BIG RED FACTOR

2021—Issue 1

Inside this issue:

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

A Farewell Address from Misti Mitchell

To the Nebraska Bleeding Disorders Community and Supporters,

It is bittersweet to announce my departure from the Nebraska Chapter, but I am so excited for what this next chapter will bring for me. I have grown so much through my time at NENHF and am thankful for the relationships and connections I have made. I have learned so much about hemophilia and VWD throughout my time here as I was not fully aware of these disorders before I took this job. Thank you all so much for sharing your personal stories with me to help me learn and understanding what living with a bleeding disorder is like for each of your families. I have enjoyed watching everyone we serve flourish through the programs offered and the children who fearlessly learned to self-infuse! You all are such an inspiration!

Again, thank you all for your well wishes and encouragement as I embark on my life's next journey! You all are very much appreciated!

Thank you,

Misti

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.

Staff

Executive Director
Maureen Grace

Development Manager
Misti Mitchell

Advisory Board of Directors

President - Peter Senior
Vice President– John Ashley
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Jon Tvrdik
Suellen Colin
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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.

2021 Events

All events through June 2021 will be virtual. We hope to be in person as soon as we believe it is safe. Keep up with events on our web-site, Facebook and through text.

Save the Date

April 2021
Spring PING– April 10
The Amazing Goosechase– April 10-16th
World Hemophilia Day
April 17th
Adults with Bleeding Disorders Conference– April 24th

June 2021
Family Camp– June 4-6

August 2021
Virtual Bleeding Disorder's Conference– August 26-28th

September 2021
Family Education Weekend– September 18-19

October 2021
Unite Walk– October 2

combined health agencies drive
MEMBER CHARITY

Goodbye to Misti Mitchell

We are sad to announce the departure of Misti Mitchell, Development Manager, from the Nebraska Chapter. She has served our organization for just over two years. Her smile and presence will be missed. Misti has brought us through three Unite Walks, ran successful and fun events and shifted fundraising efforts in a pandemic and made many community connection for our chapter. She has brought great insight and vision into our growth and reaching out to all communities and populations to bring awareness to bleeding disorders. We are sad to see her go but thrilled for her next chapter.

Misti's last day will be Wednesday, March 31st.

Thank you for all you've done for the Nebraska Bleeding Disorders Community Misti!

KAYLEAN GENTRY

Kaylean Gentry passed away on March 28th after a tragic motorcycle accident. Kaylean was a staple of the Nebraska Bleeding Disorder Community and heavily involved with the Coalition for Hemophilia B. She is survived by her husband Brandon and their five children, Liam, Annabelle, Barrett, Nikolaus and Emmitt.

Kaylean was an absolute joy and light to everyone who met her. She didn't know a stranger and was always there for anyone who needed her, especially in the bleeding disorder community. She will be remembered for her smile, her kindness and energy. She made having 5 children look easy and never let hemophilia slow her family down. She was the most amazing advocate for her children, for her community and for everyone who needed a voice.

Celebration of Kaylean's life will be held 2:30 PM **Friday, April 2, 2021** at Christ Lincoln Church, 4325 Sumner Street. Visitation will be held from 4-8 PM Thursday, April 1, 2021 with family greeting friends from 6-8 PM at Colonial Chapel Funeral Home, 5200 R Street.

Memorials can be directed to the family for future designation.

The Amazing Goose Chase: Bleeding Disorders Edition

In honor of World Hemophilia Day, 9 chapters throughout the country are partnering for **The Amazing GooseChase: Bleeding Disorders Edition**.

This multi-chapter scavenger hunt will run from April 10-16. Prizes will be announced on April 17th, World Hemophilia Day!

GooseChase is a virtual scavenger hunt in which participants compete in various missions. You can download the app to your phone to play. To complete a mission, you will select it from the list and follow the instructions to receive the allotted points. Some missions are answering questions, while others involve sharing photos or videos, and point amounts vary.

Chapters are limited to 20 participants each, and participants will register by family. Once you register, you will be sent the link to the game, and the password to register. Each family that registers and completes at least one challenge will receive a $10 Amazon gift card.

Teams that receive the most points will be entered into drawings for prizes, and each chapter will also award a top prize based on their own criteria. Registration deadline is April 7th.

Thank you to Octapharma for sponsoring this event.

Register now on our chapter website: www.nebraskanhf.org

PARTNERING CHAPTERS

- Bleeding Disorders Alliance of North Dakota
- Florida Hemophilia Association
- Hawaii Chapter of the National Hemophilia Foundation
- Hemophilia Association of the Capital Area
- Hemophilia Association of San Diego County
- Hemophilia Foundation of Northern California
- Lone Star Bleeding Disorders Foundation
- Midwest Hemophilia Association
- Nebraska Chapter of the National Hemophilia Foundation

Nebraska Legislature and Advocacy

How Does the Nebraska Legislature Work and How Can I Influence My Senator?

Many of you probably already know, but the Nebraska Legislature is the only one-house legislative body in the nation. All other states have two chambers patterned after our federal House of Representatives and Senate. Additionally, the Nebraska legislature is officially non-partisan. Our state senators are not labeled as Republican, Democrat, Independent, etc. and partisan politics are not practiced during the sessions, officially anyway. Our nation's polarizing politics does make it difficult for our legislature to remain non-partisan; but recent attempts to add partisanship to the process have not been successful.

So, how does Nebraska's unicameral legislature work? There are essentially four steps in the lawmaking process.

1. Introduction of a bill.
2. The bill is heard at a committee that would have expertise in the bills purpose. (Bills relating to health issues, the hemophilia community's main interest would be heard in the Health and Human Resources Committee and bills relating to payment of health claims would be heard in the Banking, Commerce and Insurance Committee). If the committee votes to not advance the bill, it dies right there. If, however, it votes in favor of the bill, it passes to the next stage of three stages for floor debate and voting.
3. These stages of floor debate (General File, Select File and Final Reading) take place before the entire legislature and have been referred to as the "sausage-making" of a bill. This where a bill may be changed by additions and deletions and also where compromises occur.

    A) General File – This the first time that the entire legislature has the opportunity to debate and vote on bills. This is the stage where most bills see compromises and changes to the original bill. If a majority of the Senators approves, the bill is moved to the next stage.

    B) Select File – This is the second stage where bills are debated, amended and advanced, or killed.

    C) Final Reading – All bills at this stage must be read aloud by the Clerk of the Legislature (unless three-fifths of Senators vote to not have it read). This stage also allows debate and amendments and may be voted to be submitted to the Governor. It can also be voted to go back to Select File for another amendment.

4 If a bill makes it through the three stages, it goes to the Governor to be signed into law or vetoed, which returns the bill to the legislature for vote to override or uphold veto.

At any time from when a bill is assigned to a committee to the Final Reading stage, we can contact the Committees and Senators and express our thoughts about whether a bill, or parts of it, are good or bad and ask the Senator for a vote to approve, change or not approve but explain why we are asking him or her to do so.

Nebraska Legislature and Advocacy

Nebraska Unicameral
Lincoln Journal Star
Justin Wan

There are a number of ways to express our thoughts regarding bills at any stage of the above process, but the first step is to see where the bill is in the process. The easiest method is to use the legislature's website – http://nebraskalegislature.gov. At the top right-hand corner of the home page is a search box labeled "Search Current Bills" and box to enter the bill's number. Enter the bill number in the box, click on the search icon and a new page will come up with the history of the bill up to that point. The full bill can also be accessed from the page.
If the bill has been assigned to a committee, we have two ways to express our thoughts to the committee – direct testimony at the hearing (very effective), written testimony by letters or e-mail (e-mail preferrable). Instructions explaining how to do either can also be found at http://nebraskalegislature.gov.

When a bill has not been voted out of committee, we can do nothing but drop all our efforts, or continue working with the Senator who introduced the bill to improve it for introduction again next year. However, all bills voted out of committee still require us to continue to communicate our thoughts to Senators by personal visits to their offices, phone calls, or e-mails. Regardless of how we choose to communicate to our Senators or the committees as a whole, be sure to introduce yourself and why you are commenting on a bill. Always be friendly, reasonable and to the point. Think of yourself as a resource for them.

Understanding the legislative process and working with our state Senators can seem daunting; but the more familiar we become about the issues that affect us, the surer we are that we can be part of the process. And that is exactly what democracy is about!

Washington Days and Local Advocacy

This year advocacy went virtual yet again! Advocates from Nebraska joined advocates from across the country for two days of virtual congressional visits. Representing the Nebraska Bleeding Disorders community were Maureen Grace, Dale Gibbs, Kaylean Gentry and Erica Bailey from NHF. We had meetings with the staff of Congressmen Don Bacon and Adrian Smith and Senators Deb Fisher and Ben Sasse. We asked for continued financial support of the NIH, CDC and HRSA which support our HTCs and hemophilia research. Additionally, we focused on prohibiting accumulator adjustor programs in the United States. We asked our representatives to sign onto the McEachin-Davis letter urging President Biden to prohibit these programs. Accumulator adjustors or co-pay accumulators affect the bleeding disorders community hard and we want to see these programs out of our insurance plans, protecting consumers and their affordable accesses to their care and medication. Our meetings were productive and we shared the lived experiences of the realities of a bleeding disorder. We hope to be back in Washington DC next year to advocate on the Hill but are so proud of our advocates who joined us for our virtual Washington Days.

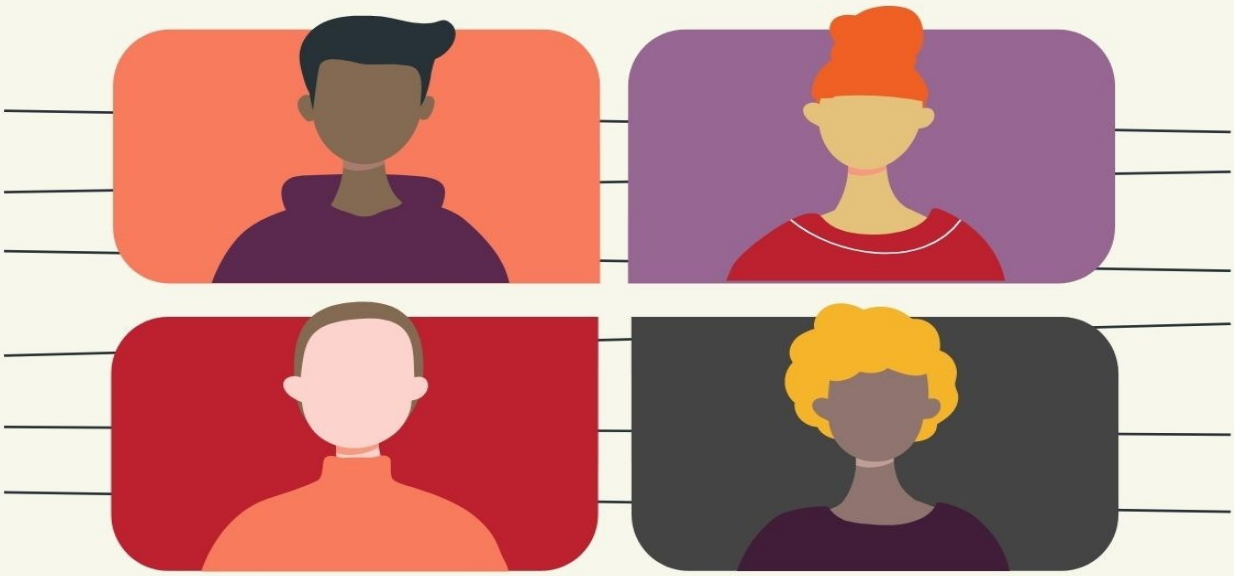
We've been busy on the local front as well. Nebraska NHF has been working with the Step Therapy Coalition to bring about reform to the current step therapy laws. LB337 was submitted this year to protect patients regarding their prescribed medication, ensuring they will be able to be on the medication they need, not the ones insurance wants them to fail on first. This is a huge win for not only our community, but also medical communities across the State of Nebraska. LB337 was voted on 47-0 and has been sent to the Governor's office for a signature. We have also been working on our Medicaid formulary to ensure there's access to the medication that doctors prescribe as well.

Last week, we held our local advocacy training and have held meetings with local senators to thank them for their support of LB337, give them bleeding disorders 101 and to make sure they know how their policies affect those living with Bleeding Disorders here in Nebraska.

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

Adults with Bleeding Disorders

Saturday, April 24th



A Virtual Conference

10:00 am – 4:00 pm

Bleeding Disorders are life long. We bring you this web conference that focuses on adults with bleeding disorders focused specifically on aging with a bleeding disorder, pain management, mental health, your HTC and so much more.

Registration includes access to all education sessions, an event box with information from sponsors, goodies and everything you need to experience the event in the comfort of your own home.
Please register by April 15th to receive an event box.

www.nebraskanhf.org

Parent Information Networking Group

Join us for a fun filled afternoon of education and art!

Education Session: Building Skills to Address Bullying with Takeda Followed by 'Tell a Tale Comic Style' with Multimedia Story Teller An interactive art class to create your own Super Hero to combat bullying! Use your ideas and her teaching skills to help you create your own comic booklet. You will be glad you did and even be inspired to create a series of stories about the comic hero you have created.

PING (Parent Information Networking Group) is intended for families with children under 14. However, all ages are welcome to attend. Registration includes event box with all materials needed for the Comic Book art and drawing Session.

Please RSVP by April 2nd to receive event box. Must be part of NE NHF's local bleeding disorders community to attend this virtual event.

Inhibitors 101

Paul Clement

For many parents of children newly diagnosed with hemophilia, the word "inhibitors" soon becomes part of their vocabulary. And although they may not know at first what an inhibitor is, they may have learned to associate the word with something fearful. But for people with hemophilia A and inhibitors, things aren't as bad as they once were.

What exactly is an inhibitor? Who gets them? What happens when you get an inhibitor? How do you treat bleeds if you have an inhibitor? Do inhibitors go away on their own, or can you grow out of them or eliminate them?

What Is an Inhibitor?

Inhibitors are specialized proteins called *antibodies*. They're a part of the immune system that protects us from bacteria, viruses, and foreign proteins—in other words, anything that the body identifies as not belonging, and as being potentially harmful. But sometimes the immune system makes mistakes: it may even attack the body itself, as in autoimmune diseases including rheumatoid arthritis or multiple sclerosis. With hemophilia, the immune system also makes a mistake: it misidentifies a helpful agent—infused clotting factor—as something harmful, and then mounts an immune response against the factor to neutralize it and mark it for removal from the body.

Inhibitors are very efficient. When an inhibitor is present in hemophilia, some or all of the infused factor is neutralized within minutes. This prevents the factor from participating in the clotting process to stop bleeding. And it means that people with inhibitors can't use standard clotting factor concentrates to control bleeds.

Unfortunately, the alternative therapies we have for treating bleeds with inhibitors aren't as effective as standard factor at controlling bleeds. As a result, people with inhibitors tend to bleed longer, develop target joints (joints that bleed frequently), and suffer from joint damage more often than people without inhibitors. Fortunately, for people with hemophilia A and inhibitors, treatment has improved dramatically over the past three years.

Diagnosing Inhibitors

How do you know if you have an inhibitor? There are usually no outward signs. Inhibitors are sometimes diagnosed during routine hemophilia treatment center (HTC) clinic visits; and sometimes inhibitors are suspected after you notice that factor infusions fail to adequately control bleeding. Your HTC should test for inhibitors at least annually and always before any surgery, and you should request a test whenever you feel that bleeds aren't being controlled effectively with your usual dose of factor.[1]

When an inhibitor is suspected, a diagnostic test called a *mixing study* (activated partial thromboplastin time, or aPTT) is performed: the patient's blood plasma is mixed with normal plasma to see if this corrects the clotting time. In someone with hemophilia without an inhibitor, a mixing study results in a normal clotting time; but if an inhibitor is present, then the clotting time is abnormally prolonged. If this happens, then another test, the Bethesda inhibitor assay, is done to determine how much of the inhibitor-causing antibody is present.[2] The Bethesda assay is a quantitative assay, meaning that it measures the amount of inhibitor and the results are expressed in numbers.

Note: Testing for inhibitors is a bit tricky. It's best to have a Bethesda assay done at an HTC, because the lab techs there have more experience performing the tests, and the results are more likely to be accurate when compared to tests done at other hospitals.

Inhibitor 101 Continued...

Strength of the Inhibitor

To develop a strategy for treating bleeds, your doctor will need to know the strength, or concentration, of the inhibitor. The inhibitor strength is reported as a "titer" and is expressed in Bethesda Units (BU).[3] Inhibitor titers can be as low as 1 BU or higher than 10,000 BU.

An inhibitor titer less than or equal to 5 BU (≤5 BU) is considered a low-titer inhibitor. An inhibitor greater than 5 BU (>5 BU) is considered a high-titer inhibitor. If you have a low-titer inhibitor, you can still use standard factor to treat bleeds, although in higher doses to accommodate for some of the factor being neutralized by the inhibitor. If you have a high-titer inhibitor, standard factor concentrates are not effective because all the factor is quickly neutralized after an infusion.

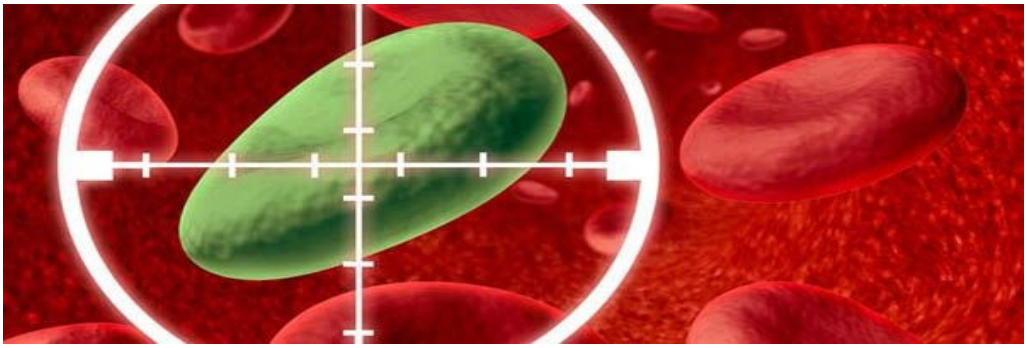
In addition to the inhibitor titer, inhibitors are categorized by how the immune system responds to infused factor. For some people, the inhibitor titer stays more or less stable and doesn't rise after the patient is exposed to factor. If your child has an inhibitor titer ≤5 BU, and it remains at or below 5 BU for several days after an infusion, he is a low responder.

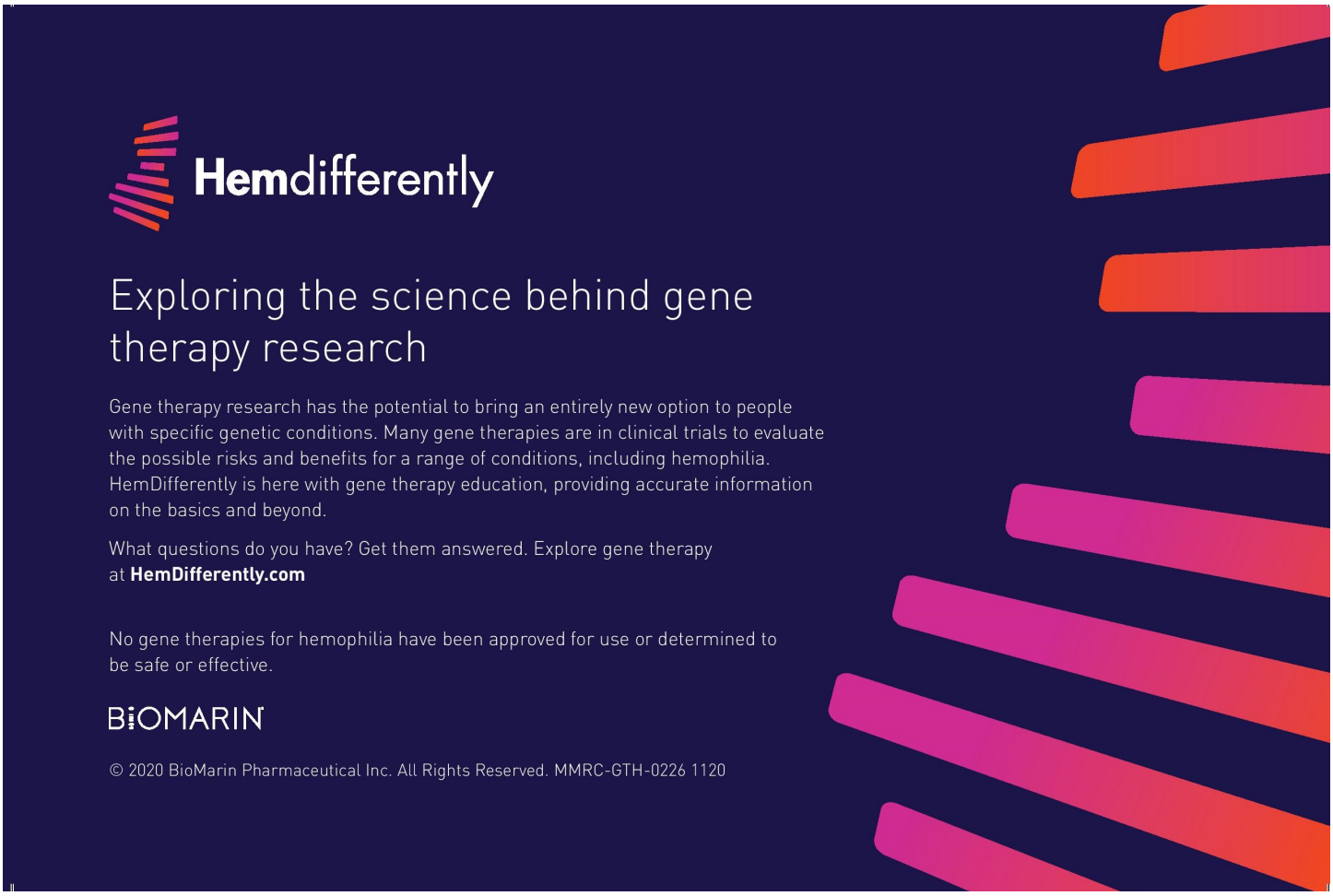
For others, when factor is infused, the immune system quickly ramps up inhibitor production in an effort to neutralize the infused factor. This results in an increase of the inhibitor titer within four to seven days of exposure to factor, peaking within one to three weeks. This ramping up of inhibitors after factor exposure is an anamnestic response (meaning a memory or recall response). If, after exposure to factor, the inhibitor titer rises above 5 BU over a few days, then your child is classified as a high responder. High-responding inhibitors are more challenging to treat than low-responding inhibitors because normal factor concentrates are useless with high-titer, high-responding inhibitors. Treating bleeds with these inhibitors requires special factor concentrates called bypassing agents, such as FEIBA or NovoSeven.

But there's one case where standard factor can be used to treat bleeds in high responders. In high responders, the immune system often produces fewer and fewer antibodies over time if it isn't exposed to factor. If someone hasn't been exposed to factor for several months, then the inhibitor titer may have decreased to a level low enough that normal factor concentrates may be used to treat bleeds successfully for a few days—that is, before the anamnestic response kicks in and the inhibitor titer increases again, making the factor ineffective.

In Part 2 of this series, learn about the risk factor for inhibitors, how common inhibitors are, how to treat bleeds when you have inhibitors, and how to eliminate inhibitors.

1. You can get free inhibitor testing at federally funded HTCs by participating in the Centers for Disease Control and Prevention's (CDC) Community Counts Registry for Bleeding Disorders Surveillance program. 2. There are several different types of inhibitor assays; the Bethesda assay is the most widely used. 3. A Bethesda Unit (BU) is the amount of an inhibitor that will neutralize 50% of factor VIII in normal plasma after 120 minutes' incubation at 37°C.





FINANCIAL AID

HOW NENHF CAN HELP IN 2021 and beyond!

The Financial Assistance program is part of NENHF's continuing effort to improve the quality of life of individuals and families affected by bleeding disorders by providing financial support. Families can request up to $500 per year of support.

Example eligible expenses include, but are not limited to, the following:

- Expenses incurred in the care, treatment, or prevention of a bleeding disorder
- Transportation services to medical appointments and HTCs
- Medical supplies not covered by insurance
- Basic living expense emergencies (rent, mortgage, utilities, food, etc.)
- Unexpected home or car repairs
- Medic Alert Bracelets
- Dental expenses
- Health insurance premiums

Find more information and apply at: https://www.nebraskanhf.org/support-resources/financial-assistance-program.html

At Pfizer Hemophilia, we have always been deeply committed to listening to what you have to say. Our programs and resources are all designed in response to the needs of the hemophilia community.

We are grateful for having the chance to partner with you.

—Your Pfizer Hemophilia Team

SAVE THE DATE!

Virtual Family Camp

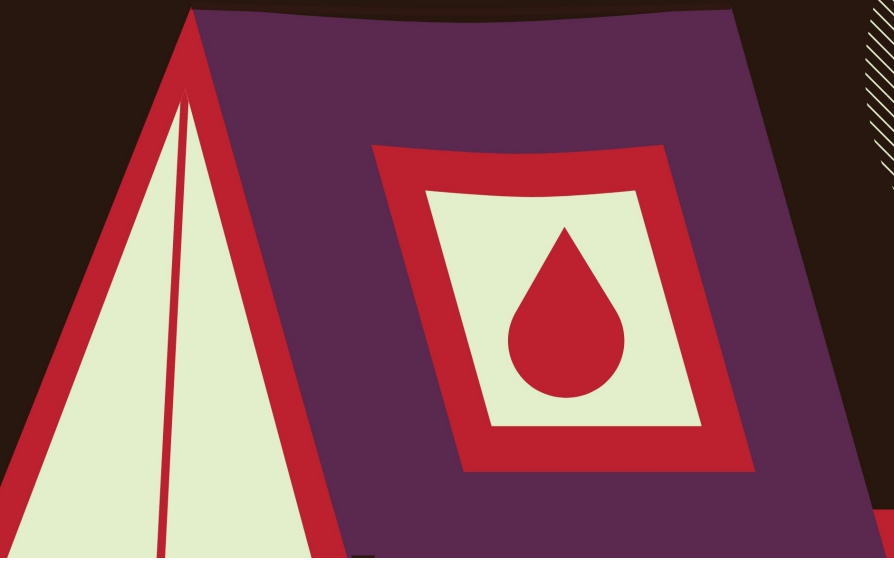
Celebrate the importance of play and living with a Bleeding Disorder

JUNE 4TH-6TH, 2021
A VIRTUAL CAMP EXPERIENCE

We want you experience the joy of play, family time and so much more with this year's virtual family camp.

We guarantee a fun filled weekend for the whole family.

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION



SANOFI GENZYME

family

Save the date for our 2021 **World Hemophilia Day** celebration.

Connect with your blood brothers and sisters to celebrate the diversity that makes the hemophilia community special. This all-ages virtual event explores how blood unites us and how unity can help us create brighter futures together.

Date: April 13, 2021 @ 6pm CST

Contact us to learn more:

Contact name: Mauren Grace

Contact email: mgrace@hemophilia

Phone number: 402-499-8025

WORLD HEMOPHILIA DAY APRIL 17 Celebrating 30 years

NEBRASKA CHAPTER NATIONAL HEMOPHILIA FOUNDATION

To me, it's personal.

As a Community Relations and Education Manager for Sanofi Genzyme, I'm here to help provide support and resources for you and the Nebraska community.

Danielle Kempker
CoRe Manager for Nebraska

Let's connect.

Call, text, video chat: 816-946-1870
Email: danielle.kempker@sanofi.com
Facebook: @HemophiliaCoRes

SANOFI GENZYME

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. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA),** a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events),** which may form in blood vessels in your arm, leg, lung, or head

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

Genentech
A Member of the Roche Group

Kid's Corner: Inhibitor Invasion

Art Therapy for Kids with Bleeding Disorders

Hark! Who goes there? If it's a nasty bug, your body is ready to attack.

Your body is a fortress, and every day, a battle is going on inside. Your body fights to keep the good stuff healthy, like your organs and your blood, and keep out bad stuff, like bacteria and viruses that make you sick. We all have special soldier proteins called antibodies patrolling our blood, looking for invaders. When they find them, these soldier proteins sneak up on the invaders and—hiyah!—they destroy them.

If you have an inhibitor, your soldier proteins are also trying to kill your hemophilia factor. To them, factor is just another alien invader that must be kicked out. The trouble is, when your soldier proteins attack the clotting factor, it can't work. So you might bleed more than other kids with hemophilia.
Scientists aren't sure why some kids have "soldiers" that cause inhibitors. But you aren't the only one with this kind of overactive immune system. Kids with allergies to pollen, pets or peanuts also have immune systems that attack things they shouldn't.

And just like kids with allergies, some medications will work for you and some won't. There is a special kind of factor just for kids with inhibitors, but it doesn't work for everyone. And because your defense system is so strong and stops the factor from working, your bleeds might last longer, hurt more and cause more damage. Sometimes kids with inhibitors have to use wheelchairs or crutches.

The good news is that scientists are trying to stop your super-strong soldier proteins from overworking, or at least find a factor that works for all kids with inhibitors.

Remember, you're on your body's defense team, too. So gear up. Be careful playing with your friends and running around in the house. And look for signs that you could be bleeding, like areas on your body that feel warm, tight, tingly or bubbly. Let your parents or another grown-up know if you feel pain, even if it's just a headache. Being responsible is important, so you can get treated faster and feel better soon.

Come to your body's defense—and don't let an inhibitor get you down.

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