BIG RED FACTOR

2021—Issue 2

NATIONAL HEMOPHILIA FOUNDATION
CHAPTER OF EXCELLENCE
2018-2020

Inside this issue:

Nebraska Chapter
National Hemophilia Foundation
www.nebraskanhf.org

Happy Summer Everyone!

The time has FINALLY come for us to get back to in person programming and we are thrilled!

All of our remaining 2021 programs will be in person or hybrid and we cannot wait to see your shining faces (behind masks still). It's been a long year and then some so we are working hard behind the scenes to get back to our regularly scheduled programs, events and in person support.

As we return to in person this year, we will still be requiring masks. We hope to be done with them soon but until all members of our families have access to vaccination and we have a better grasp on variants throughout the country, we will still be requiring masks for indoor events, regardless of vaccination status. It's a small price to pay for being back in person and will reassess constantly with our National organization on protocol.

This will be a very full summer and fall with amazing events, programs and connection. We are thrilled to welcome you back and rebuild what we've lost over the last year and a half. Thank you for your participation and understanding in our year of virtual programming.

I cannot wait to see you all again!

Stay safe and register for everything soon.

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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Maureen Grace

Development Manager
Misti Mitchell

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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

July 2021

July 17– Infusion Bloody Mary Mix
Off TO GO

August 2021

August 11th
Baseball Game with Octapharma and Paragon

August 21
Women's Retreat

August 26-28th
NHF's Virtual Bleeding Disorder's Conference

September 2021

September 18-19
Family Education Weekend

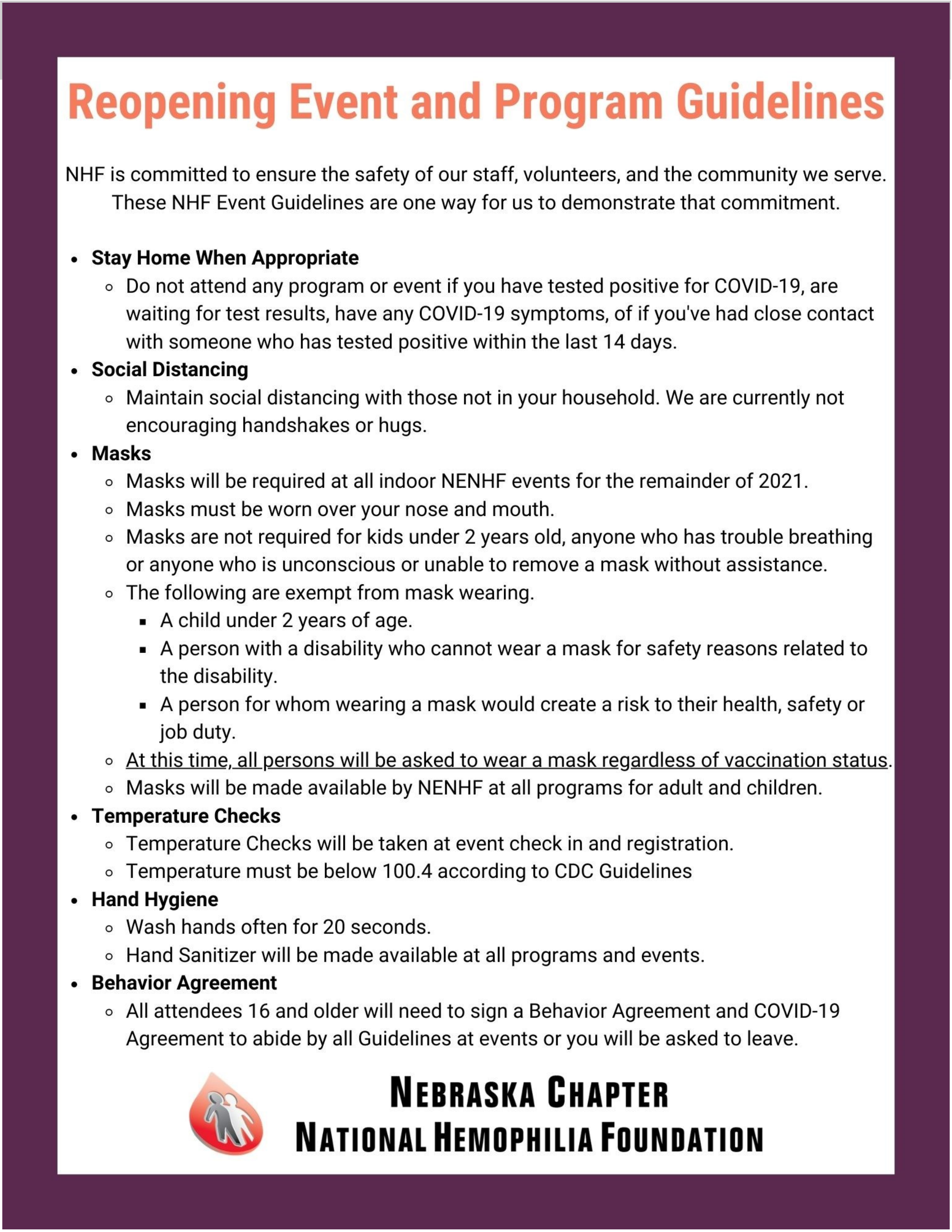
October 2021

October 2nd
Unite Walk

October 8-10th
FAB Women's Retreat

October 23rd
Harvest Festival

combined health agencies drive
MEMBER CHARITY



Reopening Event and Program Guidelines

NHF is committed to ensure the safety of our staff, volunteers, and the community we serve. These NHF Event Guidelines are one way for us to demonstrate that commitment.

- **Stay Home When Appropriate**
  - Do not attend any program or event if you have tested positive for COVID-19, are waiting for test results, have any COVID-19 symptoms, of if you've had close contact with someone who has tested positive within the last 14 days.
- **Social Distancing**
  - Maintain social distancing with those not in your household. We are currently not encouraging handshakes or hugs.
- **Masks**
  - Masks will be required at all indoor NENHF events for the remainder of 2021.
  - Masks must be worn over your nose and mouth.
  - Masks are not required for kids under 2 years old, anyone who has trouble breathing or anyone who is unconscious or unable to remove a mask without assistance.
  - The following are exempt from mask wearing.
    - A child under 2 years of age.
    - A person with a disability who cannot wear a mask for safety reasons related to the disability.
    - A person for whom wearing a mask would create a risk to their health, safety or job duty.
  - At this time, all persons will be asked to wear a mask regardless of vaccination status.
  - Masks will be made available by NENHF at all programs for adult and children.
- **Temperature Checks**
  - Temperature Checks will be taken at event check in and registration.
  - Temperature must be below 100.4 according to CDC Guidelines
- **Hand Hygiene**
  - Wash hands often for 20 seconds.
  - Hand Sanitizer will be made available at all programs and events.
- **Behavior Agreement**
  - All attendees 16 and older will need to sign a Behavior Agreement and COVID-19 Agreement to abide by all Guidelines at events or you will be asked to leave.

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

Welcome to Sarah Arietta

Please join me in welcoming Sarah Arrieta to the Nebraska NHF team!

Sarah joined us as the new Program Manager for Nebraska Chapter on Monday June 28, 2021.

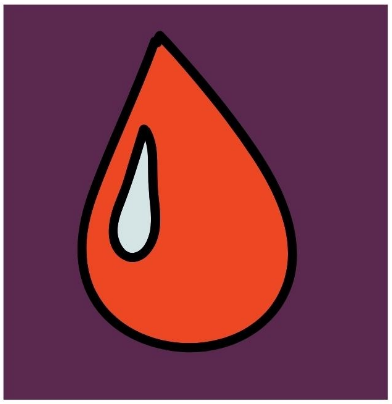
Sarah was born and raised in Omaha, Nebraska, where she still lives today with her husband and three children. She earned an associate's degree in liberal arts from Metropolitan Community College, before continuing her education at the University of Nebraska at Omaha. It was there that she earned her bachelor's and master's degree in sociology. Her research about bilingual education in the Basque regions of France and Spain was recently published earlier this year. During her time as a graduate student in the University of Nebraska at Omaha she was served as a student worker and assistant in the Sociology and Anthropology department. Prior to that, Sarah was employed as a project manager at a research firm where she managed patient satisfaction research projects for various healthcare facilities. Sarah loves animals, especially her dog and cat and enjoys traveling, keeping active, and being outdoors in her free time.

Sarah will be taking over program management and engagement for our community. She is excited to meet our Nebraska Bleeding Disorders Community and will be at all the upcoming events and programs happening this summer and fall. Sarah's main focus will be on program management and developing and growing newer programs like our Teen program, men's and women's programs, new program outreach and ensuring we transition back in person events safely and effectively. She's ready for new ideas and feedback to help better serve the Nebraska Bleeding Disorders Community.

You can find her at upcoming events and programs but if you need to reach Sarah at any other time, don't be afraid to reach out.

You can reach Sarah at sarrieta@hemophilia.org or at 402-889-0572.

New Staff Alert!!



FAMILY ED WEEKEND

SEPTEMBER 18-19

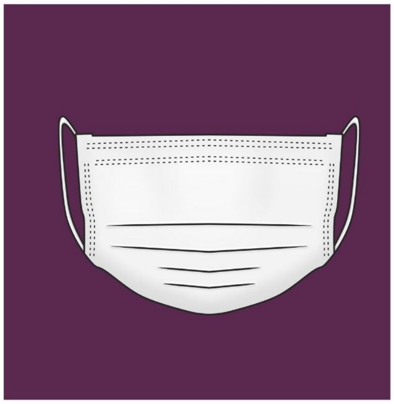
HYBRID-
IN PERSON & VIRTUAL OPTIONS

EDUCATION
RECONNECTION
FUN & GAMES

**EMBASSY SUITES
LA VISTA
NEBRASKA**

MASKS REQUIRED FOR ALL

In Person event guidelines and registration are available on our website.



FOR MORE INFORMATION, VISIT WWW.NEBRASKANHF.ORG

LB260– Unemployment for Caretakers

June 1, 2021, Maureen Grace and Advocacy Committee members were given the opportunity to meet with Nebraska State Senator Megan Hunt. Senator Hunt had recently championed LB 260 and was able to successfully gain the bill's passage.

LB 260 adds "caring for a family member with a serious health condition" to the other reasons you may file for unemployment in the state of Nebraska. The Nebraska Chapter of NHF was very excited to be able to discuss this bill with her further and how our community may benefit. This bill passed with 25 cosponsors and no amendments added to it. It will take effect in late August 2021. The passing of this bill does not add any additional costs to employers in the state.

How can you use this if it is necessary? First, you need to approach your employer and exhaust all options towards working around your employment and fitting the needs of your family member. If you, as the employee, are unable to continue and concessions cannot be made between the employee and employer, you are able to quit and file for unemployment with the Nebraska Department of Labor.

The Department of Labor will contact your employer to ensure that your claim is legitimate. You may have to provide proof of this claim of caring for a family member with a serious health condition. The Nebraska Department of Labor is following the same definition that is outlined under the Family Medical Leave Act. The information necessary will be relayed to you from the Department of Labor.

This additional reasoning for being able to collect unemployment does not change the steps necessary for you to receive these funds. A person collecting unemployment in Nebraska must be ready and willing to work by applying to three jobs weekly. You are eligible to receive unemployment in Nebraska for 26 calendar weeks a year, the max amount allotted is ⅓ of your total base wages from your previous employment.

We are thankful for Senator Megan Hunt for taking her time to recognize the importance of people living with serious medical conditions and trying to provide any assistance.

TAKE YOU OUT TO THE BALLGAME!

Wednesday, August 11th
Omaha Storm Chasers Game
Werner Park
6:00 pm Dinner- 7:05 Game Time

octapharma PARAGON HEALTHCARE

Food, Education, Connection and a Fun Night at the Ball Field
Register at www.nebraskanhf.org

RSVP BY AUGUST 5, 2021

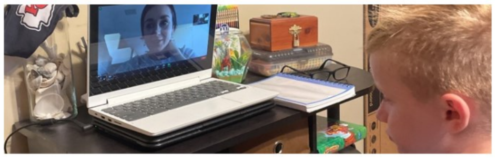
VIRTUAL FAMILY CAMP

Pfizer Takeda CSL Behring Biotherapies for Life BAYER SANOFI GENZYME

We took one last crack at our virtual family camp and had a blast! Everything we did focused on the importance of PLAY, as kids, as adults, as families. We started the weekend out with a key note from Pat Torrey from GutMonkey. He got us laughing, moving and understanding the importance of play at every age and making it work with a bleeding disorder. Saturday morning we welcomed Carissa Rowberry, a physical therapist from Children's Hospital who spoke to us about playing it safe while still having fun! The afternoon was full of at home tie dye kits and Goosechase activities getting ready for our Empanada cooking night with Chef Mike! Cooking together on Zoom was an adventure and a TASTY one. We finished out Sunday morning with the winners of our archery contest! The Henson's took the title, followed by the Henrys and the Quiroz Family. WELL DONE!

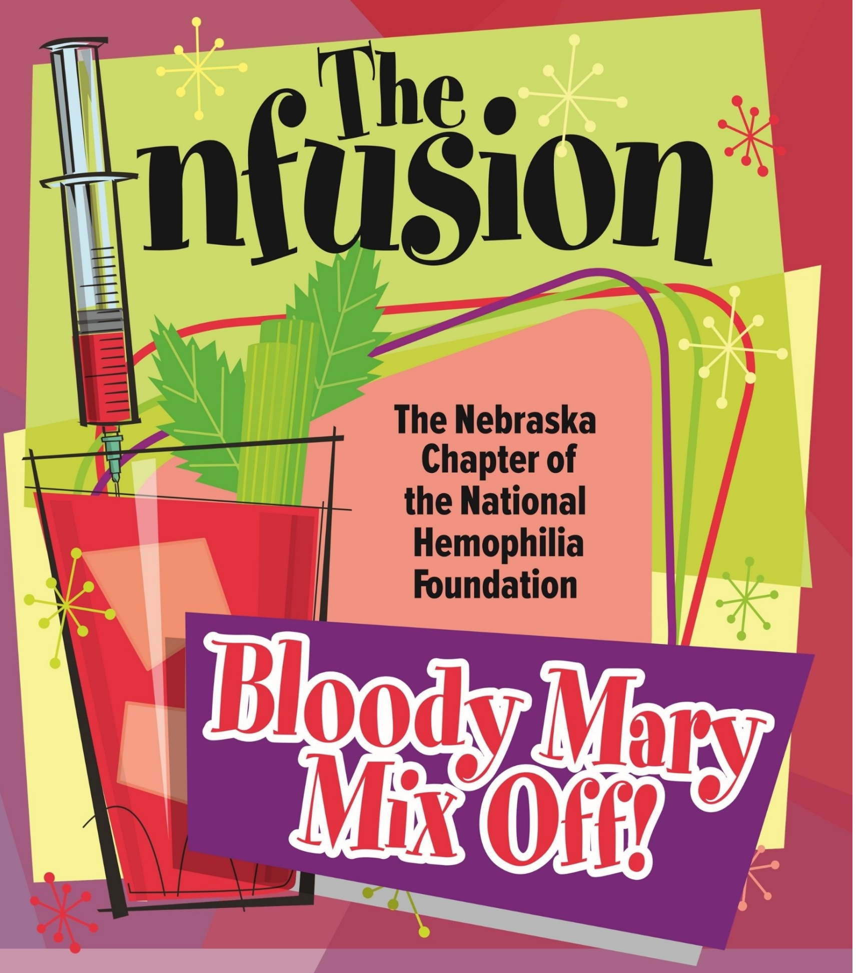
Our Goosechase winners were: 1) Henson Family 2) Quiroz Family and 3) Henry's!

We had a great send off to our fully virtual programs and can't wait to be back in person for camp next summer! We appreciate your patience and virtual involvement this year!



NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
PRESENTS:

TO GO BOX & VIRTUAL EVENT



Tito's®

AWARD WINNING · DISTILLED 6 TIMES

EVENT BOX $45

BOX INCLUDES:
6 OZ BLOODY MARYS FROM 6 BARS
GARNISH
375 ML TITO'S VODKA
TASTING GUIDE
PROMOTIONAL ITEMS
SUPPORTING THE BLEEDING DISORDERS COMMUNITY!

JULY 17, 2021
PICK UP 9-11 AM
VIRTUAL EVENT 12 PM

Krug PARK · spirit world (cafe·wine·liquor·beer, Est. 1974) · SIPPIN' SIRENS · CADDY'S KITCHEN & COCKTAILS · Donahue's Pub · AND MORE!

BOXES CAN BE PURCHASED ON EVENTBRITE STARTING JUNE 10

FAB Women’s Conference

Join us for our FAB 'Females and Bleeding' Conference
A regional women's retreat brought to you by:
Nebraska NHF
Gateway Hemophilia Association
Hemophilia of Iowa
Midwest Hemophilia Association
Funding provided by Octapharma.

DATE:

October 8-10th, 2021

LOCATION:

Margaritaville Resort, Missouri

Cost: $20 per person. Gas cards available.

Registration is limited so don't hesitate to register!

This conference is open to women aged 18+ served by one of the four host chapters. In order to register you must be either:
*A Person with a bleeding disorder
*A Parent of a person with a bleeding disorder (or legal caregiver/guardian)
*A Carrier of a bleeding disorder
*A spouse of someone with a bleeding disorder
*HTC Staff

Space is limited and and such we are unable to accept those who are do not fall into a category listed above or aren't direct, daily legal caregivers of children with a bleeding disorder. Grandparents, aunts and additional family members do not qualify at this time. If you are unsure if you qualify, please reach out to your chapter.

Your health and safety are at the forefront of our minds regarding this program. Prior to the Covid-19 pandemic, we had asked you to share a room with another member of your community but with current CDC guidelines and social distancing, we no longer feel that is in your best interest. We have expanded our room pool to allow for private rooms but do ask that members who reside in the same household share a room to keep space open for as many registrants as possible. Please indicate if you are in need of a private room or if there is a household member you will be sharing with. Thank you for your patience and understanding as we navigate safety protocols for in person and/or hybrid events.

Register online here: https://www.nebraskanhf.org/get-involved/programs/womens-retreat.html/event-form/fab-conference/62485/tickets

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION

NEBRASKA WOMEN'S RETREAT

Join us for a day of connection, education, support and relaxation for women in the Nebraska bleeding disorders community.

What's the difference between this and FAB?

We are so excited about FAB in October but we recognize that not all community members can get to Missouri so we want a women's program locally as well. Additionally, our community lost Kaylean Gentry in March and needs time to grieve and heal together. We hope you can attend both programs! They will complement each other. One is not meant to replace the other.

Saturday, August 21, 2021
The Event Space at 5550
Lincoln, Nebraska
9:00 am - 4:00 pm
Masks Required

The COVID-19 Vaccine and Bleeding Disorders

Is it safe to get the COVID-19 Vaccine if I have a bleeding disorder?

Short answer is– YES but we know you have concerns so here's more information.

NHF recognizes that people with bleeding disorders may have questions and concerns related to the variant coronavirus' causing COVID-19 and the new COVID-19 vaccines, including any implications specific to their conditions. The following FAQs are therefore meant to address some of the most common questions from our community members. Please note that these answers were created for broad purposes and that affected individuals should engage closely with their healthcare provider to discuss the possibilities of disease signs and symptoms and vaccination, including potential contraindications (if any), and specific questions related to safety and efficacy. Given the nature of this virus, rapid developments in vaccines, and the ongoing transitions in our federal government, this continues to be a very fluid situation. If you have additional questions or need more information, please consult with your healthcare professional.

Is it safe for a person with a bleeding disorder to receive the COVID vaccine?

If you have a bleeding disorder, there are no contraindications to being vaccinated with any of the three vaccines now available via EUA status for intramuscular administration. It should be noted that, immune tolerance therapy, treatment for hepatitis C, and HIV and other conditions including the use of immunosuppressive agents do not preclude a person from receiving the available vaccines. For patients in a clinical study, vaccination should be reported to the study investigators.

Is there a particular type of vaccine I should choose?

Currently there is no reason to choose a particular type of vaccine. If you are considering enrolling in a gene therapy clinical trial, you should avoid any vaccines that use a modified adeno-associated virus (AAV) since these viruses are used in gene therapy. **No vaccinations currently authorized are using AAV vectors or viruses.** The Janssen Biotech vaccine contains a type of a human adenovirus. Adenovirus is NOT used in hemophilia or any form of gene therapy and therefore is not a concern for our community including those who are considering receiving gene therapy in the future.

Will the vaccines change my DNA?

mRNA vaccines do not interact with a person's DNA or cause genetic changes because the mRNA does not enter the nucleus of the cell, which is where our DNA is kept.

The Janssen Biotech COVID-19 Vaccine is a viral vector vaccine, meaning it uses a modified version of a different virus (the vector) to deliver important instructions to our cells. Viral vector technology has been used by Janssen for other vaccine development programs. Vaccines that use the same viral vector have been given to pregnant people in all trimesters of pregnancy, including in a large-scale Ebola vaccination trial.

COVID-19 Vaccine Info continued...

Will I have a bleed if I receive the vaccination?

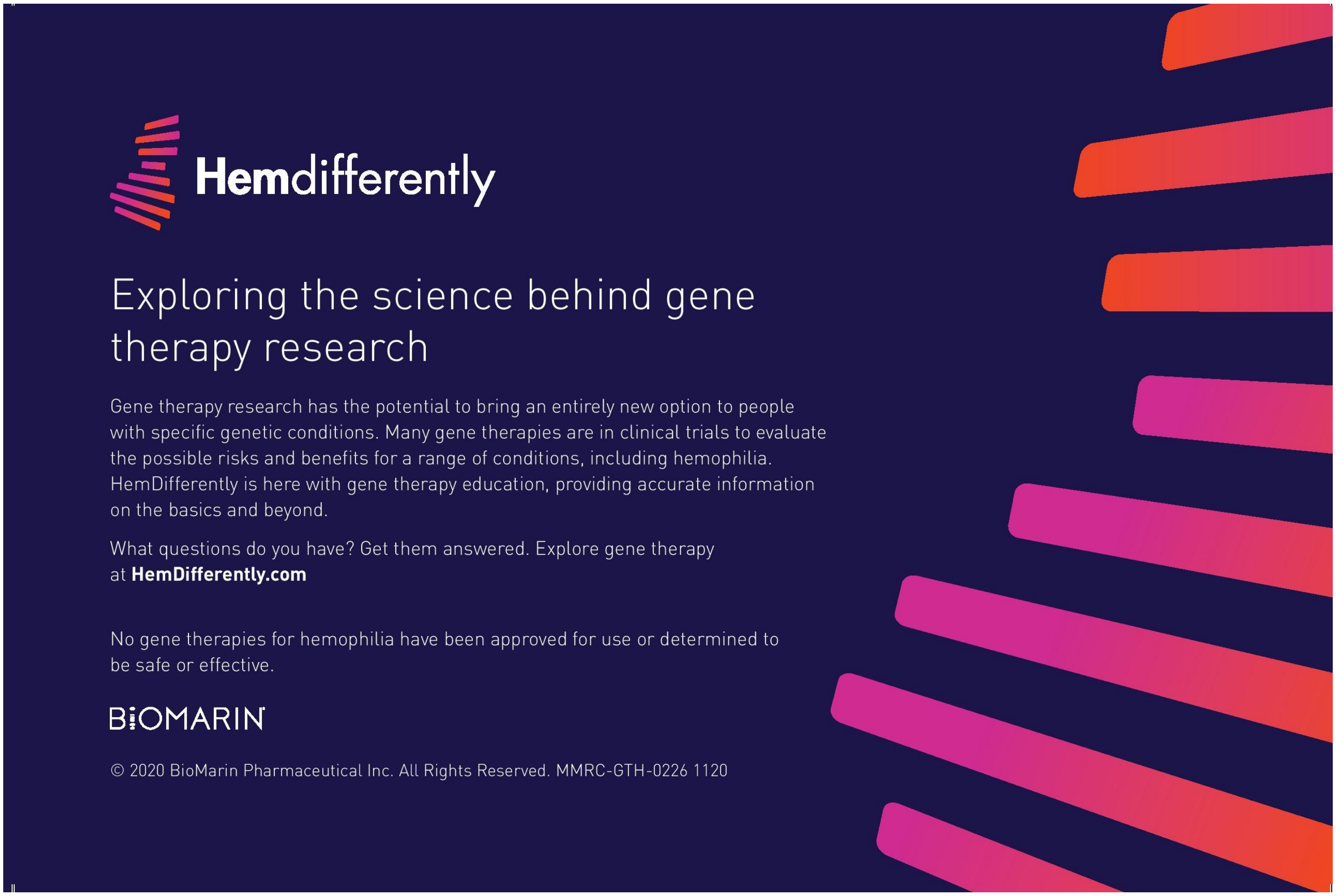
The vaccination is administered intra-muscularly but the smallest gauge needle should be used (25-27 gauge), if possible. Some vaccines must be administered using the accompanying needle–syringe combination, and so the use of an alternative needle may not be possible or desirable.
It would be preferable for you to infuse with a factor replacement product prior to or right after the vaccination and applying pressure for 10 minutes after the vaccination. Patients receiving emicizumab may be vaccinated by intra-muscular injection at any time without receiving an additional dose of FVIII. Patients with von Willebrand disease or a rare bleeding disorder should consult with their hematologist regarding special precautions prior to receiving the vaccination. All rare bleeding disorder patients (including those with thrombocytopenia and/or platelet function disorders) should be vaccinated. Patients on warfarin should have prothrombin time testing performed within 72 hours prior to injection to determine international normalized ratio (INR); if results are stable and within the therapeutic range, they can be vaccinated intramuscularly. Patients receiving other anticoagulants, such as enoxaparin, apixaban, dabigatran, rivaroxaban should consult their prescribing doctor or practitioner for advice on how to safely prepare for the COVID-19 vaccine.

Following the vaccination, the area should be monitored for hematoma formation immediately for 10 minutes to reduce bleeding and swelling and by self-inspection 2-4 hours later at home to ensure that there is no delayed hematoma. Discomfort at the injection site is to be expected. Discomfort in the arm felt for 1-2 days after injection should not be alarming unless it worsens and is accompanied by swelling.

Do you have a bleeding disorder or have any issues with bleeding?
A bleeding disorder neither increases the risk for getting coronavirus infection nor having a serious infection, being hospitalized, or dying if you are infected.

Likewise, having a bleeding disorder is not a reason to avoid getting the vaccine. Following precautions such as infusing with a factor replacement product prior to or right after the vaccination and applying pressure for 10 minutes after the vaccination should be considered. Contact your hematologist or healthcare professional to plan to safely receive the vaccine.

Patients receiving emicizumab may be vaccinated by intra-muscular injection at any time without receiving an additional dose of FVIII. Patients with von Willebrand disease or a rare bleeding disorder should consult with their hematologist regarding special precautions prior to receiving the vaccination. All rare bleeding disorder patients (including those with thrombocytopenia and/or platelet function disorders) should be vaccinated. Patients on warfarin should have prothrombin time testing performed within 72 hours prior to injection to determine international normalized ratio (INR); if results are stable and within the therapeutic range, they can be vaccinated intramuscularly.



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

Let's make today brilliant.

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.

bleedingdisorders.com | Takeda

Keep track of your bleeds, infusions, and activity.

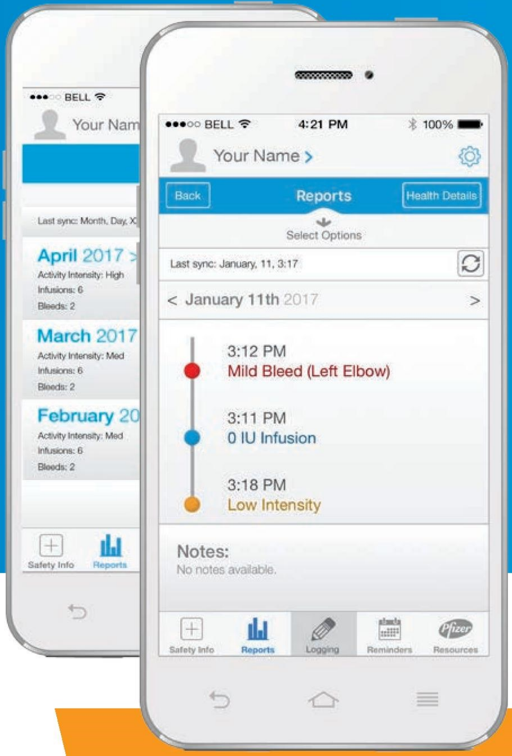
HemMobile™

with *enhanced* activity tracking

The little app is getting bigger.

**Talk to your doctor about HemMobile™—
and which activities may be right for you.**

- Log daily activities, infusions, and bleeds
- Share single consolidated reports with your treatment team
- Set reminders for resupply, appointments, etc
- Sync with fitness apps and wearable devices



Last sync: Month, Day, X

April 2017 >
Activity Intensity: High
Infusions: 6
Bleeds: 2

March 2017
Activity Intensity: Med
Infusions: 6
Bleeds: 2

February 20
Activity Intensity: Med
Infusions: 6
Bleeds: 2

Last sync: January, 11, 3:17

< January 11th 2017 >

3:12 PM
Mild Bleed (Left Elbow)

3:11 PM
0 IU Infusion

3:18 PM
Low Intensity

Notes:
No notes available.

Hemophilia can be difficult.
Tracking it shouldn't be.

HemMobile™ was designed to help you keep track of your bleeds, infusions, and factor supply.*

Now it can also help you keep track of your daily activities and, when paired with our custom wearable device, track your heart rate, steps, distance, and activity duration. You can have an even more informed discussion with your treatment team about your activity level as well as your dosing regimen.

Download the app,
pair your device,
and start tracking

Download on the App Store
ANDROID APP ON Google play

For iPhone® and Android™

For more information, contact Pfizer Hemophilia Connect, one number with access to all of Pfizer Hemophilia's resources and support programs.

Call **1.844.989.HEMO (4366)** Monday through Friday
from 8:00 AM to 8:00 PM Eastern Time.

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*HemMobile™ is not intended for curing, treating, seeking treatment for managing or diagnosing a specific disease disorder, or any specific identifiable health condition. iPhone is a trademark of Apple Inc., registered in the US and other countries. App Store is a service mark of Apple Inc. Android and Google Play are trademarks of Google Inc.

PP-HEM-USA-0692-01

January 2017

CELEBRATING 35 YEARS

NEBRASKA CHAPTER NATIONAL HEMOPHILIA FOUNDATION

www.nebraskanhf.org

UNITE FOR BLEEDING DISORDERS

1. REGISTER

Register yourself and your team on our Unite for Bleeding Disorders website.

2. FUNDRAISE

Set your team goal and begin fundraising.

3. CELEBRATE

Celebrate with the Nebraska Chapter Bleeding Disorders community on walk day!

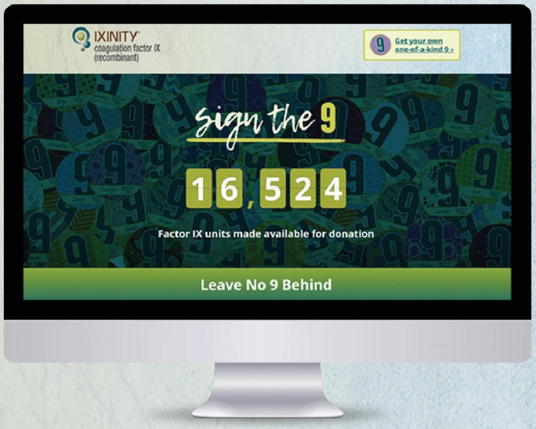
Unite for Bleeding Disorders Walk

Saturday, October 2, 2021

Chalco Hills Recreation Center

Register your team today!

Www.uniteforbleedingdisorders.org


IXINITY coagulation factor IX (recombinant)
Get your own one-of-a-kind 9
sign the 9
16,524
Factor IX units made available for donation
Leave No 9 Behind

Men’s Program

Last night, June 30th, we hosted out first in person event of 2021 AND our first men’s only program. Thank you to BioMarin for making this night possible. Alisa Reidl from BioMarin presented on Gene Therapy and then we spent the evening at Top Golf, and the guys were nice enough to let the staff tag along.

We are excited to start offering more specialized programming for adult men with bleeding disorders and male caregivers. If you have ideas you would like to see for ongoing men’s programming and education topics, please don’t hesitate to let us know.

Keep your eyes peeled for more ongoing adult men events and programs in the coming months. This is your community and we want it to serve you the best it can.

NENHF is excited to make this program flourish!

BIOMARIN®

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

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.

Author: Heather Boerner

HemaWare Junior