Hemogram

Western Pennsylvania Chapter of the National Hemophilia Foundation

Summer 2018

Inside this issue

DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

If your company is participating in the United Way campaign, you may designate all or a portion of your gift to the Chapter.

WPCNHF Contributor Agency Code Number is: **83**

WPCNHF's 4th Semi-Annual Cornhole Tournament

WPCNHF's Fourth Semi-Annual Cornhole Tournament was held on April 7, 2018 at The Cornerstone at Tonidale. This double elimination tournament was managed by Steel City Cornhole. Warm up and registration started at 1:00pm and the tournament began at 2:00pm. Each participant received an event t-shirt and each participant over 21 years received a drink ticket.

It was a full house as 19 Competitive Teams and 17 Social Teams competed for the first place prize in their division. A Chinese Auction was held and we raffled off some great items including an overnight stay at the Mountaineer Grande Hotel, Gateway Clipper Fleet Captain's Dinner Cruise, a variety of amusement park tickets, and tickets to the Pittsburgh Pirates, Washington Wild Things and the Altoona Curve.

Congratulations to the winners of the Cornhole Tournament!

Competitive Division
First Place -
Trey Burchfield and Adam Hissner

Second Place -
Joey Castellano and Dave Kolenc

Social Division
First Place - Keith Jackson and Matt Maples

(Continued on next page)

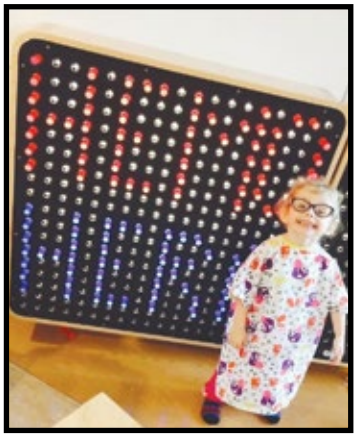
WPCNHF's 4th Semi-Annual Cornhole Tournament

(Continued from previous page)

WPCNHF would like to thank everyone who participated in the event, sponsored the event, donated items, and volunteered their time to help make the event a success! Special thanks to Joe Castellano of Steel City Cornhole for doing an amazing job running the tournament, Lindsay McNany for literally recruiting a bus full of participants, Melissa Kendrick from Cottrill's Pharmacy for sponsoring a number of teams, Michelle from The Cornerstone at Tonidale, and our amazing volunteers Allie and Chrissy!

Thank you to our sponsors: Corn in the Hole Sponsor: CSL Behring, Corn on the Cob Sponsors: The Hemophilia Center of Western Pennsylvania, Novo Nordisk, and Shire, Woody Boarder Sponsors: Bayer and HPC Specialty Pharmacy. We are excited to report that over $7,500 was raised! 100% of this money will stay local to support the members of the Western PA Chapter of the National Hemophilia Foundation. Please be sure to save the date for WPCNHF's Fifth Semi-Annual Cornhole Tournament which will be held on Saturday, September 15, 2018 at the North Park Boat House in conjunction with the Hemophilia Walk and Run for Their Lives 5k. We hope to see you there!

Meet Charlotte's Hemo Heroes



Charlotte's Hemo Heroes are an amazing group of 20 individuals who come together throughout the year in support of 4 year old Charlotte. In March of 2015 Charlotte was diagnosed with a bleeding disorder after she had a bad nose bleed that lasted overnight. After a week-long stay at the Children's Hospital of Pittsburgh she started receiving treatment at the Hemophilia Treatment Center of Western Pennsylvania. Charlotte now receives factor 3 days a week to put clotting agents back into her blood. One day a week she receives an ethanol lock to help keep her port clear of bacteria.

Charlotte's Hemo Heroes work tirelessly to bring awareness to Charlotte's disorder and help other children like her. They describe themselves as a team of Heroes that plan to help Charlotte live her life as she chooses and with as much ease as possible. They realize not every child can afford factor and every child's struggle is different. Each year they participate in the Unite for Bleeding Disorders Walk and hold many fundraisers in support of the Western Pennsylvania Chapter of the National Hemophilia Foundation and the Children's Hospital of Pittsburgh. We are so thankful for their passion and dedication to making the world a better place for those with bleeding disorders.

Charlotte's Hemo Heroes Upcoming Fundraisers

- July 28th - Motorcycle/Car Poker Run at Super Shooters in Kittanning, PA Learn more at: https://www.facebook.com/events/182540769130775
- September 2nd- Superhero Fun Run – More Details TBA

HCWP Corner

Greetings from HCWP:

Summer is upon us and it looks to be a hot one! Camp registration is officially closed. The superhero planning committee is adding the final touches to what is sure to be an action-filled, super week! If you have any questions, please reach out by phone 412-209-7344 or e-mail CampH2C@itxm.org

If you are traveling this summer (by plane, train, boat, or car), it is a good idea to have a travel letter with you. This letter is provided to you by your HTC and signed by your doctor outlining your diagnosis, treatment, and other important information that can be helpful to you whether you are transporting your medication or need to visit a medical center while away. If you provide the location of where you are going, your center can also add the nearest HTC and local emergency department contacts and addresses.

Please make sure to keep your appointments current with HCWP. Your health is a priority and we need to see you regularly (yearly or every other year depending on your diagnosis and unique situation) so your plan of care stays accurate and up-to-date for prescriptions and procedures. We are sending reminder cards to patients to give you a gentle reminder to set up an appointment.

If you are experiencing barriers to your care, please reach out to the HCWP social workers who can help connect you to resources to breakdown those barriers. In addition to community resources, HCWP has a Patient Assistance Fund (PAF) as part of our grant through the Pennsylvania Department of Health's (DOH) Specialty Care Program (SCP). This PAF is designed to pay for unmet needs of financially eligible individuals being seen at the Hemophilia Center for condition-specific services. The intent of the funding is to assist patients in addressing barriers that prevent them from keeping appointments to comply with treatments to maintain or improve their health. This will not replace the Chapter Patient Assistance Program.

There are corporate changes at the parent organization that manages the Hemophilia Center of Western Pennsylvania ("HCWP"). This corporate change will not affect your care or the services you receive from HCWP.

As you may have heard over the past year, Blood Systems, Inc. ("BSI") is now the over-arching parent organization of the HCWP as a result of its relationship with The Institute for Transfusion Medicine ("ITxM"). Similar to HCWP and ITxM, Blood Systems is a 501(c)(3) non-profit corporation that is focused on transfusion medicine. It is one of the nation's oldest, largest and most-respected non-profit transfusion medicine organizations, with a long and valued commitment to the hemophilia community. Blood Systems provides blood and blood-related services to more than 1,000 hospitals in 28 states. We believe that the expertise, resources and dedication of BSI, ITxM and HCWP in the areas of transfusion medicine and research will enhance the delivery of care to the patients in western Pennsylvania.

This behind the scenes change will not change the medical care or factor program services we provide. Your health is our highest goal. We consider it a privilege to provide you with the best possible care and treatment! If you have any questions or concerns, please do not hesitate to contact the HCWP staff at (412) 209-7280.

Letter From The Executive Director, Alison Yazer

I can't believe how quickly time has flown by and that it's almost time for Camp Hot-to-Clot again! The Chapter hosted many great educational programs and fundraisers over the past few months, made several advocacy trips and things are shaping up for the rest of the year. I hope that each of you had an opportunity to attend at least some of the events we held. We are trying to continually increase our programmatic offerings, but we need to know from you what you're seeking…so let us know your ideas!

One of the biggest things the Chapter has done over the past few months is join the Hemophilia Federation of America (HFA). After attending their Symposium (their national annual meeting) in April, Janet and I were so impressed by them that we decided to join. See the short article a few pages away for some more information, and join us at the Erie Educational Event in November to learn even more!

Things are changing constantly within the bleeding disorders community. We hope that you will continue to rely on the HCWP and the Chapter to keep you up to date on policies and legislation that can impact you and your family. If you have questions, please let us try to help answer them!

As always, please contact the office with any questions or concerns. We are here to serve you, but we can only do so with your input!

Sincerely

Alison R. Yazer
Executive Director

Board of Directors

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Alison Yazer

Member Services Manager
Janet Barone

Marketing & Events Manager
Kara Dornish

Staff office hours are Monday through Friday from 9 a.m. until 4 p.m. Every attempt will be made to return calls received during regular office hours on the same day.

WPCNHF Wish List

The Chapter is always doing fundraisers to raise money for our educational programs and member support activities but sometimes we just need a few small things for the office. WPCNHF has a list of items needed in the office. If you, or anyone you know, is interested in donating any of the following please contact the office at info@wpcnhf.org or call us at 724-741-6160.

- White copy paper by the ream or by the case
- Sticky Notes
- Forever U.S. Postage stamps
- 10 x 13 Ready-seal envelopes for newsletter mailings

Mission Statement:

WPCNHF strives to enrich the lives of those with bleeding disorders in Western Pennsylvania and respond to the needs of the community in a dynamic environment.

Indications for FEIBA [Anti-Inhibitor Coagulant Complex]

FEIBA is an Anti-Inhibitor Coagulant Complex indicated for use in hemophilia A and B patients with inhibitors for:

- Control and prevention of bleeding episodes
- Use around the time of surgery
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes.

FEIBA is not indicated for the treatment of bleeding episodes resulting from coagulation factor deficiencies in the absence of inhibitors to coagulation factor VIII or coagulation factor IX.

Detailed Important Risk Information for FEIBA

WARNING: EVENTS INVOLVING CLOTS THAT BLOCK BLOOD VESSELS

- **Blood clots that block blood vessels and their effects have been reported during postmarketing surveillance following infusion of FEIBA, particularly following the administration of high doses and/or in patients with a risk of forming blood clots.**
- **If you experience any of these side effects, call your doctor right away.**

You should not use FEIBA if:

- You had a previous severe allergic reaction to the product (reactions causing discomforts that are damaging and life threatening)
- You have signs of development of small blood vessel clots throughout the body
- You have sudden blood vessel clots or blocked blood vessels, (e.g., heart attack or stroke)

Events involving blood clots blocking blood vessels can occur with FEIBA, particularly after receiving high doses and/or in patients with risk factors for clotting.

Infusion of FEIBA should not exceed a dose of 100 units per kg body weight every 6 hours and daily doses of 200 units per kg of body weight. Maximum injection or infusion rate must not exceed 2 units per kg of body weight per minute.

At first sign or symptom of a sudden blood vessel clot or blocked blood vessel (e.g., chest pain or pressure, shortness of breath, altered consciousness, vision, or speech, limb or abdomen swelling and/or pain), stop FEIBA administration promptly and seek emergency medical treatment.

Allergic-type hypersensitivity reactions, including severe, sometimes fatal allergic reactions that can involve the whole body, can occur following the infusion of FEIBA. Call your doctor or get emergency treatment right away if you get a rash, hives or welts, experience itching, tightness of the throat, vomiting, abdominal pain, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Because FEIBA is made from human plasma it may carry a risk of transmitting infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

The most frequent side effects observed during the prophylaxis trial were anemia, diarrhea, bleeding into a joint, signs of hepatitis B surface antibodies, nausea, and vomiting.

The serious side effects seen with FEIBA are allergic reactions and clotting events involving blockage of blood vessels, which include stroke, blockage of the main blood vessel to the lung, and deep vein blood clots.

Call your doctor right away about any side effects that bother you during or after you stop taking FEIBA.

Please see next page for Important Facts about FEIBA.
To see the Full Prescribing Information, including BOXED WARNING on blood clots, go to www.FEIBA.com.

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.

References: 1. Pergantou H, Matsinos G, Papadopoulos A, Platokouki H, Aronis S. Comparative study of validity of clinical, X-ray and magnetic resonance imaging scores in evaluation and management of haemophilic arthropathy in children. Haemophilia. May 2006;12(3):241-247. **2.** Gringeri A, Ewenstein B, Reininger A. The burden of bleeding in haemophilia: is one bleed too many? Haemophilia. Jul 2014;20(4):459-463. **3.** FEIBA Prescribing Information. **4.** Antunes SV, Tangada S, Stasyshyn O, et al. Randomized comparison of prophylaxis and on-demand regimens with FEIBA NF in the treatment of haemophilia A and B with inhibitors. Haemophilia. 2014;20(1):65-72.

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Important Facts about FEIBA (Anti-Inhibitor Coagulant Complex)

What is FEIBA used for?

FEIBA (Anti-Inhibitor Coagulant Complex) is used for people with Hemophilia A or B with Inhibitors to control and prevent bleeding episodes, before surgery, or routinely to prevent or reduce the number of bleeding episodes. It is NOT used to treat bleeding conditions without inhibitors to Factor VIII or Factor IX.

When should I not take FEIBA?

You should not take FEIBA if you have had hypersensitivity or an allergic reaction to FEIBA or any of its components, including factors of the kinin generating system, if you have a condition called Disseminated Intravascular Coagulation, which is small blood clots in various organs throughout the body, or currently have blood clots or are having a heart attack. Make sure to talk to your healthcare provider about your medical history.

What Warnings should I know about FEIBA?

FEIBA can cause blood clots, including clots in the lungs, heart attack, or stroke, particularly after high doses of FEIBA or in people with a high risk of blood clots. Patients that have a risk of developing blood clots should discuss the risks and benefits of FEIBA with their healthcare provider since FEIBA may cause blood clots. FEIBA can cause hypersensitivity or allergic reactions and infusions site reactions, and these reactions can be serious. Because FEIBA is made from human plasma, it may carry the risk of transmitting infectious agents, for example, viruses, including Creutzfeldt-Jakob disease (CJD) agent, and the variant CJD agent. Although steps have been taken to minimize the risk of virus transmission, there is still a potential risk of virus transmission.

What should I tell my healthcare provider?

Make sure to discuss all health conditions and medications with your healthcare provider. If you are pregnant or are planning to become pregnant, or are a nursing mother, make sure to talk with your healthcare provider for advice on using FEIBA.

What are the side effects of FEIBA?

The most frequent side effects of FEIBA are: low red blood cell count, diarrhea, joint pain, hepatitis B surface antibody positivity, nausea, and vomiting. The most serious side effects of FEIBA include: hypersensitivity reactions, including anaphylaxis, stroke, blood clots in the lungs, and blood clots in the veins. Always immediately talk with your healthcare provider if you think you are experiencing a side effect.

What other medications might interact with FEIBA?

The use of other clotting agents with FEIBA is not recommended, for example, tranexamic acid and aminocaproic acid. Be sure to talk with your healthcare provider and pharmacist about all medications and supplements you are taking.

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 FEIBA with your healthcare provider or pharmacist. The FDA-approved product labeling can be found at http://www.feiba.com/us/forms/feiba_pi.pdf or by calling 1-800-423-2090 and selecting option 5.

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Calendar of Upcoming Events

Tuesday, July 10
Recognizing and Responding to a Bleed
Altoona, PA

Saturday, July 14
Annual Meeting & Walk Kickoff
Pittsburgh, PA

Sunday, August 5 – Saturday, August 11
Camp Hot-to-Clot
Fombell, PA

Wednesday, August 8
Setting Educational Expectations
Seven Fields, PA

Saturday, August 25
New Parent Network
Ligonier, PA

Tuesday, September 11
Open to All Members
Overcoming Challenges
Punxsutawney, PA

Wednesday, September 12
Open to Amish Only
Overcoming Challenges
Punxsutawney, PA

Saturday, September 15
Unite for Bleeding Disorders Walk
North Park
Allison Park, PA

Saturday, September 15
Run for Their Lives 5K
North Park
Allison Park, PA

Saturday, September 15
Cornhole Tournament
North Park
Allison Park, PA

Saturday, September 22
Coalition for Hemophilia B
Pittsburgh, PA

Saturday, October 6
Oktoberfest
Pittsburgh, PA

Thursday, October 11-Saturday, October 13
NHF's Bleeding Disorders Conference
Orlando, FL

Saturday, October 13
Pittsburgh's Bloody Bar Crawl
Fundraising Event in Pittsburgh's South Side

Thursday, November 8
Women's Night Out
Pittsburgh, PA

Friday, November 16
New Parent Network
Erie, PA

Saturday, November 17
Fall Program
Erie, PA

March 22-24, 2019
Education Weekend
Seven Springs, PA

Ask us about sponsorship opportunities and how you can help!

CFC®
Combined Federal Campaign

Combined Federal Campaign

WPCNHF is an approved charitable organization for the Combined Federal Campaign (CFC). If you participate in the CFC, please consider designating all or a portion of your donation to the Chapter.

WPCNHF CFC Number is: 81343

Why did WPCNHF join the Hemophilia Federation of America (HFA)?

NHF and HFA are very different organizations and they're really not in competition with one another; they're more like complimentary organizations. Many other Chapters are members of both NHF and HFA as we now are. HFA is a non-profit 501(c)(3) organization incorporated in 1994 to address the evolving needs of the bleeding disorders community. HFA serves as a community-based organization, committed to championing the needs of families living with chronic, often painful, and debilitating bleeding disorders. They advocate for safe, affordable, and obtainable therapies and health coverage. Ultimately, HFA seeks a better quality of life for all persons with bleeding disorders.

For nominal dues that the Chapter pays, WPCNHF now has access to a wide variety of educational programming that we can bring to you, in addition to resources for our various support groups; and our membership gets YOU access to their own support programs, as well as to their financial aid program – which can pick up where our patient assistance program leaves off. Additionally, you will soon start receiving their newsletter, which is packed full of great information. Don't worry – your information is kept confidential and is only seen by the mail-house. If you'd prefer to not receive it, please just let someone at the Chapter know and we'll remove you from the list.

A representative from HFA will be presenting an HFA 101 – an overview of who they are and what they do – at our Erie education event on November 17, but if you'd like more information in the meantime, don't hesitate to call the Chapter office or visit HFA's website at hemophiliafed.org.

Chapter Survey

In the near future, the Chapter will be conducting an important member survey to better understand your current needs and communication preferences. Since we conducted our last survey, a couple of years ago, our Chapter membership has grown significantly and our communication options have increased. In order to serve you best, it's critical for us to know what type of information, educational programs, and social events are most relevant to you. In addition, we need a clearer understanding on how you want to receive information and notifications about programs and other events (i.e., U.S. mail, e-mail, social media, text messages, etc.).

Please take the survey. It is important for all Chapter members to provide input to WPCNHF.

Hemophilia Federation of America Annual Symposium 2018

By Jen Miller

In late April, we travelled to Cleveland, Ohio to participate in The Hemophilia Federation of America's 2018 Symposium, thanks to WPCNHF. We arrived mid-day Thursday and, following check-in, were immersed in the festivities. The kids got to join others in their age group for fun activities and we headed to our first session - not really knowing what to expect.

Our first session was a group panel featuring four unique individuals: a mother of an affected son, an affected man who had transplant surgery, an affected woman whose twin sister was not affected and a man who grew up in India and could compare his experience with treatment there versus in the United States. It was a mix of storytelling and Q&A. The time went quickly and was a good reminder of how strong and determined many in the bleeding disorder community really are. We participated in another session - a group rap session - before rejoining the kids for a big dinner and trivia night.

Friday was a full day with lots scheduled. The kids joined their groups early for a busy day which included a trip to the Great Lakes Science Center. We started the day with a session on advocacy. This turned out the theme of the morning. After a big lunch, we joined a session on gathering research before finding a large session on insurance—an ever changing and scary subject for most in attendance. This session broke into groups to allow everyone to get specific questions and concerns addresses. Feeling pretty worn down by pick-up time, we took the kids to the indoor hotel pool for some fun.

Saturday was the best day of the event. The day started with a study review on stress. It was interesting and confirmed that parents in this community live with sky high levels of stress daily. Not a surprise at all. The big medical research panel occurred Saturday morning and was the best attended session we witnessed. It was a bit of history, a lot of talk on new drugs hitting the market now and in the near future and some research in its infancy. Can you imagine factor delivered through rabbit milk you can drink? How about in lettuce? This time was well spent and provided a ton of good information.

We spent the final afternoon listening to a psychologist talk about helping your child transition into different phases in their life. It was common sense information delivered with a unique spin and in a useful manner. The final session broke up the Moms and Dads into separate groups to spend time asking questions, getting tips and lending support to other parents.

The symposium wrapped up with a big event at The Rock & Roll Hall of Fame. There were all kinds of foods that represented Cleveland, a live band and plenty of time to tour the museum and soak in the history.

The trip was a lot of fun and a good experience. While a bit overwhelming at times, since it was our first national conference, we were fortunate to meet many wonderful people, gather a lot of useful information and spend time together.

Infusion Day

Our annual infusion day was held on Saturday, April 21, in partnership with staff from the Hemophilia Treatment Center of Western PA. Although attendance was lower than in past years, the families in attendance received critical instruction and support, and had time to practice the infusion process with a training kit and on themselves!

We thank Bayer Healthcare for providing the BayCuff™ training kits and we thank the following for supporting the event through exhibit displays: Bayer Healthcare, CSL Behring, Genentech, Octapharma, and Pfizer. We also thank Scott Domowicz and the volunteers from the Career Training Academy.

The Chapter and HCWP are dedicated to continuing to provide this important learning opportunity to patients and their families. Next year, we will hold this event in conjunction with the Chapter's Education Weekend at Seven Springs Mountain Resort, during the weekend of March 22-24, 2019. We hope to see you there!

Thank You Matthew Berry!

Matt sold red ties at his high school, the Cathedral Preparatory School, and raised an amazing $650 for WPCNHF!! Thank you Cathedral Preparatory School, its students and faculty, Father Scott Jabo, and Principal Mr. Jim Smith for allowing Matt to set up this awareness and fundraising function to support WPCNHF.

Mid-Atlantic Region III HTCs

By Janet Barone

It's very likely that you or someone you know receives care at a Hemophilia Treatment Center (HTC). For those of us living in Western PA, we are fortunate to have the Hemophilia Center of Western PA (HCWP) in our region! Did you know that the HCWP is one in a national network of over 140 HTCs? HTCs in this network are supported and funded by the Maternal and Child Heath Bureau (MCHB) of the Health Resources and Services Administration (HRSA). In addition, they receive funding from the Centers for Disease Control and Prevention (CDC). The HTCs are divided into eight regions and the HCWP is located in Mid-Atlantic Region III.

Each region has a Core Center, which works to ensure that individuals with hemophilia, von Willebrand Disease, and other bleeding disorders have access to appropriate, comprehensive care. The Core Centers oversee the services provided by the HTCs in their region and collaborate with MCHB and the CDC to improve treatment and support patients with inherited bleeding and clotting disorders. Mid-Atlantic Region III consists of 15 HTCs, which are located in Pennsylvania, Delaware, Maryland, Virginia, West Virginia, and the District of Columbia. The Core Center for Region III is located at The Children's Hospital of Philadelphia (CHOP).

Every year the Mid-Atlantic Region III holds an annual meeting attended by treatment center staff including physicians, physical therapists, social workers, clinical nurses, research nurses, and genetic counselors. In addition, Chapters in the region may send up to two people. This year, our Chapter sponsored two individuals to attend the annual meeting, which was held in Alexandria, VA: Brendon Simpson and Kimberly Walsh. The agenda included Recent Additions to the VWF test menu, Improving the Evaluation and Management of Abnormal Uterine Bleeding in Adolescent Women Presenting for Emergency Care, Novel Biomarkers for Inhibitors in Hemophilia A, Sports Participation in Patients with Bleeding Disorders, and Breakout Sessions—including one for Consumers.

During the Consumer breakout session, we talked about patient engagement and how the treatment centers in Region III could better serve patients. Topics included patient portals, advisory boards, training programs, and communication methods & technology. The suggestions were reported back to all in attendance and the Regional Executive Committee will review and discuss them further.

What did Kimberly and Brendon think of the meeting?

Brendon: "I found the Region III meeting to be quite informative. It was good to see how information was shared among the different treatment centers. The presenters were professional and their presentations were well done. All in all it was a good couple of days."

Kimberly: "I would like to thank the WPCNHF for allowing me to attend the Region III meeting. I had no idea how dedicated our physicians, nurses, social workers and therapists were. I learned that it's a huge collaborative effort currently happening to possibly advance treatments available for my bleeding disorder. I learned that our community has become more inclusive by addressing as many disorders as possible."

2018 Volunteer Opportunities

Packet Pick Up- Volunteers are needed on Thursday, September 13 from 6pm-8pm and Friday, September 14 from 4pm-8pm to work Run for Their Lives 5k packet pick up at Pro Bike + Run in Robinson Twp.

Walk Day Volunteers Opportunities – Saturday, September 15th

Set up- Arrive at 6:30am- Help set up tables, chairs, and signage.

Direct Parking/Traffic- Arrive by 7:15am- Wave in and direct vehicles to parking lot, assist pedestrians with safely crossing the street to the Boat House.

Run Registration & Check-In- Arrive at 7:15am- Help register onsite individuals and check-in already registered individuals.

Cornhole Registration & Check-In- Arrive at 7:45am- Help register onsite individuals and check-in already registered individuals

Photographer- Arrive at 8:00am- Capture candid moments and important parts of the day. Must have own equipment and share all rights to photos after the event.

Race Water- Arrive at 8:00am- Stand along the race route to direct runners and walkers and pass out water to the runners and walkers.

Chinese Auction & Food Table- Arrive at 8:30am- Sell tickets for the Chinese auction. Help set up food table and make sure area is kept clean.

Walk Registration & Check-In- Arrive at 8:30am- Help register onsite individuals and check in already registered individuals.

Unite Table - Arrive at 8:30am- Organize and pass out Unite t-shirt, bags, and swag.

Team T-Shirt Contest – Arrive at 9am – Accept and keep track of donations received for the Team T-Shirt Contest.

Clean Up & Break Down Crew- Arrive by 11:30pm- Help break down tables and chairs, clean up, and load up truck.

Please e-mail Kara Dornish at kara@wpcnhf.org or call 724-741-6160 to sign up for any of the above volunteer opportunities. We appreciate all help and would like to thank you in advance for your interest and support!!

SAVE THE DATE

WPCNHF PRESENTS
PITTSBURGH'S
BLOODY
BAR CRAWL

MAKING THE WORLD A BETTER PLACE FOR THOSE WITH BLEEDING DISORDERS

SATURDAY, OCTOBER 13TH

VISIT WPCNHF.ORG FOR MORE INFO

The Hemophilia Center of Western Pennsylvania

The Hemophilia Center of Western Pennsylvania clotting factor program was established in 2000 as a complement to the Center's other comprehensive care services. The clotting factor program allows the Center the opportunity to offer clotting factor to its patients, thereby supplementing its comprehensive treatment care model and providing the best possible care for its patients.

Please contact the Center at (412) 209-7280 for more information about how this program can benefit you and the entire bleeding disorder community.

The Hemophilia Center of Western Pennsylvania supports patient choice consistent with the Veterans Health Care Act of 1992 and maintains a freedom of choice policy where patients are informed of their choices regarding factor replacement products.

Factor Program Services

- All factor product brands available
- Online factor ordering available
- 24 – 48 hour delivery
- Same day courier service for emergent needs
- On-call services, 24/7
- Home treatment supplies
- Lot tracking for recall notification
- Online home treatment records
- Insurance benefit information assistance

Patient Benefits

- Direct communication and service from the Center's treatment team
- Support of the Center's operations
- Expansion of patient services

International Study Group Findings Suggest Prophylaxis Could Reduce Hospitalizations for VWD Patients

Researchers from Sweden and the U.S. recently published an article that focused on potential correlations between patients with von Willebrand disease (VWD), hospitalizations and prophylaxis. The authors conducted a retrospective study of inpatients and outpatients, both with and without VWD. Their objective was to investigate the frequency of hospital admittances and determine whether the implementation of a prophylactic treatment regimen is associated with a reduction in hospitalizations.

The lead author of the article was Elena Holm, MD, Department of Translational Medicine, Lund University, Skåne University Hospital in Lund, Sweden. Holm and her colleagues were joined by Thomas Abshire, BloodCenter of Wisconsin and Departments of Pediatrics and Medicine, Blood Research Institute, Medical College of Wisconsin in Milwaukee.

The authors reviewed patient data from two primary groups. The first group encompassed population-based registers from the National Board of Health and Welfare and Statistics Sweden. Data from these registries were incorporated into Sweden's Congenital Bleeding Disorders study. These registries included 2,790 individuals with a diagnosis of VWD between the year 1987 and 2009. They found that VWD patients were admitted to hospitals at a rate 2.3 times higher than the unaffected control groups, and spent on average, 2.0 times as many days as hospitalized inpatients. The most common impetus for these hospitalizations were gastrointestinal (GI) bleeding, menorrhagia (heavy menstrual bleeding) and epistaxis (nose bleeds). Outpatient visits were also twice as common amongst VWD patients.

For the second segment of their research, investigators tapped the von Willebrand Disease Prophylaxis Network (VWD PN), an international study group established to evaluate the prophylactic regimens of patients with VWD. In all, 105 patients from participating treatment centers in North America and Europe were counted in this study, including individuals with type 3 (52%), type 2A (22%), type 1 (12%), type 2B (9%) and other types (4%). As in the registries, GI bleeding was the most common cause of hospitalization. Of the 122 bleed-related hospitalizations

(Continued on page 17)

Meet Rolling for Ryker

Team Rolling for Ryker is composed of the people who love Ryker the most, his grandparents, aunts, uncle, cousins, and of course his mom and dad. Ryker is 8 months old and was diagnosed on Christmas with hemophilia after an emergency run to Children's Hospital. When they ran a routine blood test the doctors found out Ryker had hemophilia. Turns out Ryker has more in common with his Great Grandfather than we thought.

Fundraising Tips from Mindy Perry (Ryker's Mom and Team Captain of Rolling for Ryker): My family hasn't done much fundraising in the past, but has found that facebook has helped a lot, or family and friends have donated, and even contacts through my husbands company. When we found out about the walk my mother and I printed out packets with information regarding hemophilia, and mailed them to large companies my husband works closely with. The packets of course included an adorable picture Ryker. Who can say no to an adorable baby's face!

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

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

Discover **HEMLIBRA.com**

WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

HEMLIBRA™
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

HOW SHOULD I USE HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

WHAT ARE THE OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

The most common side effects of HEMLIBRA include: redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

Medication Guide Brief Summary
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with aPCC (FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
  - confusion
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
  - swelling in arms or legs
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - eye pain or swelling
  - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

WHAT IS HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children with hemophilia A with factor VIII inhibitors.

- Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.
- HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

BEFORE USING HEMLIBRA, TELL YOUR HEALTHCARE PROVIDER ABOUT ALL OF YOUR MEDICAL CONDITIONS, INCLUDING IF YOU:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

HOW SHOULD I USE HEMLIBRA?

See the detailed "Instructions for Use" that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.
- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

WHAT ARE THE POSSIBLE SIDE EFFECTS OF HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

The most common side effects of HEMLIBRA include:
- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

HOW SHOULD I STORE HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than 7 days at 86°F (30°C) or below.
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

GENERAL INFORMATION ABOUT THE SAFE AND EFFECTIVE USE OF HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

WHAT ARE THE INGREDIENTS IN HEMLIBRA?

Active ingredient: emicizumab

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Issued: 11/2017

HEMLIBRA™
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Genentech
A Member of the Roche Group

International Study Group Findings Suggest Prophylaxis Could Reduce Hospitalizations for VWD Patients

(Continued from page 13)

reported, 75 occurred prior to the initiation of prophylaxis and 47 after start of prophylaxis, which translates to 712 and 448 events per 1000 patient years. These findings would indicate that significantly fewer hospitalizations occurred after the initiation of a prophylactic treatment regimen.

The authors cited limitations such as a dearth of data on additional variables that could inform study conclusions and a lack of information that could help remove sources of bias or to investigate outcomes related to VWD type or mode of treatment. On the other hand, a major strength of this type research is that general population data fed by national registries allow investigators access to decades worth of healthy control data to match with affected patients, allowing for long term comparisons.
Holm and her fellow investigators also note the potential positive impact of prophylaxis in VWD patients as demonstrated by the VWD PN.

"The VWD PN enrolled the largest cohort using prophylaxis for the management of VWD, concluded the authors. "Prophylaxis using well defined regimens, as in this study, reduced the need for in- and outpatient visits which should translate to increased quality of life for patients and their families."

The article "Bleeding-related Hospitalization in Patients with von Willebrand disease and the Impact of Prophylaxis: Results from National Registers in Sweden Compared with Normal Controls and Participants in the von Willebrand Disease Prophylaxis Network," was published in the February 2018 edition of the journal *Haemophilia*.

Embracing the Unique

By Laurie Kelley

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

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

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

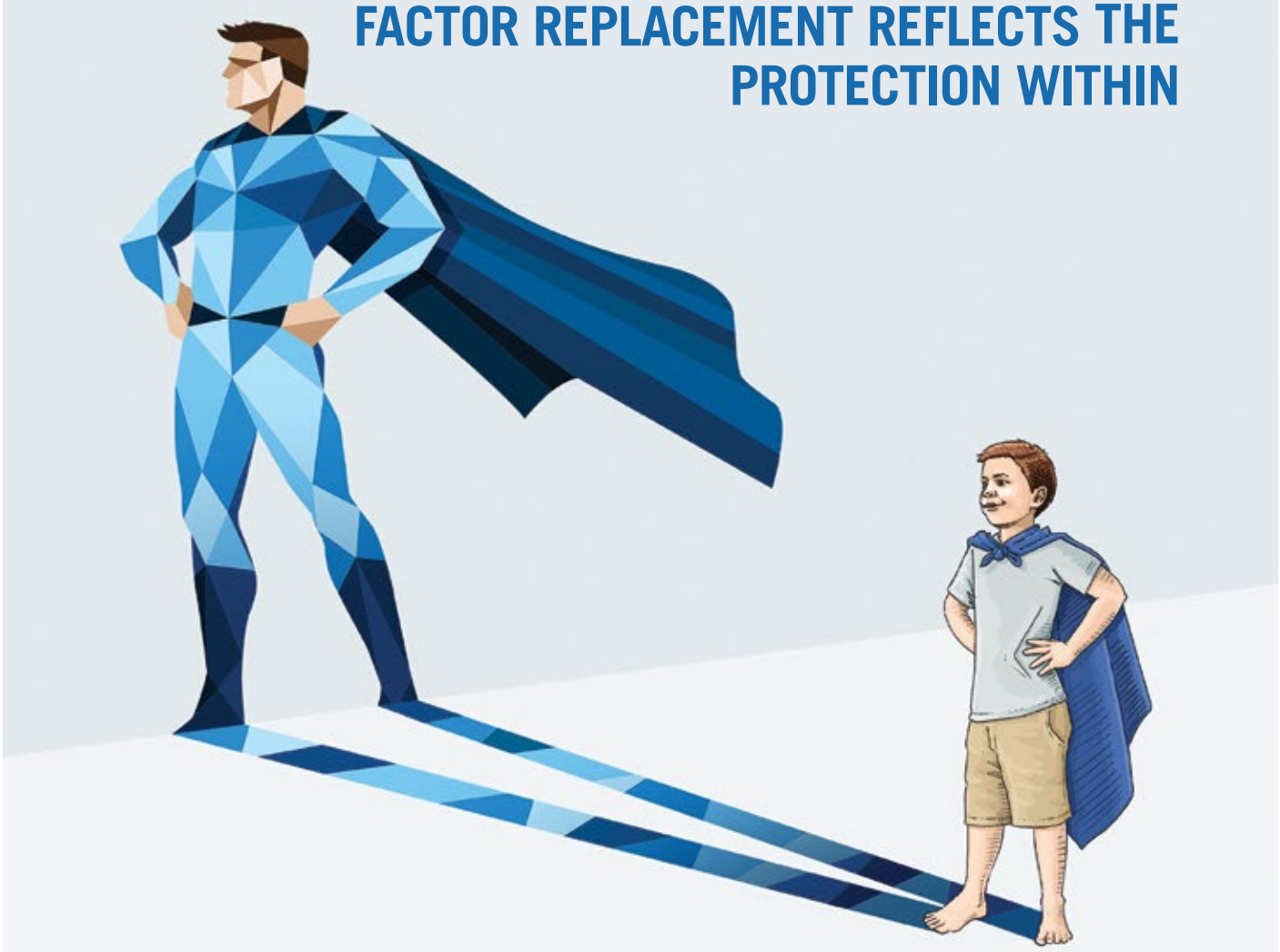
Up until about the last 10 years, hemophilia treatment centers (HTCs) often prescribed factor dosages based on weight, and determined a prophylaxis regimen based on a strict protocol from clinical studies. We now know that every child needs to have a pharmacokinetic (PK) or recovery study done to determine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

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

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

(Continued on page 19)

FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



For people with hemophilia, Factor treatment temporarily replaces what's missing.[1,2] With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.[2-6]

Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 70 years.[7]

Stay empowered by the possibilities.

References: 1. Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet.* 2016;388:187-197. **2.** Canadian Hemophilia Society. Factor replacement therapy. http://www.hemophilia.ca/en/bleeding-disorders/hemophilia-a-and-b/the-treatment-of-hemophilia/factor-replacement-therapy/. Accessed May 18, 2018. **3.** Franchini M, Mannucci PM. The history of hemophilia. *Semin Thromb Hemost.* 2014;40:571-576. **4.** Hvas AM, Sørensen HT, Norengaard L, Christiansen K, Ingerslev J, Sørensen B. Tranexamic acid combined with recombinant factor VIII increases clot resistance to accelerated fibrinolysis in severe hemophilia A. *J Thromb Haemost.* 2007;5:2408-2414. **5.** Antovic A, Mikovic D, Elezovic I, Zabczyk M, Hutenby K, Antovic JP. Improvement of fibrin clot structure after factor VIII injection in haemophilia A patients treated on demand. *Thromb Haemost.* 2014;111(4):656-661. **6.** Berg JM, Tymoczko JL, Stryer L. Many enzymes are activated by specific proteolytic cleavage. In: *Biochemistry.* 5th ed. New York, NY: WH Freeman; 2002. https://www.ncbi.nlm.nih.gov/books/NBK22589/. Accessed May 18, 2018. **7.** Shire. Shire's 70+ year commitment to the hemophilia community. https://www.shire.com/en/newsroom/2018/january/7sossj. Accessed June 6, 2018.

Shire

Embracing the Unique

(Continued from page 17)

And then there is Jen Miller's five-year-old with severe hemophilia A. Jen calls him a "typical boy" who enjoys video games, swimming, T-ball, and playing with his friends. His factor half-life is very short, which is not typical, but this doesn't seem to impact his bleeding patterns.

When a shorter half-life does impact bleeding patterns, and parents instinctively know something isn't right, they need to alert their HTC staff, sometimes to prove that their child does not fit a category or label. In these cases, parents should request a PK study. Crystal laments, "My boys' hematologist makes me feel like I'm doing something wrong, but refuses to do a PK study." June adds, "For years, our medical staff acted as though we were to blame when he'd have bleeds—even though he was infusing regularly."

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

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

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

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

Crystal laughs, "I could probably write a book about all the ways my boys 'differ' from the typical definition of hemophilia."

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

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Column: YOU
Sponsored by Shire

Getting to Know HCWP Staff

Cheri McShea
Physical Therapist @ HCWP

Birthplace: Sewickley Hospital

First job: Non-professional: Selling hotdogs at Pup-A-Go-Go, Greengate Mall

Professional: Physical Therapist at Mercy Hospital, Pittsburgh

Accomplishment you're proudest of: Raising two amazing daughters

What three words describe you best? Patient, sensitive, focused

Dream vacation: Hiking, biking, and exploring non-tourist areas of Ireland and Scotland

Things you can do without: Negative energy

Person you'd most like to have dinner with: Barack Obama

Movie you could see anytime: Jason Bourne movies

TV show you try not to miss: I don't watch any TV shows!

Three things that can always be found in your refrigerator: Organic fat-free milk, tart cherry juice, Vermont maple syrup

Secret vice: Not so secret – dark chocolate ☺

Who would play you in the movies? ??? With not watching TV, I am not very knowledgeable about actresses.

Your petpeeve about [city]: Poor access between Pittsburgh and the eastern suburbs

People may be surprised to know that: I've never traveled outside of the US (yet!)

WPCNHF'S 5TH SEMI-ANNUAL

CORNHOLE TOURNAMENT

SATURDAY, SEPTEMBER 15, 2018

NORTH PARK BOAT HOUSE
10301 PEARCE MILL ROAD
ALLISON PARK, PA 15101

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TOURNAMENT:9AM

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NOW THROUGH SEPTEMBER 14
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WPCNHF.ORG

THIS DOUBLE-ELIMINATION TOURNAMENT, RUN BY STEEL CITY CORNHOLE, WILL BE HELD IN CONJUNCTION WITH THE HEMOPHILIA WALK AND THE RUN FOR THEIR LIVES 5K. REGISTER ONLINE OR IN PERSON THE DAY OF THE TOURNAMENT.

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ALL PROCEEDS STAY LOCAL TO BENEFIT INDIVIDUALS LIVING WITH BLEEDING DISORDERS IN WESTERN PENNSYLVANIA.

QUESTIONS? CONTACT KARA AT KARA@WPCNHF.ORG OR 724-741-6160

Western Pennsylvania Chapter of the National Hemophilia Foundation
20411 Route 19, Unit 14
Cranberry Township, PA 16066
Phone: 724-741-6160 Toll Free: 800-824-0016 Fax: 724-741-6167
info@westpennhemophilia.org