BIG RED FACTOR

2020—Issue 2

Inside this issue:

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

WELCOME, OWEN!

On Tuesday, April 28th, Maureen and Jon welcomed a new addition to their family, Owen Thomas. Maureen and her family are doing well! I have seen pictures of Eloise and she looks like she is enjoying being a big sister.

Maureen will return on July 22.

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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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.

2020 Events

Please be aware that 2020 dates are tentative depending on COVID 19 updates. We are doing our best to reschedule or reformat events throughout the year to continue to serve our community.

July

July 9
Virtual Campfire with John Ashley

July 18
Infusion: Virtual Bloody Mary Event

August

August 29
Virtual Event: Kearney Education Day

October

Unite for Bleeding Disorders Walk
(more details to come)

November

November 14 & 15, 2020
Family Education Weekend &
Industry Symposium

combined health agencies drive
MEMBER CHARITY

Dear NHF Community,

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

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

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

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

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

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

Sincerely,

Leonard A. Valentino, M.D.

NHF CEO

Nebraska NHF's COVID-19 Update

Dear Friends, Community Members & Supporters,

As reopening is occurring and new information is released on COVID-19 in the United States and around the world, it can be easy to get overwhelmed and being to ask questions. At the Nebraska Chapter of the National Hemophilia Foundation, we take this global pandemic seriously. Although the days ahead will doubtlessly require us to adapt, we will remain resolute in our efforts to meet this unprecedented challenge together.

The Nebraska Chapter of the National Hemophilia Foundation's first priority is the health and safety of our community. As a health focused organization, we must consider the impact on the health of our community in all our work. We are continuing to discuss what our events will look like in the fall, but we are also preparing to take the rest of the events this year, virtual.

We are here for our community! We have a lot of exciting events taking place over the next couple of months! We prioritize our work in continuing to be a resource for the bleeding disorders community as the unknown continues. While the nature of our programs may adjust to accommodate health and safety protocols, we will continue to provide web-based and mailed education, financial assistance, bleeding disorders information and remain in regular communication with the Nebraska bleeding disorders community.

As we continue to monitor the COVID-19 cases and its effects in Nebraska, we know that our bleeding disorders families will need the support, assistance, and resources offered by the Chapter. We need our supporters to help us continue to serve them during this time of crisis. We anticipate an increase of financial assistance requests as families feel the effects of reduced work and pay. We ask for your continued partnership to help our community.

What to expect from NENHF

Communication: The Nebraska Chapter Team will continue to be available by text, phone and email during business hours of 8:30 am – 4:30 pm M-F as our office remains closed. You can continue to expect a 1-2 business day response time from staff.

Expedited Financial Assistance: All Financial Assistance Requests will be expediated with a goal of processing within five business days of receipt of application.

Continual Updates: We will continually communicate information and updates to the bleeding disorders community through email, social media, texting, and our website.

Donor Commitments: We will be in direct communication with donors and sponsors of specific programs that need to be adjusted. We are committed to meeting our donor expectations as best we can within this unexpected situation.

KEARNEY EDUCATION DAY

08·29·2020

The safety of our community is our top priority! This year's event will be held via Zoom.

World Federation of Hemophilia COVID 19 Recommendations

From the World Federation of Hemophilia Medical Advisory Board (MAB)* and the WFH Committee on Product Availability, Safety, and Supply (CPSSA):**

For hemophilia patients currently treated with standard or extended recombinant half-life FVIII or FIX concentrates, FEIBA, FVIIa, or emicizumab:

1. No reason to change the recommended treatment regimen
2. No reason to fear at this stage a shortage of treatment supplies, manufacturing issues or interruption in the supply chain
3. Contact hemophilia treatment centres (HTC) if stock at home or at hospital is limited
4. If you treat at home, do not order more replacement products than reasonably needed. However, a few extra doses for home use are prudent in case of any delivery delays or disruptions.

For patients treated with plasma-derived FVIII/FIX

1. Viral inactivation and elimination procedures employed are sufficient to destroy lipid-enveloped viruses like SARS-CoV-2[1]
2. Not recommended to switch product
3. No supply disruptions in plasma-derived product supplies have been detected to date. The primary concern is a decrease in plasma collections at the front end of the plasma-derived product production at this stage.[2,3]
4. Blood and plasma donation continue to be a safe process, and the need for plasma donations is a great as ever. The support of current and new donors remains critical to maintain an adequate supply of blood and plasma during the pandemic.
5. All HTCs and blood and plasma collection centres are reminded to follow guidelines to protect both personnel and donors to prevent the spread of SARS-CoV-2 through human-to-human contact via respiratory droplets, as well as fomites.[4]

For patients treated with other blood-derived products which are not virally inactivated (e.g., cryoprecipitate, platelets),treatment decisions should be based on clinical risk/benefit analysis balancing the safety of not treating a bleeding event and any residual risk of acquiring another infection.

For patients currently in clinical trials (excluding post-marketing trials)[5]

1. Contact your HTC to discuss the implications of the pandemic
2. Ensure availability of study drugs and that the treatment is not interrupted
3. Discuss modalities of follow-up/monitoring with an HTC study team. Remote follow-up visits are strongly encouraged unless an investigational product has to be administered and face to face monitoring is needed to prevent dangerous side effects.
4. For patients who recently received a gene therapy product (≤12 months after infusion), scheduled liver function testing should remain a priority for safety and efficacy purposes.

Do not discontinue or switch treatment if you are currently receiving a clinical trial treatment unless directed to do so by the study team.

For patients who are scheduled to be soon enrolled in a trial testing a new treatment[5]

1. Postponement of enrollment should be discussed with the study team
2. Many medical centres have banned initiation of new clinical trials so as to not distract medical resources needed to deal with the pandemic

Specific measures to reduce exposure of SARS-CoV-2, the virus that causes COVID-2 in patients with hemophilia

1. All measures to reduce exposure to persons with COVID-19 should be proactively promoted in all patients with comorbidities (cardiovascular disease, hypertension, obesity, diabetes, HIV, old age), or on steroids or other powerful immunosuppressant drugs.[6,7]
2. Exposure to everyone, including lower risk individuals and children, is the single most important precaution to avoid infection. Sheltering in place and social distancing are the most important tools to use.
3. Minimize the need to visit health care professionals in hospitals or offices. Non-urgent care and elective surgeries should be postponed.
4. Paracetamol (acetaminophen) reduces fever without inhibiting the inflammatory response needed for fighting coronavirus and is recommended for persons with bleeding disorders
5. Paracetamol (acetaminophen) should not exceed 60mg/kg/day or 3g/day, since it causes liver damage at higher doses

6. Ibuprofen and other non-steroidal anti-inflammatory drugs (NSAIDs) are usually not advised in patients with bleeding disorders because they may increase bleeding though inhibition of platelet function. In addition, in particular ibuprofen has been suggested to either make COVID-19 worse or enhance risk of infection with SARS-CoV-2 due to up-regulation of the entry receptor, angiotensin converting enzyme 2. However, the evidence supporting this is limited at this time.[8-10]
7. Remember, specific hygienic measures, such as regular hand washing with soap, not touching one's face, not aerosolizing a cough, and maintaining at least 2 metres (6 feet) distance from other people are key to preventing coronavirus transmission.

Specific measures in case of hospital admission of a bleeding disorders patient with COVID-19 infection

1. Good liaison between the hospital where patient is admitted and the HTC
2. Arrange replacement therapy / secure venous access.
3. Inform team in case of treatment with emicizumab (risk of mis-management and mis-interpretation of hemostasis laboratory tests by unfamiliar health professionals).[11]
4. Inform if you are part of an ongoing experimental treatment with rebalancing agents (anti-TFPI and fitusiran) and you have a risk of thrombosis or other clotting system imbalances, or you've undergone a recent treatment with gene therapy. If so, liaise with HTC.

If you have COVID-19 infection, some clinicians suggest prophylactic therapy and maintaining higher clotting factor levels as a precaution against bleeding into lungs from potentially severe damage inflicted by SARS-CoV-2 and severe coughing/nose blowing creating increased blood pressure in brain that might lead to bleeding. There are case reports providing evidence to support this statement.

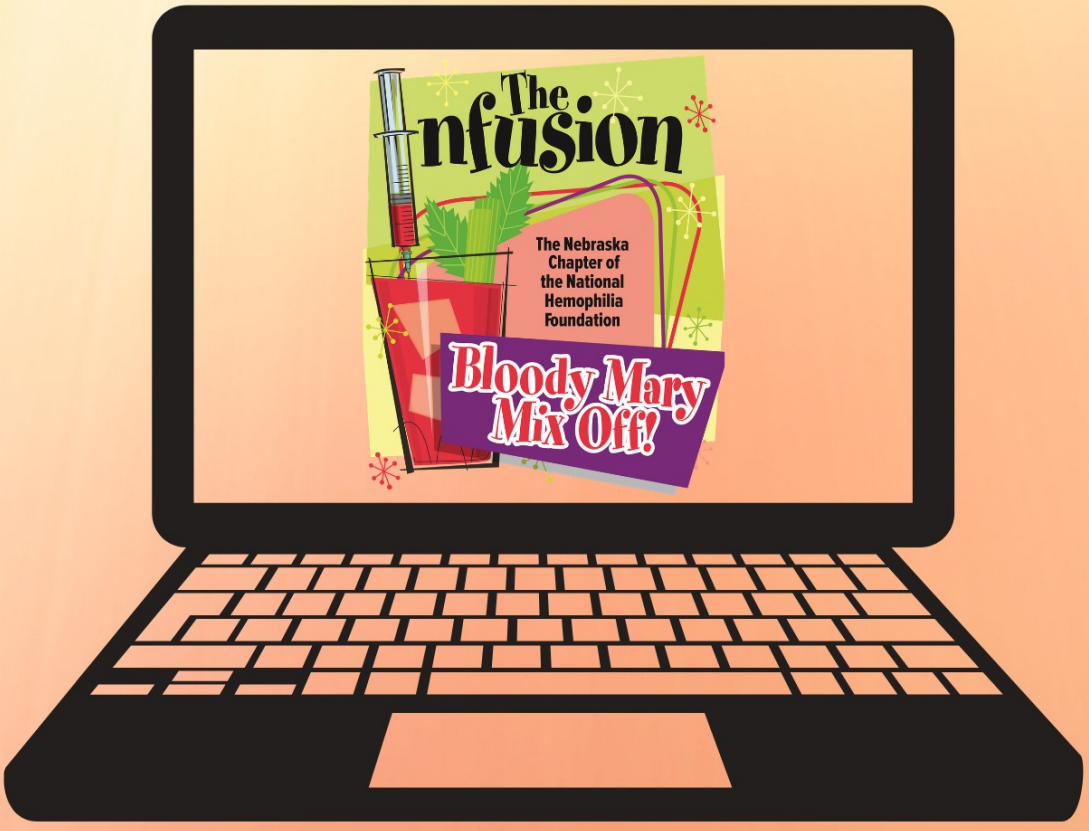
Information directly from the World Federation of Hemophilia. For references please visit:

https://news.wfh.org/covid-19-coronavirus-disease-2019-pandemic-caused-by-sars-cov-2-practical-recommendations-for-hemophilia-patients/

CELEBRATING 35 YEARS

Nebraska Chapter
National Hemophilia Foundation

www.nebraskanhf.org



Join us for our first virtual Infusion Bloody Mary Event!

Host: Zach Peterson, Comedian

Bartender: Alex Lund, Krug Park

Saturday, July 18, 2020

11am-12pm

Tickets: $20

One of our participants will have a chance to win BEST GARNISH this year! Will it be you?

*Proceeds from ticket sales will support programming and financial assistance for the NENHF bleeding disorders community..

HEMOPHILIA CAN BE DIFFICULT.

TRACKING IT SHOULDN'T BE.

HemMobile® App

TRACK BLEEDS
Photograph, map, and log each bleed

TRACK INFUSIONS
Record the date, time, and location of every infusion

SHARE REPORTS
Create consolidated reports to share with your treatment team

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Pfizer Hemophilia

NENHF: 35th Anniversary

With so much going on in the world around us, our focus has on the well-being of our loved ones and our bleeding disorders community. Though this year has looked much different than we are used to, we still want to celebrate the Nebraska Chapter of the National Hemophilia Foundation's 35th Anniversary year, with all of you! We want to celebrate how much we appreciate our bleeding disorders community, supporters and friends. Below you will see just a few of the ways we will celebrate over the next few months. We are excited to celebrate YOU!

CELEBRATING 35 YEARS

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

35th Anniversary Celebration

**Date coming soon*

- 35th Anniversary posts on social media
- 35th Anniversary Trivia Night*
- Special History of NENHF email
- 35th Anniversary Celebration themed Unite for Bleeding Disorders Walk*

...and more!

Unite for Bleeding Disorders

www.uniteforbleedingdisorders.org

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!

More details to come!

www.uniteforbleedingdisorders.org

For more information, contact Misti Mitchell at mmitchell@hemophilia.org or 402-889-0572

Peer-to-Peer Fundraising Tips

- For your birthday or anniversary ask your friends to keep the cards and gifts, and instead make a donation towards your fundraising.
- Get a percentage of sales from your favorite fitness center, hair salon, coffee shop, pizza place, etc. Ask them to donate $1 or $2 from each transaction over the course of a weekend or a few week days.
- Ask your gym for support. Ask them to donate a one, two or three-month free membership. You can use it as a raffle prize for anyone who donates to you or your team.
- Ask your grocer or gas station if you can put a jar out to collect spare change.
- Adjust the signature on your e-mail to indicate that you are participating in the Unite for Bleeding Disorders Walk. Direct people to your personal page.
- Allow staff/students/employees to purchase dress down days for $5.00 per person/ per day.
- Change your outgoing voicemail message to indicate that you have accepted the challenge of raising funds for the Unite for Bleeding Disorders Walk. Provide the website Unite For Bleeding Disorders www.uniteforbleedingdisorders.org so people can make a donation online.
- Have a garage sale. Ask friends and family to donate items. Sell the items you can & donate the remaining items.
- Offer your services as a babysitter; donate the proceeds to your walk team.

Unite
for Bleeding Disorders

Bulletproof Your Target Joints

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Dr. Michael Zolotnitsky, PT, DPT

Growing up with hemophilia, I endured frequent joint bleeds into my ankles and knees while playing basketball. I was told that those were my target joints because I continued to bleed into the same joints, and that ultimately, this would cause hemarthropathy. I was put in braces, and told to use crutches, ice, rest, and elevate. All good things, right?

Well, have you heard of Steph Curry, the all-pro basketball superstar? He continuously experiences ankle sprains that force him to miss games. In our community, we would say that Steph has an ankle target joint; but he doesn't have a bleeding disorder. So why do some people with a bleeding disorder get target joints, and others who experience similar injuries do not?

If an athlete has a low-level ankle or knee sprain, it takes 4–6 weeks for a ligament injury to recover. Recovery includes exercise to strengthen the lengthened ligament and exercises to stabilize the joint. A more intense sprain or strain takes 8–12 weeks to heal, with additional stability training recommended. Someone with a bleeding disorder has different recommendations: usually rest, avoid weight bearing, and ice. If this is all we do, we develop scar tissue, lose range of motion, and lose muscle mass. This turns into a negative cascade of events, because now that particular joint has limited mobility, stability, and flexibility.

When a joint is in a weakened state, it's more likely to be reinjured. After four to six injuries per year, we call this cascade a target joint. This is all preventable with the appropriate post-injury exercise regimen. We must "bulletproof" our target joints, but how?

Let's look at different treatment stages following an injury. When the initial injury occurs, we feel pain, our joint swells, it feels warm and tingly, and we begin to limp. First, follow the treatment protocol that is recommended by your hematologist. After that, consider this four-step return-to-activity protocol that I recommend:

Step 1: The initial focus is to reduce swelling, so apply kinesiology taping specifically for edema reduction by using the fan strip.1 (See "HemoDoc" videos on YouTube.)

Step 2: Active range of motion of the joint can improve blood flow in a non-weight-bearing position. For the ankle specifically, you can trace the alphabet with your foot, make ankle circles, and do gentle towel curls.2 This will reduce scar tissue adhesion and reduce the loss of range of motion.

Step 3: Now begin to strengthen the joints and ligaments by employing gentle resistance. It takes three days to lose strength, but six weeks to regain it, so for a low-level ligament sprain, I recommend performing these exercises three to four times per week, for six to eight weeks.

Step 4: Gently and gradually return to activity.

In my first 13 years of life, I was continuously in and out of the hospital for insidious joint bleeds. I began to exercise and took control of my own life. This is what inspired me to become a physical therapist. And for the past 15 years, I have not experienced joint bleeds, and I can say that I don't have target joints. My dedication and focus now are to help people affected by bleeding disorders.

We are just like normal people. We get hurt; our muscles and joints are weakened. If we don't take the appropriate measures to rehabilitate them, then we're more likely to reinjure them, just like NBA star Steph Curry. Joint injuries are preventable with appropriate workouts and mobility exercises. Allowing our muscles to regain their strength is possible, and will ensure improved overall joint health. Let's all bulletproof those target joints!

A fan strip is a piece of tape that is cut in the shape of a fan. The head of the fan is placed above the area of the swelling, and four pieces are applied over the area without tension. This will allow a negative pressure gradient to occur to reduce swelling and improve circulation.

Towel curls strengthen the inner foot. Place a towel flat on the floor and use your toes to grab the towel and curl it toward you. Then use your toes to push it away from you. Increase resistance by placing a weight on the towel.

Dr. Michael Zolotnitsky is director of neurological rehabilitation at New Jersey Spine and Wellness in Old Bridge, New Jersey. He also has severe hemophilia A. He can be reached at 732-952-2292 and michael.zolotnisky@spineandwellness.com.

Dear Community Members,

The National Hemophilia Foundation's priority has always been the health and safety of the bleeding disorders community. As the COVID-19 pandemic unfolds, it is clear that in the face of an unprecedented situation, we need to make difficult decisions to protect the health of our community and staff. NHF will host the 2020 Bleeding Disorders Conference virtually in order to keep our community safe and help prevent the spread of COVID-19. By creating a virtual environment for the 2020 Bleeding Disorders Conference, we will make the experience consistent with the top-level education you are used to receiving from NHF.

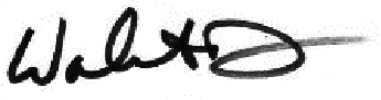
The virtual Bleeding Disorders Conference will be held Saturday, August 1st through Saturday, August 8th.

For questions regarding the event, registration, or refunds, we will have updated information on our 2020 Bleeding Disorders Conference website. Our staff is working tirelessly to develop the most engaging ways to bring education to each of you. We are incredibly grateful to our sponsors for their support of this decision.

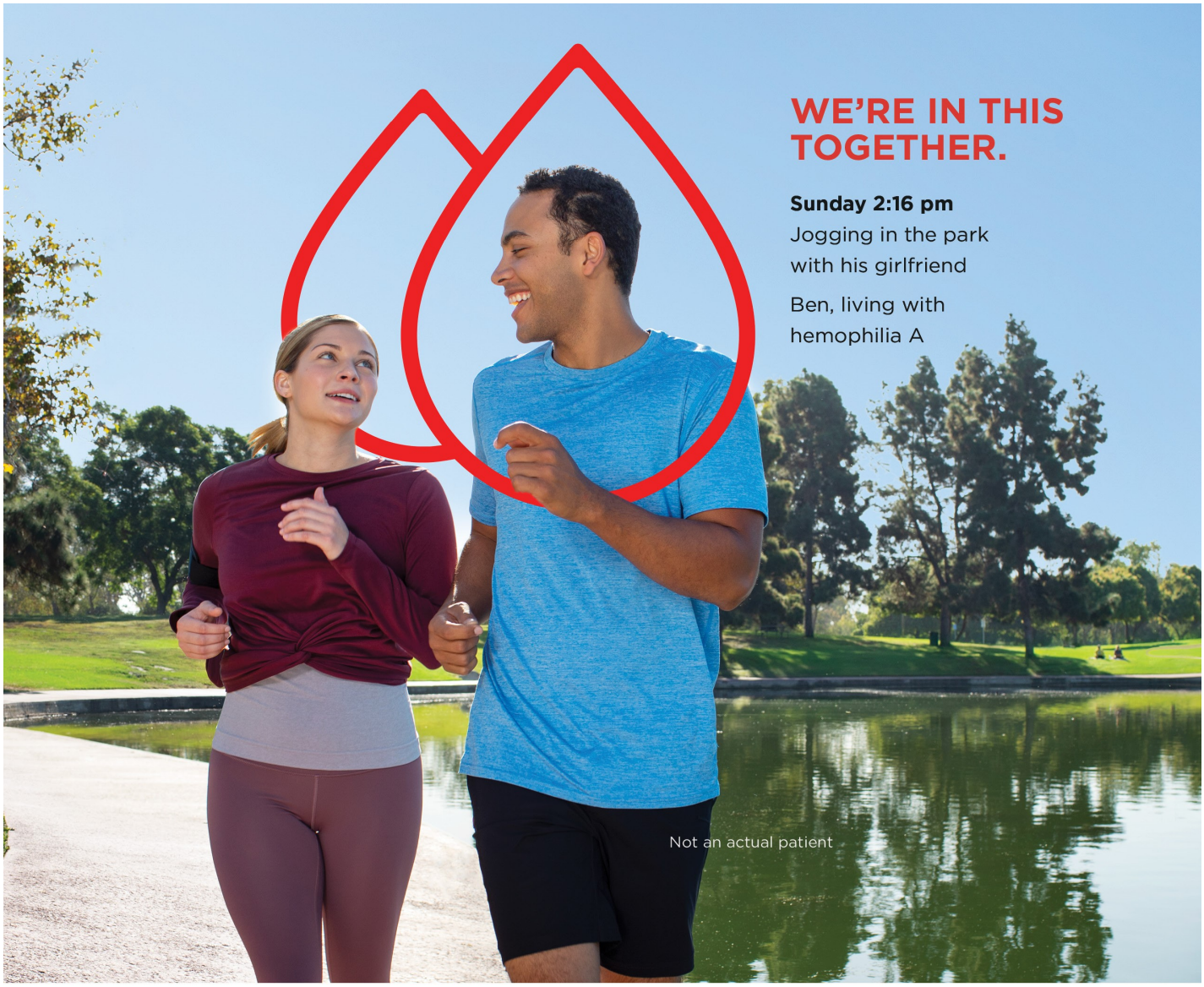
One of the greatest strengths of the bleeding disorders community is our ability to adapt and reinvent ourselves when needed. NHF will work diligently to bring the 2020 Bleeding Disorders Conference to you, in the safety of your own home.

Thank you and please stay tuned for more developments.

Sincerely,



Leonard A. Valentino, M.D.



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

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Joint Damage: The Aftermath of an Inhibitor

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Cazandra Campos-MacDonald

When a bleed occurs in a joint, it is being damaged. I remember a physical therapist saying this many years ago, during a workshop at a local bleeding disorder chapter event. At the time, I didn't give much thought to joint bleeds because my older son, Julian, who has severe hemophilia A with a history of an inhibitor, was very young and hadn't yet experienced this type of bleed. But I kept this comment by the PT tucked away in the back of my mind. When my second son, Caeleb, began having joint bleeds, those words came back to haunt me. Not only did Caeleb have more frequent bleeding episodes, he also had an inhibitor and developed two target joints.

Watching Caeleb endure extreme pain in his right knee and right ankle was very difficult. Because his inhibitor level was extremely high, his hematologist did not recommend immune tolerance therapy (ITT).1 Treating Caeleb's bleeds with bypassing products and R.I.C.E.2 therapy was the only option. During those early years of repeated bleeds into his knee and ankle, I knew that Caeleb's joints were being damaged. Still, I hadn't truly considered how the long-lasting effect of these bleeds would impact his life. I was too concerned with doing everything possible to stop his repeated bleeds.
Caeleb's ITT protocol of daily infusions with a plasma-derived factor product kept him bleed-free from 2015 to 2017. A three-year period of not bleeding is amazing when you have severe hemophilia with an active inhibitor. In 2018, Caeleb's hematologist recommended a new subcutaneous treatment that has continued to keep him bleed-free and has improved his quality of life without daily infusions. Despite a five-year streak of not bleeding, the aftermath of the damage to knee and ankle began to surface.

Over the past two years, Caeleb began having significant pain in his knee and ankle. The pain wasn't caused by strenuous activity; it simply began while he was walking. His pain is worse during the winter, but even during the heat of the summer, he often uses a crutch to get around. He hurt so much that our hematologist ordered an MRI to find out how much joint damage had happened from the earlier bleeds. The damage to Caeleb's knee revealed a spot where his bones rub together, causing debilitating pain. His ankle is in worse shape compared to his knee; I found this surprising because the majority of his joint bleeds have been in his knee. What can I do for him so that he won't hurt?

Helping a 14-year-old boy accept and deal with chronic pain isn't easy. While acute pain can be severe, it normally lasts a short time. Chronic pain lasts for several months or longer, and is usually associated with a long-lasting condition—like degenerative joint disease. Sometimes Caeleb's pain isn't at the forefront of his daily life, but he now experiences days when his pain is constant. Most people don't live with pain as he does, and he accepts this while realizing that his "normal" is very different than most people's. It's when his pain gets to the point of affecting his daily life that the damage sustained as a result of his inhibitor takes center stage, even though he is not bleeding.

Caeleb's hematologist and orthopedist have both told him that he is many years away from even considering any type of surgical intervention. Because of his youth, surgery isn't in his best interest. The implants used in joint replacements have a limited lifespan, and younger patients end up needing multiple revisions as they grow—with each revision becoming increasingly riskier. Younger patients are more active and wear out the implants faster than an older adult would. The good thing is that Caeleb can still walk. He is no longer wheelchair-bound, as he was when bleeding regularly, and his daily activities keep him busy.

My goal is to keep Caeleb active and attending school despite any flare-ups. For Caeleb, these flare-ups come without warning. As he is walking, pain shoots through his knee and/or ankle, and he stops in his tracks, bending down to catch his breath. Sometimes it takes him a few minutes to compose himself before he can continue, but most often he needs to sit for a short time to let his pain calm down. I use several tools help him through times when he hurts.

Our PT recommended exercises to help strengthen Caleb's muscles. When the PT made his initial evaluation, Caeleb was stunned at how limited his range of motion was, particularly in his ankle. This was a key moment that continues giving him a goal to increase his range of motion. "I knew I had issues with my ankle," he told me. "I just didn't realize how bad it really was." Caeleb also insists on walking to and from school. When his pain is significant, I drive him to school, but he insists on walking as much as possible. He tells me that he wants to make sure that he continues moving forward.

Another tool in helping my son is medication, especially Tylenol®. Caeleb chooses not to take opioids; he never liked how he felt when using narcotics. He manages his pain with only Tylenol and R.I.C.E. While Caeleb was hospitalized, he took pain meds to get through his bleeds. He always complained about how he felt when taking morphine, which gave him relief while he waited for bleeds to resolve. I'm glad he remembers the effects of prescription pain meds. Opiates, NSAIDS, and acetaminophen all carry risks; I just hope that when Caeleb does need to rely on stronger pain meds, we will talk about it and use them only as needed.

Perhaps the most effective tools, at least for Caeleb, are knee and ankle compression sleeves. After trying many types of wraps and braces, we finally found compression wear that works well on both his knee and his ankle. When he's doing a lot of walking or activities, these sleeves are needed to minimize pain and swelling. Sometimes Caeleb tries to avoid wearing them because he wants to forget that he has issues with his joints. But then, he often wishes he had worn his sleeves instead of being sidelined because of pain.

Although I can't go back and undo the damage, I can help my son look ahead and do what he can to keep his joints healthy. Preserving what's left of his joints requires a lot of work. Caeleb needs to be as active as his body allows, while using therapy and medication. His inhibitor is no longer the center of his life, but unfortunately it has left him with an all-too-familiar reminder of his past. A surgical intervention will be in Caeleb's future, but for now we are moving forward with a positive attitude. Each day is filled with moments where pain is not center stage, and for all of those moments I give great thanks.

1. Immune tolerance therapy is the administration of high, frequent doses of factor in an attempt to desensitize the immune system to factor VIII or factor IX infusions. The goal of ITT is that the body will "learn" to recognize factor over time and stop producing inhibitors.

2. R.I.C.E. (Rest, Ice, Compression, Elevation)

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.

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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
injection for subcutaneous use
150 mg/mL

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Blue Cross and Blue Shield of Nebraska Sponsors CHAD and Its 21 Statewide Health Agencies

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Omaha, Neb. – Blue Cross and Blue Shield of Nebraska (BCBSNE) announced sponsorship of Combined Health Agencies Drive (CHAD) and the 21 charities under its umbrella, which continue to support Nebraska's most vulnerable populations in the face of the coronavirus (COVID-19) pandemic.

CHAD is a local organization that has been raising funds with and for Nebraska's premier health charities since 1972. Member agencies across the state include The ALS Association Mid-America Chapter; Alzheimer's Association Nebraska Chapter; American Lung Association in Nebraska; Arthritis Foundation Nebraska; Autism Action Partnership; Brain Injury Alliance of Nebraska; Crohn's & Colitis Foundation, Nebraska/Iowa Chapter; Cystic Fibrosis Foundation – Nebraska Chapter; JDRF Nebraska – Southwest Iowa Chapter; Leukemia & Lymphoma Society – Nebraska Chapter; March of Dimes, Nebraska & Western Iowa Market; Muscular Dystrophy Association of Nebraska; National MS Society – Mid America Chapter; Nebraska AIDS Project; Nebraska Chapter of the National Hemophilia Foundation; Nebraska Community Blood Bank; Nebraska Hospice and Palliative Care Association; Nebraska Kidney Association; Susan G. Komen® Great Plains; Team Jack Foundation and United Cerebral Palsy of Nebraska.

BCBSNE's sponsorship will directly benefit the missions of each of these 21 organizations, as well as enhance CHAD's existing inter-agency collaboration, community awareness, education and fundraising efforts.

"We have always been committed to improving the health and well-being of people across Nebraska, and CHAD's focused partnership with statewide health agencies is perfectly aligned with that part of our mission," said Kathy Nellor, health transformation leader at BCBSNE. "It's our honor to support the work they're doing in our communities and workplaces as an extension of our corporate social responsibility."

BCBSNE's sponsorship announcement comes just prior to the start of CHAD's 2020-21 fundraising year in July. During its annual campaign, CHAD works with employers across the state to drive employee engagement by connecting individuals with health causes that are important to them. Funds raised go to the member charities – toward vital programs and services for those affected by a diagnosis, education and prevention programs across the state, and medical research and advocacy.

-- continued on Page 2 –

"We are thrilled to team up with BCBSNE and this generous donation couldn't come at a better time," said Michelle Grossman, president and chief executive officer of CHAD. "Our member agencies provide critical care and resources to families and individuals suffering from chronic conditions – many of whom are disproportionately impacted by the COVID-19 crisis and need more support than ever."

In the 2019 calendar year, CHAD's 21 member charities collectively referred more than 7,500 Nebraskans to professionals or resources, ensured access to a specialized care center for 1,150 patients, and invested $567 million in medical research alongside their national affiliates. They have been working diligently through the pandemic to continue offering vital programs and support to their constituents.

For more information about CHAD and the work of its member charities, or to donate, visit chadnebraska.org.

About Blue Cross and Blue Shield of Nebraska

Through births and broken bones, tests and treatments, trauma and triumphs, BCBSNE is there with you. Since 1939, we have ensured access to the providers you trust, coverage for the care you need and support from a team that's right here in Nebraska. As an independent licensee of the Blue Cross and Blue Shield Association, BCBSNE represents the nation's most experienced health insurance brands that collectively cover one in three Americans. Learn more at **NebraskaBlue.com**.

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Blue Cross and Blue Shield of Nebraska is an independent licensee of the Blue Cross and Blue Shield Association.

Kid's Corner: Hey, Sleepyhead

When your mom's cellphone battery runs down, she charges it. And that's what sleep does for us, too! A good night's sleep gives your body rest and stores up energy for the next day.

But many of us are not getting enough sleep to fully recharge. Kids ages 5 to 12 years old need about 10–11 hours of sleep each night. So if you need to wake up by 7 a.m. in time for school, you'll want to hit the sack by 8 or 9 p.m.

It may be fun to stay up late watching TV or playing games, but if you don't rest, you may get sick more and miss play time with friends! Not getting enough sleep can lead to more colds, flu and stomachaches. That means missing school and being stuck inside the house.

Sleep also helps you get better after an illness, injury or surgery. That's why rest is so important if you've had a bleed. Sleep lets your body focus on fixing itself.

You know you're not getting enough sleep if you:

- Feel sleepy after you wake up.
- Sleep late on weekends and days when you don't have school.
- Get tired during the day and wish you could take a nap.

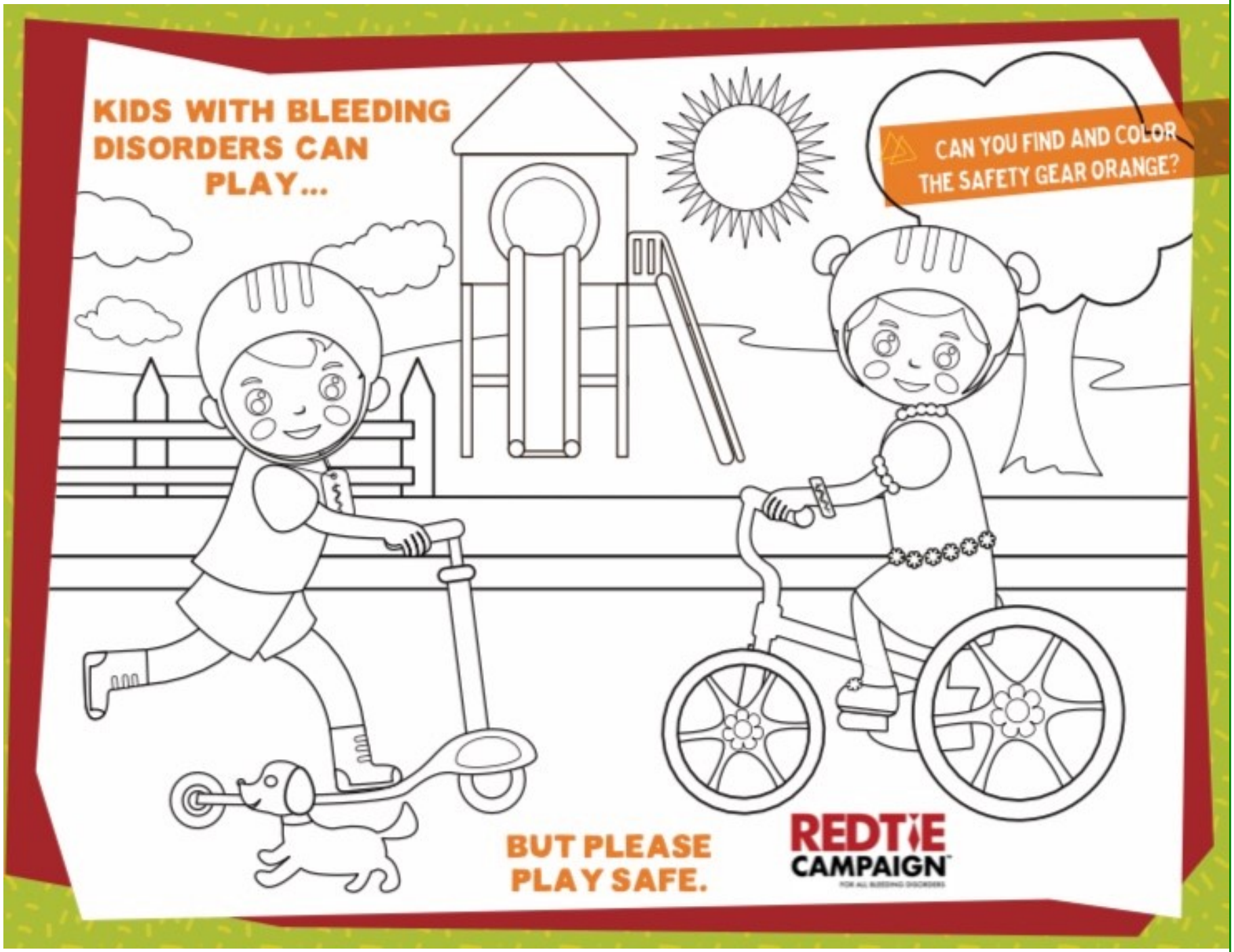
Here are seven tips to get a good night's sleep:

1. Get moving! All that time on the playground and playing with friends can help you sleep longer at night.
2. Go to bed and get up at the same time every day, even on weekends.
3. Don't play with video games or a cellphone after you get in bed. It's tough for your body to wind down afterward.
4. Ask Mom or Dad to read a book with you every night. Having a routine like this helps your body know it's time for bed.
5. Don't eat big meals right before bedtime. Try having a warm glass of milk or a healthy snack instead.
6. Don't drink sugary sodas, especially in the afternoon or night. Many sodas contain caffeine, which can keep you up and make you jittery.
7. Ask your parents to help make your bedroom feel cozy. A cool, dark and quiet bedroom helps you fall asleep.

With this advice in mind, you're on your way to getting a great night's sleep—every night!

Author: Kadesha Thomas Smith

February 2, 2015; HemaWare Junior


KIDS WITH BLEEDING DISORDERS CAN PLAY...
CAN YOU FIND AND COLOR THE SAFETY GEAR ORANGE?
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