



# BIG RED FACTOR

2017—Issue IV

## Nebraska Chapter News

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The Nebraska Chapter of the National Hemophilia Foundation has had an incredibly busy fourth quarter. We have been busy planning and looking towards 2018 with big eyes and opportunity.

We have seen everyone come together in 2017 to support the chapter; raising the most money at our TWO walks than ever before, as well as advocating here in Nebraska and Washington D.C. for our rights. This has been instrumental in raising awareness for ALL bleeding disorders.

We want everyone to take a moment and look back upon some of the best parts of 2017 with your Nebraska Chapter. Whether large or small, these moments make us great and we appreciate you and everything you offer on a daily basis to the Chapter.

When you are looking towards the future with YOUR Nebraska Chapter, take a moment to think of everything we can do together with your help. Either monetary or time offered, our growth is led by you and we appreciate everything you have given and continue to give to us.

-Kelsey Cunningham  
Development Manager



### **Our Mission:**

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

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

## **2018**

### **First Quarter Events**

January 21-22

**Advocacy Dinner Training**

**Advocacy Day**

Lincoln Nebraska

February/March

**TBA Community Afternoon of Fun**

Fun afternoon of Chili/ sides and sports watching

### **Save the Date**

## **2018**

March

**Bleeding Disorders Awareness Month**

March 7-9

**Washington Days**

***More Activities Coming Soon!  
Watch our website for updates and register Online!***

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## Industry Symposium and Town Hall Meeting Recap



Our Industry Symposium and Townhall was a chance to follow up on the Townhall from 2016 and voice concerns, as we move forward into 2018 with new goals and opportunities for the Nebraska Chapter.

We were happy to have CSL Behring and Novo Nordisk speak at our Industry Symposium. This gave our community an opportunity to learn first hand about their products and other amenities their brand offers their customers.

We heard again and again at the Townhall that some of our events had changed and all you wanted was time together to hang out! We heard you and we are busy planning a chili day/potluck for the first quarter of 2018. This will strictly be a hang out opportunity and get together. This also translated to our Harvest Fest no longer being a day together and actually a day apart at Vala's. Be on the look out for a change in 2018. Your suggestions are welcome for the 2018 Harvest Fest! But, it will be an event that keeps our community together while we enjoy the Nebraska Fall weather and hopefully some education too!

Thank you to everyone that took the time to make sure your voice was heard. This provides us with the opportunity to serve you better and we appreciate your time and efforts in helping our Nebraska Chapter



# Finding a Sport for your Child with a Bleeding Disorder

Author: Ian Landau

Prophylaxis and other medical advancements have helped make it possible for people with bleeding disorders to lead full, active lives. But if you have a bleeding disorder, you do need to put some extra thought and planning into what recreational activities and sports you pursue.

Thankfully, the National Hemophilia Foundation's (NHF's) revised *Playing It Safe: Bleeding Disorders, Sports and Exercise* guide is here to help. Along with key questions and topics to discuss with your or your child's care team, the guide's Physical Activity Ratings provide details of the benefits and risks of no fewer than 82 sports and activities—everything from archery to Zumba®—plus ways to make them less risky. Activities are rated from 1 (low risk) to 3 (high risk), although many fall within a range, depending on how the sport or activity is performed.

## New data on sports and activities for kids with bleeding disorders

The activity ratings form the heart of the guide, and a wealth of data has been published on sports and exercise injury risks since the last edition of *Playing It Safe* in 2005.

That evidence resulted in some changes to ratings. Fans of indoor rock climbing and indoor or outdoor ropes and challenge courses, rejoice! The risk of those activities was downgraded. "If you're doing these things safely, with instructors and all the safety equipment and it's well supervised, then it can actually be a really safe activity. The previous data didn't state that," says physical therapist Angela Forsyth, PT, DPT, co-author of the current and previous *Playing It Safe* editions. She and co-author Alice Anderson, PT, DPT, PCS, were happy about the change because climbing and challenge courses are popular camp activities. Now kids (and adults) can feel safer taking part.

An addition to the ratings that kids probably won't be happy about is inflatable bounce houses, which are a 2.5 to 3, the same risk level as hockey. The rating simply reflects the data, Anderson stresses. Still, she's aware that kids will go in bounce houses regardless of the *Playing It Safe* rating, which is why the guide provides suggestions to make jumping around in them less risky, such as removing footwear, eyeglasses and jewelry, and grouping children together by size and not only age.

## Lowering risk

The suggestions to minimize the risk of all the included sports and activities are new to the *Playing It Safe* guide. "We tried to give more information so people can decide to do something more safely at one level versus another level," Forsyth says. For example, basketball is rated 1.5 to 2.5, depending on whether a person takes part in a casual game with limited contact or a more intense and competitive one.

Anderson and Forsyth stress that people should consider more than just the ratings numbers when deciding to do a sport or an activity. "Each person presents with an individual body and individual strengths and challenge areas," says Anderson. Anderson says adults and kids should consult their healthcare team regarding their physical limitations. A physical therapist, for instance, can evaluate strength and flexibility and then provide exercises to help better prepare you for your activities.

In the end, it's about making informed choices. "We don't want people just following recipes or seeing an infomercial on TV or just following the crowd as to what's popular," Forsyth says. "We want them to really think. Because many exercises and sports can be really good for you and your health, but we don't want good things to cause an injury or a bleed."

## PING 2017

Ping at the Lincoln Children's Museum was a roaring success! Thank you to all our industry partners in making this event phenomenal. We learned a lot from Jessica Walker with Bayer, enjoyed Valentino's, and then got a couple hours to enjoy the Lincoln Children's Museum.







**It has been a pleasure serving our  
Nebraska Chapter in 2017. We  
look forward to sharing 2018 with  
everyone.**

**Happy Holidays- The Nebraska  
Chapter Advisory Board**

**Geri Murphy- Presiden**

**Dale Gibbs- Vice President**

**Zach Blackman — Secretary**

**Scott Gass**

**Rebecca Runge**

**Peter Senior**



## STRENGTH TRAINING 101

Author: Matt McMillen

Build muscle, and your whole body will benefit. Strength training leads to weight loss, improved heart health, better bone strength and even boosts in mood. Stronger muscles also provide protection against joint bleeds, which makes them an important part of any exercise program if you have a bleeding disorder.

“When you don’t train your muscles, you put so much more pressure, tension and compression on your joints, and that increases your risk of injury,” says Luke Smith, PT, DPT, OCS, CEAS, CSCS, a physical therapist at Thomas Jefferson University Hospital in Philadelphia. “Strong muscles help relieve that burden.”

But don’t dive right into weightlifting. Instead, make an appointment with your physical therapist, who will evaluate your abilities and any special concerns you have. Your PT can then help you develop a suitable program and teach you how to do exercises properly and safely.

### Be cautious

Physical therapist Cindy Bailey, PT, DPT, OCS, SCS, encourages her patients to join a gym.

“Your PT can put together a work-out program for you based on your gym’s equipment,” says Bailey, who practices at the Orthopaedic Hemophilia Treatment Center at the Orthopaedic Institute for Children in Los Angeles.

For beginners, Bailey recommends machines over free weights, because machines require less muscle coordination. That makes it easier to do the exercise properly. However, machines work fewer muscles. So, once you develop some strength, add dumbbells, kettlebells or other free weights to your routine.

If you prefer not to join a gym, ask your PT to help you develop a home-based program. You can focus on body-weight exercises like pushups, pullups, lunges and squats. As you get stronger, add elastic resistance bands, cuff weights for your ankles or wrists, and, eventually, free weights.





## Building a program

Once you select the best exercises for you, your PT will help you set a reasonable workout schedule. To avoid injury, start with light weights and focus on proper form.

“Your body needs to learn how to put these movements together and adapt to them in order for your muscles to work effectively,” says Smith. That usually takes a few weeks, and you may have some discomfort in the first few days.

At the start, Bailey recommends two moderately easy sets of 10 repetitions, three to four times per week. After the first week, bump it up to three sets. As you grow stronger, slowly boost the difficulty, but increase only one variable at a time: the weight, the number of reps or the number of sets.

Also, if you’re new to weight training, begin with just two different exercises at a time, says Bailey. For example, do two upper-body exercises on one day. The next day, do two lower-body exercises. Your PT may decide you can handle more, but don’t push yourself beyond your PT’s recommendations.

Strength training is a safe exercise, if performed properly. However, both Bailey and Smith say to avoid power lifting, which can invite muscle tears and joint injuries.

Finally, be patient. If you stick with your strength-training program, you will benefit.



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We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

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## 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 with hemophilia A with factor VIII inhibitors.

## WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

**HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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 signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **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 the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

**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.**



#### 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.**

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 OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

**The most common side effects of HEMLIBRA include:** redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or [www.fda.gov/medwatch](http://www.fda.gov/medwatch). You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.



**Medication Guide Brief Summary**  
**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. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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	– stomach (abdomen) or back pain
– weakness	– nausea or vomiting
– swelling of arms and legs	– feeling sick
– yellowing of skin and eyes	– 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	– cough up blood
– pain or redness in your arms or legs	– feel faint
– shortness of breath	– headache
– chest pain or tightness	– numbness in your face
– fast heart rate	– 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 with hemophilia A with 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.
- 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.
- 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 before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose 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 7 days at 86°F (30°C) or below.
- 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

**Inactive ingredients:** L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

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 For more information, go to [www.HEMLIBRA.com](http://www.HEMLIBRA.com) or call 1-866-HEMLIBRA.  
 This Medication Guide has been approved by the U.S. Food and Drug Administration  
 Issued: 11/2017



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## Kids Who Volunteer Make a Difference



Author: Amy Lynn Smith

Volunteering and helping other people makes you feel good about yourself. No matter how old you are or what type of bleeding disorder you have, you can make a difference.

If you want to volunteer, begin by asking yourself some questions: Do I want to help kids or older folks? Do I want to help raise money for a good cause, like a hemophilia walk? Could I help at an animal shelter or pet rescue? Next, talk with your family about what's available in your community.

Search online for groups that can help you find the right fit for volunteering. GenerationOn helps organize local Kids Care Clubs for elementary and middle school children. Clubs are formed at schools, houses of worship and other community-based organizations. Learn more at: [generationon.org/kids-care-clubs/about](http://generationon.org/kids-care-clubs/about). Visit a local school, pet shelter or nursing home to see what kind of help they need. There are lots of ways to get involved in your community. Just find a cause that means something to you and get started.

### 10 to Try

Here are some other ideas for volunteering:

1. Read books to people who are visually impaired through a community organization.
  2. Make care packages for the homeless.
  3. Help adults pack donations of clothes, books and toys.
  4. Present a talent show with your friends at a local nursing home.
  5. Offer to do yard work for a neighbor.
  6. Run a lemonade stand and donate your earnings to a charity.
  7. Pitch in to clean up a local park or beach.
  8. Organize a penny drive with your friends and neighbors. Donate the money to a local charity.
  9. Make handmade cards to send to people in a nursing home or soldiers serving far away. Your cheery surprise could make someone's day.
- Start a club at your school to help stop bullying





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# Advocacy Days

Dinner Training

And

Hill Day

January 21-22 2018

Join your Nebraska Chapter on January 21, 2018

In Omaha

6:00 PM Lazlo's Restaurant

This dinner training will give you the opportunity to learn how to tell your story and advocate for the needs of those with bleeding disorders at the state level.

January 22 9:00 AM

Join us in Lincoln for a light breakfast and briefing of our state legislature and their activities. Then, we will be meeting with our senators while they are in session. Once session is over, you will hopefully have the opportunity to have a scheduled appointment with your representative.

Please RSVP for one or BOTH events as soon as possible in order for us to help schedule your appointment with your representative

For questions please contact Kelsey at  
[kcunningham@hemophilia.org](mailto:kcunningham@hemophilia.org)



**The Nebraska  
Chapter thanks you  
for your continued  
support in 2017.**

**Happy Holidays.  
We are excited to  
see you in the New  
Year.**

**Maureen & Kelsey**