



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

Fall 2016
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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

Family Camp

By Judy Walsh

In June, I attended the Chapter's first family camp with my grandchildren and found the experience to be fun, educational, and nourishing! Family camp was held at Jumonville, near Uniontown, PA; we stayed in comfortable rooms in a lodge and ate well. We were offered free time to enjoy the campgrounds and activities on Friday and Saturday afternoons. We also had the option to stay and enjoy the activities after checking out on Sunday.

We enjoyed doing new things together. One of the highlights of the weekend was a low-ropes challenge course. The course was both mentally and physically challenging and it was something that I've never done before. We were grouped in teams with other families and adults and children worked together and collaborated on strategies to accomplish the tasks and meet the challenges! The experience demonstrated what can be accomplished when you work together.

On Saturday afternoon, there was time set aside for adults and children to spend time with their peers. The adults participated in a discussion on relationships with bleeding disorders, led by Chapter members Matt and Brianna Pace. During this time, the children participated in climbing wall activities and other games. Each evening there was time to relax by a fire and enjoy s'mores!

Chapter members Jessica and Bob Graham created a camp song to be sung and video recorded by bleeding camps around the world. We enjoyed singing the song and knowing that others around the world would know they are not alone. According to Bob, the hope is that this common experience will help connect people and encourage them to learn more about other people and places in the bleeding disorders camp community. At time this article was written, the song has been sung in Pennsylvania, Romania, and Canada, and would next be coming to the Netherlands and New York State.



Saturday night was a fun family night! Everyone had the opportunity to participate in Families on Stage (a program sponsored by Biogen) and learn a new skill to perform in an entertaining variety show! Members of my family enjoyed balancing feathers, twirling flags and hoops! Others learned how to spin plates, perform tricks with yoyos, rope, and more! This program was a hit with all ages.

(Continued on page 15)

2016 Hemophilia Walk, Run For Their Lives 5K, and Cornhole Tournament

Local families & friends gathered at the North Park Boat House to support a very important cause, the 2016 Western Pennsylvania Hemophilia Walk, Run for Their Lives 5K, and the First Ever WPCNHF Cornhole Tournament on Saturday, September 17, 2016. The Hemophilia Walk and Run for Their Lives 5K continues to be a resounding success with the help of so many individuals and business sponsors.

This year's highlights included 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, Stacy McCarthy for the Henna Tattoos, Cynthia Jewel from Face Paint Pittsburgh, Balloon Artist Faerie Grace, and special appearances from the Pittsburgh Volunteer Princesses, Star Wars Characters from Garrison Carida 501st Legion, the Pittsburgh Pirate Parrot, Pittsburgh Steeler's Steely McBeam, and Tall Cathy from KISS 96.1 FM.

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 this year's Walk Chair, Kelly Baker. Whether it is gathering and putting together baskets for the raffle, putting together Walk wrap events, and selling calendars to support the Chapter, Kelly continues to go above and beyond to support the Chapter.

Congratulations to our top fundraising team Conor's Clan who raised an amazing \$8,115, our top fundraising individual Emily Nikithser who raised a total of \$3,914, and our top youth fundraising individual Jaxson Baker who raised a total of \$1,137. A special shout out to Jen Miller and Luke's Lineup for continuing to be our largest walk team and for raising an incredible \$6,796. Thank you for your passion and dedication!

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 Papa's Peeps as the official T-shirt winner, raising over \$170.

Thank you to Elite Runners for the great job they did managing the Run for Their Lives 5k and to everyone who participated in the



run. Congratulations to the top three overall winners of the Run for Their Lives 5k. First place went to Jeremy McNamara, second place went to Dan Rabe, and third place went to Joseph Pershina.

Thank you to Joe Castellano from Steel City Cornhole for running our first ever Cornhole Tournament and Pfizer Hemophilia for sponsoring this event! Congratulations to the winners of the tournament! First place went to Adam and Barry of the 12 Packers, second place went to Joe and Dan of Steel City 1, and third place went to Chad and Dave of Hanging Chads.

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 and will increase awareness of bleeding disorders, provide education to help people with bleeding disorders, and support advocacy initiatives at both state and national levels to help ensure access to medical care and equitable insurance reimbursement for all.

Mark your calendar now for our next event, Boo-ling for Bleeding Disorders! This Halloween Costume Party and Bowling Fundraiser will be held on Sunday, October 30th from 2pm-5pm at Paradise Island Bowl! The cost is \$25 per person and includes bowling, shoe rental, prizes, and unlimited pizza, wings, and soft drinks! Visit wpcnhf.org for more information.

Walk Sponsors-

National Sponsors

National Presenting Sponsor - Baxalta Now Part of Shire

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Silver Regional Sponsor- Hema Biologics

Principal Partner- Accredo Specialty Pharmacy

Local Sponsors

Gold Sponsor- UPMC

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Supporter Sponsors- The Beaver Area Jaycees, Buffalo Wild Wings of St. Clairsville, OH,

Cronimet Specialty Metals, Dick's Sporting Goods, My Hero's Sub Shop, Law Office of Scott E. Miller, Power Contracting Company, and Vantage Corporation.

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In-Kind Sponsors- Dunkin Donuts, Eat N Park, First Class Entertainment, Garrison Carida 501st Legion, Kona Ice Pittsburgh, Nature's Bakery, Pittsburgh Pirates, Pittsburgh Steelers, Pittsburgh Volunteer Princesses, Trader Joes, and Wise Foods.

Run Sponsors-

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Calendar of Upcoming Events

Saturday, October 8
Oktoberfest
Pittsburgh, PA

Sunday, October 9
Teen Meeting
Pittsburgh, PA

Sunday, October 30
Bowling Fundraiser
Neville Island, PA

Friday, November 11
New Parent Network
Erie, PA

Saturday, November 12
Erie Fall Program
Erie, PA

Winterfest
Date & Location TBD

Friday, January 6 – Sunday, January 8
Teen Retreat
Mars, PA

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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



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

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Indications and Usage

NUWIQ is a Recombinant Antihemophilic Factor [blood coagulation factor VIII (Factor VIII)] indicated in adults and children with Hemophilia A for on-demand treatment and control of bleeding episodes, perioperative management of bleeding, and for routine prophylaxis to reduce the frequency of bleeding episodes. NUWIQ is not indicated for the treatment of von Willebrand Disease.

Important Safety Information

NUWIQ is contraindicated in patients who have manifested life-threatening hypersensitivity reactions, including anaphylaxis, to the product or its components. The most frequently occurring adverse reactions (>0.5%) in clinical trials were paresthesia, headache, injection site inflammation, injection site pain, non-neutralizing anti-Factor VIII antibody formation, back pain, vertigo, and dry mouth. Development of Factor VIII neutralizing antibodies (inhibitors) may occur.

Please see adjacent page for Brief Summary of Prescribing Information.

References: 1. Sandberg H, et al. Thromb Res 2012; 130:808-817. 2. Casademunt E, et al. Eur J Haematol 2012; 89:165-176. 3. Kannicht C, et al. Thromb Res 2013; 131:78-88. 4. Valentino LA, et al. Haemophilia 2014; 20:1-9.

HIGHLIGHTS OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use NUWIQ safely and effectively. See full prescribing information for NUWIQ.

NUWIQ®, Antihemophilic Factor (Recombinant) Lyophilized Powder for Solution for Intravenous Injection Initial U.S. Approval: 2015

INDICATIONS AND USAGE

NUWIQ is a recombinant antihemophilic factor [blood coagulation factor VIII (Factor VIII)] indicated in adults and children with Hemophilia A for:

- On-demand treatment and control of bleeding episodes
- Perioperative management of bleeding
- Routine prophylaxis to reduce the frequency of bleeding episodes

NUWIQ is not indicated for the treatment of von Willebrand Disease.

DOSAGE AND ADMINISTRATION

For intravenous use after reconstitution

- Each vial of NUWIQ is labeled with the actual amount of Factor VIII potency in international units (IU).
- Determine dose using the following formula for adolescents and adults:
$$\text{Required IU} = \text{body weight (kg)} \times \text{desired Factor VIII rise (\%)} (\text{IU/dL}) \times 0.5 (\text{IU/kg per IU/dL})$$
- Dosing for routine prophylaxis:

- Frequency and duration of therapy depends on severity of the FVIII deficiency, location and extent of bleeding, and patient's clinical condition.

DOSAGE FORMS AND STRENGTHS

NUWIQ is available as a white sterile, non-pyrogenic, lyophilized powder for reconstitution in single-use vials containing nominally 250, 500, 1000 or 2000 IU Factor VIII potency.

CONTRAINDICATIONS

NUWIQ is contraindicated in patients who have manifested life-threatening hypersensitivity reactions, including anaphylaxis, to the product or its components.

WARNINGS AND PRECAUTIONS

- Hypersensitivity reactions, including anaphylaxis, are possible. Should symptoms occur, discontinue NUWIQ and administer appropriate treatment.
- Development of Factor VIII neutralizing antibodies (inhibitors) may occur. If expected plasma Factor VIII activity levels are not attained, or if bleeding is not controlled with an appropriate dose, perform an assay that measures Factor VIII inhibitor concentration.
- Monitor all patients for Factor VIII activity and development of Factor VIII inhibitor antibodies.

ADVERSE REACTIONS

The most frequently occurring adverse

reactions (>0.5%) in clinical trials were paresthesia, headache, injection site inflammation, injection site pain, non-neutralizing anti-Factor VIII antibody formation, back pain, vertigo, and dry mouth.

USE IN SPECIFIC POPULATIONS

Pediatric Use: Lower recovery, shorter half life and faster clearance in children aged 2 - ≤12 years. Higher doses and/or a more frequent dosing schedule for prophylactic treatment should be considered in pediatric patients aged 2 to 5 years.

PATIENT COUNSELING INFORMATION

Advise patients to read the FDA-approved patient labeling (Patient Information and Instructions for Use).

Because hypersensitivity reactions are possible with NUWIQ, inform patients of the early signs of hypersensitivity reactions, including hives, generalized urticaria, tightness of the chest, wheezing, hypotension, and anaphylaxis. Advise patients to stop the injection if any of these symptoms arise and contact their physician, and seek prompt emergency treatment.

Advise patients to contact their physician or treatment center for further treatment and/or assessment if they experience a lack of clinical response to Factor VIII replacement therapy, as this may be a manifestation of an inhibitor.

Advise patients to consult with their healthcare provider prior to traveling. While traveling, patients should be advised to bring an adequate supply of NUWIQ based on their current treatment regimen.

To report SUSPECTED ADVERSE REACTIONS, contact Octapharma USA Inc. at 1-866-766-4860 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

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Distributed by:
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Issued September 2015.

Revised September 2015

For all inquiries relating to drug safety, or to report adverse events please contact our local Drug Safety Officer:
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Spotlight on the Member

Meet Sean Janoss

Many of us in the bleeding disorders community are generally familiar with bleeding disorders such as hemophilia A (factor VIII deficiency), hemophilia B (factor IX deficiency) and von Willebrand Disease (VWD) it is likely that you have met others who have these bleeding disorders—especially if you’ve ever attended a Chapter event! According the National Hemophilia Foundation’s website, VWD is the most common affecting up to 1% of the US population. Hemophilia A and hemophilia B are considered rare diseases (defined in the U.S. as diseases that affect fewer than 200,000 people), with approximately 1 in 5,000 male births. But what about those other factor deficiencies, such as I, II, V, VII, X, XI, XII, and XIII? It’s very rare to meet someone with one of those bleeding disorders—even in the bleeding disorders community. Take factor VII for instance—factor VII is considered the most common of these rare factor deficiencies and the incidence is estimated at only 1 per 300,000-500,000 (with men and women being affected equally).

Over the last several years, I’ve had the pleasure of getting to know a gentleman from our community with factor VII deficiency and I’d like to introduce him to you. Sean Janoss, now 38 years old, was diagnosed at age 22. Up until that point, neither Sean nor his family suspected he had a bleeding disorder. Looking back, he did have his share of bruises, pain, and nose bleeds over the years, but nothing that seemed unusual for a boy his age. Sean played baseball up until the age of 15, and as the catcher on the team, he experienced knee pain. The pain stayed with him, though, even after he quit baseball. He also had a couple of knee injuries over the years for which x-rays were ordered, but nothing showed up.

At age 19, Sean had a tonsillectomy and adenoidectomy. When he was in the recovery room, he coughed and began to hemorrhage. He was rushed back into the operating room and woke up in the ICU. Blood oozed for the next 24 hours and the medical team informed him of the possibility of another surgery; however, the bleeding finally stopped. Sean healed without any further complications and would go another three years without a diagnosis.

When he was 22 years old, he had x-rays for knee pain and the doctor could see he had diminished cartilage in both of his knees, but at this time, he had not yet been diagnosed with a bleeding disorder. In 2002, Sean was scheduled for hernia surgery and explained to his doctor that he had hemorrhaged after the tonsillectomy and adenoidectomy. His doctor ordered pre-op testing and the results came back with factor VII (FVII) deficiency. FVII is a protein that, when bound to tissue factor, initiates the clotting cascade, which leads to the formation of a blood clot (www.hemophilia.org/). He was referred to Dr. Ragni, at the Hemophilia Center of Western PA, and further testing confirmed his diagnosis. He was treated prior to the surgery and didn’t have any complications.

In 2010, Sean had a pacemaker implanted and again, was treated prior to surgery. He had complications, though, following the surgery—blood oozed through the closure, which was held together with surgical glue, and clots developed on top of the pacemaker. He was taken back into surgery to have the clots removed. This time, the incision was closed with sutures and he healed without any further complications.

Sean now treats on demand when he has a bleed and treats prior to surgeries. His veins can be difficult to access and when he has a major bleed, he will go to the ER and they will insert an IV needle for infusions.

Sean lives in McKeesport with his wife, Tina, and their two sons, Paul (age 14) and Alex (age 11). His family is involved in his care and is active in learning more about his bleeding disorder. When Sean has a bleed, he will either self-infuse or his wife will infuse him. His oldest son is also learning how to infuse him. Paul began to learn this skill at a retreat the family attended—they have been fortunate enough to participate in the Factor VII Retreat (run by Comprehensive Health Education Services and the Lady Bugs Foundation) twice in recent years.

Sean and his family enjoy spending time together at the park, going to baseball games, and swimming. He feels that it can be somewhat challenging to keep up with his sons, as he needs to be cautious of where he steps on uneven ground, to avoid falls and potential ankle, knee, or hip bleeds. He also needs to monitor activities that could lead to shoulder bleeds. Over the years, Sean and his family have participated



in a number of Chapter events. A favorite of theirs is the Chapter’s Annual Meeting. He and his oldest son also look forward to the Men’s group events.

The message Sean would like to send to others that have symptoms of a bleeding disorder is to get tested so you can avoid pain, complications, and consequences from permanent damage. Well after Sean received his diagnosis, he learned that he had a great-aunt who had also been diagnosed with Factor VII deficiency. If you have a bleeding disorder, take time to learn your family history and share the information, as you feel appropriate, with relatives who could potentially be affected and/or pass the gene on to their children.

AmazonSmile

Do you shop on Amazon? If so, consider shopping at AmazonSmile and designate the Chapter to receive a donation for each eligible purchase you make! AmazonSmile is a simple and automatic way for you to support the Chapter, at no cost to you. AmazonSmile has the same low prices as Amazon. To shop, simply go to smile.amazon.com on your computer or mobile device. Eligible products are marked as “Eligible for AmazonSmile donation” on their product detail pages. If you already have an Amazon account, you can use the same account on AmazonSmile.

The first time you visit AmazonSmile, you need to select a charitable organization to receive donations. Simply select *The Western Pennsylvania Chapter of the National Hemophilia Foundation* and the Chapter will receive a donation for each eligible item you purchase. That’s all there is to it!



Camp Hot-To-Clot

By Diane Standish, LSW, HCWP

While the rest of the world shifted its gaze toward Rio in August, 61 campers enjoyed a mini-version of the Olympics at Camp Kon-o-Kwee in Fombell, PA. It wasn't Brazil, but with temperatures in the 90s, Camp HOT-to-Clot really lived up to its name this year!

Some Highlights:

- Campers made up their own "countries," complete with country names, flags, and mascots. Wouldn't you like to travel to Brolandia, Tigertopia, and A-bear-ica?
- We had land and water Olympic competitions, complete with a medal ceremony at the end. Let me just say that I will never see a synchronized swimming event that can match the spirit and creativity that our campers put into it!
- In keeping with our international theme, campers learned about other countries in many ways:
 - attending an International Festival complete with foods from many countries, including the memorable "dulce" (kind of a dried seaweed, I think?) from Canada;
 - participating in an interactive phone call with a representative of Save One Life, a sponsorship program for people with bleeding disorders in developing countries. The campers learned about Nepal and what it is like to have a bleeding disorder there;
 - doing a service project, which involved assembling gift bags of fun and useful items, which we shipped to a bleeding disorders camp in Nepal for their campers to enjoy;
 - participating in World Federation of Hemophilia's Journey Around the World, which educates children about how bleeding disorders are managed in other countries.
- We sent a video greeting to campers at Camp Tapawingo in Oregon, who were having their camp during the same week. They issued an NHF Red Tie Challenge to our camp, which the campers gladly accepted. We took photos and videos of our campers wearing red ties in the pool, at meals, and during many camp events, and sent another fun video to the Oregon camp. We challenged Tapawingo campers to



the "Running Man" dance challenge, and they reciprocated, sending us back a hilarious video of themselves doing the Running Man in various camp locations, including the high ropes!

- Two campers earned the Big Stick award this year by demonstrating all of the steps needed to self-infuse for the first time! Many campers who do not have bleeding disorders 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: archery, high ropes, zip line, swimming, canoeing, fishing, and playing games.

The exhausted but proud and happy camp staff members are taking a break before starting to plan Camp Hot-to-Clot 2017. We look forward to seeing familiar and new faces at camp next year!

If you want more information about Camp Hot-to-Clot, please call either the WPCNHF or HCWP staff.



Getting to Know the HCWP Staff

Name/Title: Michelle Alabek, Genetic Counselor

Birthplace: Pittsburgh, PA

First job: Hostess at my best friend's family's restaurant

Accomplishment you're proudest of: Moving to Louisville, KY on my own! I took my first job as a genetic counselor there and didn't know anyone in the area. It was a big test for me, both professionally and personally...but I ended up loving it! I left with treasured friendships, great experiences, and many lessons learned.

What three words describe you best? Considerate, rational, adventurous

Dream vacation: Anywhere, anytime...I love exploring new places!



(Michelle Alabek, Iceland 2015)

Things you can do without: Chocolate, malls

Person you'd most like to have dinner with: Steve Harvey

Movie you could see anytime: My Best Friend's Wedding

TV show you try not to miss: I get hooked on almost any competitive reality TV show...Bachelor/Bachelorette, Amazing Race, Survivor...you get the idea!

Three things that can always be found in your refrigerator: Cheese, cheese, and cheese! (Literally...I always will have at least three different kinds of cheese!)

Secret vice: Crafting/DIY projects

Who would play you in the movies: Jennifer Aniston

Your pet peeve about the city: People not knowing how to drive in the rain or snow.

People may be surprised to know that: I have been to five continents...only two more to go!

Annual Meeting & Walk Kickoff

Nearly 120 people attended the Chapter's Annual Meeting & Walk Kickoff on August 4, 2016. This evening included exhibits by manufacturer and home healthcare companies, presentations, and dinner.

The Annual Meeting was led by our Board President, Nathan Rost. The Walk kickoff included a video that film students from LaRoche College created, which featured a teenager from our community, who has a bleeding disorder and is raising funds through his Walk team. Following the Walk kickoff, representatives from many of the

factor manufacturing companies gave brief presentations on their company's research, products, and/or services. When the program was over, many people stayed to socialize and enjoy time together at Dave & Buster's.

We thank the following for supporting this event through exhibits, sponsorships, or charitable donations:

Accredo	CVS/Caremark
Aptevo	Grifols
Baxalta, now part of Shire	Hemophilia Center of Western PA
Bayer Healthcare	Matrix Health Group
Biogen	Novo Nordisk
BioRX	Octapharma
Cottrill's Pharmacy	Pfizer
CSL Behring	Option Care



Meet This Year's Top Fundraising Team: Conor's Clan!

Conor's Clan is great group of friends and family who have come together to support little 9 month old Conor who has severe Hemophilia A. Mom (Emily) and Dad (Pat) are new to everything, being first time parents and having the first hemophilia in the family since 1956! They are so lucky to have such wonderful and supportive friends and family that are helping them along the



way, as well as support from the WPCNHE. Conor is a happy little boy and getting bigger by the day.

Conor's Clan raised an incredible \$8,115! They held many fundraising events to



support their Walk Team including a car wash which brought in over \$1,200! You are truly amazing. We can't thank you enough for your hard work and dedication!



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Community Resources

Learn about support programs like HemMobile™, Patient Affairs Liaisons, scholarship assistance, and the educational speaker series.

*Terms and conditions apply; visit PfizerFactorSavingsCard.com for complete terms and conditions. For commercially insured patients only. Medicare/Medicaid beneficiaries are not eligible. The Card cannot be combined with any other rebate/coupon, free trial, or similar offer for the specified prescription. The card will be accepted only at participating pharmacies. This coupon is not health insurance.

If you have any questions about the use of the Pfizer Factor Savings Card, please call 1.888.240.9040 or send questions to: Pfizer Factor Savings Program, 2250 Perimeter Park Drive, Suite 200, Morrisville, NC 27560. For more information, please visit www.HemophiliaVillage.com.

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There are no membership fees to participate in this service. Estimated savings is 36% and depends on such factors as the particular drug purchased, amount purchased, and the pharmacy where purchased. Pfizer RxPathways is a joint program of Pfizer Inc and the Pfizer Patient Assistance Foundation™.

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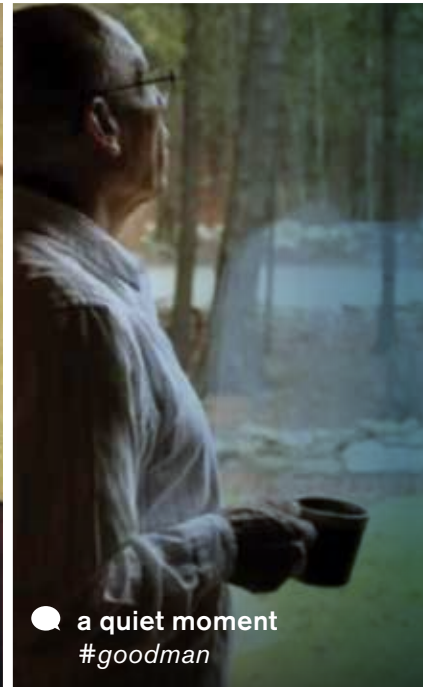
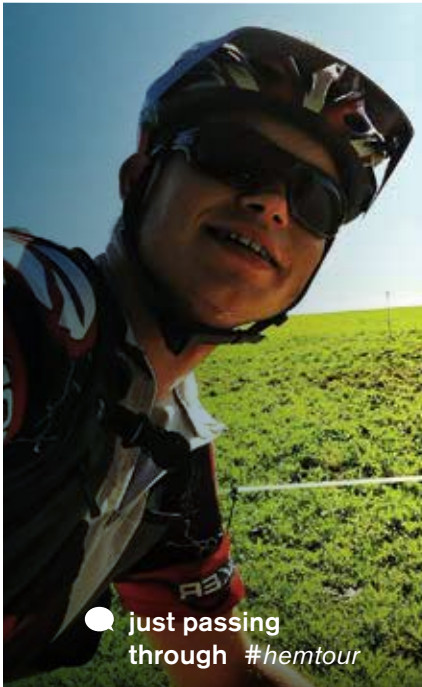
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The Journey, Celebrated

Life is made of small moments that inspire, motivate, and make us feel that our work is worthwhile. As a company, as a team, and simply as individuals, we strive to discover, enable, and celebrate more of them.

Today, possibility is in the air.



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Want to Know More

about your factor options?

When it comes to your factor therapy, you have choices. And at Biogen, we recognize the importance of continued research as well as supporting the hemophilia community. See if now might be the right time for you to make a change—learn more about our therapy options as well as our range of financial, educational, and community support programs.

To learn more about these options, contact your CoRe Manager:

Christine Rowe | **Phone:** 267.249.8372 | **E-mail:** Christine.Rowe@biogen.com

Letter From The President, Nathan Rost

Dear Chapter Members and Stakeholders,

I am pleased to announce the winners of the 2016-2017 WPCNHF Scholarship: Congratulations to Lucas Berry and Nikole Scappe! Lucas is a student at Penn State Behrend and Nikole is a student at LaRoche College with a double major in Marketing and Management.

I would also like to take this opportunity to thank our members who participated in the Chapter Evaluation & Needs Assessment earlier this year. The Chapter staff has been busy planning events to support your needs and I hope that you are taking advantage of these opportunities to learn more about bleeding disorders and grow your peer networks. As always, the Chapter welcomes

feedback and suggestions for programs and events. Please feel free to contact the Chapter anytime at 724-741-6160 or at info@wpcnhf.org.

Sincerely,

Nathan Rost
WPCNHF Board President

Letter From The Executive Director, Alison Yazer

Happy Fall, y'all!

I can't believe how quickly time has flown by. So much has happened so quickly that it's difficult to keep track of everything the Chapter has been doing!

Camp Hot-to-Clot, the Walk, Run for Their Lives and Cornhole Tournament and many educational events have taken place the past few months. We also had a New Parent Networking Summer Social. This series of events is one of the things that came from your suggestions and ideas, so please, keep 'em coming! We are here to serve you. That said, when we offer educational events on specific topics that our members have

requested, please make an effort to attend. We understand that lives get hectic, but we try to give you more than enough notice to get these events on your calendars. It is frustrating when we lose money because of forfeited deposits when we have to cancel events. We would much rather that money be used to help our community!

Things are changing constantly within the bleeding disorders community. Industry is changing rules and regulations for support of Chapter events, but there are also constant changes ahead in the insurance world. Chapter staff will continue to work with legislators in Washington DC to encourage support of H.R. 3742. As you

may know, H.R. 3742 would mandate that insurers in the ACA Marketplace accept third party premium payments from nonprofits such as PSI. We are also working with state officials to have a similar policy implemented in Pennsylvania.

As always, please contact any of the staff at the office with any questions or concerns. Thank you for all that you do on behalf of WPCNHF.

Sincerely,

Alison R. Yazer
Executive Director

Board of Directors

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Janet Barone

Marketing & Events Manager

Kara Dornish

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

WPCNHF Wish List

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

- ♦ White copy paper by the ream or by the case
- ♦ Colored copy paper by the ream for invitations and newsletter inserts
- ♦ 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.

Family Camp

(Continued from cover page)

Sunday morning we said our good-byes, until we meet again. Family camp was a fun, educational, and well-run program. I hope to see everyone back next time and hope others will join us!

Note from Janet Barone:

I would like to thank my fellow committee members who volunteered their time to help plan and support the weekend:

Cheri Mcshea, HWCP, PT, Diane Standish, HCWP, LSW, Matthew Pace PhD., LMFT, Karen Slater, and Victoria Baker.

The Chapter also thanks the following companies for their support through exhibits, sponsorships, or charitable

donations: Baxalta, Bayer Healthcare, Biogen, Grifols, HCWP, Matrix Health, Octapharma, and Pfizer.



New Parent Network Picnic

On Saturday, August 20, we had the pleasure of spending time with some of our cutest and youngest members at the New Parent Network Picnic! This event was held at Idlewild & SoakZone, in Ligonier, PA. Everyone enjoyed a picnic lunch, an opportunity to meet other families, and the afternoon at Idlewild & SoakZone.

This was the most recent event in the 2016 New Parent Network Series, an initiative created to provide new families with opportunities to learn more about their child's bleeding disorder, as well as to network and build relationships with their peers. The events in this program are a collaborative effort between the Chapter and the HCWP.

We thank the following for supporting the New Parent Network with Educational Grants, Sponsorships, or Charitable Contributions:

Aptevo
Baxalta, now part of Shire
Bayer Healthcare
Biogen
CSL Behring
Novo Nordisk



Gene Therapy for Hemophilia – Are we there yet?

This is an exciting time for hemophilia care because several new treatments are available (e.g. extended half-life factor products) and others are expected soon.

The Hemophilia Center of Western Pennsylvania is participating in an early phase gene therapy trial for adult males with Hemophilia B, with FIX 2% or lower. The study is sponsored by Spark

Therapeutics and Pfizer. The treatment is a one-time infusion of SPK-9001, an AAV vector carrying a factor IX gene. The vector travels to the liver to deliver the factor IX gene so the liver can make factor IX. The factor IX gene used in the study is a factor IX variant, factor IX-Padua, which has approximately 8 times more factor IX activity. By using a stronger factor IX gene, lower doses of the AAV vector can be given. This decreases the chance that the immune system will interfere with making factor IX.

Preliminary results indicate factor IX levels of about 32%, 12 weeks after the infusion, the highest level of in any gene therapy

trial to date. The patients do not show any immune response so that participants were able to stop their prophylaxis or on-demand factor treatments, and remain free of bleeding episodes. All of the patients report that they are able to be more active and have a better quality of life.

If you have any questions about gene therapy for hemophilia, please call Dr. Margaret Ragni at 412-209-7288, or contact Ms. Judith Kadosh, RN, BSN, Lead Research Nurse at 412-209-7263, or at jkadosh@itxm.org.



Don't let insurance or financial challenges get between you and your treatment

Free Trial Program*

- Enroll today for up to 6 free doses†
- Delivered to your home free of charge

Access to Therapy

We might be able to provide treatment at no cost if you‡:

- Experience challenges getting insurance coverage for a Bayer product
- Are uninsured or underinsured
- Are between jobs and are experiencing a gap in insurance coverage

\$0 Co-pay Program§

If you have private insurance, you may be eligible for the \$0 Co-pay Program.

- You may be able to receive up to **\$12,000 in assistance** per year, regardless of income
- **Assistance is awarded per patient.** Multiple members of the same household can apply
- Enrollment can be completed in **one short phone call**

Live Helpline Support

- Consult with an expert in insurance
- Spanish-speaking Case Specialists are also available



CALL
1-800-288-8374
8:00 AM-8:00 PM (ET) Monday-Friday. Spanish-speaking Case Specialists are also available.

*The Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Participation in the Free Trial Program is limited to 1 time only. This program is complimentary and is not an obligation to purchase or use a Bayer product in the future. Reselling or billing any third party for the free product is prohibited by law.

†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.

‡The program does not guarantee that patients will be successful in obtaining reimbursement. Support medication provided through Bayer's assistance programs is complimentary and is not contingent on future product purchases. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

§People with private, commercial health insurance may receive co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription reimbursement under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.

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