Hemogram

Western Pennsylvania Chapter of the National Hemophilia Foundation

Fall 2017

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

Fall Programs

We are off to a running start with our fall programs. We held two programs during the first official weekend of the season and have several more coming up right around the corner! On Friday, September 21, we held a dinner program in Erie for our New Parent Network families. Nancy Stinely, RN and Kathaleen Schnur, LSW, both from the Hemophilia Center of Western PA (HCWP), co-presented Prepping for Pokes & Prophy to parents of children ages 6 and under, while babysitters watched the children in a nearby room. We thank Bioverativ, CSL Behring, CVS Specialty, Novo Nordisk, Octapharma, Pfizer, and Shire for sponsoring the New Parent Network series of events.

The next day, Infusion Day was held at the same location. Johana Schafer, Research Nurse and Katherine Bush, LSW, from the HCWP, joined Nancy and Kathaleen and staffed the learning stations for Infusion Day, which included a station for finding good veins, a station for infusing a fake vein with a training kit, and a station to practice accessing a vein and infusing with saline. Everyone who tried was successful! It was truly an empowering event. We thank Bioverativ, CVS Specialty, Diplomat, HCWP, and Novo Nordisk for sponsoring Infusion Day. In addition, we thank Bayer Healthcare for supplying the BayCuff™ self-infusion training kits.

The next weekend, men of the Chapter enjoyed Kayaking in North Park. Afterward they gathered for lunch and a discussion led by fellow member, Matt Pace.

By the time you are reading this article, Oktoberfest will have also taken place. We reached the maximum capacity for this event—200 people—early on! Maria Santaella, RN-BC, MSN, CPHON®, University of Miami Hemophilia Treatment Center, presented the program *It's Not Too Late to Save Your Joints*. Afterward, our members enjoyed the rest of the day at the Pittsburgh Zoo & PPG Aquarium. We thank Accredo, Cottrill's Pharmacy, CSL Behring, Diplomat, Genentech, HCWP, Novo Nordisk, Pfizer, and Shire for sponsoring this event.

Before the season is over, we will also be holding an event for women, for teens, and our annual "Winterfest" for all members. We will also be quite busy planning the calendar of events for 2018!

Camp Hot-To-Clot 2017

By: Michelle Alabek, MS, LGC
and Cheri McShea, DPT

Last summer, Camp Hot-to-Clot held a contest among former campers to help us decide on our theme for Camp Hot-to-Clot 2017. After reviewing several excellent and entertaining submissions, the Camp Planning committee selected emojis. In August, 76 Hot-to-Clot campers checked-in for a week-long "Emoji-con" at Camp Kon-o-Kwee in Fombell, PA.

Some highlights from the week include:

- Daily emoji appearances were used to highlight the four core values of Camp Hot-to-Clot: Caring, Honesty, Respect, and Responsibility. Each day focused on one core value. Staff members were able to recognize campers demonstrating that day's core value by providing them with a sticker to place in our camp-wide "Value Thermometer". By the end of the week, the thermometer was overflowing with all of the camper recognition.
- Campers not only left with great memories and friendships, but also took home some personally-designed emoji items, including hats, pillows, pencil holders, and more!
- At the request of some of our teen campers, based on their personal experiences, this year's annual service project benefitted the Children's Hospital of Pittsburgh. Campers worked together to compile care packages for patients, including a card, handmade friendship bracelet, and various activities to help pass the time while they are in the hospital.
- Jim Donovan, drummer from Rusted Root, led a drum circle with all of our campers and staff. Somehow the hour of nearly 100 people in a small room playing musical instruments was energizing and relaxing at the same time!
- Camp Hot-to-Clot piloted a Camp Preview Program this year during the week of Camp. The purpose of this program is to expose eligible or soon-to-be-eligible campers and parents to Camp Hot-to-Clot. Two potential future campers joined us at Camp Thursday afternoon with their parent(s)/guardian(s). The children had the opportunity to participate in Creative Arts while their parent(s)/guardian(s) were given a tour of Camp Kon-O-Kwee. The program wrapped up with all guests eating dinner in the cafeteria with the rest of Camp Hot-to-Clot. This program seemed to be a huge success, and we look forward to continuing this program in future years.
- Two campers earned the Big Stick award this year by demonstrating all of the knowledge and

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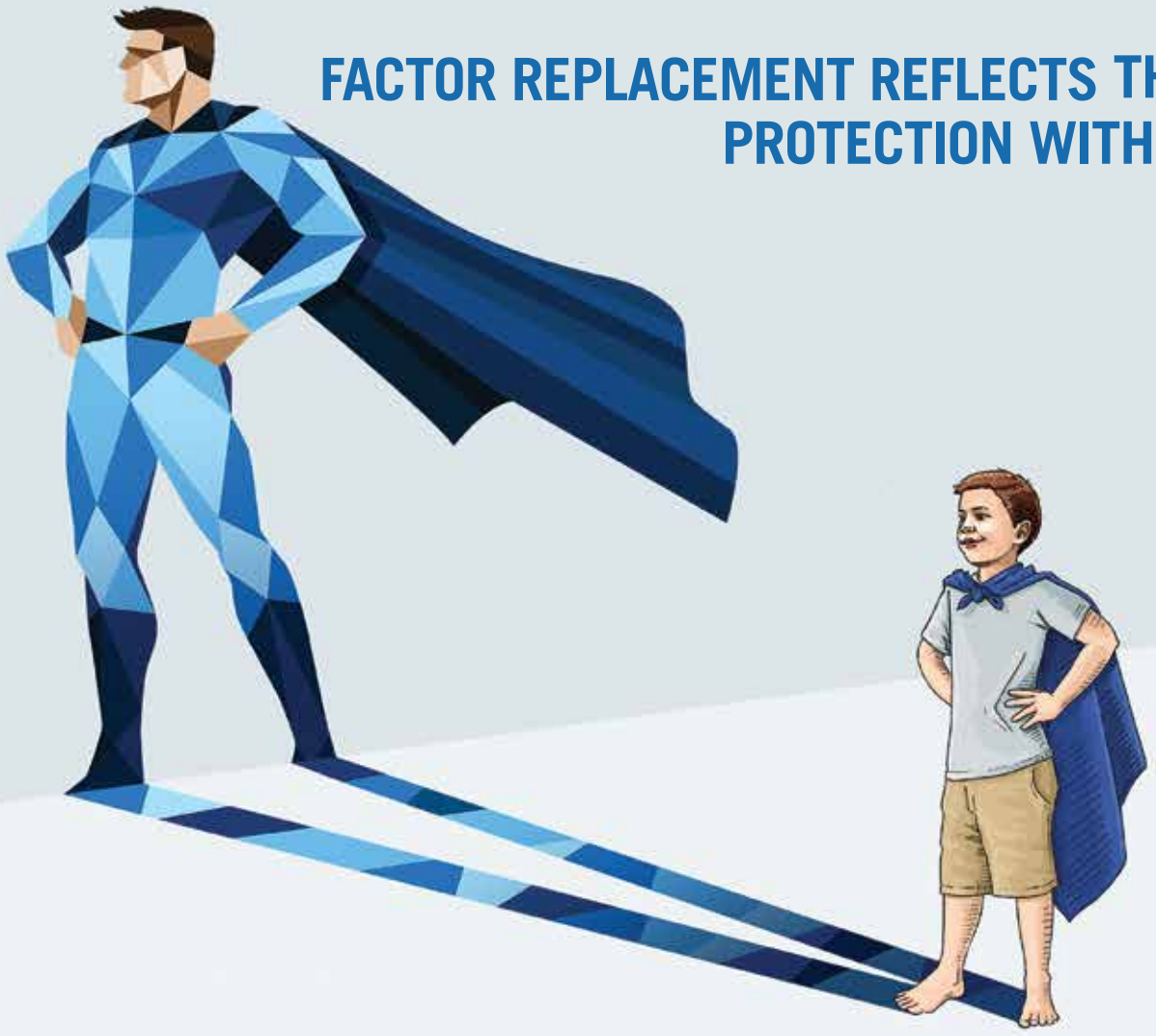
FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



For people with hemophilia, Factor treatment temporarily replaces what's missing.[1] *With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.*[2,3]

Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 60 years.

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.** Wolberg AS. Plasma and cellular contributions to fibrin network formation, structure and stability. *Haemophilia.* 2010;16(suppl 3):7-12. **3.** King MW. Introduction to blood coagulation. http://themedicalbiochemistrypage.org/blood-coagulation.php. Last modified January 2, 2017. Accessed January 2, 2017.

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Letter From The Executive Director, Alison Yazer

Greetings!

I can't believe that by the time you're reading this, I will have started my sixth year at the Chapter! The time has truly flown by.

This year has been nothing short of incredible. We held a stand-alone cornhole tournament fundraiser for the first time and had our most successful Walk to date (& IT DIDN'T RAIN!!).

Our community successfully lobbied state legislators to maintain the Hemophilia Line Item in the state budget after one version of the budget proposed completely eliminating it. We also – along with millions of others – defeated several attempts to repeal the Affordable Care Act.

The threats to our community are ongoing, though. There will be repeated attempts to drastically change or repeal the ACA and our line item will undoubtedly come under attack again. We will always remain vigilant, working to maintain these protections, but we will also ask you to participate in these efforts. When we put out calls to our community throughout the year, you responded!

As always, if you have any suggestions for the Chapter, or you need our help with something, please don't hesitate to reach out to us. We are here to serve you.

Best,

Alison R. Yazer
Executive Director

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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.

NEW Board Member: Shannon Howard

Shannon Howard joined the Board in the Summer of 2017. A resident of Richland Township, Shannon lives with her husband Dan and two teenage daughters, Madison and Caitlin.

Shannon currently serves as a Middle School Assistant Principal in a suburban community. In addition to being a school administrator, Shannon also has served as a part-time faculty in the Education Department at Point Park University since 2012.

Shannon Howard earned a Bachelor of Arts degree in Communications from the University of Pittsburgh. After some time working in the private sector, she returned to school to earn her Masters of Arts in Teaching from Chatham University and then taught in both suburban and urban school districts in Pittsburgh and Virginia. Shannon went on to get her Principal Certification from Point Park University and her Superintendent Letter of Eligibility from Gannon University. She is currently working on her doctorate at Point Park University.

In addition, she is a black belt in Tae Kwon Do, and enjoys taking classes with her family (all of whom are black belts). She also enjoys watching movies, spending time with her friends, and roasting marshmallows on a fire.

Shannon learned about the WPCNHF Board through her friend, Matt Pace. She says that she is extremely grateful for the opportunity to serve such an outstanding organization. Although neither she nor her family are affected with a bleeding disorder, she says that she welcomes the opportunity to join this dynamic organization, led by a dedicated board and staff. She says that she hopes that she can utilize her talents and experiences to continue the great work of the organization.

HCWP Update

By: Kathleen Schnur, LSW

Dear HCWP patients and families:

I hope everyone is enjoying the late arrival of summer temperatures. We have a few updates to share with all of you.

First, the Hemophilia Center is a grantee of the Pennsylvania Department of Health's (DOH) Specialty Care Program (SCP). The SCP awards financial support to the Hemophilia Center for its comprehensive care provided to the resident bleeding disorders patients of western Pennsylvania.

Recently, the DOH informed the Hemophilia Center of the creation of a new Patient Assistance Fund (PAF). 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.

Restrictions and qualifying criteria apply. If you are interested in learning more about the newly created PAF, please reach out to one of the Hemophilia Center's social workers.

Next, the integration of the Hemophilia Center into the Blood Systems (BSI) organization continues. As previously announced, The Institute for Transfusion Medicine (ITxM) merged with BSI effective March 1, 2017. Since that time, the BSI integration team has been busy learning the operations of ITxM and identifying synergies between the two organizations. Thus far, the actual transitioning of ITxM processes and employees into BSI has been minimal. The one exception is the ITxM quality team which has been fully transitioned and has joined the BSI quality department. The finance and human resources departments are next to follow and are scheduled to be integrated effective October 1, 2017. All remaining units of ITxM are scheduled to be transitioned in calendar year 2018 including the Hemophilia Center which is currently scheduled to be integrated effective November 2018. Even though the transition of the Hemophilia Center is a bit down the road, we will continue to provide updates and share information with our patients and partners.

Additionally, My Life, Our Future is a national program which offers free genetic testing for males with hemophilia and females with a family history of hemophilia. This program is available at participating Hemophilia Treatment Centers, including HCWP, until the end of December 2017.

We have just completed our final carrier series event. We thank everyone that has participated. We look forward to your feedback.

Physical Therapist Award

Congratulations to **Cheryl (Cheri) McShea, PT, DPT**, of the Hemophilia Center of Western PA! Cheri received the Physical Therapist of the Year award at the National Hemophilia Foundation's 2017 Annual Meeting. Physical Therapist of the Year, named in honor of Donna Boone, PT, honors an individual who has demonstrated service to the bleeding disorders community above and beyond daily responsibilities. This person serves as a role model for others in the field and has a minimum of two years' experience working with people with bleeding disorders. Donna Boone, a pioneer in the area of physical therapy and bleeding disorders, is a mentor for many professionals practicing today.

Calendar of Upcoming Events

Sunday, October 29
Booling for Bleeding Disorders
Neville Island, PA

Thursday, November 9
Women's Group
Robinson Township, PA

Sunday, November 12
Teen Event
Pittsburgh, PA

Sunday, December 3
WinterFest
Wildwood Highlands

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

Ask us about sponsorship opportunities and how you can help!

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Sponsored by Shire

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

By: 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.[1] 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)![2]

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

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2017 Hemophilia Walk, Run For Their Lives 5K, and Cornhole Tournament

Families & friends gathered at the North Park Boat House to support a very important cause, the 2017 Western Pennsylvania Hemophilia Walk, Run for Their Lives 5K, and the WPCNF's 3rd Semi-Annual Cornhole Tournament on Saturday, September 9, 2017. All three of these events continue to be a resounding success with over $75,000 raised to support the bleeding disorders community in Western Pennsylvania.

This year's highlights included appearances and a song and dance performance from Elsa, Anna, Pocahontas, Belle, Spider Man, Iron Man, Merida, Captain America and Moana from Angel's From the Heart, a face painter, balloon artist, DJ, photo booth and a lot of special touches that made this day fun for the entire family. Thank you to: First Class Entertainment for the DJ and Photo Booth services, Cynthia Jewel from Face Paint Pittsburgh, Balloon Artist Faerie Grace, Sheetz Brother's Coffee Truck, Kona Ice Pittsburgh, WISH 99.7 Street Treat Patrol, Star Wars character from Garrison Carida 501st Legion, and the very talented princesses and super heroes from Angels from the Heart.

This day would not be possible without the support of our many team captains who rallied their runners and walkers and went over and beyond in all that they did. Thank you to all 34 of our Walk Teams! A special shout out to the teams who have raised $1,000 or more: Conor's Clan, Luke's Ewoks, The Garrett & James Gang, Team Pace, Gino's Gang, Team Jaxson, Clotting Cavaliers, Cooper's Troopers, Red 'N Plenty, Maxwell House, and Cameron's Walking Sticks.

Congratulations to our top fundraising team, Conor's Clan, who raised over $8,640! Thank you to this year's Walk Chair and Top Individual Fundraiser, Emily Nikithser. Emily joined the Hemophilia Walk last year as the Team Captain of Conor's Clan. In her first year as Team Captain, Conor's Clan raised over $8,150! This year, Emily did an incredible job holding two very successful fundraisers including Conor's Clan's Car Wash and Conor's Character Breakfast. On top of fundraising, Emily is an active member of the Chapter and volunteers time at the Chapter helping with mailings.

Congratulations to the winner of the Awesome John Eyrolles Top Youth Fundraiser Award, Luke Miller, who raised an incredible $3,035.40! Every year Luke raises money for the Walk by holding a lemonade stand. Luke's cousins started Luke's Lemonade Stand. In the first year they sold just lemonade. Over the years, they have added snacks & hot dogs. Each year they get a decorated envelope on walk day with all of their collections. This year Luke, his brother Sam, and one of their friends took over running this very successful lemonade stand!

Thank you to all of our Factor Club Members who have raised $500 or more for the Hemophilia Walk! Medals were awarded to the following Factor Club Members:

Emily Nikithser of Conor's Clan, Luke Miller of Luke's Ewoks, Gabbie Rose of Clotting Cavaliers, Gwen Austin of Clotting Cavaliers, Eileen Nikithser of Conor's Clan, Nikki Micholas of The Garrett & James Gang, Russell Werme of Conor's Clan, Tracy Sethman of Red 'N Plenty, Cooper Aberegg of Cooper's Troopers, Dave, Richelle, Triston, Mason, and Avery Sasala of The Garrett & James Gang, Barbara O'Connor of Luke's Ewoks, Jen Werme of Conor's Clan,


National Hemophilia Foundation and
Western Pennsylvania Chapter of NHF Present
HEMOPHILIA
walk


STEELERS

Kara Dornish of Kara's Walkers, Dawn Rotellini of Gino's Gang, Jaxson Baker of Team Jaxson, Kelly Baker of Team Jaxson, Gavin Coblentz of Coblentz Clotters, Charlotte Rosborough of Charlotte's Hemo Heroes, Janet Barone of Cameron's Walking Sticks, and Chelsea Greer of Team Greer.

This year's event had fabulous t-shirts designed by many of our walk teams. Thank you to Jamie and Darin from Printeesweet for the printing of them, and for the many families that took time out to vote for their favorite t-shirt the day of our Walk. Congratulations to Luke's Ewoks as the official Team T-shirt Winner, raising over $100.

Thank you to Pro Bike + Run for the great job they did managing the Run for Their Lives 5k and to everyone who participated in the run. We are excited to announce that over $15,000 was raised from the Run and will stay local to support the members of WPCNHF.

Congratulations to the winners of the Run for Their Lives 5k!!

Top 3 Youth Finishers
1.) Dominik Gladish - 25:47
2.) Gavin Coblentz - 28:15
3.) Kayli Yip - 29:49

Top 3 Female Finishers
1.) Jodie White - 26:40
2.) Jennifer Bobonski - 27:00
3.) Kristina Roland - 27:42

Top 3 Male Finishers
1.) Robert Richards - 19:40
2.) Francis McCaffrey - 22.:30
3.) Todd Pingley - 22:31

Thank you to Joe Castellano from Steel City Cornhole for running our 3rd Semi-Annual Cornhole Tournament! The Cornhole Tournament brought in over $4,000 all of which will stay local to support individuals with bleeding disorders in Western PA. Congratulations to the winners of the tournament! First Place went to Tybo and Bernie of Gators, second place went to Tyler and Ryan of Dayton Breakfast Club, and third place went to Joe and Joey of the Double J's!

Lastly and most importantly, thank you to each and every one of you that literally 'took steps' to join our cause. 100% of the money raised from the Walk, Run, and Cornhole Tournament stays local to promote patient advocacy and blood safety for everyone, support families in need by offering assistance with medical bills, travel, knee/elbow braces and other medical devices, provide medical ID jewelry to our members at no cost to them, provide local educational programming throughout the year, provide a support network to all our community members, and create and increase awareness about bleeding disorders.

Mark your calendar now for our next fundraiser, Boo-ling for Bleeding Disorders! This Halloween Costume Party and Bowling Fundraiser will be held on Sunday, October 29th from 2pm-5pm at Paradise Island Bowl! The cost is $25 per person and includes bowling, shoe rental, prizes, pizza, wings, and unlimited soft drinks! Visit wpcnhf.org for more information.

Camp Hot-To-Clot 2017

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skills needed to self-infuse for the first time! Several campers who do not currently require infusions earned the Stick Together award for learning the self-infusion process and infusing themselves with saline (with guidance), as a show of support for their siblings and friends with bleeding disorders. Congratulations to all of them!

- Campers enjoyed the usual camp activities: GaGa, swimming, archery, high ropes, zip line, canoeing, fishing, and playing games.

The camp staff is taking a short break to recover from a fun-filled, exhausting week at Emoji-con before beginning preparations for Camp Hot-to-Clot 2018! We hope to see lots of familiar and new faces at camp next year!

Save the date: August 5-11, 2018

If you want more information about Camp Hot-to-Clot, please visit our website (www.hcwp.net/camp) or contact us by phone (412-209-7344) or e-mail (CampH2C@itxm.org).






Spotlight on Fundraising: Kelly Baker of Team Jaxson

Team Jaxson was formed in August 2014, two months after Jaxson was diagnosed with Severe Type A Hemophilia. The Bakers heard about the Hemophilia Walk and, being so new to the bleeding disorders community, knew that it was something that they wanted to support and get involved in. The Baker family consists of Josh, Kelly, Analise (9), and Jaxson (3) and their two dogs Bella and Leo. Team Jaxson is made up of their immediate family, grandparents, aunts, uncles, cousins and very close friends of Josh and Kelly. Since Jaxson's diagnosis, Kelly takes pride in educating others about hemophilia and spreading awareness. Kelly is very passionate about fundraising and tries to think of new ideas to raise money for the Chapter each year.

This year, Team Jaxson held two very successful fundraisers to raise money for the Chapter. Their first event, which raised $384.98, was held at Chipotle in St. Clairsville, OH. Kelly decided to hold this fundraiser because Chipotle is very popular in her area and she heard other organizations had a lot of luck holding fundraisers with them.

Kelly used social media A LOT to get the word out about this event. After creating an event page for the fundraiser on Facebook, Kelly and Josh invited everyone on their friends list to attend, which caused others to also share the event. When asked how she was able to rally participants and get the community involved in her event, Kelly responded, "Our family and friends shared the event on Facebook, which led to people we didn't even know sharing it as well. We had a lot of people showing the flyer at Chipotle and I honestly didn't know them, but they were there thanks to the support of our friends and family who also advertised the event for us." Team Jaxson's Chipotle fundraiser event was shared on Facebook so many times that it got the attention of another organization, A Special Wish-Ohio Valley Chapter, who grants wishes for children with life-threatening illnesses. This organization recently granted Jaxson's wish of getting his very own swimming pool!

Kelly and Josh also printed flyers and distributed them to homes in their community, Jaxson's school and daycare, the grocery store and gas station where they live, Analise's dance studio, and at Wheeling Hospital when they took Jaxson to his treatments. They also handed out flyers to their co-workers and their neighbor who works at a pediatrician's office handed them out there.

When asked what advice she would give to someone who wanted to hold a similar fundraiser, Kelly responded, "Don't be hesitant to share too much on social media. Create the event and share it a couple times a week, and then every day prior to the event the week of. People get busy and this is a good reminder for them to attend. We also included the importance of the fundraiser and what the funds would go to, so people knew exactly where their support was going. Also, think of the resources you have to get the word out about your fundraiser, like we did with the hospital, school, daycare and our own community."

For the past two years, Kelly has teamed up with the t-shirt printing company, Printeesweet, to hold a t-shirt fundraiser in the month of July. Kelly found that friends who were not able to make it to the Hemophilia Walk still wanted team t-shirts to show their support for Jaxson. As Kelly said, "We found people like to have something where they can show their support for Jaxson. They are able to order online and I delivered to those who live locally, so they didn't have to pay shipping. But this is also great for those who have friends and family throughout the country, because they can have their t-shirts shipped to them."

This year, Kelly created a Facebook event for the Team Jaxson T-Shirts and invited her friends list. She included a photo of the t-shirt so people knew exactly what they would be ordering. She shared the event frequently and posted reminders as to how many days were left in the fundraiser, to push urgency in getting the orders in. When asked what advice she would give others who want to hold a similar fundraiser, Kelly responded, "Make sure you have it early enough that the shirts are delivered before the walk, so those who can't be there, are able to support you wherever they are." Team Jaxson raised $245 from their t-shirt fundraiser all of which will stay local to support the members of the Western PA Chapter of the National Hemophilia Foundation.

Interested in holding your own fundraiser? Contact Kara at kara@wpcnhf.org or call 724.741-6160.

as i see it: For the Younger Ones, Things Can Change

By: 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.

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.

Getting to Know HCWP Staff: Frederico Xavier, MD

Birthplace: Munich, Germany

First job: IHTC Indianapolis, IN

Accomplishment you're proudest of: Two young kids and six house moves!

What three words describe you best? Sometimes difficult understanding

Dream vacation: Middle of nowhere in the Mediterranean sea

Things you can do without: My pager!!!!

Person you'd most like to have dinner with: Pope Francis

Movie you could see anytime: ANY non-cartoon or Disney movie!!! (life of a parent with young kids, ha)

TV show you try not to miss: Believe it or not, I do not watch TV…

Three things that can always be found in your refrigerator: Milk, meat and yogurt

Secret vice: Hum…Do I have to disclose it???…ok ok…LEGO

Who would play you in the movies? Some good-looking dude…ha

Your pet peeve about Pittsburgh: Google maps does not know the way!!!

People may be surprised to know that: I have more than 13 years of training after med school…

NHF's 69th Annual Meeting

By: Allie Baker

My name is Allie Baker; I have Von Willebrand's disease. My sister and father also have the same bleeding disorder. My sister and I recently had the opportunity to attend the NHF Annual Meeting in Chicago through an educational grant from the Western PA Chapter of the National Hemophilia Foundation.

The meeting began with an opening from NHF's CEO Val Bias. He talked about all of the advancements the bleeding disorders community has accomplished. We then got to go to the exhibit hall, which was amazing. The vendors were all friendly and the exhibits were very interactive.

My days were spent attending sessions from the Women with Bleeding Disorders track, the Young Adult track, and the VWD track. In these sessions, we learned about advancements in research for VWD, and we learned more about the NYLI program.

On the final night, we were bussed to the Field Museum of Natural History. When we got to the museum we were greeted with several buffet style menu items such as a nacho bar, pasta bar, and pizza bar. The museum was closed to the public so we were able to explore all of the exhibits at our own pace.

During my time in Chicago at the Annual Meeting, I was able to learn more about my bleeding disorder, connect with some new and old faces, and hear about the new advancements in VWD. I would like to thank WPCNHF for selecting me to be the Education Grant recipient. I am looking forward to attending another annual meeting in the near future!

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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Shire

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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Annual Meeting & Scholarship Winners

Congratulations to Ryan Balog and Emma McCarthy, recipients of the WPCNHF Scholarship for the 2017-2018 school year. Ryan is a student at LaRoche Collage with a major in Middle Level Math Education. Emma is a student at Arizona State University with a major in Biomedical Sciences. We wish them both much success!

The scholarship winners were announced at WPCNHF's Annual Meeting, on July 19, 2017. The Annual Meeting was held at Dave & Buster's in Homestead and was attended by over 130 people. We thank the following for supporting the Annual Meeting: Aptevo, Bayer Healthcare, Bioverativ, Cottrill's Pharmacy, CSL Behring, CVS Specialty, Diplomat, Grifols, Hemophilia Center of Western PA, Matrix Health, Novo Nordisk, Pfizer, Option Care, and Shire.

Arjun Limbu
NP 050

2016 Beneficiary Annual Report
Western PA Chapter of NHF

Greetings from Nepal!

I am 24 years old and am continuing to work towards my bachelor's degree in Education. I am a dedicated student and am progressing well with my studies. My favorite subject this year has been computer science. When I complete my education, I would like to work as a teacher. I like to spend time with my friends in my free time. I also really love to sing.

Over the past year, I have experienced numerous bleeds in my elbows, groin, and knees. These bleeds were treated with infusions of factor. Thankfully, I have been receiving physiotherapy to help maintain good mobility in my joints.

I am an active member of my local hemophilia chapter, the Nepal Hemophilia Society, and I benefit from their services and support. I attended their youth camp in the eastern part of Nepal. I enjoy spending time with other people living with hemophilia.

My parents and I still live in the same small home that we own in the village. Our home is in need of minor repairs. It has electricity and running water, however, we are without a refrigerator. My father works as a laborer to support our family.

This year, your sponsorship gift was used to pay for my education. My family and I would like to express our gratitude for your continued support! It makes such a difference in our lives!

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

(Continued from page 6)

physicians' experiences and perceptions about bleeding disorders, particularly VWD.[3] 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.

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.4 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.5 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.[6]

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.[7] 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 lower than 50%, request a diagnosis of mild (6% to 49%) or moderate (2% to 5%) hemophilia!

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," Haemophilia 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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Study Yields Important Findings on the Functions of von Willebrand Factor

Researchers at the Boston Children's Program in Cellular and Molecular Medicine and the Harvard Medical School recently made important discoveries relevant to the functioning of von Willebrand factor (VWF). The study, "Flow-induced Elongation of von Willebrand Factor Precedes Tension-Dependent Activation," was published online, August 23, 2017, in the journal *Nature Communications*.

Using fluorescent imaging and microfluidic tools, Jiang and his colleagues recreated the blood flow that occurs in humans, particularly the function of VWF within the bloodstream. Through a series of valves, cylinders and tubes, investigators were able to mimic the increase in blood flow that occurs after an injury.

Experiments showed that as the blood flow grew more intense, changes in the shape of VWF would occur. VWF molecules, which are normally rounded and compact, quickly became rapidly elongated in response to the increased tension. Scientists also observed that as VWF elongates it binds with platelets to ensure that a viable blood clot forms. Notably, VWF activates locally at the site of an injury and not in other parts of the body.

"If you can imagine stretching out your arms, and then opening your hands to capture platelets, that's basically what we are seeing VWF do in response to bleeding," said researcher Wesley P. Wong, PhD. "It's so important that this process occurs only when and where it is needed—this two-step activation process makes that possible."

While these findings could have future implications for treatment, leading to more novel therapies, they are also scientifically noteworthy. Researchers are no doubt excited to uncover such valuable molecular-level insights on the intricacies of the bloodstream and the mechanisms of VWF.

"This experiment really represents a new platform for seeing and measuring what's happening in the blood on a molecular level," said Wong. "Through the use of novel microfluidic technologies that allow us to mimic the body's vasculature in combination with single-molecule imaging techniques, we are finally able to capture striking images that uncover the mystery of nature's forces at work in our bodies."

Source: Genetic Engineering & Biotechnology News, August 23, 2017

Spotlight on Fundraising: Emily Nikithser of Conor's Clan

Emily and her husband Pat are parents to almost 2 year old Conor who has severe Hemophilia A. He was diagnosed at birth. Emily remembers she was contacted almost immediately by WPCNHF to see if her and her family needed support. Emily and her family made an effort to be active members ever since. As Emily explained, "Conor's Clan is a great example of how wonderful our support system is. Our team is a group of family and friends that mean the world to us and we are so thankful to have them."

Conor's Clan held two very successful fundraisers to raise money for the Hemophilia Walk this year. Conor's Clan Car Wash was the first event they organized this year. They also held this event last year and had great success. Emily stated, "We came up with this idea by brainstorming and trying to come up with an idea that we felt would be feasible and had the potential to make an impact. This was the perfect fundraising starter. We are lucky enough to have a close friend that owns a business in a great visible location in our town. I contacted him and he was kind enough to let us use his parking lot and water on a Saturday when his office was closed."

In order to plan the car wash, Emily started a private Facebook group that she used for communication to Conor's Clan members. She started there by taking a poll on potential dates for the event to see who would be available to help. After establishing a date, her family and friends work together to make the event fun by providing music, food and drinks. Emily's husband, Pat, is an active member in their local chapter of the Jaycees and their members are always so willing to help!

To advertise the event, Emily relied heavily on social media. As Emily explained, "I created a flyer that could be shared on Facebook, Instagram, and other social media platforms. We are so lucky to have so many people in the community that follow Conor and share our events around. We also made large posters to advertise on the street the day of the carwash." Conor's Clan raised an incredible $1,006 at their car wash!

When asked what advice Emily would give to others who would like to hold a similar fundraiser, Emily said, "Just give it a shot! I'm also surprised at how much fun we have with this event and how profitable it is. It's a perfect way to fundraise even if you've never planned an event before. There is minimal preparation and if you can find a location willing to let you use their water the

overhead costs stay pretty low. It's a cool way to spend time with friends and family on a summer day, for a wonderful cause, and it's a great workout too!"

Conor's Clan also held Conor's Character Breakfast which raised an amazing $1,300 for the Chapter! Conor's Character Breakfast came from a similar event that Emily had seen advertised. She thought it was such a great idea and that the kids in our community

would LOVE it! Emily hired the character through Lovely Day Events who gave her a significant discount. She also had Iceburgh from the Pittsburgh Penguins donate an hour of his time. Emily learned that you can request to have most Pittsburgh sports mascots for fundraising events through their websites by filling out a form and submitting it. It helps to do this very early though because their time fills up quickly.

Emily wanted the event to be in her hometown because she wanted her friends and family to be able to easily visit with the characters. She ended up renting a local fire hall that had plenty of room and would accommodate the characters. She received help from her husband and brother-in-law who stood in the kitchen of the fire hall throughout the entire event cooking and serving pancakes and sausage!

Emily and her team advertised this as an event on Facebook. She relied on her contacts to share the event to spread the word. She also created flyers that she put up in different locations around the community. When asked what advice she would give to others who would like to hold a similar fundraiser, Emily stated, "Start early! The earlier you start with the planning the better chance you have for lining up sponsors and volunteers. We are hoping to make this event annual and this year we would like to seek out more sponsors and in-kind donations to help with the overhead costs involved. Try not to stress about success or failure. No matter the outcome the smiles we saw at the event were worth it all."

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

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