

BIG RED FACTOR

2017—Issue II

Nebraska Chapter News

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The Nebraska Chapter has had a busy few months with several fundraising events, industry partner programs and events. It's hard to believe we are now half way through 2017! We've worked hard to listen to your feedback from our 2016 Townhall and as a result we changed the Red/White game back to a tailgate, we offered education in Central Nebraska and are working hard to keep everyone informed of all our changes at the chapter. Our goal is to serve this community as best as we can. However, we still need your support to do this.

The 2017 Nebraska Hemophilia Walk is coming up on September 30th this year and we have set a higher goal and we know we can meet it. Can you help us raise \$50,000 for the Chapter? The funds raised go back to directly serve our community through education, travel grants, financial assistance and advocacy support. We hope with your help we can reach and even exceed our goal. Walk is the best opportunity for you to tell your friends and family about NHF and bleeding disorders and we can help you do it. Please join us for our 2017 walk, raise some funds, eat some delicious pancakes and have SO MUCH FUN. Can't wait to see you there and at the rest of our 2017 events.

-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.

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2017

Third Quarter Events

July 27, 2017

Walk Kick Off

UNO/Elmwood Park

August 11-13th

Nebraska NHF Family Camp

Eastern Nebraska 4-H Camp

September 2-3rd

Kearney Outreach

Education Day and State Fair

SAVE THE DATES

October 14

Harvest Festival

Vala's Pumpkin Patch

November 4

Townhall and Industry Symposium

Mahoney State Park

December 9

PING

Lincoln Children's Museum


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

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Foundations UNITE against the BCRA

On Thursday, June 22, 2017, Senate Republican leaders released the draft text of the Better Care Reconciliation Act (BCRA), legislation to repeal the Affordable Care Act (ACA). The National Hemophilia Foundation, Hemophilia Federation of America, Hemophilia Alliance and Coalition for Hemophilia B, which represent people with hemophilia, von Willebrand disease, and other bleeding disorders— are united in their opposition to BCRA because of its damaging impact on our community and urge the Senate to reject these harmful policies.

People with hemophilia and other bleeding disorders live with a painful, chronic condition that requires expensive medication and specialized care provided by hemophilia treatment centers (HTCs) and other specialists. Without access to comprehensive insurance, our community members will suffer. We oppose the Senate bill because:

- BCRA will lead to significant coverage losses: With 15 million Americans projected to lose coverage in 2018 under the BCRA, our community is in danger. Repeal of the Medicaid expansion and significant cuts to Medicaid financing will jeopardize coverage for those in our community insured by the program. Lowering income thresholds for tax credits, tying tax credits to less generous coverage, and repealing cost-sharing reduction payments will make **coverage out of reach for low- and middle-income Americans.**
- People that maintain coverage will pay more for plans that cover less: Premiums, deductibles, and out-of-pocket costs are all expected to rise. In addition, the state waivers of essential health benefits (EHBs) jeopardize access to comprehensive coverage by undermining critical patient protections – such as the ban on lifetime and annual limits – that apply only to EHB services. **Pre-existing conditions protections are meaningless if insurance companies can remove services for expensive conditions.** “The Senate must maintain the ban on lifetime and annual limits, which is a life-saving policy for people with bleeding disorders. Allowing states to define the essential health benefits will allow these caps to return, which harms not only our patient community, but other people with acute and chronic medical conditions,” said Val D. Bias, CEO of the National Hemophilia Foundation.

“BCRA’s drastic cuts to Medicaid would devastate the most vulnerable members of our community. Its estimated that some 30% of the bleeding disorders community rely on health coverage through Medicaid. BCRA’s proposals to phase out the Medicaid expansion, cap federal Medicaid spending, and index future increases to an unreasonably low metric of inflation would be ruinous for people with bleeding disorders and other chronic conditions,” added Kimberly Haugstad, President & CEO, Hemophilia Federation of America.

“As the organization that represents hemophilia treatment centers (HTCs), we know how vital comprehensive insurance coverage is to the bleeding disorders community. We don’t want any of our patients to lose coverage. We will continue our work with Congress on policies that protect our vulnerable patient population,” said Joe Pugliese, President of the Hemophilia Alliance.

This bill will be harmful to not only the bleeding disorders community, but many other vulnerable people living with expensive chronic conditions. Robust and fully-funded state Medicaid programs, Essential Health Benefits that include comprehensive drug coverage, protection from sky-high out of pocket costs, and access to affordable coverage are all vital to our community – and all are threatened by the Senate bill. The bleeding disorders community urges Senators to vote no on the Better Care Reconciliation Act.

Advocacy in Nebraska

Every day since the November 2016 elections, I have been constantly watching the news, waiting to see what the future would look like in healthcare. What would lawmakers decide, which pieces of the healthcare law would be repealed, and which would be deemed valuable enough for both parties to keep? In the competition between lives, quality of life, and cost, how would it all balance? I have watched others expressing their views, sometimes forcefully, sometimes politely. I have seen hundreds of articles on advocacy, but rarely have I been provoked enough to write my senator or representative. Being a quiet type of person, I felt that it was all too big for me to change, that it needed someone bigger and more eloquent and talented than I am to get it right.

But now something is different. I went to my first town hall meeting put on by my State Representative. I stood in line for an hour and a half just to get in, and watched all of the everyday people like me with signs and opinions. I wrote my question down on the sheet of paper for the Representative to consider and answer later by mail if he chose. I saw how many of the people around me had concerns about their ability to get proper healthcare just to survive. I saw how easily the House Representative who had voted for changes and cuts in healthcare shifted the conversation, and the crowd's reactions.

There is a cost to silence. We are not the only group of people with high medical costs who have concerns. Approximately 19 percent of the U.S. population has some type of disability, according to the last 2010 Census, with over half of those categorized as severe. When we don't speak up and make our Senators and Representatives aware of how changes in healthcare affect us, we are failing not only our family members, but those who face many of the same challenges along the path that we do.

What can we do as everyday people? If you are really time-crunched, join an advocacy group where you can work with others to make the few minutes you have this month count. Sign an emailed petition and pass it on.

Take 1 minute to look up a number for your Senator or Representative at

<https://www.contactingcongress.org/>

and leave a 30 second message on their phones. Do it today, before it's too late. The NE Chapter is starting an advocacy committee to let our members know how simple, quick actions can make sure our concerns are heard on critical healthcare bills BEFORE they become laws. Please call Maureen today at 402-499-8025 to see how you can make a difference!

Volunteering is the ultimate exercise in democracy.

You vote in elections once a year,

but when you volunteer,

You vote every day

About the kind of community you want to live in

-Marjorie Mead

Senator Deb Fischer [202-224-6551](tel:202-224-6551) Email: <https://www.fischer.senate.gov/public/?p=email-deb>

Senator Ben Sasse [202-224-4224](tel:202-224-4224) Email: <https://www.sasse.senate.gov/public/index.cfm/email-ben>

Mini Golf Fore Good

Mini Golf Fore Good was held on June 2, on a wonderful, albeit slightly hot, summer night. The competition was fierce among our community and friends, although no one was able to get the hole in one on the selected hole.

Nearly 50 people from our bleeding disorder community AND the general public came out to support the Nebraska Chapter with a fun night of mini golf and Runza!

We were blessed to have Runza donate dinner and Hy-Vee help sponsor the sides and drinks. Papio Greens is a gracious host and we are looking forward to next year when Mini Golf is lined up with our Annual Education Conference. Join us May 18, 2018 for our next Mini Golf Fore Good event!



Mini Golf Fore Good



Harvest Festival 2017



We cannot wait to see everyone out at Vala's Pumpkin Patch again this year on October 14! We will again be serving up the hot dogs and s'mores in the big pavilion, along with some fantastic hands-on education for the families. Last year, the weather was perfect and we are again hoping for a wonderful day with all of you there.

Vala's Pumpkin Patch tickets will only be provided to immediate affected families. We would love for all your friends, cousins, aunts, uncles, and grandparents to join us at our education and lunch, but please ensure you plan accordingly and have their tickets purchased ahead of time or at the gate. The Nebraska Chapter will only have tickets available to our affected community members and their immediate family.

Special Needs Trusts

WHAT PARENTS NEED TO KNOW ABOUT SPECIAL NEEDS TRUSTS

For parents of a child with special needs, the true cost of supporting the child in 2017 often goes above and beyond the benefits provided by Social Security and Medicaid. Parents are also confronted with the added pressure of ensuring their child's needs will continue to be met once the parents are no longer around to care for the child.

Enter the special needs trust. The special needs trust holds and manages assets for the child in a way that ensures government benefits, such as supplemental security income (SSI) and Medicaid, remain available to the child. The two most common types of special needs trusts are third-party special needs trusts and self-settled special needs trusts.

The first type, third-party special needs trusts, are created by parents in connection with their estate plan. The concept behind this type of trust is that parents do not want any inheritance their child receives to disqualify the child from receiving government benefits.

The third-party special needs trust is funded by assets belonging to the parents. Money left in the trust is used to provide extra or supplemental benefits for the child. The trust may provide for quality-of-life purchases and services such as education programs, a new iPad, or vacations to visit friends or family. The trust could also be used to cover costs for physical therapy or specialists not covered by Medicaid.

The second type of trust, a self-settled special needs trust, holds assets belonging to the child. This type is more typically appropriate when the child is older and has developed a disability after accumulating assets or has received a settlement from a personal injury claim. Any assets remaining in the trust when the individual dies would be used to pay back Medicaid for expenses incurred by the State in administering care. If excess monies remain after the State debt is repaid, those assets would pass to the individual's heirs.

There are a few key things to remember about special needs trusts. First, the trusts can only be used for extra or supplemental purchases or services. The trusts cannot provide for basic, everyday needs like food and shelter. Those needs are to be covered by SSI. Second, for any purchases made through the trust, the check must be sent to the vendor or service provider, and not the beneficiary. Third, the wording of special needs trusts is critical. If the trust is not worded properly, the trust will be deemed noncompliant. A noncompliant trust could result in the suspension of government benefits until all of the trust assets are spent down.

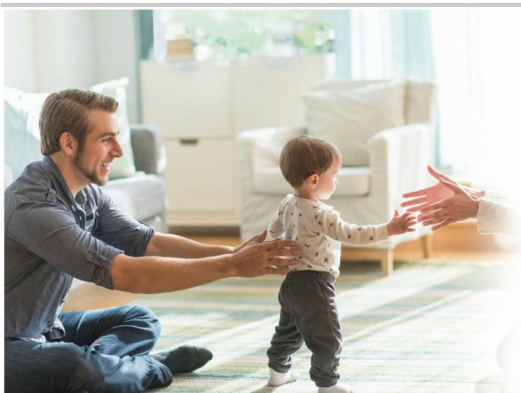
In establishing a special needs trust, careful consideration should be given to selecting the Trustee. Mistakes in the trust's administration can lead to loss of government benefits. Parents will want to consider the pros and cons of hiring a professional trustee, versus asking a family member or friend to serve as Trustee.

When properly worded and administered, the special needs trust allows parents to improve the quality of life for their child, without jeopardizing eligibility for government benefits. The special needs trust is an instrument that should be implemented in any estate plan of parents with a special needs child.

About the author:

Joseph C. Byam is a partner at Byam & Hoarty, where his practice area includes all estate planning services, including Special Needs Trusts, Wills, Trusts, Durable Powers of Attorney, Living Wills, as well as advising Personal Representatives and Trustees on Estate and Trust Administration.

Byam & Hoarty is located in Omaha, Nebraska, and works with clients throughout Nebraska. For more information on the firm's practice areas, firm services, or to schedule an initial consultation, contact the firm at 402-397-0303



Don't let insurance or financial challenges get between you and your treatment

Free Trial Program*

- Enroll today for up to 6 free doses†
- KOVALTRY®, Antihemophilic Factor (Recombinant), or KOGENATE® FS, Antihemophilic Factor (Recombinant), is delivered to your home free of charge
- Any patient who has not taken KOVALTRY® or KOGENATE® FS is able to participate, regardless of type of insurance or if you have insurance

Access to Therapy

Concerned about maintaining access to treatment?

We might be able to provide KOVALTRY® or KOGENATE® FS at no cost if you are‡:

- Experiencing challenges getting insurance coverage for KOVALTRY® or KOGENATE® FS
- Uninsured or underinsured
- Between jobs and experiencing a gap between insurance coverage

\$0 Co-pay Program§

If you have private insurance, you may be eligible for the \$0 Co-pay Program.

- You may be able to receive **up to \$12,000 in assistance** per year, regardless of income
- **Assistance is awarded per patient.** Multiple members of the same household can apply
- Enrollment can be started and completed in **one short phone call**

Live Helpline Support

- Consult with an expert in insurance
- Spanish-speaking Case Specialists are also available



Call **1-800-288-8374** 8:00 AM–8:00 PM (ET) Monday–Friday.

*The Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Patients currently using KOVALTRY® or KOGENATE® FS are not eligible for the respective Free Trial programs. Participation in the Free Trial Program is limited to 1 time only per treatment. The medication provided through this program is complimentary and is not an obligation to purchase or use KOVALTRY® or KOGENATE® FS in the future. Reselling or billing any third party for the free product is prohibited by law.

†The Free Trial Program includes up to 6 free doses to a maximum of 5,000 IU for new patients and 40,000 IU for previously treated patients.

‡The program does not guarantee that patients will be successful in obtaining reimbursement. Support medication provided through Bayer's assistance programs is complimentary and is not contingent on future KOVALTRY® or KOGENATE® FS purchases. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

§People with private, commercial health insurance may receive KOVALTRY® or KOGENATE® FS co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription reimbursement under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.

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Kogenate® FS
antihemophilic factor
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Kovaltry®
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Iron-Rich Foods for Your Child's Diet by Dr. Martha Nepper

Iron helps the blood carry oxygen throughout the entire body. When children do not have enough iron in their bloodstream, they may feel tired, run-down or dizzy or have a headache or pale skin. It is important that children get enough iron every day to make them feel healthy and prevent an iron deficiency.

Your child needs anywhere from 7 mg to 15 mg each day (see chart below).

	Milligrams (mg)
Infant, 0-6 months	0.27
Infant, 7-12 months	11
Child, 1-3 years	7
Child, 4-8 years	10
Child, 9-13 years	8
Male, 14-18 years	11
Female, 14-18 years	14

The best food source of iron comes from animal sources, such as lean beef, turkey, chicken, lean pork, and fish. Plants sources of iron, such as beans (ex: pinto, kidney, soybeans and lentils), dark green leafy vegetables, fortified breakfast cereals, enriched and whole grains breads) are good sources of iron, but are not absorbed in the body as well as animal sources. To increase the absorption of both animal and plant sources of iron, eat a food rich in Vitamin C, such as tomatoes, orange juice, peppers, or strawberries, along with the iron-rich food. For example, chili is a great source of iron. The ground beef contains iron and is absorbed more readily because of the tomatoes, which contain Vitamin C. The list below shows the amount of iron commonly found in foods.

Food with at least 2 mg iron per serving

Food	Serving Size
Beef, veal	3 ounces
Clams, oysters, shrimp, sardines	3 ounces
Bran flakes	$\frac{3}{4}$ cup
Cream of wheat	$\frac{1}{2}$ cup
Oatmeal (iron-fortified)	$\frac{3}{4}$ cup
Baked potato with skin	1 medium potato
Dried beans, cooked (kidney, lentils, lima, navy	$\frac{1}{2}$ cup
Soybeans	$\frac{1}{2}$ cup
Tofu	$\frac{1}{2}$ cup
Spinach	1 cup
Dried prunes	4 pieces

Iron-Rich Foods for Your Child's Diet cont...

Foods with 1-2 mg iron per serving

Food	Serving Size
Poultry	3 ounces
Corned beef	3 ounces
Cooked kale	1 cup
Dried apricots	7 halves
Raisins	5 Tablespoons
Whole wheat bread	1 slice
Nuts: cashews, brazil nuts, walnuts	1 ounces

To make sure your children get the iron that they need each day, limit milk to 24 ounces, if they are between 1 and 5 years old. Too much calcium can hinder iron absorption. Also, for young adults, it is best not to drink too much tea or coffee with meals, as these beverages also affect iron absorption.


To help you with selecting foods high in iron, look for the nutrients listed on the bottom of the Nutrition Facts panel. For example, the label below contains 8 mg of iron. The updated Nutrition Facts panel will be arriving on food products in 2018, so look for this important feature when you are choosing foods high in iron.

NEW LABEL / WHAT'S DIFFERENT

Servings:
larger,
bolder type

New:
added sugars

Change
in nutrients
required



Serving sizes
updated

Calories:
larger type

Updated
daily
values

Actual
amounts
declared

New
footnote

Read on for an iron-rich recipe for you and your family to try!

Dr. Nepper has been a Registered Dietitian for almost 20 years and is passionate about healthy eating. She has her PhD in Nutrition from the University of Nebraska-Lincoln and has researched the home food environment among school-aged children. Martha works for the Center for Diabetes & Nutritional Health at Methodist Hospital and counsels patients with diabetes and other nutritional concerns. In her past time, she likes to try new recipes, read and exercise.

Iron-Rich Foods for Your Child's Diet cont...

Vegetarian Taco Salad

Ingredients

- 2 tablespoons extra-virgin olive oil
- 1 large onion, chopped
- 1½ cups fresh corn kernels or frozen, thawed
- 4 large tomatoes
- 1½ cups cooked long-grain brown rice
- 1 15-ounce can black, kidney, or pinto beans, rinsed
- 1 tablespoon chili powder
- 1½ teaspoons dried oregano, divided
- ¼ teaspoon salt
- ½ cup chopped fresh cilantro
- ⅓ cup prepared salsa
- 2 cups shredded iceberg or romaine lettuce
- 1 cup shredded pepper Jack cheese
- 2½ cups coarsely crumbled tortilla chips
- Lime wedges for garnish

Directions

- Heat oil in a large nonstick skillet over medium heat. Add onion and corn; cook, stirring, until the onion begins to brown, about 5 minutes. Coarsely chop 1 tomato. Add it to the pan along with rice, beans, chili powder, 1 teaspoon oregano and ¼ teaspoon salt. Cook, stirring frequently, until the tomato cooks down, about 5 minutes. Let cool slightly.
- Coarsely chop the remaining 3 tomatoes. Combine with cilantro, salsa and the remaining ½ teaspoon oregano in a medium bowl.
- Toss lettuce in a large bowl with the bean mixture, half the fresh salsa and ⅔ cup cheese. Serve sprinkled with tortilla chips and the remaining cheese.

Nutrition information (serving size: 1 ½ cups)

Per serving: 392 calories; 16 g fat(5 g sat); 9 g fiber; 52 g carbohydrates; 14 g protein; 87 mcg folate; 20 mg cholesterol; 10 g sugars; 0 g added sugars; 1,962 IU vitamin A; 24 mg vitamin C; 218 mg calcium; 3 mg iron; 481 mg sodium; 767 mg potassium

Source: <http://www.eatingwell.com/recipe/250064/vegetarian-taco-salad>
<https://www.nutritioncaremanual.org>

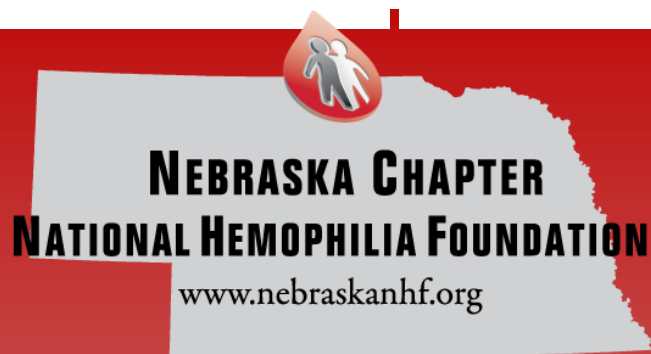
The Infusion: A Bloody Mary Mix Off

Our second annual Infusion at the Ralston Arena was a roaring success. Our goal was to reach the general public with a great event and get others thinking about the Nebraska Chapter of the National Hemophilia Foundation.

We were honored to have six bars competing for top bloody and best garnish. In no particular order we had Pitch Pizzeria, Tracks, Liv Lounge, Beyond Golf, Report In, and Krug Park serving up some bloodies to 200 people! Jim Kalal emceed the event, but even his charm could not get out some of these secret recipes.

Pitch used their own house made chorizo to garnish their bloodies, but the best garnishment went to Beyond Golf with a jalapeno popper and bacon topped bloody mary. If you loved spice, that was the bloody mary for you! Tracks came out as a first time competitor and took the top bloody with a very enthusiast team. They brought you not one but TWO different bloody marys to try—and you guys LOVED it. It was an overwhelming success for Tracks and we can't wait to see them back next year!





The Nebraska Chapter of the National Hemophilia Foundation
invites you to our
First Annual Kearney Outreach Education Day
in conjunction with the Nebraska State Fair!
September 2, 2017 * Hampton Inn Kearney

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!

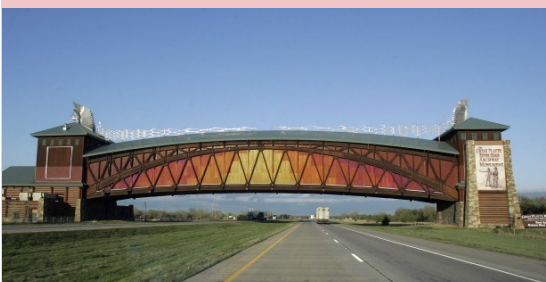
Your registration includes:

- ◆ Several education sessions presented by our Industry Partners at Pfizer, Bayer and CSL Behring.
- ◆ Lunch
- ◆ An Infusion Clinic where you can brush up on your self and home infusion routine.
- ◆ Dinner at the Alley Rose with Octapharma
- ◆ Free hotel night covered by NENHF on Saturday, September 2, 2017
- ◆ Tickets to the Nebraska State Fair on Sunday, September 3 in Grand Island, Nebraska

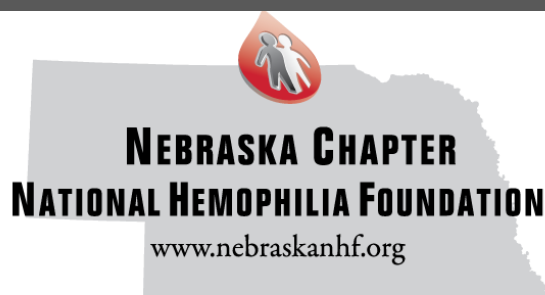
Registration Cost: Family- \$50 Individual-\$25

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

Please register online at www.nebraskanhf.org by August 11, 2017 for hotel confirmation!



Kearney Education Outreach Agenda



Kearney Education Outreach Day

Saturday, September 2, 2017

Hampton Inn Kearney

507 W Talmadge Road, Kearney, Nebraska 68845

9:30 AM- 10:30 AM Registration Open/ Industry Tables Open

10:30 -10:45 AM- Welcome and Announcements (Kelsey Cunningham)

10:45- 11:45 AM- **Sharing our Stories- Cazandra- Campos-MacDonald- CSL Behring**

Sharing Our Stories – when you are in the middle of the worst that a bleeding disorder and/or inhibitor can bring, it is easy to only see the chaos and pain; keeping a positive outlook through the worst of times is hard, but crucial not only for yourself, but for your child and family. The power of our stories can get us through some of the darkest of times.

- * Acknowledge the times when a bleeding disorder can completely disrupt your life
- * Give examples of times when the bleeding disorder became the center of your life.
- * Offer encouragement that leads to finding hope in every situation.

12:00 PM – 1:00 PM- Lunch

1:00 PM- 2:00 PM- **Being Prepared for a Hemophilia Emergency- Jessica Walker, RN – Bayer**

Are you prepared for an emergency? Learn what to do in case of a hemophilia emergency including navigating the ER, working with emergency responders and how to best advocate for your care.

2:00 PM- 2:15 PM- Break

2:15- 3:15 PM- **Planning Your Future with Hemophilia- Joe Schuch- Pfizer**

Focuses on the challenges older adults with hemophilia face, including financial planning, long-term care, and changes in their support system.

3:15-3:45 PM- **Chapter and Walk Update- Kelsey Cunningham, Development Manager, NE NHF**

3:45-4:45 PM- Infusion Clinic

4:00- 6:00 PM- Hotel Check In and Industry Tables Open

6:30 PM- 9:00 PM- Offsite Dinner and Education with Octapharma- Alley Rose

Hemophilia Memorial

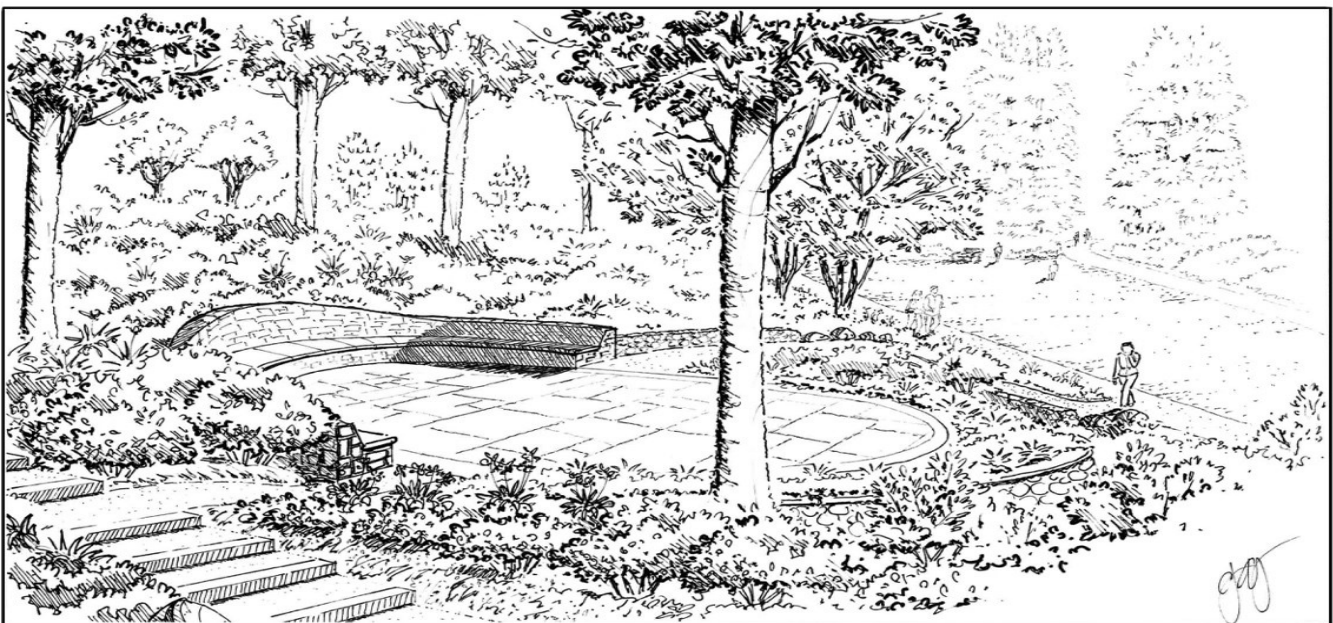
By now you should have received emails from NHF, HFA (or both!) about the creation of the Hemophilia Memorial at the National AIDS Grove in San Francisco, CA. I know many of you maybe hearing about this for the first time, so I just wanted to explain a little

The Hemophilia Memorial will be a permanent commemoration of the tragedy of HIV/AIDS in the hemophilia community. It will be the first of its kind, and will reside in the National AIDS Grove, which is a federally-recognized memorial (the same designation as the Vietnam or WWII Memorial). This project was spearheaded by Jeanne White-Ginder, mother of Ryan White, and has the full support of not only NHF, but also HFA and the Committee of Ten Thousand. NHF and HFA have contributed funds to the building of the memorial, which is already underway

NHF, HFA and COTT will be working together to raise \$50,000, which will go towards the upkeep of the memorial in perpetuity. All donations will be given directly the Hemophilia Memorial, and the Grove will only be accepting donations from individuals, chapters and other bleeding disorders organizations

The creation of this memorial has been a moving experience for all of us who have been involved. It will be an important part of the legacy of NHF. I hope you will go to <http://www.aidsmemorial.org/news/hemophilia>, where you can find out more about the project, including a video about the history of HIV/AIDS in the community and a sketch of the memorial. While you're there, you can donate in memory of a loved one, or just donate to the memorial as a whole.

—Beth Marshall, Director of Communications-NHF





**A Night at the Ball
Park with NCHS and
Nebraska NHF**

NEBRASKA CHAPTER
NATIONAL HEMOPHILIA FOUNDATION
www.nebraskanhf.org

nchs
we care. for life.

Friday, August 18, 2017
Werner Ball Park
RSVP to Maureen by August 4

Help us wrap up summer and join us for a night at the ballpark with NCHS! Dinner and a ticket to the Omaha Storm Chaser game are included. Friday nights are fireworks night at Werner Park so plan to stick around.

Space is limited so RSVP right away.

**Limited to affected members
and their immediate family only!**

Inhibitor Family Camp-Lake Hughes, California



Friday, Oct. 6th thru Monday, the 9th, 2017
The Painted Turtle - Lake Hughes, CA

Registration opens July 7th at
comphealthe.com/ifc

Make plans now to attend our 8th annual Inhibitor Family Camp, a four-day experience designed exclusively for those in the bleeding disorder community who are living with inhibitors. From arrival to departure we'll fill your days with fun, adventure, and education - all in a sharing, supportive atmosphere.

Our campers can look forward to meeting other families, enjoying outdoor activities, "Stage Night," educational classes (including an optional self-infusion class), and other fun family activities. But mostly they return home happy to have made life-long friends!

Space is limited and available slots will be allotted on a first-come, first-served basis, so please register early. We'll see you at camp!

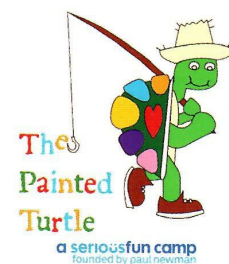
How does CHES fund programming?

CHES competes rigorously for grants provided by manufacturers to support educational programming. We are an independent chronic disorder education company, unaffiliated with any one entity that provides products to the communities we serve.

Presented by



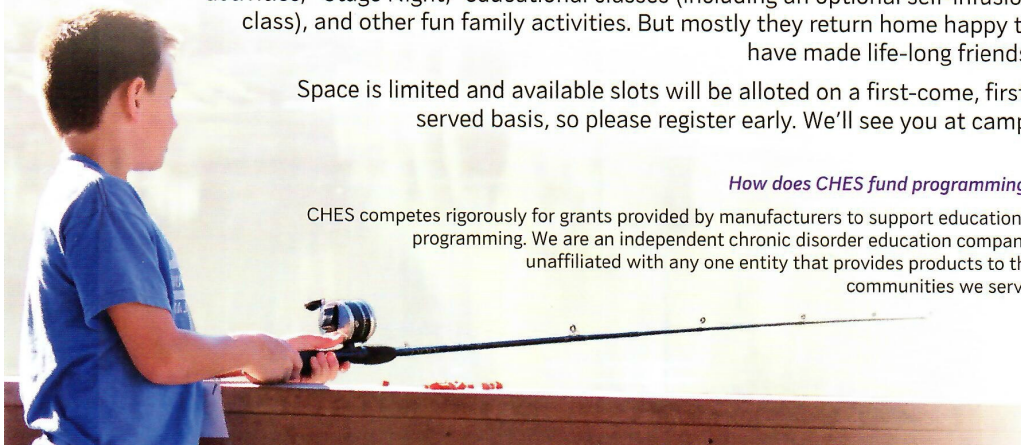
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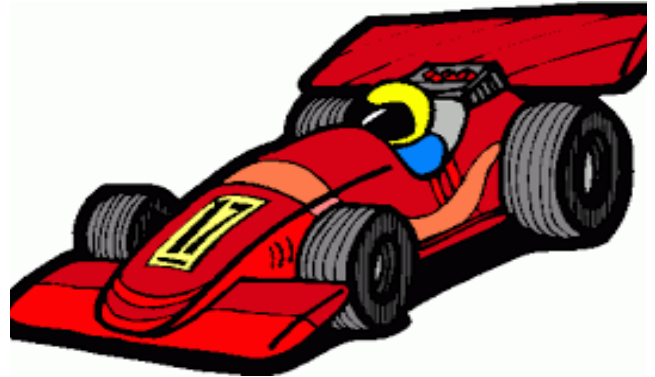
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2017 Inhibitor Family Camp



Racing to Raise Funds for Bleeding Disorders—Walk 2017



2017 NEBRASKA WALK FACT SHEET

- WHAT:** The Hemophilia 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 66th 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 30th, 201**
- WHERE:** **Chalco Hills Recreation Area— 8901 So. 154th Street, Omaha, NE 68164**
Check-in begins at 9:00am / Walk begins at 10:00am
- DISTANCE:** 1 mile or 5k option
- HOW:** Sign up for the Walk online by visiting www.hemophilia.org/walk. Click the NE icon and register or gather information! Everyone is welcome to participate!
- 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. Contact Kelsey Cunningham, Development Manager at 402.889.0572.
- CONTACT:** Kelsey Cunningham, Development Manager, Nebraska Chapter of the National Hemophilia Foundation 402.889.0572 or kcunningham@hemophilia.org

HOW TO BE A FAST FUNDRAISER!

It can be challenging to ask for donations, however you never know what one might say or give for that matter until you ask. We hope the information provided about fundraising in the workplace, utilizing social media and how to raise \$500 in 7 days are beneficial in your fundraising efforts.



Workplace Fundraising

Organize some fun activities to raise funds at your office— here are a few examples but limit yourself to other options.

1. Jeans Day/Dress Down Day: Arrange with your employer a Jeans Day or Dress Down Day for a donation of \$5 to the Hemophilia Walk.
2. Food/Beverage Sale: For a donation, sell cookies, donuts, bagels, popcorn etc.
3. 50/50 Drawing— Sell tickets and the winner gets half of the money received while you keep the other half for the Hemophilia Walk.
4. Coin War: If you work in a office with several departments start a little competition by placing jars in the office for “extra change” and compete to raise the most money.
5. A Day of Silence for the Hemophilia Walk: Accept donations to silence an “exuberant” employee for the day.

Utilizing Social Media

Here are a few suggestions you can use social media to increase your Hemophilia Walk Fundraising!

1. Use your status updates to motivate and fundraise. Share your progress and be sure to give the link to your fundraising page.
2. Say thanks & get sponsors— when someone makes a donation to your page, make a big deal out of it.
3. Create a Team Page— Encourage your team captain and help with the efforts.
4. Download the new Hemophilia Walk App for your smart phone! Fundraising has never been so easy!
5. Retweet! Become a follower of the Nebraska Chapter and the National Hemophilia Foundation.
6. Have a Facebook Fundraising Sale— Facebook allows you to sell stuff by “Selling for a Cause.”

HOW TO RAISE \$500 IN 7 DAYS!

1. Sponsor yourself first:
\$50.00
2. Ask 4 family members to sponsors for \$25 each:
\$100.00
3. Ask 5 co-workers to contribute \$15 each:
\$75.00
4. Ask 5 friends to contribute \$15 each:
\$75.00
5. Ask 5 neighbors to sponsor you for \$15 each:
\$75.00
6. Ask your boss for a company contribution of \$50;
\$50.00
7. Ask 3 businesses you frequent for a donation of \$25 each:
\$75.00

Add it all up and what do you get?

\$500.00

Who else could you ask? Here are some ideas.....

Mother, Father, Brother, Sister, Cousins, Uncle, Aunt, Doctor, Neighbor, Roommates, Pharmacist, Accountant, Landlord, Dentist, Hair Stylist, Dry Cleaner, Bank-

DON'T STAND ON THE SIDELINES

LEARN IF RIXUBIS®
MAY BE RIGHT FOR YOU

Visit RIXUBIS.com to find your
local Shire sales representative

Indications for RIXUBIS [Coagulation Factor IX (Recombinant)]

RIXUBIS is an injectable medicine used to replace clotting factor IX that is missing in adults and children with hemophilia B (also called congenital factor IX deficiency or Christmas disease).

RIXUBIS is used to control and prevent bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Detailed Important Risk Information

You should not use RIXUBIS if you are allergic to hamsters or any ingredients in RIXUBIS.

You should tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies, have any allergies, including allergies to hamsters, are nursing, are pregnant or planning to become pregnant, or have been told that you have inhibitors to factor IX.

Allergic reactions have been reported with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea, or fainting.

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for development of inhibitors to factor IX.

If you have risk factors for developing blood clots, the use of factor IX products may increase the risk of abnormal blood clots.

Common side effects that have been reported with RIXUBIS include: unusual taste in the mouth, limb pain, and atypical blood test results.

Call your healthcare provider right away about any side effects that bother you or if your bleeding does not stop after taking RIXUBIS.

Please see following page for RIXUBIS Important Facts.

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.



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RIXUBIS

**[COAGULATION FACTOR IX
(RECOMBINANT)]**

MOVING FORWARD

RIXUBIS

[COAGULATION FACTOR IX (RECOMBINANT)]

Important facts about

RIXUBIS [Coagulation Factor IX (Recombinant)]

This leaflet summarizes important information about RIXUBIS. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about RIXUBIS. If you have any questions after reading this, ask your healthcare provider.

What is RIXUBIS?

RIXUBIS is a medicine used to replace clotting factor (Factor IX) that is missing in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Hemophilia B is an inherited bleeding disorder that prevents blood from clotting normally. RIXUBIS is used to prevent and control bleeding in people with hemophilia B. Your healthcare provider may give you RIXUBIS when you have surgery. RIXUBIS can reduce the number of bleeding episodes when used regularly (prophylaxis).

Who should not use RIXUBIS?

You should not use RIXUBIS if you

- are allergic to hamsters
- are allergic to any ingredients in RIXUBIS.

Tell your healthcare provider if you are pregnant or breastfeeding because RIXUBIS may not be right for you.

What should I tell my healthcare provider before using RIXUBIS?

You should tell your healthcare provider if you

- have or have had any medical problems
- take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies
- have any allergies, including allergies to hamsters
- are breastfeeding. It is not known if RIXUBIS passes into your milk and if it can harm your baby
- are pregnant or planning to become pregnant. It is not known if RIXUBIS may harm your unborn baby
- have been told that you have inhibitors to factor IX (because RIXUBIS may not work for you).

How should I infuse RIXUBIS?

RIXUBIS is given directly into the bloodstream. RIXUBIS should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia B learn to infuse their RIXUBIS by themselves or with the help of a family member.

Your healthcare provider will tell you how much RIXUBIS to use based on your weight, the severity of your hemophilia B, and where you are bleeding. You may have to have blood tests done after getting RIXUBIS to be sure that your blood level of factor IX is high enough to clot your blood. Call your healthcare provider right away if your bleeding does not stop after taking RIXUBIS.

What are the possible side effects of RIXUBIS?

Allergic reactions may occur with RIXUBIS. Call your healthcare provider or get emergency treatment right away if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting. Some common side effects of RIXUBIS were unusual taste in the mouth and limb pain. Tell your healthcare provider about any side effects that bother you or do not go away. These are not all the side effects possible with RIXUBIS. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about RIXUBIS?

Your body may form inhibitors to factor IX. An inhibitor is part of the body's defense system. If you form inhibitors, it may stop RIXUBIS from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor IX.

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

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.

The risk information provided here is not comprehensive. To learn more, talk about RIXUBIS with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at http://www.shirecontent.com/PI/PDFs/RIXUBIS_USA_ENG.pdf or by calling 1-800-FDA-1088.

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Kid's Corner

Bleeding Disorders and Martial Arts



Illustration by John Haslam

Do you ever pretend you are a karate master? Sneaking behind the sofa, you spy your enemy—the cat. And then... Hiiii-yah!

But you should get training first. You will get to wear one of those white jackets and wrap it up with a white belt. In time you could get a black belt, and know how to deal with bullies and protect yourself.

Karate and other martial arts can give you a place to punch and kick where your mom won't yell at you and the cat won't hiss. But you have a bleeding disorder, so is it safe for you?

The good news is that a lot of martial arts, such as karate, kung fu and tae kwon do, are great exercise, great fun and pretty safe—at least to start. Plus, unlike team sports, you can learn at your own pace. If you get a bleed and need to take a break, your new instructor, your friends and the mat will be there for you when you're back!

Other forms of martial arts, such as judo and jujitsu, are rougher. That means more chances to get punched, kicked or hit in the head. Ouch! That could cause a big bruise or a bleed, and nobody wants that.

Dojo Mojo

Your parents will look for just the right martial arts academy, or dojo, for you. They'll watch a few classes and see how safe it is. Then they'll talk to your instructor about your bleeding disorder. After you sign up for classes, you and your parents can meet with your instructor to talk about making some of the moves safer and what to do if you get a bleed.

Earn Your Belts

Now that you've got your white jacket and white belt, it's time to get busy! You will learn all kinds of new things, like blocks, punches and kicks. With some careful planning and hard work, you could have a black belt in just a few years. But it's not all work. You'll find friends in your classes, too. Some students become teacher's assistants. Some join elite performance teams that perform for other people. But just about all students can learn to demonstrate controlled punches, kicks and pivots, known as forms, in class and in public.

The key to keeping it safe and fun is to focus on proper control and form. Actions can be changed if you have problems with your knees or ankles. Just ask your instructor. He or she will be happy to help.

Later, you may even get to learn to twirl and defend yourself with a bo staff—a weapon that looks like a walking stick—or nunchucks, two shorter staffs connected by a chain. There's no contact, and you get to feel how strong your body is. If Mom and Dad say it's OK, you might be able to compete.

Board Corner

One minute, kids are getting out of school and the next thing you know, it's the middle of July. Where does the time go? As I reflect on what has happened since the last newsletter, I realize our Chapter has been very active. I hope you were able to take part in one or more activities; whether it was educational or strictly for fun. Our events are for YOU!

June was a busy month! I was able to participate in Mini Golf Fore Good. I brought along a few friends, whom I have not seen in years. We had a great time and they learned a little about hemophilia. Which is what we want right? Little conversations here and there with people who know little or nothing about hemophilia. This is how we spread the word about bleeding disorders.

Maureen and I attended a training for the Board Development Cohort. The Nebraska Chapter along with six others have come together to strengthen and grow our boards under the direction of NHF. This work will continue for nine months. But it will be a process well worth the effort.

The Infusion: A Bloody Mary Mix Off was a HUGE success! I sampled Bloody Mary's from various local establishments and enjoyed a delicious brunch. I will need to visit a few of the establishments again. Thanks to all who participated! I cannot wait for next year's Infusion.

Next month is the annual National Hemophilia Foundation conference in Chicago, IL. I have been involved in the bleeding disorder community for almost 6 years. I am looking forward to learning all I can from conference.

As a reminder, one of the takeaways from the Town Hall, held in November 2016, was that the community wants to be more involved. If you are interested in volunteering, please contact Maureen. There are many ways for you to become more involved. The Chapter needs help with some administrative tasks (putting packets together, filing, mailing, etc.) to assisting at events. We heard you. We want you to help us grow.

Enjoy the last month or so before kids head back to school. Time is precious. Slow down, breathe and enjoy. And don't forget to smile! You might just make someone's day.

—Geri Murphy, Board President



Meet Bioverativ: putting patients first

A new company dedicated to the hemophilia community and building upon Biogen's legacy of science and innovation

Bioverativ has a singular purpose: striving for progress when and where people need it most

The pioneering hemophilia treatments provided by Biogen are now available to you through Bioverativ with a continued focus on quality, safety, manufacturing, and product accessibility.

Many of those who worked to advance treatments at Biogen are continuing their scientific pursuits at Bioverativ. Our dedicated team of Community Relations (CoRe) Managers will continue with Bioverativ to create lasting relationships with the hemophilia community using their decades of experience and understanding. Together, we are deeply committed to developing meaningful therapies for people with hemophilia and their caregivers.

We challenge the status quo at every step. Bioverativ is passionate about making a substantial impact in the lives of people with hemophilia and other rare blood disorders.

**Visit Bioverativ.com for more about us
and our mission**



–The Bioverativ Community Relations (CoRe) Managers

Don't Forget to Register!



Camp Tap-A-Vein-A-Day-A

Family Camp August 11-13th 2017

Schedule of Activities

Friday, August 11 th , 2017		
Time	Activity	Location
5pm-6:00pm	Check-In	Main Lodge
6pm-7pm	Welcome/Dinner	Main Lodge
7:00 pm – 9:00 pm	Ice Breakers/ NHF Jeopardy	Main Lodge
9:00pm	Retire to Cabins	Main Lodge
Saturday, August 12 th , 2017		
8:15am-9am	Breakfast/Announcements	Main Lodge
9:00am – 12pm	Family Free Time Including Zip Line, Climbing Wall, Archery, Canoeing, Hiking	
11:45am	Group Camp Photo	Grass Area in Front of Lodge
12pm-1pm	Lunch	Main Lodge
1pm-3:30pm	Tie Dying	Grass in Front of Cabins
2:00- 4:00 pm	Games/Activities with Andy	Main Lodge/TBD
3:30pm-5pm	Water Fun/Slip and Slide	Main Lodge
5pm-6pm	Infusion Fun Clinic	Main Lodge
6pm-7pm	Dinner	Main Lodge
7pm-8pm	Minute to Win It Challenge	Main Lodge
7:30pm-9:30pm	Campfire Activities	Main Campfire Ring
9:30pm	Retire to Cabins	
Sunday, August 13 th , 2017		
8:30am – 9:00am	Breakfast	Main Lodge
9:00am – 10:00am	Family Scavenger Hunt	Main Lodge
10:00am – 10:30am	Closing Activities	Main Lodge

REGISTER NOW

Getting in the Game with CSL Behring

PROGRAM OVERVIEW

Developed by CSL Behring, the Gettin' in the Game Junior National Championship (JNC) was the first and is currently the only national golf, baseball, and swimming competition designed specifically for the bleeding disorders community. The JNC features accomplished Gettin' in the Game Athletes, who themselves have been diagnosed with bleeding disorders, such as hemophilia and von Willebrand Disease.

During the program participants will have the opportunity to:

- **Take part in either golf, baseball, or swimming activities to learn the fundamentals and enhance their skills in that sport.**
- **Learn about the importance of physical fitness in managing a bleeding disorder and receive instructions on proper stretching techniques and good athletic form.**
- **Show off their golf, baseball, or swimming abilities in a national competition with fellow participants from around the country.**
- **Connect and build relationships with fellow members of the bleeding disorders community by sharing their personal experiences with one another.**



Each year, CSL Behring allows the Nebraska Chapter to send two youth aged 7-18 years old with a bleeding disorder to their Gettin' In the Game Program held in Phoenix, Arizona. This year it will be taking place November 2-4th.

We are looking for 2 participants interested in attending this year. You can choose between baseball, golf or swimming! Hotel accommodations, meals and airfare for each attendee and one parent will be covered by the program. It's an amazing opportunity and we want to make sure everyone has a chance to go. Preference will be given to those who have not participated before.

If you are interested in attending Gettin' in the Game with CSL Behring, please contact Maureen Grace at 402-499-8025 or mgrace@hemophilia.org for more information.

Attendees will be announced in September from interested parties.

Get ready to play ball, make a splash and get a hole in one in warm, sunny Phoenix!