



Inside this issue:

Calendar of Events	2
Changing Landscape	3
New Board Members	4
Infusion: Bloody Mary Mix Off	6
Ed Weekend Overview	8
Embracing the Unique	10
Upcoming Events	12
Walk	16
Kid's Corner	21

BIG RED FACTOR

2018—Issue II

Nebraska Chapter News

It's hard to believe we are already through 2018. We had a busy first half of the year, but as you know, it's just really starting to ramp up. We have so much going on in the next couple months and I'm SO excited to do it all with you. So buy your tickets to Infusion, sign up for Family Camp and Kearney Ed weekend and start recruiting those walkers for your team! It will all be here before you know it. It is shaping up to be a grand time with a lot of fun, education and a few drinks for a good cause (our cause!)

Please be patient with me as we go through this summer with just one staff person. We are currently in the hiring process for a new full time Development Manager. This is an extremely wonderful opportunity for the organization and we are working hard to find just the right person to serve this community. We have a lot of exciting things on the horizon and we want someone to enhance this. If you know of a qualified person for this position, please send them our way!

I'm so excited for the rest of 2018 and looking forward to all of the amazing events, programming and education heading your way soon,

Maureen Grace, Executive Director



Our Mission:

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

Staff

Executive Director
Maureen Grace

Development Manager
Open Position

Advisory Board of Directors

President - Dale Gibbs
Vice President - Geri Murphy
Secretary - Zach Blackman
Dan Henson
Peter Senior
Rick Starks
Joe Mickeliunas
Ann Foster
Jon Tvrdik
Bob Dick

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

Third Quarter Events

July 20

Unite Walk Kick Off

Omaha, NE

July 29

Infusion: Bloody Mary Mix Off

Omaha, NE

August 10-12

Family Camp

Gretna, NE

August 25-26

Kearney Education Day

Kearney, NE

September 22

Unite Walk!

Omaha, NE

Save the Date

October 6

VWD Education Day

October 20

Harvest Festival

Roca Berry Farm

November 10

Women's Retreat

Location TBD

December 8

PING!

Lincoln Children's Museum

December 15

Industry Symposium

Mahoney State Park

A Proud Member of



COMMUNITY
HEALTH CHARITIESSM
NEBRASKA

The Changing Landscape of the Hemophilia Community

The hemophilia community is incredibly strong, with a rich but heavy history. Very few rare disease groups have the same support, family and tight knit community as the bleeding disorder community does. We are so fortunate to be able to provide year round education, advocacy and support to those in our chapter. However, the culture of the community is changing, and we are evolving along with it. The mission of NE NHF has always been to provide these things to our community and that dedication will not waiver. Some of these programs and events will start to look different over the coming years as we work to ensure the needs of the community are met while balancing the costs of programming with changes in our funding structure.

We have always been fortunate to have most of our funding come fairly easy from our industry partners. The way these companies are now supporting chapters is changing and funding isn't at same level it has been sustained at for years. Their focus is shifting more to direct education and advocacy efforts and funding fewer fundraisers and social events. We knew the change was coming eventually, but it has arrived sooner than we anticipated. It is imperative that we diversify our revenues at a chapter level so that we can continue to offer the same amount of programming and events as we have for years. This is affecting chapters all across the country, not just Nebraska. We are working closely with our National team to create a development plan that will assure that NENHF is financially stable for years to come. Part of this plan is to hire a full time development manager to grow our fundraising efforts beyond industry support and become less financially reliant on industry. We are excited for this growth and what it means for our chapter. Transitioning this position to full time and filling it with a greatly qualified individual will take us a long way.

You may wonder what this will look like for our chapter as we work on growth, change and stability while still serving our mission for the Nebraska bleeding disorder community. We are still incredibly dedicated to providing advocacy on a state and national level and meaningful and relevant education throughout the year through multiple educational events. We just have to be extremely cognizant of our budget so that we can continue these programs as our funding shifts. This does mean that some events that have been the same for years, will start to see some changes. NE NHF loves offering fun, networking events for our families but starting with Harvest Festival this year, you will see some venue changes and we are looking into trying new events in place of the ones we have been seeing for years. We want to ensure that we are offering meaningful programming, reaching all areas of our community and that we are supportive of everyone in Nebraska affected by a bleeding disorder.

Change is scary, but it can also be very refreshing. I truly believe the next couple years will be a little bit of both. That being said, we are very open to input, ideas and assistance from anyone in our chapter who wants to step up or give us new ideas. At the end of the day, this is your life and your community, and we want the chapter to reflect that. The next few years will be ever changing as we find our new stride, but through it all, NENHF is dedicated to remain on mission with our bleeding disorder community and family in the forethought of everything we do.

Thank you for letting us be part of your family and your lives. We love this community and it's our pleasure to serve you. Thank you from myself and our Board of Directors for this amazing ongoing opportunity to be your hemophilia chapter.

Maureen Grace, Executive Director

New Board Members

Joe Mickeliunas



Joe was born and raised in Omaha, Nebraska. A passion for history brought him to study secondary education with an endorsement in social studies at the University of Nebraska at Omaha. After graduation, Joe was hired at historic Central High School where he is currently in his ninth year teaching Advanced Placement World History, Advanced Placement Human Geography, and is coach of Central's Academic Decathlon team. In order to teach his high school courses for college credit, Joe returned to the University of Nebraska at Omaha to complete a Master's Degree in History with a minor in Ancient Mediterranean Studies. In his spare time Joe enjoys writing and playing music, watching baseball, and traveling with his wife Jenny and two children, Amelia and Elliott.

Educated in Advertising, Design & Filmmaking, Jonathan Tvrdek has spent the past 15 years creating and directing experiences through all manner of media. Thanks to a borderline-unhealthy obsession with Bruce Wayne, he has learned to effectively work in several places at once.

Formerly as Executive Creative Director of Phenomblue, a connected communications firm, Jon has conceived and overseen hundreds of global technology and creative initiatives for clients including Samsung, Diet Coke, eBay Inc. and Nike. As Principal of the Tvrdek Group, Jon works with business of all shapes and sizes to articulate business goals into measurable strategies brought to market by transformative creative marketing solutions and technological product innovations.

When not working all hours of the night, Jon keeps his dance card full by owning a craft beer bar, consulting for his wife's e-retailer and managing the development of several technology R&D projects.

Jon Tvrdek



Bob Dick



Dick joined the Bland CPA as a Director in 2015. He works with closely-held businesses and not-for-profit organizations to develop business strategies and improve operations. He also prepares business valuations to help individuals understand the value of their business.

He has known since high school that he wanted to pursue a career in Accounting, after achieving perfect scores on his tests and discussing the field with his teacher. Dick went on to earn a BS in Accounting and Finance from Kansas State University in 1988. Throughout his career, he has worked for various firms, starting in Wichita, Kansas and, most notably, spent some time at Bland when the firm was still known as Bland, Datesman & Associates in the early 1990s. Prior to joining Bland & Associates in 2015, Dick spent 22 years as a Principal at another CPA firm in Omaha. He is a Certified Valuation Analyst as well as a Certified Public Accountant.

New Board Members

Ann Foster



Ann graduated from Wayne State College with a Bachelor of Science in Elementary Education. In 2010, she graduated from the University of Nebraska at Lincoln with a Master of Science in Leadership Education and in 2015, graduated from Concordia University in Seward with a Master of Education in K-8 Administration. She currently is the Curriculum Coordinator for Lexington Public Schools. She has two children, Ava age 9 and Weston age 2. She enjoys traveling, golfing, being outdoors, Husker Football, and traveling and vacationing as often as possible. Hemophilia has always played a roll in her life. She is a carrier of Hemophilia A and has low factor levels which classifies her as having Mild Hemophilia A. They discovered soon after Weston's birth that he also has Hemophilia. Their priority was educating themselves, their family, and care-givers in Weston's life about Hemophilia. Hemophilia is such a rare disease that not many people know of, so bringing awareness out to her small town and to Western Nebraska is a priority of hers. The Nebraska Chapter has been instrumental in providing them with educational information and opportunities as well as networking with others.

Rick Starks

Rick resides in Haigler, Nebraska and is well known in the bleeding disorder community as the Tai Chi Guy. He is very involved with the Coalition for Hemophilia B and comes with a life time of knowledge and life experience on living with severe hemophilia B. He is very interested in advocacy, recently speaking to NeDHHS Medicaid, advocating for choice in factor products. His passions include fitness, living well, reading and music. He is excited to be part of the Nebraska bleeding disorder community and to help shape the organization over the years.



2018 Advisory Board of Directors



The Nebraska NHF Board of Directors met on May 12th to participate in a board retreat led by Michael Craciunoiu and Kenneth McElderry from NHF. Every single member of our board was in attendance, with attendees coming from as far West as Haigler and Gothenberg. The board came out of the retreat with 4 main goals for the organization moving forward. These goals are to grow the committee structure within the organization, focusing on governance, advocacy, education and fundraising, work on growing our community engagement, determining the long term plan for NE NHF through strategic planning and creating a development plan that will diversify our revenue beyond industry dollars.



The Infusion

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

You won't want to miss this fun event.

The Nebraska Chapter of the National Hemophilia Foundation

Bloody Mary Mix Off!

**Sunday
July 29, 2018**

10 am to 1 pm

Must be 21+ to attend.

The Waiting Room Lounge • 6212 Maple Street Omaha, NE

Omaha bartenders face off to showcase their signature Bloody Mary recipes at The Waiting Room Lounge.

Guests enjoy bloody marys from every bar, brunch selections from your favorite local restaurants and the chance to vote for their favorite Bloody in Omaha.

Two prizes will be awarded: Best Overall Bloody and Best Garnish.

Tickets are \$40, Early Bird Available Before 6/30 are \$35 and Designated Driver Tickets are \$20

Sponsored by:



Scan for Tickets

The Infusion: Bloody Mary Mix Off

Join us for our 3rd Annual Infusion: Bloody Mary Mix Off!

We are so excited for this event and it keeps getting better year after year. The Infusion is finding it's new home in Benson at the Waiting Room Lounge with more participating bars than ever before. Tito's is our generous vodka sponsor this year bringing all the vodka for our competitors, so you know everything will be delicious.

Come sample Omaha's best bloody marys, support your favorite cause and eat some absolutely delicious breakfast foods from Omaha's finest.

If you want to come to the event, but don't want to pay, we are always looking for volunteers to help at the event. It will get you in for free and you still get to enjoy all the benefits of brunch and bloodys. Contact Maureen Grace today to volunteer.

We cannot wait to see you there. Get your tickets today!



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EXPERTISE IN:

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- Hemophilia B
- Von Willebrand's Disease
- Other Bleeding Disorders

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Experienced ARJ pharmacists and nurses are delivering Nebraskans personalized quality home infusion care every day.

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Where Caring is the Ultimate Factor.

Family Education Weekend Overview

The education highlight of the year for the Nebraska Chapter has always been our Family Education Weekend. This year, we brought the event back to Omaha at the Embassy Suites in La Vista, Nebraska. We had over 30 families attend, including several that had never been to one of our Education weekends in the past. The 2018 FEW brought in families from all across the state, many travels hours to attend.

We kicked the morning off with our amazing keynote speaker, Chris Bombardier, who spoke about his recent accomplishment of climbing the Seven Summits, all while maintaining and treating his severe Hemophilia B. His story about doing what you love, advocating for others and living his dreams while living with a bleeding disorder was touching and inspiring. Chris' keynote was a wonderful way to set the tone for a day full of education and networking. We offered more break out sessions than ever before with topics ranging from taking care of your joints, to self care in caregivers and VWD. Dr. Harper from the Nebraska HTC came in the afternoon to give updates on the state of care in Nebraska and what's in the pipeline for upcoming care and treatment for bleeding disorders.

An amazing group of talented and patient nurses hosted our infusion clinic where kids and adults alike were able to brush up on their infusion skills, some learning for the first time about self infusion or the infusion process on others. This is one of the most amazing part of our education day and we love to see people gain more confidence and ability in infusion and sterile techniques. NENHF wants to extend a huge thank you to those who participated in and led our infusion clinic.

We wrapped up the first day officially with an awards dinner where we honored those who have made a difference in our chapter. Each year, we acknowledge our industry and home health partner of the year. This year's awards went to Novo Nordisk and HPC Specialty Pharmacy for the services they have done for the chapter and going above and beyond the call of duty for their positions. Additionally, we awarded the Carl and Sharon Clark Service Award to Ann Foster of Gothenberg, NE. Ann was our founder and walk chair for our Gothenberg Walk in 2017. Her dedication to bringing awareness for bleeding disorders throughout Nebraska through our Walk program is incredibly admirable and amazing. We cannot wait to watch her program grow and for our chapter to be present throughout the state.

Our Saturday night family event was an awesome game night hosted by Spielbound. They came armed with a bunch of volunteers, games and event a giant jenga set and connect four. We spent the night learning and playing new board games, playing in the pool and having a wonderful night recharging with all of our families. It was an absolutely fabulous way to round out an extremely full day.

Sunday morning, Maureen gave an update on the chapter, where we are going and what we are doing going forward. There will be a lot of changes in the next couple of years but they are all going to be wonderful and allow us to serve this community even better. Our advocacy committee then did an update on the importance of year round advocacy, what we are doing on the state level and the easiest way for you to be involved in advocating for your self and your healthcare on both a state and national level. Lastly, Kristin Burns, PT, came in and taught us about KT Tape, how to use it and the benefits in regards to joint and muscle health. It was interactive, fun and we got to learn about a new tool that can be used for pain management and taking care of our bodies.

This event would not be possible without the support of our Industry sponsors. Our 2018 were wonderful and can be seen in the center of our photo collage. Thank you again from NENHF for everything you do for our chapter and our continuing educational programming.

Save the Date for our 2019 Conference! April 27th– 28th, 2019 | Embassy Suites Downtown Lincoln

Family Education Weekend Overview



NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nhff.org

THANK YOU!
2018 Education Weekend Sponsors!

Diamond Level Sponsors

Genentech

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briovara[®] nchs[®] we care. for life.

Exhibit Level Sponsors

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Shire[®] SUPERIOR BIOLOGICS SOLEO HEALTH Innovations in Specialty Infusion

Embracing the Unique

EMBRACING THE UNIQUE

By Laurie Kelley

When children are diagnosed with hemophilia, they are each given an essential diagnostic label: for example, hemophilia A or hemophilia B, severe, moderate, or mild. These labels originate from a lab analysis of the child's blood. The diagnosis determines what type of factor replacement therapy each child will get. Labels like these can help draw a picture of who your child is and what he or she needs. But when it comes to dosing and prophylaxis regimen, sport choices and bleeding patterns, and even pain management, your child with hemophilia is unique. Diagnostic labels don't adequately explain a person's individuality and needs.

We asked parents from Facebook about their children with hemophilia: Has anyone ever used the labels of hemophilia to categorize your child, which resulted in limiting treatment options, or limiting what people think your child can do? What is it about your child that is not "typical" for someone with hemophilia? The responses poured in. While a child's uniqueness may be revealed in a preference for certain sports or a physiological reaction to a particular product, most of the parental responses we received were about each child's unique half-life, and about subsequent bleeding patterns.

Half-life was barely mentioned when my son was born. In the late 1980s and early 1990s, we dosed his factor using a chart based on his weight; it was very mathematical. We took one-half of his weight in kilograms times the factor level we desired, and this equaled the number of units of factor VIII we needed to infuse. Over time, as parents, we developed intuition about how much or how little factor our son needed based on his response to factor and his bleeding patterns, and we could adjust his dosage ourselves.

Up until about the last 10 years, hemophilia treatment centers (HTCs) often prescribed factor dosages based on weight, and determined a prophylaxis regimen based on a strict protocol from clinical studies. We now know that every child needs to have a pharmacokinetic (PK) or recovery study done to determine his or her individual, unique half-life response to a specific factor VIII product. Determining the unique half-life can help hone the amount of factor a child should receive, or indicate the best prophylaxis regimen. A short half-life may mean more frequent infusions, higher doses, or the use of extended half-life products.

If anyone knows about the uniqueness of factor half-lives in children with hemophilia, it's June Reese, who has four sons with hemophilia. She says, "One son has always had a short half-life and has really struggled with bleeds. His teachers often compare him to his brothers, one of whom never bleeds." And this was a problem for the Reese family: in categorizing two brothers with textbook half-lives as "normal" for hemophilia, teachers dismissed the third brother's frequent bleeds—they thought he was being careless, or worse, that he was imagining the bleeds.

Embracing the Unique continued...

Crystal Eskine has two sons with severe hemophilia A, ages 9 and 10. “I expected two similar stories,” she laughs. Despite having the same diagnosis as his brother, Crystal’s 10-year-old bleeds spontaneously, “if you look at him too hard.” Her younger son “never needs factor,” and “he isn’t even on prophylaxis he bleeds so little!” When Crystal’s doctor wanted her to adhere to a traditional dosage and infusion schedule with her older son, her gut instinct told her it wasn’t good enough. She knew her children’s unique responses to factor. “I started giving my older son double doses. I took notes, showed our doctor, but he still he thinks I’m worrying too much, while I still don’t think the dosing regimen is good enough.” Crystal continues, “I’ve asked for a PK test, with blood samples taken over a much longer time period, but he has said no.”

And then there is Jen Miller’s five-year-old with severe hemophilia A. Jen calls him a “typical boy” who enjoys video games, swimming, T-ball, and playing with his friends. His factor half-life is very short, which is not typical, but this doesn’t seem to impact his bleeding patterns. When a shorter half-life does impact bleeding patterns, and parents instinctively know something isn’t right, they need to alert their HTC staff, sometimes to prove that their child does not fit a category or label. In these cases, parents should request a PK study. Crystal laments, “My boys’ hematologist makes me feel like I’m doing something wrong, but refuses to do a PK study.” June adds, “For years, our medical staff acted as though we were to blame when he’d have bleeds—even though he was infusing regularly.”

Kate Stotz, who has a 22-month-old with severe hemophilia A, felt she had to fight against the standard prophylaxis infusion schedule of three times a week. “This was not working for our son,” she explains. “He was having frequent bleeds on Sunday, the day he was unprotected. Trough levels indicated that in order to maintain a minimal 1% trough, we could not exceed 48 hours between infusions.” Though Kate wanted to infuse every other day to keep him protected, her son’s hematologist didn’t want to break from the traditional schedule the HTC normally prescribed. “It took a lot of advocating on our part and ultimately finding a new doctor at a different HTC.”

Sarah Hueston successfully advocated for a new prophylaxis regimen for her 16-year-old son with severe hemophilia A, who plays two varsity sports. When they determined he had a short half-life, the HTC team, Sarah, and her son developed his treatment plan together. He now infuses standard factor daily. “It’s what works for us,” says Sarah, “and his doctors are so proud of him, as are we, his family! Never did we think he’d be doing the things he’s doing even 10 years ago!”

By logging her son’s bleeds, Stacey Mollinet was able to convince her HTC team to change the treatment schedule. When her son with severe hemophilia A was a young teenager, he didn’t bleed like a typical severe and was not very active by nature. “I had to push the HTC,” she recalls, “so he could treat only twice a week, instead of a standard prophylaxis schedule.” Around age 14, he started to bleed more like a typical severe. So Stacey worked with the HTC to adjust her son’s dosing schedule, and ended up dosing every other day until he switched to extended half-life factor two years ago.

“There’s not a one-size solution for everyone,” Stacey has learned. “Keeping good infusion and bleed logs so you know what schedule works best to prevent bleeding is important.”

Crystal laughs, “I could probably write a book about all the ways my boys ‘differ’ from the typical definition of hemophilia.”

And in a community where boys “typically” have hemophilia while women are carriers, women are now advocating to redefine what it means to have hemophilia. Labels have their place, but when we define hemophilia and determine treatment plans, we sometimes need to look outside the box at hemophilia—and trust the parents and patients when they describe their own uniqueness and needs.

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Family Camp



Nebraska Chapter NHF

We are now hosting family camp EVERY YEAR!!!

Please join us this summer for our 6th Annual Family Camp!

Friday, August 10th - Sunday August 12th, 2018

Eastern Nebraska 4-H Center in Gretna, Nebraska

The fun starts Friday night at 5 pm and goes through Sunday morning at 10 am.

Enjoy camp activities like the zip line, canoeing, archery, camp fires, crafts, tie dye shirts and water games.

Education and Infusion clinic will be part of the fun!

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



2018 Family Camp
Camp Tap-A-Vein-A-Day-A
Nebraska NHF
August 10-12th, 2018

Family Registration:

\$35

Individual Registration:

\$25

Register Online at:

www.nebraskanhf.org

By August 1, 2018

Kearney Education Day



The Nebraska Chapter of the National Hemophilia Foundation
invites you to our
Second Annual Kearney Outreach Education Day
in conjunction with the Nebraska State Fair!
August 25, 2018 * Younes Conference Center, Kearney, NE

We are working to reach all of our families in our bleeding disorder community across the state and we can't wait to see you in Kearney to learn and network with people from across Nebraska. Come spend a day with the Nebraska Chapter for our Education Day in Kearney!

Your registration includes:

- ♦ Education sessions focused on advocacy, self care and bleeding disorder health and wellness.
- ♦ Lunch
- ♦ An Infusion Clinic where you can brush up on your self and home infusion routine.
- ♦ Amazingly delicious and educational dinner event!
- ♦ Free hotel night covered by NENHF on Saturday, August 25th, 2018
- ♦ Tickets to the Nebraska State Fair on Sunday, August 26th in Grand Island, Nebraska

Registration Cost: Family- \$50 Individual-\$25

If you are unable to afford registration but still want to attend— contact Maureen!

(If you need travel assistance, there are limited funds available for gas cards to get to Kearney!)



Saying Goodbye to Kelsey Cunningham



For 18 wonderful months, we were honored to have a wonderful development manager, Kelsey Cunningham. She brought with her a lot of energy, attention to detail and a huge love of walk season. Kelsey loved getting to know the bleeding disorder community but is moving on to a position at her son's school. Her last day with the chapter was May 20th, rounding out Family Education Weekend. We are extremely sad to see her go, but she promised to not be a stranger and is willing to still serve on our Infusion and Advocacy Committee.

Thank you to Kelsey for all the hard work and dedication to the Nebraska Chapter, especially to our walk program. We hope your next chapter is just as wonderful and that you will always hold the bleeding disorder community in your heart.

2018 Getting in the Game

Physical activity is important for everyone, with special benefits for people with bleeding disorders. "Gettin' in the Game" was developed by CSL Behring to help children with bleeding disorders exercise, play sports, and learn more about their disease state. Exercise can help people with bleeding disorders build stronger muscles and joints and improve their venous access. Sports and exercise can also help build self-confidence, teach teamwork, and create a sense of community.

This year's sports clinics include Baseball, Golf and Swimming. You don't need experience in the sport to participate. All ability levels are welcome.

Nebraska can send TWO youth ages 7-18 with a bleeding disorder. If you are interested in participating please let Maureen know ASAP! Preference will be given to those who have not attended in the past.

September 28-30th in Phoenix, AZ.

Travel and program cost covered for attendee and one guardian.

Deadline for applying is NOW!!!!



Mini Golf Fore Good

We kicked off our Education Weekend with a little family fun at our Mini Golf Fore Good event. The weather was right on the edge of storming but held off long enough for us to have a beautiful night out trying to out putt one another for a good cause. Twelve teens battled it out for the top team award which went to Greg, Kelsey and Montana. Peter Senior was our top golfer and Leah Dixon blew us all away with the most putts, topping in over 100 with 19 on one hole. She is nothing, if not persistent! This family friendly fundraiser turned out to be a lovely evening full of laughs, burgers and root beer floats.

Thank you to our sponsors, Novo Nordisk, NCHS, Bayer, CSL Behring, Superior Biologics, Aptevio and Christiansen Drywall and Construction.



Most Putts

Best Score

Top Team



2018 Unite Walk for Bleeding Disorders



Unite

for Bleeding Disorders



SEPTEMBER 22, 2018



CHALCO HILLS RECREATION CENTER

1 MILE | 5K WALK

WWW.UNITEFORBLEEDINGDISORDERS.ORG

2018 Unite Walk for Bleeding Disorders

• **Walk Kick Off! • Friday, July 20, 2018 •**

UNO Community Engagement Center

Join us for our 2018 Walk kick off with tips and tricks on making this your best fundraising year yet. Bring your team, your top funders and anyone you think would benefit from some peer to peer fundraising tips.



**Following the education portion of our kick off event
Head over to Elmwood park to play and have a BBQ dinner!**

RSVP at www.nebraskanhf.org

Happy Fundraising!!

2018 NEBRASKA UNITE WALK FACT SHEET

WHAT: The Unite for Bleeding Disorders Walk is NHF's largest event dedicated to finding better treatments and cures for bleeding and clotting disorders, and to preventing the complications of these disorders through awareness, education, advocacy and research.

WHY: Established in 1948, NHF is the premier organization in the U.S. serving the bleeding and clotting disorders community. Now in its 70th year, NHF continues to be a vital resource for prevention education and provides a network of support for Americans living with bleeding disorders and their families.

WHEN: Saturday, September 22nd, 2018

WHERE: Chalco Hills Recreation Area— 8901 So. 154th Street, Omaha, NE 68164

Check-in begins at 8:30am / Walk begins at 10:00am

DISTANCE: 1 mile or 5k option

HOW: Sign up for the Walk online by visiting www.uniteforbleedingdisorders.org. Click on Omaha or Gothenberg, NE walk and register.

VOLUNTEER: Help us make our event a success. Volunteers are appreciated before and/or during the Walk. Unable to do the Walk but still want to participate? Enlist as a Volunteer.

A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS

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.

Discover **HEMLIBRA.com**

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. 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.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
 1 DNA Way, South San Francisco, CA 94080-4990
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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.

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Kid's Corner



Getting Help at School for Your Bleeding Disorder

Author: Ian Landau | Illustration by John Haslam

When you're at home and you get hurt or feel a bleed starting, you know to go to your parents or another grown-up who takes care of you for help. But it's important to know that if you're hurt at school, you are definitely not on your own! There are adults there, too, who can help you when you need it.

Your School Team

If your school has a nurse, that's the No. 1 person you should see if you fall on the playground or get hit by a ball in gym class, or even if you are just worried you might be having a bleed. The school nurse may not know as much about bleeding disorders as the nurses at your hemophilia treatment center (HTC). But she or he will know what to do, or whom to call, so you get the treatment you need. Some kids keep factor at school and can infuse right there with help from the nurse—and then get back to class in a flash!

If your school doesn't have a nurse or if the nurse isn't available, there will always be another staff member who can help you. It might be the school secretary in the main office, a counselor or a teacher. Your parents and a nurse from the HTC have probably met with these people so they're ready to swing into action and support you. Ask your parents which adults you should seek out if you have a problem.

You Have a Role to Play, Too

While there's a team of adults at school looking out for you and making sure you're safe, no one knows how you're feeling better than you do. If you get a knock or accidentally injure yourself, or your ankle, knee, elbow or another body part starts to hurt or feels warm or bubbly inside, speak up and ask to go to the nurse or one of the other adults at school right away.

Don't feel bad about asking for assistance. Rest assured that everyone at school wants you to feel your best so you can focus on what you're there to do: Learn, grow and have fun!

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We hoped to have the June newsletter be printed with assistance from our HTC. We are still working on the proper content for this printed newsletter and it will be coming later this year. Thank you for your patience. We can't wait to hit your mailbox with everything we've done this year and what we plan to do moving forward.

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