Fall/Winter 2018

KHF Hemosphere

2018 Kentucky Unite Walk

The theme for this year's Kentucky Unite for Bleeding Disorders Walk was Superheroes under a more inclusive and embracing new name. In addition to being a fundraiser for KHF's programs and services, our Walk has truly been a community event since the beginning.

This was our 5th Walk at Wetherby Park in Middletown. Twenty teams were registered and several individual walkers for a total of one hundred and forty-nine walkers raising awareness and raising funds for Kentucky's bleeding disorders community. The newly added pinwheel ceremony put into words the impact and inspiration that this special event holds for its participants who came from all parts of Kentucky to gather in unity and walk in hopes of a better future and better treatments every step of the way, but also in gratitude and excitement over the tremendous advances that have been made in the treatment of bleeding disorders for the current and future generations, and thirdly in memory of those loved ones who perished when treatment was non-existent or flawed.

The Walk's atmosphere was so uplifting and moving, giving bleeding disorders a hopeful and united voice, face, and humanity. There was lots of fun and merriment to be had via the clown couple who makes balloon animals and does face painting, the ever popular bouncy house and decorating pumpkins into round little superheroes. The musical backdrop provided by our favorite DJ added to a carnival like feeling. Donuts and robust Heine Brothers coffee provided an initial burst of energy. After several rounds of walking in the park, pizza slices donated by Papa John's Middletown, were a welcome treat along with popcorn, granola bars, and fruit roll-ups. Door prizes, prizes for best costume, and for top fundraisers and team winners rounded out the event.

We congratulate all teams and walkers who participated and supported the Walk. We especially congratulate the top three fundraising teams and individual fundraiser. Each of the top six teams raised over $1,000. They were "Team LEVI," "Team Mac's Pack," "Team Tag's Turtles," "Team GG Babies," "Team Andy's Avengers," and "Team Jackson's Globeclotters." The winning Team as determined on the day of the Walk was "Team LEVI" from Cynthiana, KY who raised an amazing $4,724. In second place was "Team Mac's Pack" from Lawrenceburg who raised $3,838, and in third place with $3,000 was "Team Tag's Turtles," who participated as a virtual team this year, since the date of our Walk coincided with little Tag's birthday. Top individual fundraisers were team captains of their respective teams: Karen Lucky/Levi Hill with $4,399, Maclan Foley with $2,380, and Tag Poynter with $2,595. The Walk raised $42,156.74, which was 84% of our goal.

We're in awe of your achievements, enthusiasm, and commitment to our shared cause, and we thank you from the bottom of our hearts. We thank all our volunteers and Board members who planned for and helped at the event and our donors and sponsors. Sponsors were Novo Nordisk, Gold Sponsor; Bioverativ, CVS Caremark, Genentech, Silver Sponsors; Octapharma, Bronze Sponsor; and First Choice Infusion and Republic Bank & Trust Company, Kilometer Sponsors.

Special News

504s and IEPs in Action

Jessica O'Donnell

Sending a child with a bleeding disorder to school can be scary, and parents may feel vulnerable and stressed. Many aspects of your child's health and safety are not in your hands.

To ensure that healthcare needs are met and your child succeeds academically, it's important to establish good lines of communication between yourself and the school. How do you make sure your child's needs are met? How can parents guarantee that their children are receiving the care and support needed from school nurses, administrators, and teachers?

Parents often look to 504 plans, IEPs, IHPs, and ECPs to establish formal action plans for prevention and treatment of everyday concerns that may arise at school.[1]

504 versus IEP

It's important to distinguish between 504 plans and individualized education plans (IEPs). As defined by the US Department of Education, Section 504 states that students are entitled to receive regular or special education and related aids and services that are designed to meet their individual educational needs as adequately as the needs of students without disabilities. But note that under a 504 in practice, no schools offer special education services, such as various speech or occupational therapies. Section 504 also requires, among other things, that a student with a disability has equal opportunity to participate in athletics and extracurricular activities, and is free from bullying and harassment based on disability. Unlike an IEP, a 504 plan provides for small changes (called accommodations) to a student's regular education program in a regular classroom setting.

IEPs are for students who are entitled to support via IDEA (Individuals with Disabilities Educational Act). IDEA has a much narrower definition of disabilities than a 504 plan, as they relate to education. Also, to receive an IEP, the child's disability must affect educational performance and/or ability to learn. IEPs are available to students who require changes to curriculum and/or special education services. IEPs and 504s serve similar but different purposes within the school system.

Missed School

A main concern is missed school days due to bleeds, injury, or recovery from a bleed. Many parents state that 504s and IEPs not only ensure that missed school days for medical reasons are excused, and their child can make up assignments, but the plans also provide for support services such as tutoring. Again, remember that IEPs can provide many more services than 504s.

Amy Selfridge, mother of an adult son with hemophilia, recalls his early school years: "My son missed over 160 days of school in three consecutive years. He had a 504 plan that explained what hemophilia is and what plans needed to be taken into consideration when he was absent." Amy encouraged her son to take the lead in staying current with schoolwork and communicating with his teachers. "On top of the 504 plan, I had him email all his teachers while he was out of school."

A teacher herself, Amy recalls helping her son with his homework, but she stresses the value of her son's active role in his own education. "It was very import that he take care of his communication with his teachers. It was the first step to being responsible for his own education." Now, says Amy proudly, "he just graduated with a degree in business administration in May."

Empowering your child to take responsibility for missed schoolwork and maintain open lines of communication with teachers can be a great supplement to the 504 and IEP plans offered. These skills will also carry on into adulthood.

Tammy Jones has a grandson with von Willebrand disease (VWD), and has found that a 504 plan works well for his needs. The 504 plan not only ensures that her grandson's absences for doctor's appointments are excused, and outlines how he will make up work due

504s and IEPs in Action

cont…

to VWD-related absences, but also allows the family to communicate needs for specific scenarios, such as school field trips. Tammy notes, "We have a meeting at the beginning of each year with the principal, homeroom teacher, school nurse, counselor, and special ed representative. Everyone hears the history and needs of his bleeding disorder at one time and what needs to be done in case of a bleed."

When a 504 Isn't Enough

504 plans are designed to level the playing field by providing accommodations for students who have impairments that may make it hard to complete schoolwork. But IEPs can go much farther, allowing families to work with the school district to create an individualized learning plan to help students reach their goals. Like 504 plans, IEPs provide for accommodations, but they can also provide for modifications (changes to the curriculum) and can offer specialized education services. However, because of more restrictive eligibility requirements, few students with bleeding disorders will qualify for an IEP.

Jane Cavanaugh Smith's son used both a 504 plan and, later, an IEP to meet his needs. "My son has a high inhibitor," says Jane, "which was at its worst during high school. We were fortunate to have a very proactive school system and worked out many accommodations via a 504 plan. He was basically home tutored by the school due to so many absences."

Yet after a certain point, it became clear that Jane's son needed more than accommodations to find his way to graduation. "We finally got an IEP during his senior year because it helped streamline his path to graduating on time with his class—his report card was always full of incompletes." Jane points out that the IEP is what really helped her son find a clear path to graduation by providing adjustments to curriculum for his individual circumstances.

While some parents have success using various school supports, others are inspired to go above and beyond. Priscilla Oren earned a BS in elementary education and decided to teach first grade. Her classroom was across the hall from her son's. "I could infuse him at school," recalls Priscilla, "and we both didn't miss work. When he was in fourth grade, I got my MEd in special education from Lehigh University so I could understand the system. I became an advocate for other parents. I also ran for a seat on the local school board and won. This was back in the 1970s and 1980s. I've been retired for many years, and I'm sure things have changed. But being knowledgeable about the laws helped us a lot."

Not all parents feel supported by accommodation plans, and many schools need guidance in helping a child with a bleeding disorder. School districts differ in their approaches to accommodating for various medical conditions. Even so, Hemophilia Federation of America (HFA) has great resources to advise you in dealing with a variety of issues that arise when guiding your children through school to become young adults who can advocate for themselves. These excellent worksheets, booklets, and PowerPoint presentations provide specific information on the basics of bleeding disorders as well as customizable sections to detail your preferred plan of action when something comes up at school. These resources can help you and the school design a 504 plan to meet your child's needs.[2]

When developing a 504 or IEP plan, the message is clear: Be proactive. Communicate your child's needs to school administrators. Advocate for your child at school. This not only helps ensure your child's academic success, but also allows you to model what advocacy is and how to advocate for oneself—a useful skill for your child to carry into the future.

1. See our feature article, "Back to School," for details on learning accommodation plans.
2. Visit hemophiliafed.org for downloadable resources.

Event News

Teen Impact Award

We congratulate Samuel Charas from Lexington who was recognized with a Shire Teen Impact Award at the National Bleeding Disorders Conference in Orlando, Florida for demonstrated leadership as a Boy Scout and all-around athlete whose primary passion is scuba diving. Sam is one of a select group of accomplished teens from around the country who received awards for excellence and leadership in various categories of achievement.

Hemophilia: The Musical

BioMarin Pharmaceutical Inc. and Believe Limited joined forces to invite twenty-five talented teens from the bleeding disorders community to showcase their artistic skills in a Broadway production called *Hemophilia: The Musical*. We are so proud of Elijah Eke, a senior at DuPont Manual High School and Junior Counselor at KHF's Summer Camp, and of Lilly Omerso who attends New Albany High School and whose dad was a KHF Camper and Camp Counselor a few years back for being selected to participate in this wonderful production in New York City. *Hemophilia: The Musical* reflects what life is like when you are dealing with or when you are surrounded by the daily challenges of living with a bleeding disorder. In addition to educating the rest of us and giving us a window into their daily struggles, the musical also has the therapeutic qualities for this talented group of young people that expression through the arts has been found to provide to individuals for improved health and emotional well-being. We congratulate and thank Elijah and Lilly and the other cast members for this opportunity to witness their talents and for giving us a glimpse into their daily lives, feelings, dreams, and hopes. You may view *Hemophilia: The Musical* at www.facebook.com/BloodStreamMedia.

Gettin' in the Game Junior Championships

CSL Behring's popular Gettin' in the Game Junior Championships were held again this year in sunny Phoenix, Arizona in September. Each Chapter may send two participants. This is a fantastic opportunity for kids to become acquainted with or improve their skill levels in golf, baseball, and swimming. Sports and exercise in recommended disciplines is very important for strengthening bones and muscles, improved flexibility and mobility, optimal weight, self-esteem, interaction with other youngsters and above all, having fun! KHF held a drawing since lots of kiddos want to participate, and the lucky winners were Luke Gilbert from Eddyville and Landen Watson from Lawrenceburg. Luke chose baseball and Landen chose swimming. Luke and Landen had lots of fun. However, Landen's participation was cut short by a day because of a hurting ankle. Landen promised to go to physical therapy for his ankle injury in hopes of being selected again in the future to participate in the Gettin' in the Game Junior Championships.

Event News

Annual Community Event

More than one hundred and seventy community members registered to attend this annual event on a beautiful Sunday afternoon in December. The whole room at the Clifton Center in Louisville was aglow with smiling faces, festive attire, and animated friendly conversations.

The spirit of community and fellowship was in the air. The event offered an uplifting and carefree get-together to catch up with old friends and meet new ones. We had guests from the Bluegrass area, northern Kentucky, Frankfort and surrounding area, and as far south as Glasgow. Exhibitors provided valuable information about their products and services in a relaxed and casual setting. The Silent Auction/Holiday Bazaar featured attractive and seasonal items, and we appreciated the many donations for this fun activity. Moms and Dads had a chance to chat while their little ones were entertained by Connie Thacker' Arts and Crafts activity.

The Bake Contest generated fierce but friendly competition. Of several delectable entries, Karen Lucky's famous Pecan Pie won first place; Tira Miller's Peanut Butter Cake came in second, followed by Roger Harrell's Jam Cake in third place. The prizes for their efforts were respectively, an Instant Pot, a Keurig coffee maker, and an electric roaster. DJ Axel set the tone for this wonderful event with his musical entertainment, which was corroborated by the hot and cold hors d'oeuvres prepared by Chef John Taylor. Door prizes for the adults and gifts from Santa Claus for all the children present provided reverberating joy and good cheer.

We thank all volunteers who helped us get ready for this event. They are Melissa Hitt, Myra Loeser, Pete & Bev Slapikas, Chuck Oliver, Travis Price, Kim Logsdon, Paula Flink, and Connie Thacker. Exhibitor support was provided by CSL Behring, CVS Caremark, Genentech, Grifols, Matrix Health, Novo Nordisk, Octapharma, Pfizer, Shire, and Specialty Care Rx.

Upcoming Events

Vegasville Gala – February 23, Louisville, Fundraiser

Kentucky Advocacy Day – February 27, Frankfort, Peer Advocacy Event

In Memory

July 1, 2018 – November 30, 2018

Gone from our sight but never our memories; gone from our touch but never our hearts…

Mr. William L. Farmer, Sr.
Mrs. William L. Farmer, Sr.

Fred D. Goad
Mr. & Mrs. Henry W. Boyd, III

Spalding Grayson
Mary R. Burnette

Spalding Grayson
50th birthday
Ann Merrill

Spalding Grayson
in loving memory
Mary C. Adkins

Alan Taylor Hall
Norma Lee Hall
Elizabeth Watts
Elizabeth & Terry Watts

William Walter Hall
Norma Lee Hall
Elizabeth Watts
Elizabeth & Terry Watts

More News

Why You're Afraid to Switch Products

Cazandra Campos-MacDonald

A few myths about hemophilia linger in the community: "Only men can have hemophilia." "A person with hemophilia will bleed faster than someone without hemophilia." "People with hemophilia can't play sports." "You will outgrow hemophilia." Belief in these myths can spread fear, and can lead to harmful biases or behaviors: for example, prohibiting a child from playing sports, or not believing women who claim to have bleeding issues.

One fear that is still felt by many people with hemophilia, particularly those who've had an inhibitor, is the development or recurrence of an inhibitor as a result of switching factor products. Though there is some evidence to support this,[1] we also know that the risk of developing an inhibitor as a result of switching products is very small—too small to accurately measure. Yet many parents give this risk more weight than it deserves. Fear clouds their judgment when weighing the benefits of finding a better product and treatment regimen with the risk of contracting an inhibitor.

The fear of switching products became ingrained in my mind when my oldest son, Julian, was diagnosed in 1996 with a low-titer inhibitor at age one. I learned to infuse Julian with a first-generation factor VIII product (from which he developed the inhibitor), and after two and a half years of daily infusions, his inhibitor tolerized. My husband and I kept Julian on his treatment regimen while also gathering information about new factor products entering the marketplace. First-generation recombinant factor products reconstituted into 10 cc volumes, while some second-generation products reconstituted into only 2.5 cc. Yet our fear of triggering an inhibitor by switching products outweighed the promise of quicker infusions.

My second son, Caeleb, developed a high-titer inhibitor at age 11 months. He eventually began immune tolerance therapy (ITT) on a recombinant factor product, and after a couple of years of daily infusions, we moved him to a plasma-derived factor, hoping to lower his inhibitor level. Given the many complications Caeleb endured over the years, I feared that switching to a different factor product would cause his titer to spike. And daily infusions meant accessing his port every morning and pushing 30 cc of product from four vials of factor concentrate. This was not conducive to self-infusing, although he stopped experiencing episodic bleeds. Not having bleeds regularly was a great trade-off.

Whenever Caeleb visited the hemophilia treatment center (HTC) to have labs drawn, I brought along an extra-large plastic bag of his factor and supplies. Recently, Caeleb's hematologist, Dr. Shirley Abraham, suggested, "I think it's time to switch Caeleb to Hemlibra."[2] I was stunned. Another switch? I honestly couldn't understand why Caeleb needed to switch. Even though Hemlibra® is not a factor product, I realized that the fear of switching was alive and well in my mind. Caeleb still had an inhibitor, and not knowing how a new treatment would affect him was nerve-wracking. Dr. Abraham pointed to the extra-large bag and said, "That is why it's time to switch." Over the years, I had grown accustomed to carrying all those supplies for an infusion, and to accessing his port daily. With Hemlibra, a month of product and supplies fit into a small container, and Caeleb receives one subcutaneous injection weekly into his thigh—no more infusions into his port. In that moment, speaking to Dr. Abraham, I understood. Caeleb's quality of life could be even better if I trusted medical advice and didn't give in to old fears.

Products are chosen—and kept—for many reasons. For example, in families where more than one person has hemophilia, the choice may be based on another family member's experience. And if a treatment regimen or product is working well, change may not be needed. But what if you can do better? A common response to changing products came from one mother on social media. "Same manufacturer for 18 years because [the product] works. No reason to change." Claudia Mackaron, a retired HTC nurse coordinator in

Why You're Afraid to Switch Products

cont…

Albuquerque, New Mexico, says, "Even though a new product could be more beneficial, the old saying 'if it ain't broke, don't fix it' creeps in. It's very frustrating as a clinician to fight with patients in switching, knowing [a new product] could help them." Fear of the unknown may stop a patient from changing products even if the data shows that a specific product could be a better fit. "Psychologically, the fear of the unknown, and a potentially harmful and difficult unknown, can shape bias tremendously," says Dr. Mike Wang, associate professor of pediatrics at University of Colorado's School of Medicine. Inhibitors are frightening, and it's possible someone could develop an inhibitor after switching products. The fear lives on, even with no clinical evidence that the inhibitor resulted from a new product.

Why do some people embrace change without fear? Debbie Porter has an adult son with hemophilia and inhibitors who always "thought the idea of staying with the same product forever was counterproductive to advancing new and better treatments." Debbie wanted more for her son Matt, who suffered for years from inhibitor complications. Matt infused recombinant products, plasma-derived products, and bypassing agents over the years, so switching wasn't a fear. The day Hemlibra became available, Debbie immediately requested it for Matt. He has been bleed-free for seven months now, and his veins get the rest they desperately need. And of course, because Hemlibra isn't factor, it can't cause an inhibitor to factor VIII. Yet some people may be reluctant to switch, because they experience few complications with their inhibitors and their current treatment works. But for people like Matt and Caeleb, the severity of complications pushes them to anxiously wait for new products that promise better results.

We are learning more about why inhibitors form, and who is most likely to develop one. Physicians can identify patients who are more susceptible to inhibitor development based on genetics, environmental factors, race, and family history. But people seemingly not at high risk may still develop an inhibitor, and this has continued to feed fears about treatments and products. One HTC provider admitted that for years, he and his colleagues encouraged patients without inhibitors not to switch factor brands because they might get an inhibitor. While there is a risk of inhibitor development when switching products, "current evidence does not suggest that switching products significantly influences inhibitor development," declared a finding in the Eleventh Zürich Haemophilia Forum.3 Yet fears persist, even in the face of scientific evidence.

Letting go of old beliefs isn't easy. Once a myth has taken root in your belief system, it takes a lot of effort to remove it. We remain captive to treatments, protocols, and products that may not be the most effective. Staying where we are now—based on assumptions not rooted in the facts—prevents us from embracing the many possibilities that exist today.

Have the courage to overcome fear and seek out what's in the best interest of your loved ones. Gather the facts, and communicate your treatment needs and concerns to your physician. Trying a different regimen or product may change your life.

1. F. R. Rosendaal, et al., "A Sudden Increase in Factor VIII Inhibitor Development in Multitransfused Hemophilia A Patients in the Netherlands: Dutch Hemophilia Study Group," Blood 81, no. 8 (1993): 2180–86, available at www.bloodjournal.org. Thierry Calvez, et al., "Recombinant Factor VIII Products and Inhibitor Development in Previously Untreated Boys with Severe Hemophilia A," Blood 124, no. 23 (2014): 3398-3408, available at www.bloodjournal.org.
2. For more on Hemlibra, see Paul Clement, "ACE910: The First Disruptor," PEN, February 2018, 4.
3. Elena Santagostino, et. al., "Switching Treatments in Haemophilia: Is There a Risk of Inhibitor Development?" European Journal of Haematology 94 (2014): 284–89.

KHF does not give medical advice or engage in the practice of medicine. KHF under no circumstances recommends 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.

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Pfizer Hemophilia

DEDICATION AND PERSONAL SUPPORT

The Patient Affairs Liaison role was created based on community feedback about the importance of helping to connect patients and caregivers with Pfizer Hemophilia tools and resources.

PATIENT AFFAIRS LIAISONS

Working for you—From the home of Motown to the Bluegrass State

Name: Chris Liddell

Home state: Michigan

Fun fact: If I'm watching TV, it's most likely sports-related. Go Tigers!

Ideal vacation spot: Anywhere quiet, unplugged from all electronics

What past experiences can you bring to this job? I've worked in hemophilia for over 10 years, so I've collaborated with and advocated for different members of this community.

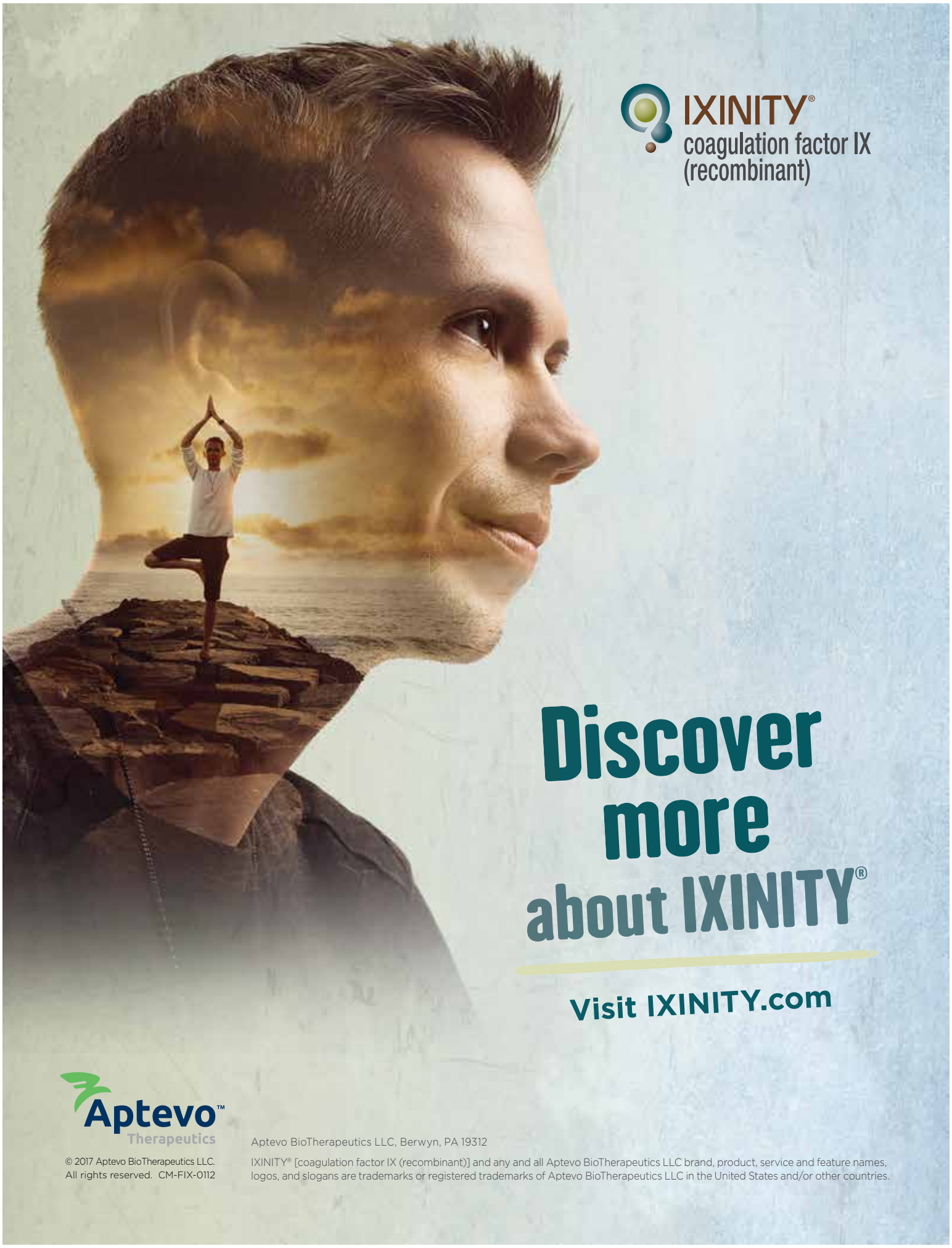
To get in touch with Chris, call
Pfizer Hemophilia Connect 1.844.989.HEMO(4366)

What we do:

- Provide helpful information about Pfizer Hemophilia programs and services
- Serve as a resource to hemophilia treatment centers to help patients obtain access to Pfizer medicines
- Serve as a primary point-of-contact for local advocacy groups
- Participate in local and national events and programs
- Upon request, meet with patients and caregivers to answer questions related to Pfizer Hemophilia resources

"IT'S IMPORTANT TO CONNECT ON ALL LEVELS: HTCs, PATIENTS, FAMILIES, THE WHOLE COMMUNITY."

—Chris Liddell



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