



BIG RED FACTOR

2016—Issue I

Nebraska Chapter News



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What is the Red Tie Challenge? The **RED TIE CHALLENGE** is a movement created by the bleeding disorders community and their advocates at the National Hemophilia Foundation (NHF) to start a conversation about inheritable bleeding disorders and support March 2016 as the first Bleeding Disorders Awareness Month. Red symbolizes the blood and ties symbolize the strong ties that bind this community of families, friends and advocates together.

How Do I Take the Red Tie Challenge? Get a red tie and record your best tie look, while pledging to support March as Bleeding Disorders Awareness Month, and challenging a few friends, too! Then post your video with #RedTieChallenge and think about making a donation at redtiechallenge.org. Be creative and have fun!

Donate to the Cause

By taking the **Red Tie Challenge**, you show us that we are not alone in the fight against inheritable bleeding disorders. By making a donation, you help accelerate more revolutionary science that will lead to better treatments and, one day, even cures. Please visit www.nebraskanhf.org to give what you can. Thank you for your support.

The Nebraska Chapter—NHF is calling you out! Take the Red Tie Challenge and join fabulous photos of individuals and groups of all ages showcasing their Red Ties on our Facebook page and Twitter.

Check out the website at www.redtiechallenge.org to learn how you can participate, challenge others, increase awareness, and donate to help support individuals living with bleeding disorders.

With your participation we can create enough momentum to establish the red tie as a universal symbol of support for the bleeding disorder community.

Consider yourself Challenged!



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

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Tami Soper

Development Manager

Maureen Grace

Advisory Board of Directors

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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.

2016 Program and Events Calendar

Tuesday, March 29, 2016

State Advocacy Day

April 9—April 10, 2016

Family Education Weekend

Ramada Plaza—Omaha, NE

Saturday, April 16, 2016

Husker Red White Game

Tuesday, May 10, 2016

NE Advisory Board Meeting

Saturday, May 21, 2016

The INFUSION Brunch

Ralston Arena

June 18—30, 2016

Hydrate for Hemophilia

College World Series—Omaha Baseball Village

Saturday, July 8, 2016

PING/New Parents Group

Tuesday, July 12, 2016

NE Advisory Board Meeting

July 21—23, 2016

NHF 68th Annual National Conference

Orlando, FL

Tuesday, September 13, 2016

NE Advisory Board Meeting

Saturday, September 24, 2016

NE Hemophilia Walk

Chalco Hills Recreation Area

Saturday, October 15, 2016

Harvest Festival

Vala's Pumpkin Patch

****Dates are Subject to change.**

More Activities Coming Soon!

Watch our website for updates and register Online!

SAVE THE DATE— SEPT 24, 2016

BIFF! BOOM! POW!

Dawn your fundraising capes and alert your super friends as the **2016 Hemophilia Walk: Heroes for Hemophilia** is just a leap and dash away! The adventure unfolds Saturday, September 24 at the scenic Chalco Hills Recreation Area in Omaha, NE.

The walk website is up and running so feel free to register NOW and begin your fundraising mission!

www.hemophilia.org/walk

For questions, comments or information about sponsorship please contact, Maureen Grace, Development/Walk Manager at 402.499.8025 or mgrace@hemophilia.org.



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Office: 844.237.3561
Fax: 844.237.3562

Vision 2016—Board Retreat

Saturday, January 9, 2016, the Nebraska Chapter—National Hemophilia Foundation board and staff, facilitated by NHF Director of Chapter Development, Michael Craciunoiu, spent the day preparing for an exciting new Calendar Year. The day began with the board business of electing new members and executive officers. Below is your 2016 Nebraska Chapter Advisory Board and staff (from left to right: Dale Gibbs, Secretary; Tami Soper, Executive Director; Sam Clinkinbeard; Kris Kreutzer; Scott Gass; Kaylean Gentry; Patrick Quintana, President; Rebecca Runge; Dan Henson; Geri Murphy, Vice President; and Zach Blackman) (Not pictured: Mark Harms, Marlee Warnekee, and Development Manager, Maureen Grace).



The group warmed up with team building before tackling the work of hashing out detailed plans for accomplishing some key fundraising, education and support events to benefit the bleeding disorder community in Nebraska. Please visit “Upcoming Events” on page 2, and be sure to watch our website and Facebook for opportunities to get involved, learn and connect with Chapter families, friends and partners.

This board of caring community leaders contributes their time, talents and resources to direct the chapter staff and volunteers in achieving our mission. If you are interested in serving on the Chapter Advisory Board or volunteering contact Tami at 402-889-0572, or tsoper@hemophilia.org.

Bowled Over!

Once again this year families, friends and partners gathered at Sun Valley Lanes in Lincoln, NE for our annual “Bowling 4 Bleeders” fundraiser. Bragging rights for the day went to: Aaron Quiroz—Our top scoring “King Pin” trophy winner (Team Quiroz); and Barry Wooge—runner up “Big Strike” trophy (Max and Hayden’s Heroes 2), and our best effort bowler of the day went to: Andrea Quiroz—Our “Spare” trophy (Team Quiroz). Rounding out the awards in a sweep, Team Quiroz was also our top fundraising team for the event.

Thank you to all participating bowlers, the youth. Bow- food, fellowship fun while they few Facebook worked hard to PBA scouts that been present.



of our partici- especially lers enjoyed and plenty of posed for a photos and avoid any may have

Like so much of

Bowling 4 Bleeders would not have been possible without the generous sponsorship of our partners from: ARJ Infusion, Baxalta, Bayer, BioEthics Advantage, CVS Caremark, CSL Behring, Emergent BioSolutions, Factor One Source, MidWest Cornerstone, Novo Nordisk, OptionCare, and Superior Biologics! (See more Bowling 4 Bleeders photos on our Facebook) Please be sure to thank representatives of these companies when you see them out and about.

what we do,

The INFUSION! - May 21, 2016

The Nebraska Chapter of the National Hemophilia Foundation is pleased to present its **1st Annual Fund-raising Brunch: The INFUSION!** with all proceeds benefiting the Nebraska Chapter of NHF.

This one of a kind event will take place at the Ralston Arena in Ralston, NE on Saturday, May 21st, 2016. This event is a whimsical Adult event that is about to become a favorite

Similar to a traditional lunch or dinner gala, this event will open with a silent auction and include a buffet style seated brunch with a brief program. In addition to providing a great opportunity to build awareness and support for the bleeding disorder community, this event will infuse a bit of adult fun—a **Bloody Mary Mix Off!**

Flagship sponsor—Liv Lounge of Omaha challenges venues across the state to bring their best Bloody Mary blend and let YOU be the judge. Winner takes the bragging rights and we keep the tips!

Doors open at 10:30

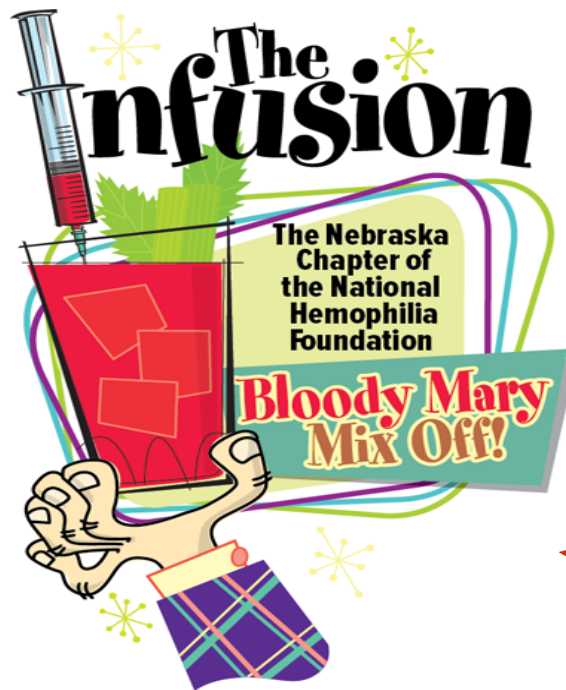
10:30am — 12:00pm

Socialize, Shop the Silent Auction and Vote for your favorite!

12:00pm — 1:00 pm

Enjoy Brunch, a Brief Program, and of course...

Announcement of the Mix Off Winner!



CALLING ALL BARTENDERS!

We still have room for competitors—if you have a Bloody Mary Favorite—nominate them to participate by contacting Tami at tsoper@hemophilia.org, or

\$40 Individual Ticket covers tasting & brunch!

How you can help make this event a success for the Nebraska Chapter of NHF:

- ♦ **JOIN US FOR BRUNCH** – As an individual or bring your friends - this is great way to have some charitable adult fun with family, friends, co-workers or neighbors. Individual tickets \$40 or reserved tables beginning at \$500.
- ♦ **SIGN UP AS A SPONSOR**– You can also take part in the festivities by sponsoring a vendor table that will display your business logo, goods and services. Sponsorships from \$500 to **\$3,500!**
- ♦ **DONATE AN ITEM TO THE SILENT AUCTION**– Anything goes, services, gift certificates, anything Bloody Mary oriented, electronics, collectables, sport event tickets or baskets of goodies.
- ♦ **RECRUIT A SPONSOR**–Is there a business you or your family frequents? Ask if them to support the Nebraska Chapter by purchasing a table or sponsoring. Full details of sponsorship are available on our website– www.nebraskanhf.org or contact Maureen Grace, Development Manager at 402-499-8025 or mgrace@hemophilia.org.



COMING SOON

KOVALTRY™

Antihemophilic factor (recombinant)

Register for updates at
www.KOVALTRY.com

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Give to Lincoln 2016—Mark Your Calendars!

Spread the Word!

May 26th, 2016 is the day to give to the Nebraska Chapter - National Hemophilia Foundation. In partnership with the Lincoln Community Foundation—we are asking you to encourage family, friends, coworkers, neighbors and caregivers to participate in this special 24 hour Day of Giving. This event is designed to motivate contributions to Lincoln & Lancaster County Nonprofits and ours is one of them! This year our goal is to raise awareness—we want to get as many people as possible to give at least the \$10 minimum to support the NE Chapter. Every donation we receive on Give to Lincoln Day will increase by a proportional match from the Lincoln Community Foundation Challenge Pool. Mark your calendars, tell your friends and give on May 26th!

Watch for the Link to donate on our website at www.nebraskanhf.org!



Advocacy Matters!

Washington Days 2016

Each year the Nebraska Chapter joins National Hemophilia Foundation chapters from around the country on Capitol Hill in Washington D.C. as part of NHF's annual Washington Days. In February, we had the opportunity to meet with our Federal Senators and Congressmen and put a face to bleeding disorders, by educating them about bleeding disorders, talking about funding and policy issues that are important to people living with bleeding disorders and presenting them with the Red Tie Challenge.

This year one of our advocacy efforts involved seeking support for a bill that would expand care access through changes in payment assistance requirements for insurance companies.

Thank you to our volunteers who brought the voice and vision of Nebraska's bleeding disorder community to Washington DC.



Nebraska Advocacy Day Tuesday, March 29, 2016:

Your Story Can Make A Difference!

Didn't get a chance to register? That's okay, join us anyway. On Tuesday, March 29, 2016, Nebraska Chapter—NHF will bring families, friends and supporters to the State Capitol in Lincoln, Nebraska to build awareness about and advocate for children and families affected by bleeding disorders throughout our state.

Agenda

8:30-9:30 am (State Capitol, Rm 1023)

Legislative Breakfast—Hosted By **Senator Sara Howard** and sponsored by CSL Behring

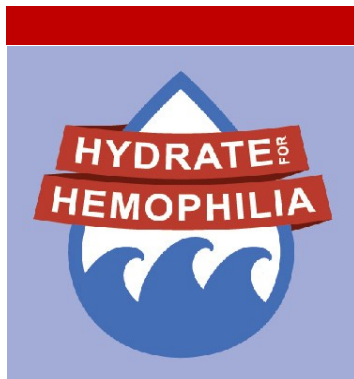
9:30-11:00 am

Advocacy and "Telling Your Story" Training—sponsored by Baxalta

11:00 am—Legislative Visits

12:00 pm—Lunch and Discussion

Contact : Tami at 402-889-0572 or tsoper@hemophilia.org



We are back at the Omaha Baseball Village for the College World Series!

Your bottled water donation makes a difference for people with bleeding disorders. Stop and Hydrate for Hemophilia in the Omaha Baseball Village throughout the entire series.

Want to make a bigger splash?!

Volunteer to help us!

Contact Tami at 402-889-0572.

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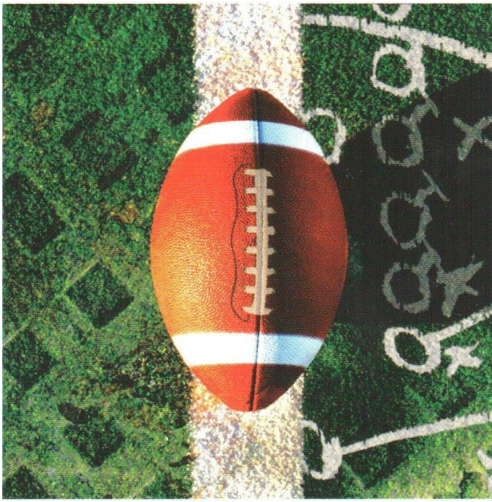
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nchswecare.com

9th Annual Red/White Game!



Lunch, Fun & the Huskers!

Join the National Hemophilia
Foundation - Nebraska Chapter
Saturday, April 16th - 11:00am
Lincoln Community Foundation Gardens
215 Centennial Mall, South
Lincoln, NE

Day of Fun Agenda

11:00—Lunch and Games

12:30—Park/Walk to Stadium

1:00—The Game Starts

Tickets are limited so register ASAP!

Register today!

Contact Tami Soper

(402)889-0572

Email: tsoper@hemophilia.org

Remembering Rita Shepherd

On Saturday, January 9, 2016 the bleeding disorder community in Nebraska lost an advocate and a friend. Rita Shepherd was born on March 27, 1954 and passed away on Saturday, January 9, 2016. Rita was the President of the (no longer active) Heartland Hemophilia Association. A parent of a child with a Hemophilia, she was a champion for raising awareness and seeking support and resources for affected families. Rita requested that in lieu of flowers, memorials be made to: Nebraska Chapter National Hemophilia Foundation. Rita was a resident of Omaha, Nebraska at the time of her passing. She was married to Kevin Shepherd. We appreciate the memorials that have been made to the Chapter in her honor.

The Nebraska Chapter—NHF was proud to call Rita Shepherd a friend. She will be missed and her impact on the community will live on.

THE FIRST FACTOR VIII WITH A PROLONGED HALF-LIFE

Learn how a prolonged half-life
may affect your infusion schedule



Meet your CoRe Manager Brenda Adamson
E: brenda.adamson@biogen.com T: 402-686-0666

Indications

ELOCTATE [Antihemophilic Factor (Recombinant), Fc Fusion Protein] is a recombinant DNA derived, antihemophilic factor indicated in adults and children with Hemophilia A (congenital Factor VIII deficiency) for: control and prevention of bleeding episodes, perioperative management (surgical prophylaxis), and routine prophylaxis to prevent or reduce the frequency of bleeding episodes. ELOCTATE is not indicated for the treatment of von Willebrand disease.

Important Safety Information

Do not use ELOCTATE if you have had an allergic reaction to it in the past.

Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.

Allergic reactions may occur with ELOCTATE. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called, "inhibitors," against ELOCTATE, which may stop ELOCTATE from working properly.

Common side effects of ELOCTATE are joint pain and general discomfort. These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, and if bleeding is not controlled after using ELOCTATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Brief Summary of full Prescribing Information on the next page.

This information is not intended to replace discussions with your healthcare provider.

FDA-Approved Patient Labeling

Patient Information

ELOCTATE™ /el' ok' tate /

[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ELOCTATE and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

What is ELOCTATE?

ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ELOCTATE when you have surgery.

Who should not use ELOCTATE?

You should not use ELOCTATE if you had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ELOCTATE?

Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby.
- Breastfeeding. It is not known if ELOCTATE passes into the milk and if it can harm your baby.

How should I use ELOCTATE?

You get ELOCTATE as an infusion into your vein. Your healthcare provider will instruct you on how to do infusions on your own, and may watch you give yourself the first dose of ELOCTATE.

Contact your healthcare provider right away if bleeding is not controlled after using ELOCTATE.

What are the possible side effects of ELOCTATE?

You can have an allergic reaction to ELOCTATE. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives.

Your body can also make antibodies called, "inhibitors," against ELOCTATE. This can stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

Common side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort.

These are not the only possible side effects of ELOCTATE. Tell your healthcare provider about any side effect that bothers you or does not go away.

How should I store ELOCTATE?

- Keep ELOCTATE in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated (2°C to 8°C or 36°F to 46°F) or at room temperature [not to exceed 30°C (86°F)], for up to six months.
- When storing at room temperature:
- Note on the carton the date on which the product is removed from refrigeration.
- Use the product before the end of this 6 month period or discard it.
- Do not return the product to the refrigerator.

Do not use ELOCTATE after the expiration date printed on the vial or, if you removed it from the refrigerator, after the date that was noted on the carton, whichever is earlier.

After reconstitution (mixing with the diluent):

- Do not use ELOCTATE if the reconstituted solution is not clear to slightly opalescent and colorless.
- Use reconstituted product as soon as possible.
- You may store reconstituted solution at room temperature, not to exceed 30°C (86°F), for up to three hours. Protect the reconstituted product from direct sunlight. Discard any product not used within three hours.

What else should I know about ELOCTATE?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ELOCTATE for a condition for which it was not prescribed. Do not share ELOCTATE with other people, even if they have the same symptoms that you have.

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