



**Western Pennsylvania  
Chapter of the National  
Hemophilia Foundation**

**Summer 2017**  
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## **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

# Hemogram

## **Spotlight on Advocacy**

As you might imagine, there's been a lot of activity at the Chapter lately surrounding advocacy. If you are on our e-mail distribution list, you've probably seen several important e-mails from the Chapter and the National Hemophilia Foundation asking for help.

Members of the Chapter have been stepping up and getting involved. One of our members, Delores Johnson-Huber, has been making phone calls, attending town hall meetings, sending letters, and participated in our state advocacy event, Harrisburg Day. We talked with Delores about her recent advocacy experiences.

Delores is the mother of two boys who have hemophilia: Ethan, age 10, and Kyrie, age 2. They both receive care from the Hemophilia Center of Western PA and are typically there twice a week. She mentioned that infusions with her youngest child used to be difficult, but the staff at the Center is able to keep him calm. She is glad for the care her family receives and values the HCWP's staff expertise regarding plan of treatment, ports, etc.

With the state funding for the Pennsylvania Hemophilia Treatment Centers in jeopardy, Delores felt it was important to participate Harrisburg Day. The event is jointly coordinated by the Eastern Pennsylvania Chapter of NHF and WPCNHF. Members of both Chapters, from across the state, meet at the Capitol Building in Harrisburg to talk with their senators, representatives, and/or their aides about issues that impact people living with bleeding disorders.

Delores stated that Harrisburg Day was an awesome experience. She was in a group with other members from our region and felt they were really supportive of letting her older son, Ethan, speak. One of their favorite visits was with State Representative William Kortz who let Kyree "destroy" his office. He even let Kyree chew on a bobblehead! It



*(Continued on page 2)*

## Spotlight on Advocacy

(Continued from cover page)

turns out that Rep. Kortz actually sponsors Ethan's baseball team! Ethan recognized him at a game after Harrisburg Day! He seemed very supportive of the community and was going to try to work things out for the community.

Back in March, Delores and her children attended a town hall meeting hosted by U.S. Representative Mike Doyle. In her words, "It was amazing!" They arrived early and Ethan asked Representative Doyle to tie his tie for him. Rep. Doyle sat and spoke (& listened!) with Ethan for 10-15 minutes and told him that he'd continue to fight for people like Ethan who have pre-existing conditions. During the town hall meeting, Delores and Ethan both told their stories to Rep. Doyle, in front of 1200 people.

Delores feels it's important to participate in advocacy activities to help preserve the access to care that is so critical to people with bleeding disorders. If you don't participate, she feels it's a missed opportunity. She says, "Who better to advocate for us than us? We need to use our voice." She also feels it's important for Ethan to learn to advocate for himself, too, as he gets older. She encourages others out there to let them and/or their kids be seen. Be persistent – make yourself and your kids noticed—if your legislators don't see you, they might think it's not important. It's imperative to be heard!

### Comments from some of the Harrisburg Day participants:

It was cool—I got to show people how my medication works—it brought tears to some staff members. I talked about learning to infuse at camp and how I now infuse myself. I definitely want to come back. – E.W.

Ethan had people engaged. He was the MVP!

Advocating is awesome. If you are on the fence, just do it! – C.M.

By educating our representatives and their staff, they come to understand what is going on. I'm feeling positive about the results. B.S.

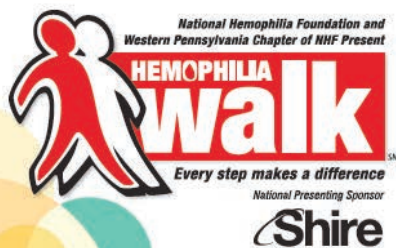
Cameron shared his story about the importance of HTCs. – K.D.

Harrisburg Day is a good opportunity for children to meet their representatives and see the Capitol Building. – A.L.

Meeting members of the hemophilia community surrounding advocacy was awesome. B.P.

It was a privilege to have an audience with aides, representatives, and senators. Having your trust and opportunity to advocate. Can't wait to continue at home! – J.Y.

# Save the Date



### SATURDAY, SEPTEMBER 9, 2017

**Join us to support the Hemophilia Walk!** We will walk to raise critical FUNDS and AWARENESS for the bleeding disorders community. Your support is greatly appreciated!

For more information, please contact: Kara Dornish, Local Walk Event Manager, at 724.741.6160 or [kara@wpcnfhf.org](mailto:kara@wpcnfhf.org) or visit [hemophiliawalk.donordrive.com/event/pittsburgh](http://hemophiliawalk.donordrive.com/event/pittsburgh).

**Registration Check-In Time:** 9:00am

**Walk/Run Start Time:** 10:00am

**Distance:** 5k (3.1 miles)

**Location:** North Park Boat House  
10301 Pearce Mill Road  
Allison Park, PA 15101

Register online now at

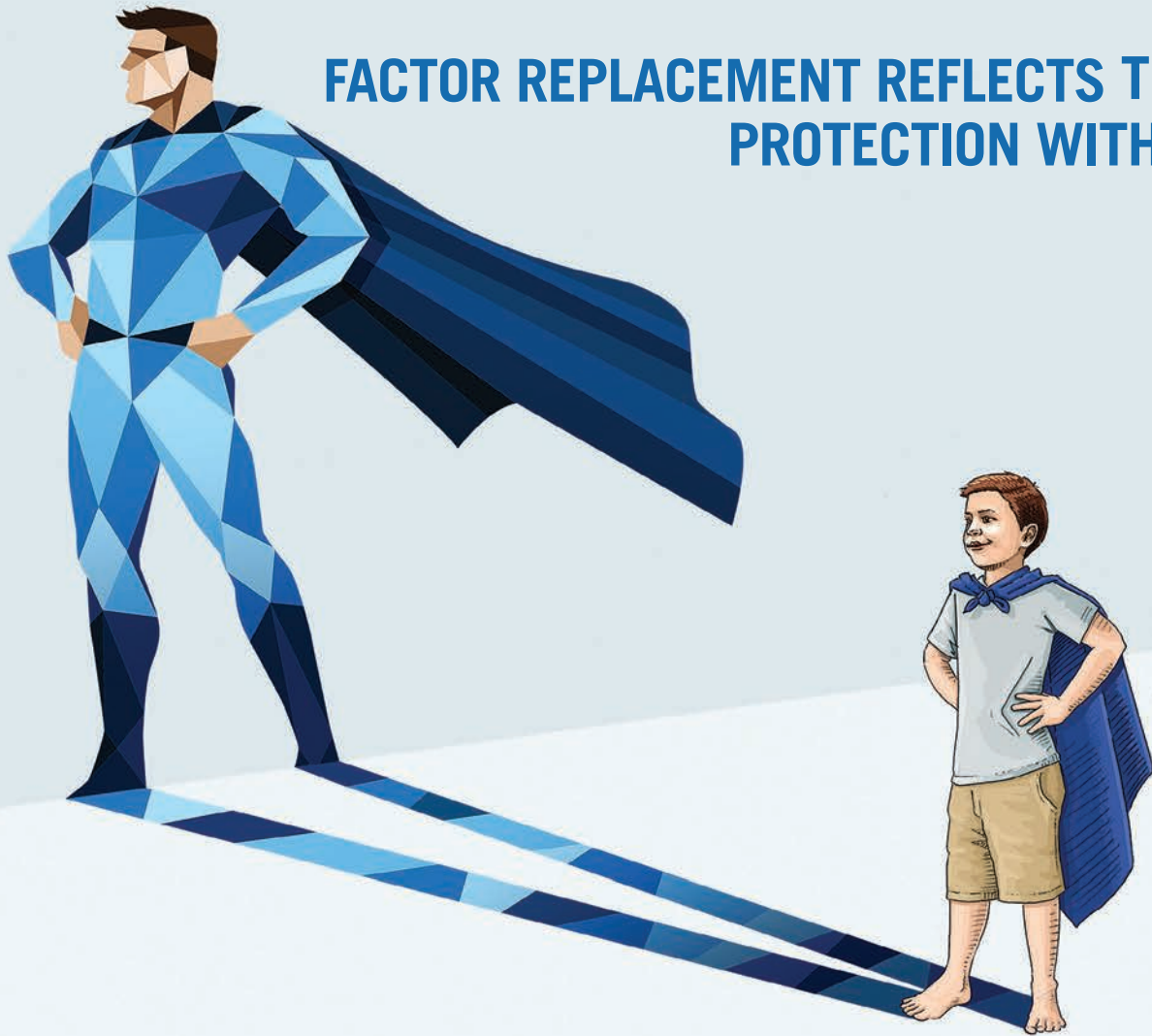
**[hemophiliawalk.donordrive.com/event/pittsburgh](http://hemophiliawalk.donordrive.com/event/pittsburgh)**

Participate. Volunteer. Donate.





## FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



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

*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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**Shire**

# Letter From The Executive Director, Alison Yazer

Dear Chapter Members and Friends,

It has been a busy few months at the Chapter! Our advocacy efforts have increased dramatically – both at the state and federal levels. In addition to Harrisburg Day (see the Spotlight on Advocacy for more details), people across the state have made several trips back to Harrisburg in addition to meeting with elected officials locally to impress upon them the importance of maintaining the

hemophilia line item in the state budget. We will keep you up to date on anything we hear as the budget is finalized. NHF also asked some Chapter staff to come back to Washington DC in early June for a “mini DC Day” where we met with key members of congress to discuss proposed changes to the Affordable Care Act.

We are always ready to go advocate on behalf of the bleeding disorders community, but elected officials need

to hear from you, too! Who else can tell YOUR story as well as you can? You don’t necessarily have to take time off work to travel to Harrisburg or DC! Not sure how to get involved? Call the Chapter office and we can talk you through the advocacy process! Together we are stronger!

*Alison R. Yazer*  
Executive Director

## Greetings from HCWP

We’ve have a busy few months here at the Center. We’ve had some familiar, long time faces leave the center (Diane and Stacy) while we welcomed some new (Johana, Diann, Katherine, and Steve). Our new pediatric hematologist, Dr. Frederico Xavier, will begin here at the Center in early July. Please check out

everyone’s bios in this newsletter

HCWP’s parent company ITxM has merged with Blood Systems, Inc. Blood Systems (BSI) is one of the nation’s largest and most respected independent blood centers in the nation. The merger will improve the ITxM organization by combining their strengths with those of BSI’s. BSI is excited to add the Hemophilia Center to its portfolio of organizations serving the medical

community. They are committed to ensuring that the high level of service our patients receive continues and are eager to begin work on improving upon our already exceptional patient care that the Center provides.

The HCWP is busy updating their website to be current and more user-friendly. We even included a tab on all things Camp Hot-to-Clot! Please take a look!

## Board of Directors

### *President*

Nathan Rost

### *Vice President*

Matthew Suarez Pace, PhD., LMFT

### *Secretary*

Mike Covert

### *Board Members*

Shannon Howard

Angelica Shepard

### *Emeritus Trustee*

Scott Miller, CPA, Esq., DBA

## Staff

### *Executive Director*

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](mailto: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
- ♦ Paper towels

## 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.

*Hemogram* is published quarterly by the Western Pennsylvania Chapter of the National Hemophilia Foundation. The contents of this newsletter may be reproduced freely. The material in this newsletter is provided for your general information only. WPCNHF does not give medical advice or engage in the practice of medicine. WPCNHF under no circumstances recommends particular treatments, and always recommends that you consult your physician or treatment center before pursuing any course of treatment.

## **NEW Board Member: Angie Shepard**

My name is Angie Shepard, and I joined the board in the Fall of 2016. My husband, 11-year-old son, soon-to-be 8-year-old daughter and I live in Indiana Township, just northeast of the city of Pittsburgh. I grew up in Oil City, PA, and still have family there. My two younger brothers live in Erie, and my younger sister lives in Coraopolis. So, my western Pennsylvania roots run deep and are fairly widespread. At a young age, I became enamored with the law while watching "Perry Mason" episodes with my grandpa during the summers. On my journey to becoming a lawyer, I attended Saint Vincent College in Latrobe, PA. While an undergrad, I majored in English and Psychology,

played on the intercollegiate volleyball team (Go Bearcats!) and sang with two of the college's student choirs.

From the relatively pastoral campus of Saint Vincent, I came into the "big city" to attend the University of Pittsburgh School of Law. After graduating and surviving the rigors of the bar exam, I joined the Pittsburgh office of the law firm of Kirkpatrick & Lockhart (now known as K&L Gates LLP). For more than 16 years (and 7 of those as a partner), I was a litigation attorney focused on solving legal disputes in various areas of the law. With gratitude for the wide and varied skill set I developed during that time, I left K&L Gates in 2016 in search of a different arena in which to use my talents. As my friends say, I am now a "recovering lawyer." As I've tried to figure out the new direction in which to pivot my career path, I've been blessed with the

opportunity to volunteer more at my children's elementary school and to earn my black belt in tae kwon do with Young Brothers (where my husband and kids also earned their black belts).

I am thankful that my friend Matt Pace approached me about the possibility of serving on the WPCNHF's Board last year. Though neither I nor anyone in my family is affected with a bleeding disorder, I welcomed the opportunity to join such a vibrant organization led by board and staff members who are bright, dedicated and eager to see the Chapter continue to grow and thrive. I hope that I can bring my talents to bear on building upon the great work the Chapter already does. Please do not hesitate to approach me with concerns or ideas you have to improve upon or expand the Chapter's services. I look forward to meeting you at a future event. Enjoy the summer!



# **Run For Their Lives 5K Run**

To Register or Donate visit,  
**<http://www.wpcnhf.org>**  
or e-mail  
**[kara@wpcnhf.org](mailto:kara@wpcnhf.org)**

**September 9, 2017**  
Check in begins at 7:30 am  
Race begins at 8:30 am

**North Park Boat House**  
10301 Pearce Mill Rd  
Allison Park, PA 15101

Benefitting the Western Pennsylvania Chapter of  
the National Hemophilia Foundation



# Calendar of Upcoming Events

Sunday, July 16  
New Parent Network  
Moraine State Park

Wednesday, July 19  
WPCNHF Annual Meeting  
Homestead, PA

Sunday, August 6 – Saturday, August 12  
Camp Hot-to-Clot  
Fombell, PA

Tuesday, August 8  
Dinner Program – School Conversations  
Seven Fields, PA

Saturday, September 9  
Hemophilia Walk  
North Park Boathouse  
Allison Park, PA

Saturday, September 9  
Run For Their Lives 5K  
North Park Boathouse  
Allison Park, PA

Saturday, September 9  
Cornhole Tournament  
North Park Boathouse  
Allison Park, PA

Friday, September 22  
New Parent Network  
Erie, PA

Saturday, September 23  
Infusion Day  
Erie, PA

Saturday, October 7  
Oktoberfest  
Pittsburgh Zoo & PPG Aquarium  
Pittsburgh, PA

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

*Ask us about sponsorship opportunities  
and how you can help!*



## 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

**WPCNHF PRESENTS**

**BOWLING FOR BLEEDING DISORDERS**

**SUNDAY OCTOBER 29 2PM-5PM**

A Halloween Costume Party and Bowling Fundraiser to benefit the Western PA Chapter of the National Hemophilia Foundation.

**Paradise Island Bowl**  
7601 Grand Ave  
Pittsburgh, PA 15225

\$25 per person includes 3 hours of bowling, event t-shirt, shoe rental, pizza, wings, and unlimited soft drinks.

Register your teams online at **WPCNHF.ORG**



**KOVALTRY®:**

Designed to closely match  
your body's natural Factor VIII

Based on a primary protein structure  
with more than 20 years of experience

Offers the potential for as  
few as 2 infusions per week

**KOVALTRY® Dosing:** The recommended dose for routine prophylaxis in adults and adolescents is 20 to 40 IU of KOVALTRY® per kg of body weight 2x/week or 3x/week. The recommended dose for routine prophylaxis in children 12 years old and younger is 25 to 50 IU of KOVALTRY® per kg of body weight 2x/week, 3x/week, or every other day according to individual requirements.

## IMPORTANT SAFETY INFORMATION (CONT'D)

- Tell your healthcare provider about any side effect that bothers you or that does not go away.
- Call your healthcare provider right away if bleeding is not controlled after using KOVALTRY®.

**For additional important risk and use information, please see Brief Summary on following page.**

You are encouraged to report negative side effects or quality complaints of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.

**Talk to your doctor to see if KOVALTRY® is right for you.**



Antihemophilic Factor (Recombinant)



**HIGHLIGHTS OF FDA-Approved Patient Labeling**  
**Patient Information**  
**KOVALTRY (KOH-vahl-tree)**  
**Antihemophilic Factor (Recombinant)**



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

**Do not attempt to self-infuse unless you have been taught how by your healthcare provider or hemophilia center.**

**What is KOVALTRY?**

KOVALTRY is a medicine used to replace clotting factor (Factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

KOVALTRY is used to treat and control bleeding in adults and children with hemophilia A. Your healthcare provider may give you KOVALTRY when you have surgery. KOVALTRY can reduce the number of bleeding episodes in adults and children with hemophilia A when used regularly (prophylaxis).

KOVALTRY is not used to treat von Willebrand Disease.

**Who should not use KOVALTRY?**

You should not use KOVALTRY if you

- are allergic to rodents (like mice and hamsters).
- are allergic to any ingredients in KOVALTRY.

**What should I tell my healthcare provider before I use KOVALTRY?**

- Tell your healthcare provider about all of your medical conditions.
- Tell your healthcare provider and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.
- Tell your healthcare provider if you have been told you have heart disease or are at risk for heart disease.
- Tell your healthcare provider if you have been told that you have inhibitors to Factor VIII (because KOVALTRY may not work for you).

**What are the possible side effects of KOVALTRY?**

The common side effects of KOVALTRY are headache, fever and itchy rash.

Allergic reactions may occur with KOVALTRY. Call your healthcare provider right away and stop treatment if you get tightness of the chest or throat, dizziness, decrease in blood pressure, and nausea.

Your body can also make antibodies, called "inhibitors," against KOVALTRY, which may stop KOVALTRY from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

These are not all the possible side effects with KOVALTRY. You can ask your healthcare provider for information that is written for healthcare professionals. Tell your healthcare provider about any side effect that bothers you or that does not go away.

**Reference:** KOVALTRY® [prescribing information]. Whippany, NJ: Bayer HealthCare Pharmaceuticals, Inc.; 2016.

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**How do I store KOVALTRY?**

Do not freeze KOVALTRY.

Store KOVALTRY at +2°C to +8°C (36°F to 46°F) for up to 30 months from the date of manufacture. Within this period, KOVALTRY may be stored for a period of up to 12 months at temperatures up to +25°C or 77°F.

Record the starting date of room temperature storage clearly on the unopened product carton. Once stored at room temperature, do not return the product to the refrigerator. The product then expires after storage at room temperature for 12 months, or after the expiration date on the product vial, whichever is earlier. Store vials in their original carton and protect them from extreme exposure to light.

Administer reconstituted KOVALTRY as soon as possible. If not, store at room temperature for no longer than 3 hours.

Throw away any unused KOVALTRY after the expiration date.

Do not use reconstituted KOVALTRY if it is not clear.

**What else should I know about KOVALTRY and hemophilia A?**

Finding veins for injections may be difficult in young children. When frequent injections are required, your healthcare provider may propose to have a device surgically placed under the skin to facilitate access to the bloodstream. These devices may result in infections.

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

This leaflet summarizes the most important information about KOVALTRY. If you would like more information, talk to your healthcare provider. You can ask your healthcare provider or pharmacist for information about KOVALTRY that was written for healthcare professionals.

**Resources at Bayer available to the patient:**

For Adverse Reaction Reporting, contact Bayer Medical Communications 1-888-84-BAYER (1-888-842-2937)

To receive more product information, contact KOVALTRY Customer Service 1-888-606-3780

Bayer Reimbursement HELpline 1-800-288-8374

For more information, visit [www.KOVALTRY-us.com](http://www.KOVALTRY-us.com)

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**Antihemophilic Factor (Recombinant)**



# WPCNHF's 2<sup>nd</sup> Semi-Annual Cornhole Tournament

WPCNHF's Second Semi-Annual Cornhole Tournament was held on April 1, 2017 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 participants received an event t-shirt and each participant over 21 years received a drink ticket.

Joe Castellano of Steel City Cornhole did a great job of managing the double

elimination tournament. Live music was provided by an incredibly talented duo out of St. Marys, PA, Evan Gerg and Zak Breniman of Dos Beardos. Competition was fierce as 26 teams competed for the grand prize of \$500.

Third place and a prize of \$100 went to Team Joey & Carlie which consisted of Carlie Edwards and Joey Castellano. Second place and a prize of \$200 went to Team Ohio Connection which consisted of Rex Uhrig and Mike Schaffer. First place and the grand prize of \$500 went to Team Jeff and Chuck which consisted of Jeff Reynolds and Chuckie Love.

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 Evan

and Zak of Dos Beardos, Joe of Steel City Cornhole, Dana and Nikole from The Cornerstone at Tonidale, and our amazing volunteers Allie, Chrissy, and Kaye! Thank you to our sponsors: Corn in the Hole Sponsor: CSL Behring, Corn on the Cob Sponsors: Bayer Health Care, Novo Nordisk, Pfizer Hemophilia, and Shire. We are excited to report that over \$8,000 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 Third Semi-Annual Cornhole Tournament which will be held on Saturday, September 9, 2017 at the North Park Boat House in conjunction with the Hemophilia Walk and Run for Their Lives 5k. We hope to see you there!



WPCNHF's  
2nd Semi-Annual

April 1, 2017

**CORNHOLE**  
TOURNAMENT



**Corn in the Hole Sponsor**

**CSL Behring**

**Corn on the Cob Sponsors**



Bayer HealthCare



Hemophilia



**Media Sponsor**

**THE INCLINE**





# Education Weekend

Education Weekend was back this year! The event was held during the last weekend in April at Seven Springs Mountain Resort. It had been three years since we last held this event and many of our members were glad it was offered again. Forty-four families attended the event! As in the past, there were programs for the adults and for the children ages 5-17. Daycare was provided for infants and preschool age children.

Several new topics were offered this year including Music Therapy, Musculoskeletal Ultrasound, and All About Camp. Arianna Bendlin, MT-BC, Wesley Spectrum, presented the session Music Therapy and led the group through some music therapy exercises. Cheri McShea, Physical Therapist at the Hemophilia Center of Western PA (HCWP) presented the Musculoskeletal Ultrasound session. During the session, participants learned about how ultrasound works, the benefits of having an ultrasound during their clinic visits, and the limitations of ultrasound. Participants also had the opportunity participate in and/or view demonstrations. Michelle Alabek, Genetic Counselor, HCWP and Mike Waine, Unit Director, Camp Kon-O-Kwee co-presented the session All About Camp for parents who are considering sending their child to camp for the first time as well as for parents whose children have attended in recent years. They were joined by two teen campers, Julia and Gavin, who did a wonderful job answering questions from parents and presenters about their camp experiences. In addition, we were grateful to have Dr. Margaret Ragni and Dr. Craig Seaman from the Hemophilia Center of Western PA present concurrent Ask the Doctor sessions: one focusing on females and bleeding disorders and the other focusing on males and bleeding disorders. Other sessions included Self-Care, Concussions, Managing Pain (sponsored by Shire), and Complementary and Alternative Medicine.





The children experienced some new and fun programs, in addition to some old favorites! For starters, I doubt anyone could have missed the Pitt Mobile Science Lab that was parked in the lot—an 80' tractor-trailer that contained a science lab! Barbara Paul, from the University of Pittsburgh, led children ages 10-17 in hands-on experiments related to DNA. Children ages 10-12 also took part in a Silly Science program led by Kayla Kline (sponsored by Octapharma). In addition to playing mini-golf and creating some cool artwork, children ages 5-9, learned about the blood clotting process through hand-on activities and they made delicious “Blood Sundaes,” in a session presented by Beth Patrick and her colleagues from Accredo.

We thank Kathaleen Schnur, LSW and Cheri McShea, PT, DPT, both from the HCWP for their participation on the planning committee and their help throughout the event. We also thank the following for supporting this important educational event: Accredo, Aptevo, Bioverativ, Diplomat, Cottrill's Pharmacy, CSL Behring, CVS Specialty, Grifols, Hemophilia Center of Western PA,



Novo Nordisk, Octapharma, Option Care, Pfizer, and Shire.

## New Parent Network – Emergency Situations

We are excited to offer a new series of events in 2017 for the New Parent Network! Thanks to our sponsors: Bioverativ, CSL Behring, CVS Specialty, Novo Nordisk, Octapharma, Pfizer, and Shire, we are able to offer this series of events to parents who have a child with a bleeding disorder, newborn – age 6, who currently receives infusions or soon will be.

The first event, an educational program called Emergency Situations, was held on May 6, at the Children's Museum of Pittsburgh. Nancy Stinely, RN, from the Hemophilia Center of Western PA (HCWP), co-presented the session with Kathaleen Schnur, LSW, also from the HCWP. Nancy, who is a clinical nurse and former ER nurse, and Kathaleen, who is a social worker, covered topics surrounding emergency situations including who to call when; talking to the doctor on call; emergency room visits; empowering phrases to use at the emergency room; and more. The families also shared some of their experiences and advice with each other.

Each family received a backpack and filled it with supplies to make future trips to the



ER and other urgent appointments easier to handle. In addition to the supplies they received that day, each family will also receive a copy of an emergency letter and wallet card to keep in the bag. Having a “Go Bag” ready makes it easier to get out the door quickly, ensures you have the

pertinent medical and contact information with you, and helps you manage the waiting time with your child(ren) at the ER or doctor's office. All you need to do is grab your factor, drop it in the bag, and head out the door.



## Getting to Know HCWP Staff: Jeff Wahal, HCWP, Executive Director

**Birthplace:** Pittsburgh

**First job:** Hieber's Pharmacy, delivering medication to Oakland physician offices

**Accomplishment you're proudest of:** Getting out of debt

**What three words describe you best?** Happy, simple and easy-going

**Dream vacation:** A very extended trip visiting the country's major cities and attractions

**Things you can do without:** Mayonnaise, yard work and traffic

**Person you'd most like to have dinner with:** Donald Trump

**Movie you could see anytime:** It's a Wonderful Life or Pale Rider

**TV show you try not to miss:** Lately, The Carbonaro Effect. I find magic and hidden cameras to be a very funny combination.

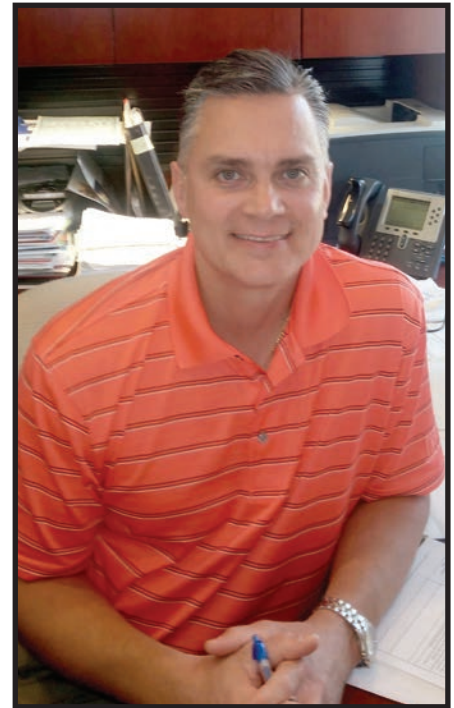
**Three things that can always be found in your refrigerator:** Yogurt, cheese and beer

**Secret vice:** Weekend lottery tickets

**Who would play you in the movies?** Jason Bateman

**Your pet peeve about Pittsburgh:** The roads

**People may be surprised to know that:** I'm a TV junkie - I always find something good to watch



## 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

# DEDICATION AND PERSONAL SUPPORT

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



## Working for you—From the Rock and Roll Hall of Fame to the Syracuse skyline

Name: Brigid Burzanko

Home state: Ohio

Hobby: Cooking—I love trying out new recipes!

Music playlist: Country and old school rock

What experiences do you have with the hemophilia community? I was a case manager for 10 years and that experience taught me the value of personal relationships and community.

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

### What we do:

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

**“IT’S GREAT TO BE  
ABLE TO HELP PEOPLE  
GET THE RESOURCES  
THEY NEED—  
THEY’RE HAPPY AND  
I’M HAPPY!”**

—Brigid Burzanko

## Caring for Carriers

The HCWP has kicked off its 3-part Caring for Carriers series. This free series was designed to support the unique educational and psychosocial needs of hemophilia carriers and potential carriers. Adult females (age 18 or over) who are carriers of hemophilia or who have a family history of hemophilia were welcomed to attend the events.

The first session was held in May at the HCWP. At this session, participants were encouraged to explore some of the perceived barriers of non-HCWP providers (i.e. PCPs, OB/GYNs)

caring for hemophilia carriers. The attendees provided valuable input and feedback on this topic. HCWP plans to use the information gathered to develop resources to facilitate better communication between carriers and their non-HCWP providers.

The second session was “Dinner with the Doctor”. This session was held in June at the Sharp Edge Loft in Downtown Pittsburgh. Attendees enjoyed dinner with Dr. Ragni and their peers in a relaxed and social atmosphere. The goal of this session was to allow the women to focus on themselves and their own needs related to being a carrier or potential carrier. Attendees were encouraged to ask

Dr. Ragni questions and were also given time to socialize with their peers.

Please be on the lookout for more details on the third session in the series, which will take place this fall. This final session will focus on the powerful role that women can play in educating and supporting their at-risk relatives, including daughters, sisters, mothers, and more distant relatives. Please reach out to Michelle Alabek (412-209-7292) or Kathaleen Schnur (412-209-7267) for more information. The HCWP wants to thank all of the women who have participated in this series so far. We hope to see YOU this fall!

## BloodCenter of Wisconsin Announces New Test for VWD

The BloodCenter of Wisconsin (BCW) recently announced the launch of a new and more sensitive test for von Willebrand disease (VWD), a genetic disorder characterized by either a qualitative or quantitative flaw in von Willebrand factor (VWF). Milwaukee-based BCW is a not-for-profit organization that specializes in blood services, organ, tissue and marrow donation, diagnostic testing, medical services and research.

Depending on the specific type, individuals with VWD can experience bleeding-related symptoms that range from mild to severe. Despite being the most common bleeding disorder VWD is historically a more challenging condition to screen for, often necessitating a battery of tests to pinpoint a diagnosis.

The “VWF GPIbM Activity” test is designed to uncover qualitative VWF defects to reduce variability and provide “more precise, reliable and sensitive test results,” according to a BCW press release. The availability of the test could be a boon to clinicians, particularly hematologists encountering potential cases of VWD.

“As a physician caring for individuals with inherited bleeding disorders, this development is an exciting advancement in von Willebrand disease diagnostics,”

said Jonathan Roberts, MD, Associate Medical Director, Bleeding & Clotting Disorders Institute, Peoria, IL. “This assay will reduce some of the diagnostic challenges in caring for

individuals with von Willebrand disease.”

*Source: BloodCenter of Wisconsin press release dated April 4, 2017*

**WPCNHF'S 3RD SEMI-ANNUAL  
CORNHOLE TOURNAMENT**  
SATURDAY, SEPTEMBER 9, 2017

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

**REGISTRATION: 8AM  
TOURNAMENT: 9AM**

**SOCIAL DIVISION**

**TEAM COST  
(PER TEAM OF TWO)**  
**EARLY BIRD: \$40**  
NOW THROUGH AUGUST 4  
**REGULAR: \$50**

**SOCIAL DIVISION PRIZE:  
1ST PLACE WINNER TAKE ALL  
\$100**

**COMPETITIVE DIVISION**

**TEAM COST  
(PER TEAM OF TWO)**  
**EARLY BIRD: \$50**  
NOW THROUGH AUGUST 4  
**REGULAR: \$60**

**COMPETITIVE DIVISION PRIZES:  
1ST PLACE: \$500  
2ND PLACE: \$200**

**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 TO PLAY ONLINE OR IN PERSON THE DAY  
OF THE EVENT IN THE COMPETITIVE OR SOCIAL DIVISIONS.**

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

**SIGN UP AT  
WPCNHF.ORG**

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



## Beams and Bubbles Deliver Gene Therapy to Mice with Hemophilia B

Scientists from the Center for Cardiovascular Research at the University of Hawaii (UH) have developed a novel approach to hemophilia gene therapy that employs microbubbles and an ultrasonic beam to deliver the treatment.

The study was led by Dr. Cindy Anderson and Dr. Chad Walton, who were both studying at UH's John A. Burns School of Medicine (JABSOM) during the breakthrough phase of research. Anderson at that time was a graduate student in the Cell & Molecular Biology Department at JABSOM and is now an Assistant Professor at Georgetown University. Walton was an Assistant Professor of Medicine at

JABSOM and is now an assistant to the Vice-Chancellor for Research at UH Mānoa. Their study was funded by the American Heart Association and the U.S. National Institutes of Health.

The UH team took genetic material that can elicit the production of factor IX (FIX) and placed it within miniscule microbubbles composed of lipid molecules that do not dissolve in water. The therapy was then injected into the bloodstream of mice with hemophilia B. As the microbubbles passed through the bloodstream they were hit by a beam of ultrasound that dispersed the genetic "payload" and deposited it into liver cells targeted for their ability to stimulate the production of FIX. The technique is known as ultrasound-targeted microbubble destruction (UTMD).

The animals subsequently showed both reductions in clotting time and increased FIX levels. An additional set of mice were treated via UTMD and evaluated for long-term effects,

the results of which demonstrated a persistent reduction in average clotting time 160 days after one administration of the therapy.

"We were able to improve clotting in mice for months after a single treatment," said Ralph Shohet, MD, Professor of Medicine and Director of the Center for Cardiovascular Research. Shohet sees unique advantages in UTMD, as it is both non-viral and minimally invasive.

"Hemophilia is a chronic debilitating disease. If we can treat it simply, cheaply, and non-invasively with gene therapy we will have helped to fulfill the promise of the modern medical era," added Shohet.

The study, "Ultrasound-Targeted Hepatic Delivery of Factor IX in Hemophiliac Mice," was published in April, 2016, in the journal *Gene Therapy*

Source: JABSOM news release dated March 10, 2017

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# Meet the HCWP Staff

## Frederico Xavier, MD, MS

Frederico Xavier, MD, MS, will be joining the Hemophilia Center of Western PA on July 1, 2017, as Associate Director, and with a joint appointment as an Assistant Professor of Pediatrics at Children's Hospital of Pittsburgh. Dr. Xavier completed medical school in 1997 and his pediatric residency in 2001 at the University of Campinas, Sao Paulo, Brazil, and a fellowship in pediatric hematology/oncology in 2005 at Federal University of Sao Paulo, Brazil. He then completed

pediatric residency at Long Island College Hospital, Brooklyn NY in 2005 and the Schneider Children's Hospital, Long Island Jewish North Shore Program, Hyde Park, NY in 2007. He served his clinical pediatric hematology/oncology fellowship at both the St. Jude Children's Hospital, Memphis, TN, and the Hospital for Sick Children, Toronto, Ontario, Canada in 2011. He then completed a Masters degree in Clinical Research at the Indiana Hospital in Purdue University in 2014. He was Assistant Professor of Pediatrics and Director of Thrombosis and Hemostasis at the Penn State Hershey Children's Hospital, Penn State University until this year.

Dr. Xavier has distinguished himself with 8 peer-reviewed publications and 10 presentations, including at ISTH, and at the European and the American Society of Gene Therapy. He is a member of the American society of Hematology (ASH), American Academy of Pediatrics, and American Society of Pediatric Hematology/ Oncology.

We welcome Dr. Xavier, his wife, and two children to Pittsburgh and look forward to working with him beginning in July 2017.

## Johana Schafer Research Nurse



Johana has a Bachelor's degree in Nursing from Chatham University and a Master's degree in Biochemistry from the University of Illinois at Urbana-Champaign. Her research experience spans several areas including biology, chemistry, biochemistry, pediatrics and radiology. Johana worked as a neuro nurse at UPMC Presbyterian. She loves spending time with family, volunteering within the community, bike riding, the outdoors and good coffee.

## Katherine Bush Mental Health Professional



Katherine Bush, LCSW, is excited to be a new member of the HCWP team. She completed her Masters of Social Work at the University of Maryland in Baltimore, and completed her undergraduate degree at Cabrini College in Philadelphia. Prior to working at the HCWP, Katherine worked as an outpatient therapist, a behavior specialist, an insurance utilization reviewer, and a member of a community treatment team. Katherine spends most of her free time chasing after her two young sons, but when she does have a spare moment she enjoys cooking, reading, knitting, theater, and walking. Katherine recently moved to Pittsburgh from Indiana state, and she is glad to be back home in Pennsylvania. You are welcome to call her by her nickname, Kit.

## Diann Keebler Administrative Assistant

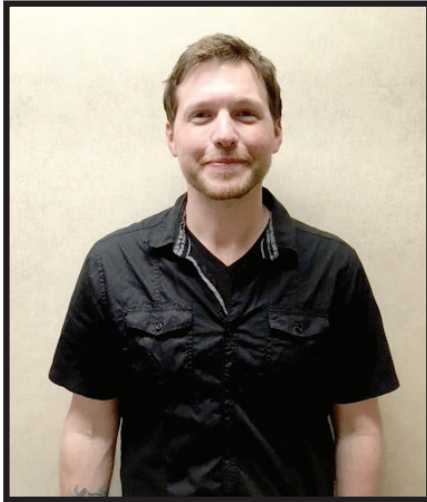


Diann Keebler has joined the HCWP as a part time administrative assistant. Diann is a 12 year U.S. Navy Veteran where she was trained as a Dental Tech and cross trained as a Hospital Corpsman. She worked for 23 years in dental offices doing everything from dental assistant to office manager. Her husband, whom she met while in the Navy, is an Allegheny County Police Officer. She has 3 adult daughters and a 16 year old son. She has spent many days at the softball field and dek hockey complex when they were growing up. Diann enjoys Irish Pubs and Dunkin Donuts!



## Meet the HCWP Staff continued

**Steve Tackett**  
**Factor Program Specialist**




Steve is an Ohio native, who has been certified and working in pharmacy since 2008. His pharmaceutical background started at a small institutional pharmacy in Youngstown, OH, where he was a compounding and special services technician. In 2011, he was offered a position with one of the largest pharmacy services providers in the country, which led him to move to Pittsburgh. While with the national pharmacy, he quickly progressed from technician to consultant extender, where his main focus was to provide on-site services to clients (skilled and assisted living facilities), through quality assurance inspections, special projects, and service issue resolution at the administrative level. In 2017, he

started his career with the HCWP Factor Program, as well as taking on a position teaching PTCB certification prep courses in the evenings.

Steve's education began in 2004 studying at the Berklee College of Music, earning his Specialist Certificate in Music Business in 2006. In 2008, he completed his pharmacy technician training online, and passed the PTCB certification exam shortly after.

When Steve is not working, he enjoys playing guitar (and other instruments), roller skating, coaching and refereeing roller derby, and of course, spending time with his wonderful fiancé and two soon to be stepdaughters.

The advertisement features a large, detailed profile of a man's head facing right. Inside the ear canal, a small figure of a person is shown in a yoga tree pose (Vrikshasana) on a rocky outcrop, with a sunset or sunrise sky in the background. The overall color palette is soft, with blues, greys, and warm sunset tones.

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## **Victor**

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To learn more about our commitment, visit us at **[BleedingDisorders.com](http://BleedingDisorders.com)**

# 2017 Hemophilia Walk Volunteer Opportunities



**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 7:30am - Help register onsite individuals and check-in already registered individuals.

**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.

**Race Medals-** Arrive at 8:15am - Hand out race medals to runners as they cross the finish line.

**Food Table-** Arrive at 8:30am - 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.

**T-Shirt and Goodie Bag Table** - Arrive at 8:30am - Organize and pass out Walk t-shirts and Walk bags.

**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](mailto: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!!



## **KOVALTRY®**, Antihemophilic Factor (Recombinant): **THE CONFIDENCE TO TAKE CONTROL**



**For children, adolescents, and adults with hemophilia A**

**For more information, visit [YourKOVALTRY.com](http://YourKOVALTRY.com)**

### **INDICATIONS**

- KOVALTRY® is a medicine used to replace clotting factor (Factor VIII or antihemophilic factor) that is missing in people with hemophilia A.
- KOVALTRY® is used to treat and control bleeding in adults and children with hemophilia A. KOVALTRY® can reduce the number of bleeding episodes in adults and children with hemophilia A when used regularly (prophylaxis). Your healthcare provider may give you KOVALTRY® when you have surgery.
- KOVALTRY® is not used to treat von Willebrand Disease.

### **IMPORTANT SAFETY INFORMATION**

- You should not use KOVALTRY® if you are allergic to rodents (like mice and hamsters) or any ingredients in KOVALTRY®.
- Tell your healthcare provider if you have heart disease or are at risk for heart disease.
- The common side effects of KOVALTRY® are headache, fever, and itchy rash.
- Allergic reactions may occur with KOVALTRY®. Call your healthcare provider right away and stop treatment if you get tightness of the chest or throat, dizziness, decrease in blood pressure, and nausea.
- Your body can also make antibodies, called "inhibitors," against KOVALTRY®, which may stop KOVALTRY® from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

### **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

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