

# BIG RED FACTOR

2017—Issue III

## Nebraska Chapter News

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The Nebraska Chapter of the National Hemophilia Foundation has had an incredibly busy third quarter! We continued our goal of reaching across the state through an Education Day in Kearney this past Labor Day weekend, as well as, hosting a satellite walk in Gothenburg Nebraska.

These two events were a major success largely in part of our community support. As we are planning 2018, please take a moment to see the events you can volunteer with, the help you may be able to offer outside of our events and programs, as well as helping us to continually raise awareness.

2017 was a very successful walk season, but our walk is just ONE day of celebration. We continue to strive for excellence, meeting the community needs, and growing our chapter to help raise awareness for bleeding disorders on a daily basis. When you are looking towards the future with YOUR Nebraska Chapter, take a moment to think of everything we can do together with your help. Either monetary or time offered, our growth is led by you and we appreciate everything you have given and continue to give to us.

-Kelsey Cunningham  
Development Manager



### **Our Mission:**

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

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#### ***Executive Director***

Maureen Grace

#### ***Development Manager***

Kelsey Cunningham

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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.*

**2017**

## **Fourth Quarter Events**

November 4

Townhall and Industry Symposium  
Mahoney State Park

December 9

PING

Lincoln Children's Museum

## **Save the Date**

**2018**

January 21-22

Advocacy Dinner Training

Advocacy Day

Lincoln Nebraska

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

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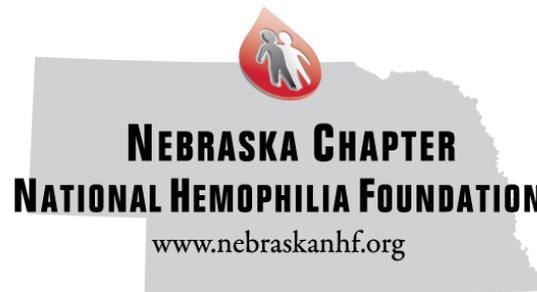
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# Industry Symposium and Town Hall Meeting



Please join the Nebraska Chapter in hosting our first ever Industry Symposium, There are many new products and therapies on the horizon. We have the opportunity hear from CSL Behring and Novo Nordisk on their products. Following our industry partner's talks will be the Town Hall meeting and Chapter update. We will discuss the outcomes from the 2016 Town Hall and how the Nebraska Chapter heard you and made changes and new programs to meet your needs. Facilitating the 2017 Town Hall will be Diana Perrault with NHF. This is your opportunity to ask questions, discuss your concerns and have your voices heard .

Please register online TODAY! The Nebraska Chapter will provide entry into Mahoney State Park. Your name will be at the main gate of entry into the park.

Childcare will be available, please register your child under 12 for childcare.

## 2017 Industry Symposium and Town Hall Meeting Agenda

**Saturday, November 4, 2017**

**Mahoney State Park, Peter Kiewit Lodge**

28500 W. Park Highway, Ashland, Nebraska 68003

8:30 am – 9:30 am– Registration, Breakfast and Exhibits Open  
9:30 am – 9:45 am – Welcome and Introductions (Kelsey and Diana)  
9:45 am – 10:30 am – Presenting Sponsor #1 Speaking Time (CSL Behring)  
10:30 am – 10:55 am – Major Sponsor #2 Speaking Time (Novo Nordisk)  
10:55-11:15 – Snack break  
11:15 am - 12:30 pm- Town Hall Meeting and Chapter Update  
12:30 pm- Closing Remarks  
12:30-1:00 pm Exhibits Open

**[REGISTER HERE](#)**

# Enabling Financial Independence

Author: Deborah Goodkin, Managing Director, Savings Plans, First National Bank

Everyone deserves the opportunity to experience financial independence. This has been the overarching goal of the Enable Savings Plan since day one. After the historic passage of the Achieving a Better Life Experience (ABLE) Act in December of 2014, the Enable Savings Plan put Nebraska on the map as a pioneer of the groundbreaking ABLE program.

“The launch of the Enable Savings Plan marked a significant milestone in the lives of many individuals with disabilities, who had previously been left with few options to save. Over the last year, we have paved the way for ABLE plans nationwide, allowing account owners and their families to save as much as \$100,000 without losing Social Security benefits. Ultimately, we strive to empower individuals with disabilities, helping them attain financial independence. We are proud of the strides we have taken toward accomplishing this goal,” said Nebraska State Treasurer Don Stenberg, Trustee of Enable.

One of the nation’s first ABLE plans, the Enable Savings Plan provides eligible individuals with disabilities the opportunity to save for their future and everyday expenses in tax-free savings accounts without impacting eligibility for resource-based public benefits. While designed and launched in Nebraska, the Enable Savings Plan is now available for individuals with disabilities across the country.

Enable is set apart by the fact that it was developed with the disability community—not just for them. By working closely with the disability community and its advocates, we designed a plan to best serve our account owners’ needs, goals, and aspirations. Through seeking out experience, advice, and insights from organizations and families involved in the disability community, we created a plan that is well equipped to meet the unique needs of prospective account owners and help them succeed.

An unwavering dedication to inclusion and encouragement fuels Enable’s efforts, and, at its core, the Nebraska Chapter National Hemophilia Foundation supports the same objective we do: improving lives and empowering individuals to pursue their dreams.

To learn more about the Enable Savings Plan, visit [EnableSavings.com](http://EnableSavings.com) or [treasurer.nebraska.gov](http://treasurer.nebraska.gov), read the Enable Savings Plan [blog](#) and like Enable on Facebook.

About the Enable Savings Plan Enable is a tax-advantaged savings plan to help make saving simple and affordable for individuals with disabilities. The Nebraska State Treasurer serves as Trustee. First National Bank of Omaha serves as Program Manager, and investments are approved by the Nebraska Investment Council. Visit [EnableSavings.com](http://EnableSavings.com) and [treasurer.nebraska.gov](http://treasurer.nebraska.gov) for more information.

**About First National Bank of Omaha:** First National Bank of Omaha is a subsidiary of First National of Nebraska. First National of Nebraska is the largest privately owned banking company in the United States. First National and its affiliates have \$20 billion in assets and 5,000 employee associates. Primary banking offices are located in Nebraska, Colorado, Illinois, Iowa, Kansas, South Dakota and Texas. Investments Are Not FDIC Insured\* No Bank, State or Federal Guarantee May Lose Value  
\*Except the Bank Savings and Checking Account Options

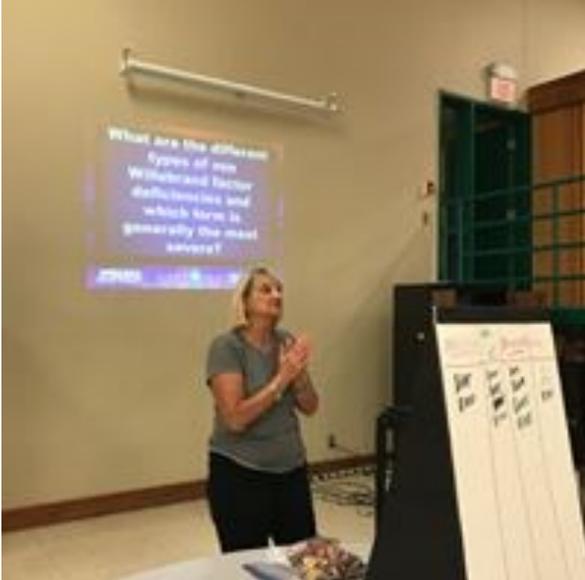
# Family Camp 2017

Camp Tap-a-Vein-a-Day-a was a major success! Our National Hemophilia Foundation brought out an amazing game of Jeopardy, where contestants fought for their rights to candy and to be crowned king of all bleeding disorder knowledge.

—Truthfully, it was a fight to the death over the candy. Levi Senior was the winner of all things sweet!

The weekend weather was perfect for trying new activities, massive slip in slides, and s'mores around the campfire. The biggest highlight was tie dying together! The amazing creations we made were all unique and we can't wait until 2018 to do it again!

Hopefully, you caught that! 2018 we will again be hosting camp! Camp is now EVERY YEAR, thanks to your dedicated support of our programs!





# PING

(Parent Information and  
Networking Group)

Please join the NHF-Nebraska  
Chapter for some

## Holiday Fun

December 9, 2017

5:30-8:30 pm

Lincoln Children's Museum

1420 P Street, Lincoln, NE

<http://www.lincolnchildrenmuseum.org>

## Walk Kick Off 2017

We hosted our very first walk kick off. This event was brought together by our wonderful walk committee. Our committed walk team captains and team mates came together to hear from a top NATIONAL fundraiser, Samantha Clinkinbeard, and her efforts to raise funds for the Nebraska Chapter. Sam recounted how she uses her son Oliver's healthcare stories to inspire others to donate, raise awareness, and support her efforts to help those with bleeding disorders.

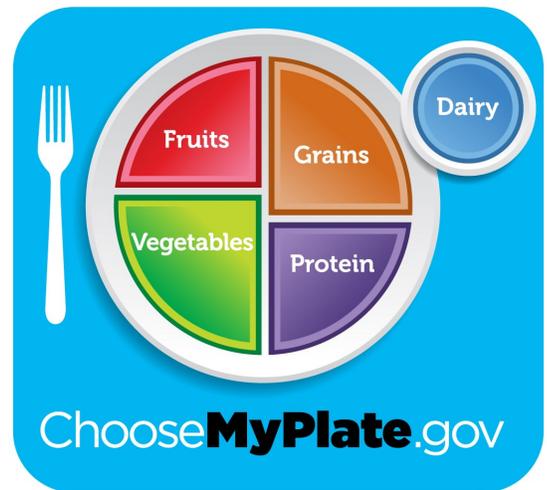
Following the presentation and discussion, we had a BBQ in Elmwood park, complete with fun games, delicious food, and amazing weather. We are so thankful that everyone was able to participate in our first ever Walk Kick Off party.

## Maintaining Your Child's Weight With A Healthy Family Kitchen

We all have seen the statistics. Today one out of three children are overweight. Being overweight may affect your child's overall health and self-esteem. However, small changes to your kitchen may not only improve your child's eating habits, but his or her weight.

When you look in your refrigerator, do you see fruits, vegetables, or low-fat yogurt or milk? Do you have fruits and vegetables on your kitchen counter? Having these foods on your counter or on the center shelf in the refrigerator at eye level helps them to choose these foods more often. Remembering to minimize unhealthy food purchases (ex: chips, cookies, candy) and storing them out of sight can help your child's weight.

MyPlate tells us to fill half of our plate with fruits and vegetables and to have low-fat milk at each meal. These foods are low in calories, which may help keep your child at a healthy weight. Whole pieces of fruit and veggies have a lot of fiber, which will help your child feel fuller, especially if he or she seems hungry all the time. Your child may then reach for unhealthy snacks less often.



Here are some tips to help you have a healthier home food environment which can help your whole family's weight and nutrition:

### What to do at the grocery store:

- Buy baby carrots or mini-sweet peppers for a ready-to-eat snack.
- Start your grocery shopping in the produce department and fill up your cart with fruits and vegetables before you shop for other foods.
- Buy frozen or canned fruit (packed in juice) and vegetables. They are just as healthy as fresh and may be less expensive, especially when some fruits and vegetables are not in season. Remember to check for added sugars and salt content, if your health requires it.
- Buy low-fat milk, lactose-free milk (if your child is lactose intolerant), or low-fat yogurt and place these foods in the front of your refrigerator, so they will see them and will choose them more often.
- Take your child to the grocery store so he or she can choose a fruit or vegetable to try each trip.
- Teach them to use the new food by finding recipes and cooking with your help.

### What to do at home:

- Keep cut-up fruits and veggies in your refrigerator on the center shelf where kids can reach them.
- Place a fruit bowl on your counter where your child can see it every day.
- Serve low-fat milk or water as a beverage at evening meals, instead of soda or lemonade.
- Store less healthy foods (ex: cookies) out of sight or don't buy them at the store.
- Be a good role model. When children see their parents eating healthier foods, they will be more likely to do the same.

## Maintaining Your Child's Weight With A Healthy Family Kitchen, continued

### What to do Now:

- If your fruits and veggies are in the produce drawer of your refrigerator, put them in a bowl and place them on the center shelf in your refrigerator.
- When you open your refrigerator, your child will see these foods and will be more likely to choose them.
- Encourage your child to eat healthy foods by serving them more often. It may take 15 to 20 times before they try a different fruit or vegetable, but patience and consistency will pay off.

Photo source: [www.choosemyplate.gov](http://www.choosemyplate.gov)

**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.**

## NHF's Annual Conference RECAP from your NE Community Attendees

The Hillabrand family had the opportunity to attend the NHF Annual Conference in Chicago this past August. We are so thankful to have their perspective on the consumer track to recap the events of the week for our community.

As told by Kelly Hillabrand

I would like to thank the Nebraska Chapter for giving us the opportunity to go to the National Conference this year. We have attended before but it was a long time ago. With Brett being a Senior in High school this year we are feeling very overwhelmed with the new begging stage of him being a young adult... going to College soon...and moving away from home more than likely.

There were so many sessions that were great for information on industry changes, new products and new hopes for our further generations. My favorite session was listening to some of the teens overcoming obstacles with their bleeding disorders. (This was one on the teen calendar) but it's great to hear how their minds think!

My 17 year old Brett would also like to thank the Nebraska chapter for the experience. He won the Teen Impact Award for Academics presented by Shire. He was able to see all of the amazing teens out there just like him! He also enjoyed some of the time away from his parent and was able to share stories with other teens.

The biggest take away for me though was talking to other parents and sharing stories and advise. I was also able to talk to some newly diagnosed families and help reassure them that everything will be okay. I remember being that new mom like it was yesterday!

## 2017 Hemophilia Walk

September 30, 2017 brought together over 320 people, in TWO locations, to celebrate your commitment and dedication towards raising funds and awareness for bleeding disorders. We kicked off our Walk with Kenneth from National on a glorious morning in Omaha. Dale Gibbs and Dr. Harper were beneficial in the execution of kicking off walk in Gothenburg to a much different type of weather, only a few hours away.

Our satellite location, in Gothenburg, felt like a pipe dream. Ann Foster came to the support and rescue of the Nebraska Chapter wanting to spear head our efforts to continue to raise awareness across the state. Through constant discussions, many long hours, social media advertising and a story in the newspaper, Gothenburg's satellite location brought over 50 people out to celebrate the Nebraska Chapter. We cannot thank Ann enough for her efforts and volunteering with the Nebraska Chapter. She is a working mom, caring for her family that includes one toddler with a bleeding disorder, she managed to dedicate her precious time to the Nebraska Chapter to further our goals. Ann's Team Weston managed to be the Top Team in Gothenburg and Ann hit Factor Club status, raising over \$500 for our community.

Combined, our two walks have raised over \$46,700! We are well on our way to \$50,000. Our walk is just one day. We still have the opportunity to continue to raise money for our 2017 walk until the year's end. We have set the specific goal of \$50,000 to help us bring camp again in 2018 to our families, expand our men and women's programs, as well as continue growing our Kearney Education Outreach program. With over 320 registered walkers, if each person takes five minutes to make an additional donation to the Nebraska Chapter of just \$11.00, we will hit our goal for 2017! This is skipping your lunch out one day of the week, or if you can related to my Target shopping...leaving target 5 minutes sooner than planned!

The Nebraska Chapter is so incredibly proud of all of our fundraisers, but we have had three persons and one team rank nationally.

Nationally Ranked **Team Elliott**

with Nationally Ranked

**Amelia Mickeliunas and Jenny Mickeliunas**

And

Nationally Ranked **Samantha Clinkinbeard**,  
representing Oliver's Clotting Crew

For the First time, we have now have another recognition for those raising \$500 or more, our Factor Club. When you see these community members, give a huge thankyou to their fundraising efforts. Each person listed below raised at least \$500 and many went above and beyond that!

**Amelia Mickeliunas, Jenny Mickeliunas**

**Joe Mickeliunas, Samantha Clinkinbeard**

**Kristin Henson, Sharon Clark**

**Carl Clark, Eric Clark, Rebecca Runge**

**Susie Zimmer, Harrison Wagner**

**Scott Gass, Patricia Rhodes Powles**

**Traci Christensen, Geri Murphy**

**Linda Ashley, Kelly Hillabrand**

**Brett Hillabrand, Ann Foster**

# 2017 Hemophilia Walk



# Harvest Festival

A rainy day at Vala's Pumpkin Patch couldn't keep our community away! We were pleased to have over 90 people come together to eat hotdogs, become gooey messes with s'mores and tromp through the muddy pathways at Vala's Pumpkin Patch this year.

We are grateful to our industry supporters that enable this fun community day to continue. A special thanks this year to Soleo, CSL Behring, Octapharma, and Superior Biologics.



## Kearney Education Outreach

This year, over Labor Day weekend, we hosted our first Kearney Education Outreach. We brought families together to hear talks from Bayer, Pfizer, CSL Behring, and the National Hemophilia Foundation. We learned how to handle life while aging with a bleeding disorder, how to handle an emergency situation, how to share our stories, as well as communicate with our healthcare providers.

We ended a wonderful Saturday in Kearney with a dinner brought to us by Octapharma at Alley Rose. We heard an amazing life story filled with inspiration, showing our crowd that you really can accomplish anything you put your mind to, and a bleeding disorder among other differences, should not stop you and your determination to accomplish your dreams.

We were able to provide tickets into the state fair from everyone that attended our Saturday events!

We are so excited to be back in Kearney in 2018, utilizing the Younes Conference Center on August 25th, 2018. Expect an amazing weekend of learning, community bonding, and a fun day at the Nebraska State Fair that doesn't fall over Labor Day weekend!

Thank you to all of our sponsors for helping us expand our programs outside of the Omaha and Lincoln areas.



## For the Younger Ones, Things Can Change

Leemar Yarde

I have hemophilia B with an inhibitor, and I live on the tropical island of Barbados. I am one of six people with hemophilia in my family, but I'm the only one with an inhibitor—in fact, the only one on the island with one. So I often meet new challenges. Growing up in a family with two older, experienced relatives with hemophilia has its benefits, but I should tell you a bit more about this lovely island, to help you grasp our situation.

Barbados is a developing country. The medical care here is free, and that is commendable, because many people can't afford medical care. However, the downside is that due to the cost of some medicine, the government can only afford either generic or very limited supplies. Budgets are often allocated to life-threatening illnesses, and the government doesn't view hemophilia as one. As a result, very limited amounts of clotting factor are imported for both types of hemophilia, and none for inhibitors.

Barbados doesn't have a hemophilia treatment center (HTC) or even a medical facility dedicated solely to hemophilia. What we do have is a hematology center that caters to various blood disorders. That center has a handful of experienced hematologists; one or two have dealt with inhibitors in different countries. Sadly, a hematologist can only work with the tools available. I remember having to wait from 8 am until 12 pm to see the doctor, then being told that the hospital had no factor at that time. Still, here in Barbados, we're fortunate because some of our neighboring Caribbean islands can't afford any clotting factor.

So for me, at one point all hope seemed lost...until I met "her."

My inhibitors surfaced when I was in my early 20s and at a difficult period in my life. In my late teens, I began suffering from frequent right knee bleeds. In time, it became clear that knee replacement surgery was inevitable. But why wasn't the factor bringing some relief? Maybe we just needed to infuse more at a single time. So I saw an orthopedic surgeon, who recommended getting tested for inhibitors. Barbados doesn't have the ability to conduct such a test, so blood samples had to be sent to the US for testing. About a month later, the results came back: there was an inhibitor. So the knee replacement was put on hold: my family couldn't afford the amount of factor needed to attempt to tolerize, plus the high cost of using bypassing agents.

As a result, I went a year without treatment. During that time, I was using crutches and putting all my weight on the other good knee, so I lost the use of that knee as well. Using crutches also damaged my right shoulder. My family and I reached out to various organizations worldwide, often being turned down. My hematologist, trying her best and with the limited resources allotted to her, managed to procure a sample donation of FEIBA from Central America.

## For the Younger Ones, Things Can Change, Continued

Remember the “her” I mentioned? She was Laurie Kelley. Coming to Barbados in response to a request from a mother of a child with hemophilia (unrelated to me), Laurie and her wonderful assistant Zoraida wanted to meet most, if not all, the people with hemophilia on the island. That’s when we met, and Laurie offered to help me in my times of need. Ever since then, Project SHARE has supplied NovoSeven and FEIBA when possible. Words cannot express how grateful my family, my hematologist, and I are for this constant support.

Sadly, though, I have lost my ability to walk, and I am dependent on family and a wheelchair for mobility. It has cost me a certain quality of life, and the dreams I had growing up. Adding to these difficulties, Barbados does not cater to physically challenged people. Society here still tends to look down on the disabled, but you eventually learn to live with it. I try to find some joy despite the hardship, and fortunately for me, I come from a very large family with no shortage of love and care. My parents work to make my life as comfortable and pain-free as possible, and for that I am eternally grateful.

So for us here in Barbados, rationing factor is a norm. Often we forgo dipping into our supply at home, because the hospital is out of factor and doesn’t know when it will acquire more. This means that if a bleed isn’t too bad (on a scale of 1–10, below a 7), we will endure pain and suffering, at the cost of a little joint damage, for the sake of not being completely out of factor. By a certain age, people with hemophilia in the Caribbean will have endured all types of pain, have a good concept of it, and know when a bleed is a bad one, a very bad one, or a “killer.” With that knowledge and experience, we know when our hand is forced and we have no choice but to use up our limited supply of factor.

My two uncles grew up at a time before factor was introduced in Barbados. Legends, you could call them, and their wealth of knowledge has been beneficial not only to our family, but to all others with hemophilia on the island.

Recently, a Barbados Hemophilia Association was established here, to advocate and bring awareness to the public. One achievement it’s working toward is the establishment of a dedicated HTC here in Barbados. Next, we’ll need to work on a supply of factor for all. I feel that not much can be done for me, but for the younger ones with hemophilia, things can change.

Leemar Yarde, 29, lives on the island of Barbados. He has hemophilia B with inhibitors. In his free time, he enjoys music, gaming, and hanging with friends and family.

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# Being Part of the Team

Cazandra Campos-MacDonald

Some of the most enjoyable times in my life were the months I spent playing softball in a summer league in Galena Park, Texas. The smell of my worn leather glove, the dirt from a great slide into home, and the team that played together with one goal in mind: to win the trophy at the end of the season. It took each of us to make our team function. Not just one person, but all of us together.

When living with an inhibitor, not only do you need a team to help determine the best treatment possible, but you also need to become a part of the team. Your firsthand knowledge of living with an inhibitor 24/7 is paramount in finding the right treatment, because you are the expert on your own story. When clinicians and families work as a team to determine the best approach to care, attention is given to the uniqueness of the inhibitor, and to understanding the patient and social environment. Then, the best comprehensive plan for treatment can be achieved.

The hemophilia treatment center (HTC) model provides a comprehensive approach to care that handles various aspects of a patient's overall well-being. About 70% of people with hemophilia in the US receive multidisciplinary, comprehensive care in a network of federally funded HTCs.<sup>1</sup> The HTC team consists of nurses, social workers, physical therapists, and other healthcare providers who specialize in treating people with bleeding disorders. This team not only manages the day-to-day care of an individual, but works to prevent and reduce complications.

Sometimes inhibitors challenge even the providers' expertise and threaten the team approach. My youngest son, Caeleb, has had a tough journey living with an inhibitor. He endured bleeds that seemed never to heal, and the joint damage to his knee and ankle were significant. Treatment with bypassing products proved difficult, and he developed an allergic reaction to infused factor VIII, in addition to his persistent high-titer inhibitor.

At the same time, our HTC was in a transitional stage with staff changes. I felt that we needed a meeting to discuss Caeleb's treatment. So my husband and I met with the interim lead hematologist and asked if he thought we needed help from an HTC in a neighboring state. The wave of relief that washed over him was obvious, and we began a new chapter in Caeleb's inhibitor journey. We began a new relationship with the HTC in Colorado. It wasn't easy at first, because we were inviting a new member to join our team—to join our family.

With regular blood draws and often daily infusions, life with an inhibitor can be demanding. "When inhibitors occur, the families of the hemophilia patient are challenged by uncertainty, unanticipated complications, costs, and difficulties that few people understand," says Dr. Stuart Winter, professor and vice chair of pediatric research, University of New Mexico Health Sciences Center. Not only was my family dealing with the enormity of the bleeds and pain that persisted for Caeleb, but we

also had to plan for regular trips out of state for treatment. At one point, we were referred to a special allergist in Colorado; this required us to stay in Denver for a week, and put a financial and emotional strain on our family. But the result was worth it.

An inhibitor heightens the stress endured by many living with hemophilia without this added complication. Dr. Shirley Abraham, director of the Ted R. Montoya Hemophilia Treatment Center in Albuquerque, New Mexico, states that "inhibitor families deal with several unusual and severe bleeds which require specific management. They deal with emotional issues such as the anxiety of having the inhibitor and not knowing what will work for them and for how long."

## Being Part of the Team, Continued

My husband and I had to figure out how to get both of our HTC's to communicate. They agreed to work together, but in the middle of a crisis, reminding one HTC to contact the other wasn't always easy. We had to advocate for Caeleb, and this became uncomfortable. The truth is that when your child is suffering, you do whatever you can to improve the situation. Sometimes you must be the squeaky wheel to get what your family needs.

Developing a relationship deeper than simply patient and provider is common with inhibitor patients. "The [inhibitor] families are seen and contacted much more frequently than most with their annual [HTC] visit," says Claudia Mackaron, RN, nurse coordinator for the Ted R. Montoya HTC. "This makes the inhibitor family more a part of the HTC members' lives." When Caeleb started spending less time in the hospital, we missed our HTC team. The constant contact we'd had with our HTC brought the staff into our family life outside of a crisis.

The comfort level varies between a patient and HTC team, and this can be challenging. At times, I disagreed with a clinician. I questioned the care my son was receiving, and despite my comfort level with the team, I had to speak up. I realized that, like family, the team members weren't easily offended, because we were all working toward the goal of giving Caeleb the best treatment. Frequent communication that is not necessarily for routine checkups often occurs as both patient and medical team work together to handle a crisis. A bleed that seems to never resolve, a product not being as effective as in the past, and issues regarding insurance and reimbursement problems are concerns that plague families with inhibitors.

Keeping an open line of communication with the HTC team is critical for optimal care and when a patient is in distress. "Sometimes anxiety and frustration can become a road block to proper communication," says Abraham. "The psychosocial support from the HTC will be crucial to help. Social workers and a psychologist or psychiatrist can guide families through different financial and emotional struggles." Trust can be established when both the HTC and the patient are actively communicating, and the best outcomes have a better chance to evolve.

When patients and providers voice their concerns about treatment, this increases the chance of obtaining the best results. "Good communication is paramount to make sure that care is delivered appropriately," says Janet Ratte, RNC, specialty nurse pediatric hematology, Ted R. Montoya HTC. When in doubt, I always call my HTC. When the HTC asks personal questions, the patient may feel threatened; but if a good relationship has been established, new findings could help

change the course of treatment, often for the patient's benefit. And when patients question the HTC, staff are pushed to think outside the box to find new approaches and ideas. As long as everyone communicates, the best comprehensive plan may be achieved.

Living with an inhibitor can be devastating. But when the patient, family, and HTC team form a strong unit, moving forward with the patient's best interests in mind, this eases some of the difficulties. "Feelings of sadness and despair impact the social fabric of the family," says Winter. To handle the emotional challenges that inhibitors bring, allowing the HTC team to become part of the extended family can bring a huge sense of relief. One doctor finally stood back, assessed Caeleb's situation, and told us that we needed a "roadmap" in place for his care. Once done, that was the final piece that both of our HTC teams needed, including my husband and myself. We could now see the big picture, communicate more effectively, and implement a team plan of treatment for a better life.

Cazandra Campos-MacDonald is a motivational speaker, educator, and patient advocate for families with bleeding disorders. She writes a blog chronicling the journey of her two sons with severe hemophilia and inhibitors, and has written articles and blog posts for various publications. Cazandra's older brother, Ronaldo Julian Campos, died of complications from hemophilia as an infant. Cazandra lives with her family, Rev. Joe MacDonald, Julian (21), and Caeleb (11), in Rio Rancho, New Mexico.

## And the Survey Says . . . Carriers, Get Tested!

Paul Clement

Women have hemophilia too! Although much progress has been made over the past two decades in getting this message out, public awareness of bleeding disorders among women is dismal. Even women who are known carriers of the gene for hemophilia often don't realize that they can have hemophilia and be at risk of bleeding. Even carriers confirmed to have bleeding problems, and diagnosed as "symptomatic carriers," have run into roadblocks in accessing proper care.

Why are so many women undiagnosed?

The main reason is that they don't suspect they have a bleeding disorder and don't seek medical treatment. In spring 2010, a national study surveyed 1,243 women from the general public, aged 18 to 25, to assess their knowledge, attitudes, health behaviors, and menstrual experiences.<sup>1</sup> Many questions were designed to determine if women knew the difference between "normal" and "abnormal" bleeding patterns. The results were disheartening. Most knew that a bleeding disorder is a condition in which bleeding takes a long time to stop (77%), or blood does not clot (66%). But the women surveyed didn't know much about bleeding disorders, and only a few could identify risk factors for a woman with a bleeding disorder: periods lasting eight days or longer; bleeding through a pad or tampon in an hour or less; feeling a sense of flooding or gushing. Of the women surveyed who were identified as having one or more of these risk factors, only 20% had sought medical attention, and only 2% had been diagnosed with a bleeding disorder. Contrast this with studies showing that on average, 13% of women seeking medical treatment for menorrhagia (heavy periods) have von Willebrand disease (VWD)!<sup>2</sup>

Bottom line: Most women don't seek medical treatment for menorrhagia, and if they do, few are correctly diagnosed with a bleeding disorder. To increase awareness, National Hemophilia Foundation (NHF), Hemophilia Federation of America (HFA), and other advocacy organizations have launched multiple programs for women with bleeding disorders. These organizations are now doing a great job providing resources for diagnosed women. But it's obvious that we must do a better job, to reach more women in the general population—to educate them about the risk factors and encourage them to seek medical treatment.

Lack of physician awareness

What happens when women do seek medical treatment? We've made some headway, as results from two different surveys show. A 2002 survey of 376 members of Georgia Chapter of the American College of Obstetricians and Gynecologists wanted to understand methods of diagnosing and treating menorrhagia, and to determine physicians' experiences and perceptions about bleeding disorders, particularly VWD.<sup>3</sup> The results were enlightening—and

shocking. Only 3% of responding physicians considered VWD a likely cause of menorrhagia in women aged 15 to 44. When asked how many women with menorrhagia might have an

inherited bleeding disorder, physicians' average response was "less than 1%." Most shocking: after practicing an average of 20 years, 42% of responding physicians reported never

having seen a woman with menorrhagia who had a bleeding disorder. But statistically, each physician annually saw several hundred patients with menorrhagia who had VWD! Not surprisingly, the survey showed that gynecologists rarely (3%) refer a woman with unexplained menorrhagia to another specialist.

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Fast forward a decade. In 2012, a similar survey of 503 ob-gyns had more positive results: nearly 39% of obstetricians and 77% of gynecologists were likely to consider VWD or another bleeding disorder as a cause for menorrhagia.<sup>4</sup> And over 80% who had seen patients with menorrhagia attributed the problem to a bleeding disorder. Perhaps most important, instead of referring patients to specialists only rarely, most physicians referred patients with menorrhagia to other healthcare providers, nearly 45% to hematology.

Although it's hard to compare surveys of different physicians a decade apart, the change in demographics of the patient population at hemophilia treatment centers (HTCs) also reflects an increased awareness in the medical community of bleeding disorders in women. Between 1990 and 2010, the HTC population grew 90% from 17,177 to 32,612—and most of this increase was due to additional VWD patients.<sup>5</sup> This increase is expected to continue; unfortunately, these numbers only scratch the surface of the estimated 3.2 million people in the US with VWD, half of them women.<sup>6</sup>

### Hemophilia carriers with low factor levels

The normal range of factor VIII and IX is between 50% and 150%, with most people being close to 100%. Factor VIII levels often vary, and may more than double due to the effects of hormones and other variables, such as stress or pregnancy. Factor IX levels

normally remain fairly stable. Being a carrier for hemophilia puts

a woman at risk of bleeding because of low factor levels. Carriers usually have factor levels between 30% and 70%, with most around 60%. But factor levels in carriers can vary widely, with some in the high-normal range and others below 10% (in extremely rare cases, below 1%). Research shows that even women with mildly low factor levels—40% to 60%—are at risk of bleeding.<sup>7</sup> They may experience not only menorrhagia, but bleeding after tonsillectomy, tooth extractions, surgery, or trauma from accidents; and prolonged bleeding from minor cuts or joint bleeds. This isn't well known among many carriers, so they may not seek treatment.

Every bleeding disorder advocacy organization offers educational materials on this topic, and it's probably a safe guess that every chapter newsletter has published multiple articles on the risk of bleeding in carriers. Yet for a variety of reasons, the message hasn't been received by everyone affected.

But simply seeking medical treatment for excessive bleeding may not be enough—you may have to advocate for yourself. Carriers with bleeding problems are often diagnosed as “symptomatic carriers,” and a course of treatment is recommended. Everything should be okay for these women, right? Not necessarily. The word “carrier” often conveys the wrong meaning. In decades past, it meant you had the gene for a disorder, but you yourself didn't show symptoms of the disorder. Many physicians who are not bleeding disorder specialists still have this definition in mind, but we now know that carriers can indeed have the genetic disorder. We don't know for sure how many carriers have excessive bleeding, but a common estimate is that about one-third of carriers have factor levels below 50%, placing them at risk. These women have a factor deficiency and mild hemophilia. They have often been diagnosed as symptomatic carriers because some doctors resist using the word hemophilia based on the simplistic notion that “only males can have hemophilia.”

The symptomatic carrier diagnosis must be laid to rest. Not only is it misleading, but it often prevents women from getting the treatment they need. And insurance companies increasingly use a literal definition of “carrier” to deny coverage for treatment, arguing that symptomatic carriers don't actually have the disorder. If your factor level is low-

## And the Survey Says . . . Carriers, Get Tested! Cont...

Knowing your factor level is essential. To rule out low levels, all women who are carriers should have their factor level checked (and if you are a carrier for hemophilia A, checked at least twice). If your levels are below the normal range, request a diagnosis of hemophilia. And get the word out: talk to your peers and let them know that most carriers are at risk of excessive bleeding.

1. Patricia A. Rhynders et al., "Providing Young Women with Credible Health Information about Bleeding Disorders," *American Journal of Preventive Medicine* 47, no. 5 (2014): 674–80. 2. M. Shankar et al., "Von Willebrand Disease in Women with Menorrhagia: A Systematic Review," *BJOG* 111 (2004): 734–40. 3. A. Dilley et al., "A Survey of Gynecologists Concerning Menorrhagia: Perceptions of Bleeding

Disorders as a Possible Cause," *Journal of Women's Health & Gender-Based Medicine* 11 (2002): 39–44. 4. Vanessa R. Byams et al., "Evaluation of Bleeding Disorders in Women with Menorrhagia: A Survey of Obstetrician-Gynecologists." *American Journal of Obstetrics and Gynecology* 207, no. 4 (2012): 269.e1–e5. 5. Judith Baker et al., "US Hemophilia Treatment Center Population Trends 1990–2010: Patient Diagnoses, Demographics, Health Services Utilization," *Hemophilia* 19 (2013): 21–26. 6. F. Rodeghiero et al., "Epidemiological Investigation of the Prevalence of von Willebrand Disease," *Blood* 69 (1987): 454. 7. I. Plug et al., "Bleeding in Carriers of Hemophilia," *Blood* 108, no. 1 (2006): 52–56.

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Virginia Kraus, RN MSN on an overview of Hemophilia A and B

RSVP to Kelsey Cunningham,

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## Board Corner

Well this is it. Kids are back in school which means your calendar is jam packed! As I look back through my calendar, August and September were filled with attending the NHF National Conference, our outreach education in Kearney, and our annual walk. Sprinkle in a few other meetings and phone calls and WOW, that time went quickly.

As I stated in the last newsletter, it was my first time attending the NHF National Conference. They pack many sessions into those few days. Kelsey and I participated in many sessions about ways to make our chapter better. We learned from National staff and shared ideas with other chapter executives and board members. I learned more about bleeding disorders and met some researchers.

I found it very exciting to talk with a couple researchers who received funding from NHF. I have asked Jennifer Baumert to highlight the research projects in future news articles. I look forward to those highlights.

Bouncing ideas off other chapter executives and board members is enlightening. We celebrate our success and offer suggestions to overcome struggles. A few thoughts that come to mind from conference are:

- The chapter should begin working on outreach to the Hispanic community.
- We need to look to other organizations to form partnerships.
- [myhealthteams.com](http://myhealthteams.com) could be a good resource for those over 18 yrs of age.

I want to mention the outreach in Kearney was a great start. I'm hoping next year we will have a greater amount of participation from families in central and western Nebraska. This event was planned based on the community request. Please put August 25-26 2018 on your calendar.

Geri Murphy

Board President



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