical attention than you and how that can be difficult growing up. The general consensus was that it wasn't all bad because they got to attend so many fun events and get to know the community through the chapter! It was a great conversation between families on how they've worked to make sure everyone in the family feels included and loved, even during an active bleed or hard transition. This great conversation was held while keeping our hands busy painting flower pots to take home and the art was outstanding! A huge thank you to Factor One Source Pharmacy, Aptevo and CSL Behring for sponsoring the event and making it possible. Save the Date for our December PING at the Lincoln Children's Museum on December 7, 2019!

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

NEBRASKA NHF'S

KEARNEY EDUCATION DAY

Saturday, August 24, 2019

Younes Conference Center and the
Nebraska State Fair!
416 W Talmadge Road, Kearney, Nebraska
68845

Register today at www.nebraskanhf.org

You are invited to an interactive workshop

THE SCIENCE OF HEMOPHILIA

A CHANGING LANDSCAPE

Join us for a one-hour interactive session to discover how our bodies form blood clots, see what happens inside the bodies of people with hemophilia A, and learn about scientific exploration.

Saturday, August 24, 2019, 6:30 PM

SoZo Restaurant
110 South 2nd Avenue
Kearney, NE 68846

Hosted By: Bobbi Sellers, Clinical Nurse Educator
RSVP: Maureen Grace at 402-499-8025

This workshop is sponsored by Genentech.

Let's put science to work

Life After Immune Tolerance

Cazandra Campos-MacDonald

There are many different treatment options for people with hemophilia. Individual variables like severity level, lifestyle, and how the patient's body reacts to certain products help determine the best treatment option. But when you throw an inhibitor into the mix, treatment options are fewer. You can treat the bleed with bypassing agents, try Hemlibra®, or try to eradicate the inhibitor through immune tolerance therapy (ITT). When ITT is successful, and the inhibitor is gone, what is life like then?

My oldest son Julian has severe hemophilia A and is now 22. He infuses twice a week and has been inhibitor-free since age four. His inhibitor was detected at age 11 months, after a torn frenulum would not stop bleeding. Fortunately, Julian's titer was below 10 BU, and we were able to start ITT immediately. A port was placed within a matter of days, which his father and I began learning how to access. For two and a half years, we gave Julian large doses of factor VIII through his port per our ITT protocol. This was a huge change in how we managed hemophilia. We went from infusing on demand to daily port access. Having a toddler with a bleeding disorder isn't easy, and wrangling him to sit still for daily infusions early in the morning before daycare became part of our routine.

When we received the news that Julian's inhibitor was tolerized, it was as if we had won the lottery! The protocol from the hemophilia treatment center was now to lower his factor VIII dosage and infuse three times a week. Infusing early in the morning before work wasn't easy, but now we had some relief. If extra activities were on the schedule, we now had control over deciding if Julian needed extra preventative infusions. Gaining more control over hemophilia gave my family a huge part of our lives back, and that was empowering. We moved from hemophilia being the focus of our lives to having it simply be part of what we did. Life after ITT was filled with adventures, and bumps and bruises. Infusing three times per week gave us a brand-new outlook on managing hemophilia.

Rich Pezzillo, executive director of the New England Hemophilia Association (NEHA), is an active, healthy man who has moderate hemophilia A. His life changed dramatically when he developed an inhibitor following dental surgery at age 17. For ten years, he lived with an inhibitor that only reached 14 BU but proved persistent. Rich's doctors prescribed various factor products for his ITT. After each failed attempt at ITT, Rich continued to have breakthrough bleeds. The half-life of his factor was very low. He accepted that this would become his normal.

The inhibitor gravely impacted Rich's quality of life, and much time was spent in a wheelchair. He suffered numerous hospitalizations, surgeries, two PICC lines, and two ports. These were the days of receiving six to seven boxes containing factor and supplies for a month's worth of treatment, with a separate refrigerator at college. It proved to be too much. Rich took a year off from school, and eventually transferred to a college closer to home. He finished school four years later than he had planned.

Rich missed the physical part of his life while treating his inhibitor. He could no longer go to the gym and weight train, and even going up a flight of stairs was difficult.

After other attempts at ITT, Rich was finally placed on a plasma-derived product with von Willebrand factor. It worked. Finally, he was able to successfully tolerize, and his inhibitor was defeated.

Life after ITT has been very fulfilling for Rich. He has run a full marathon as well as six half marathons, despite admitting that running may not have been the best form of physical activity for his joints! These days, life after ITT is not filled with a big physical goal in mind—except for being determined to meet his personal challenge of 10,000 steps daily. Keeping as active as possible is important to Rich, and he goes out of his way to make sure he meets his step count. He wants people to understand that it's not so much about training for an event as about changing your lifestyle.

Rich is passionate about his work at NEHA. When he leaves the chapter one day, he wants the organization to be thriving and working to reach everyone affected by a bleeding disorder. "There is still not a cure," he says. Despite the many advances

in treating hemophilia and inhibitors, Rich stresses, "We need to stay vigilant."

When we hear the stories of people who have been through the worst of the worst—the ones who understand firsthand the pain and suffering that hemophilia and inhibitors can cause—our community can be reminded of the significant complications of inhibitors, and how wonderful life can be after treatments like ITT.


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Printed in USA 02/19 PP-JIV-US-0467-1
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LET'S GO

FINAL DAYS TO REGISTER FOR MHA'S CAMP WILDERNESS!!!

Camp Wilderness will be held on July 29th - August 2nd, 2019

Lake Doniphan Retreat Center | Excelsior Springs, MO

Please Register online TODAY at:

https://midwesthemophilia.org/events/mha-camp-wilderness-at-lake-doniphan/

If you need financial assistance with getting to camp for drop off or pick up, please reach out to Maureen at mgrace@hemophilia.org for a gas card.

There's still space for campers but they need your sign up YESTERDAY! Register now for an adventure on the Oregon Trail with MHA.

Kid's Corner

When Your Brother or Sister Has a Bleeding Disorder

Author: Amy Lynn Smith

If you have a brother or sister with a bleeding disorder, you probably have a lot of questions. You may wonder if you will get a bleeding disorder, too. If you have a small bruise or bleed and worry it might mean you have a bleeding disorder, ask your parents about it.
You may also wonder what it's like to have a bleeding disorder. Does your sister have a special doctor? Do those needles hurt? Maybe you worry about what games are safe to play with your brother or sister.

The more you know about your sibling's bleeding disorder, the less you will feel afraid or anxious. Here are some other ideas that may help you and your family:
Learn more. Find out about your sibling's treatment. Or just be there when your brother or sister wants to talk about it.

Share your feelings. Talk to your parents if you're scared or if you feel like you don't get much attention. Those feelings are normal. Usually it feels better to share your feelings with others than to bottle them up inside.

Do things you enjoy. Your parents may encourage you to do things with your brother or sister, as long as they're safe. But it's also OK to want to do things your sibling can't, like play basketball or ice skate. Talk to your mom or dad about trying a new hobby or sport—just for you.
At times, your brother or sister will need extra attention. Sometimes it may even seem as if your sibling gets all the attention. But remember that your parents are doing their best to love and support everyone in your family, including you.


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Join us for Unite Walk 2019! This year's theme is Fantasy Football so register your team, pick a name, get shirts made and set a goal! We look forward to seeing you there!

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As a volunteer, you will:

-Assist with pre-event set up
-Oversee and assist with event registration
-Oversee the children's play area
-Assist with breakfast duties
-Assist with pose-event break down
And more!

For questions or more information contact:
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402-889-0572