



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

Winter 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

Boo-ling for Bleeding Disorders

The Western Pennsylvania Chapter of the National Hemophilia Foundation Strikes Out Bleeding Disorders

The Fourth Annual Bowling for Bleeding Disorders fundraiser, dubbed Boo-ling for Bleeding Disorders this year for its Halloween theme, was held at Paradise Island Bowl in Neville Island, Pennsylvania on Sunday, October 30, 2016. Dressed in costume, twelve teams participated in this 3-hour bowling marathon. The cost to attend was \$25 per participant which included an event t-shirt, shoe rental, bowling, pizza, wings, and unlimited soft drinks.

Participants voted and prizes were awarded for the most original costume, scariest costume, prettiest costume, funniest costume, and best group costume. The most original costume award went to Dominic Ortenzo who was dressed as a journalist with a pinstriped fedora, press pass, and camera. The scariest costume award went to Tony Ortenzo who was dressed up as a Mad Scientist in a white lab coat and a crazy unkempt grey wig. The prettiest costume award went to pretty young lady named Evelyn who was dressed as a unicorn. The funniest costume award went to Whes Ebsworth who was dressed in a teddy bear suit. The best group costume award went to Claire's Creepy Clotters who went as the Jolly Green Giant and his vegetables.

We are extremely grateful for the all bowlers who participated in this event. We are excited to report that over \$13,000 was raised from this event! 100% of this money will stay local to support the members of the Western PA Chapter of the National Hemophilia Foundation. The sponsors of the event included CSL Behring, The Hemophilia Center of Western Pennsylvania, Accredo, Grifols, Novo Nordisk, Pfizer, Shire, and 91.3 WYEP.

WPCNHF would like to thank all who participated in and sponsored this event. We can't wait to see you all next year at the Fifth Annual Bowling for Bleeding Disorders!



Spotlight on the Member: Meet Joseph Brosky



“Manage your hemophilia, don’t let it manage you” are words that Joseph Brosky lives by. It’s that very attitude that enables him to enjoy life and continue to strive and meet new goals. Joe enjoys working with his hands and keeping himself busy doing just about anything from working on his car to crocheting. He lives in Aliquippa, PA, with his wife, Michelle. He first met Michelle at a dance hall over twenty years ago. However, they didn’t start dating until the day they met at a Denny’s restaurant, so he could deliver copies to her (Joe worked at Kinko’s, at the time). They had dinner together, talked for hours, and didn’t leave the restaurant until close to 3:00 in the morning! They were married five months later. They have three children: Amanda, Nicholas, and Jonathan.

Joe was diagnosed with Hemophilia A when he was a young child. Although he had some bloody noses and skinned knees, he didn’t have any bleeds that required an infusion until he was eight years old. This is when Joe experienced his first spontaneous gastrointestinal bleed (GI) bleed. He was admitted to Children’s Hospital of Pittsburgh for approximately one week and was treated with whole blood and cryoprecipitate. This was quite a scary experience for an eight-year-old child. In addition to the bleeding, Joe had an allergic reaction to the blood products and broke out in hives. Going forward, he would need to take Benadryl prior to infusions, until advances in factor products were made. Throughout his life, he continued to deal with spontaneous GI bleeds and sometimes, as a result, anemia. Tests have been run, but no cause has ever been determined for the GI bleeds.

Even though Joe has had to deal with unpredictable GI bleeds, he feels fortunate. Growing up he had few joint bleeds—all of

which were trauma-related and typically the result of playing a bit too rough, especially during the teenage years—but he hasn’t had any long-term damage. He recalls going to the Hemophilia Center of Western PA when he was a teenager. He would notice kids his own age or younger who wore leg braces and were suffering from joint issues. Joe is now 46 years old and is the only surviving member of his family with hemophilia. His uncle, Mike, had passed away before he was born. Mike had complications and bled out after his appendix burst. Joe’s cousin, Tony, who had a black belt in karate, passed away from complications associated with contaminated blood products.

Although Joe was forbidden to play organized sports during school, he doesn’t feel that his bleeding disorder precluded him from doing most of the things he wanted to do. Although he always loved baseball and wasn’t able to play on a team, he didn’t have much of an interest in other sports. Today he enjoys going to Pittsburgh Pirates games with his family and doing some of the activities that he could not do while growing up. Joe feels blessed that he and his wife share many of the same interests. In addition to baseball, they enjoy camping, fishing, bike riding, and traveling. When Joe needs to stop for an infusion, Michelle, who is a registered nurse, infuses him.

Joe works as a Certified Nurses Aid (CNA) in a long-term care facility. He enjoys his job and greets the patients with a smile. He says



he truly cares about the patients, maintains a positive attitude, and focuses his attention on helping them. He plans to go to school in the next few years become a Licensed Practical Nurse (LPN) and eventually become a clinical instructor for CNA students. In addition, Joe and Michelle work together as CPR and First Aid instructors for the American Heart Association.

Joe and his family began attending chapter events when the Chapter hosted dinner cruises. He then began to participate in Men’s Group events. If you attended the Chapter’s annual meeting this past summer, you would have met Joe and Michelle, as they volunteered to staff the registration table. In September, they participated in the Hemophilia Walk for the first time. Joe is working on a fitness goal and is aiming to run in the Chapter’s Run for Their Lives 5K, on September 9, 2017! He is steadily losing weight and increasing his activity level. He spends a lot of time walking and uses bikes, treadmills, and free-weights in his fitness routine. He hopes to start riding his bike to work this coming summer. We wish Joe much success with all of his goals!



Every dollar raised stays local to benefit the members of The Western Pennsylvania Chapter of the National Hemophilia Foundation.

Saturday, February 25, 2017
Diamond Run Golf Club
132 Laurel Oak Drive
Sewickley, PA

The Western Pennsylvania Chapter of the National Hemophilia Foundation invites you to participate in the Second Annual Iced Tees Winter Golf Classic! This unique event will take place at Diamond Run Golf Club in Sewickley, PA on February 25, 2017. The outing will include a 9-Hole Shotgun Scramble followed by a Chili Cook Off and Awards Ceremony. We will be joined by special guest Tall Cathy from KISS 96.1!

9:00 a.m. Registration
Coffee, Donuts, & Hot Oatmeal will be provided

10:00 a.m. Event Starts
 9-Hole Scramble

1:00 p.m. Chili Cook Off
Taste and vote on your favorite chili

1:30 p.m. Awards
Hosted by KISS 96.1 DJ, Tall Cathy

Your participation includes:

- 9-Holes of Golf
- Gift Bag filled with Golf Goodies
- One Drink Ticket
- Entry to Chili Cook Off

Participation Fees:

- Individual Participant Fee: \$125
- Four-some Team Participant Fee: \$450
- Chili Cook Off Only Participant Fee: \$50

REGISTER ONLINE AT WPGNHF.ORG

Letter From The Executive Director, Alison Yazer

Happy New Year!

I can't believe that 2016 is over already – and what a great year it was for the Chapter! We held lots of educational events covering a broad range of topics in a variety of locations throughout our territory; we held our first ever Family Camp which was a resounding success; and we hosted three very successful fundraising events (with some new twists, too!) which enable the Chapter to continue providing services to our members free of charge.

While I understand the critical importance of the networking and socializing that comes with Chapter events, the Chapter has to be careful to contain the costs associated with those events so that we are able to provide ALL of our services to ALL of our members. With recent changes in the way some of our industry partners provide funding, we may not always be able to provide extensive “after-events” following an educational program. Rest assured, we will continue to provide an opportunity for socializing at EVERY educational

event, even if it's simply a meal to enjoy with your friends and family.

I look forward to seeing you at an upcoming event and wish each of you a happy, healthy 2017!

Sincerely,

Alison R. Yazer
Executive Director



SAVE the DATE!!! August 6-12, 2017

Look for a registration reminder and additional instructions in April!

IMPORTANT DATES

Registration opens: May 1, 2017
Registration closes: June 30, 2017
Medical forms due: July 14, 2017

Camp Hot-to-Clot is sponsored by the Hemophilia Center of Western Pennsylvania for children with bleeding disorders and their siblings, ages 7-17 years old. If you think your child/children are eligible, but you did not receive a Save the Date card for Camp Hot-to-Clot 2017 in the mail, please contact CampH2C@itxm.org to request that your child/children be added to the camp mailing list.

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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
- ♦ 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.

Calendar of Upcoming Events

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

Tuesday, January 17
Exploring Emotional Well-being
in the Hemophilia Community
Punxsutawney, PA (Amish Only)

Wednesday, January 18
Exploring Emotional Well-being
in the Hemophilia Community
Punxsutawney, PA (Amish Only)

Saturday, February 18
Pool Party
Cranberry Township, PA

Sunday, February 19
Men's Group
Pittsburgh Penguins game at Dave & Buster's
Homestead, PA

Saturday, February 25
Iced Tees Winter Golf Outing & Chili Cook-Off
Sewickley, PA

Wednesday, March 8 – Friday, March 10
Washington Days
Washington, D.C.

Saturday, April 1
Cornhole Tournament
Oakdale, PA

Tuesday, April 18
State Advocacy Day
Harrisburg, PA

Saturday, April 29 – Sunday, April 30
Education Weekend
Seven Springs, PA

Ask us about sponsorship opportunities
and how you can help!

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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

Join Us For
THE WESTERN PA CHAPTER OF THE
NATIONAL HEMOPHILIA FOUNDATION'S
**CHILI
COOK-OFF**
SATURDAY
FEBRUARY 25TH
1:00PM
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HELD IN CONJUNCTION WITH ICED TEES WINTER GOLF OUTING

TICKET
\$50

Join the Event!
Have a killer recipe? Win cash prizes!
Register to compete in this event!
E-Mail kara at kara@wpcnhf.org
Are you a chili lover? Vote for the best!
Purchase your ticket at wpcnhf.org

QUESTIONS?
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as i see it: My Journey from Carrier to Hemophilia A

Shellye Horowitz

I am a symptomatic carrier of hemophilia A. My father was a symptomatic carrier of hemophilia A. My grandmother was a symptomatic carrier of hemophilia A. My great-grandfather was also a symptomatic carrier of hemophilia A. With my nephew's diagnosis nine years ago, hemophilia A can be traced through five generations.

Yet, on paper, my male relatives are not acknowledged for their carrier status. By labeling them as having hemophilia A, by not acknowledging their carrier status, our medical community is discriminating against men. Yes, men are indeed carriers of hemophilia, as much as women are. But it's women who are seen as carriers or as symptomatic carriers, and they are often not acknowledged as actually having hemophilia.

It is my strong belief that the term symptomatic carrier is archaic, discriminatory, and unnecessary, and stands as an enormous barrier between women with hemophilia and the care they need.

When I was five years old, in the 1970s, I was tested by a top HTC and received a carrier label. I started off as a carrier because women were not normally diagnosed with hemophilia. The belief at the time was that because women have two X chromosomes, although hemophilia is linked to one, the other would always compensate...except when it does not. Research has evolved and proven those ideas wrong.

My life as a carrier meant that I was picked last for every elementary and middle school sports team, my ankles were always

swollen, and I hated anything that required me to run. My parents took me to doctors to see what was wrong, and they were told that I just imagined the ankle pain and swelling, that this was a ploy to get out of PE. No one thought to explore a connection with hemophilia.

My life as a carrier meant that when I was rear-ended by a one-ton truck at 55 mph, it would take over five years to heal from a traumatic brain injury, and from back and neck injuries. No one explored a connection with hemophilia.

My life as a carrier meant that I went through two gynecological surgeries, and had wounds from incision sites that continually reopened and would not heal. Still no one explored a connection with hemophilia.

My life as a carrier meant that when I needed to have multiple moles removed, the surgeons had to add extra stitches because the removal site kept bleeding, but hemophilia was not acknowledged or explored.

Throughout my life, every time I was injured, I healed slowly and no one ever offered a reason or acknowledged that this was not okay. I needed stitches so many times as an infant that my parents thought they would be turned in for child abuse, yet not once did it occur to any medical professional that the continual need for stitches could be linked to a bleeding disorder.

When I was in my mid-twenties, I finally had my factor VIII level checked—it was 35% (my numbers were never again as high as that initial test). At that time, I was told I might be a symptomatic carrier of hemophilia, a term new to me. I was told it was similar to having mild hemophilia. No treatment or treatment plans were offered.

I was then given a fantastic opportunity to work at an international school in Israel. This changed my healthcare trajectory, and

I am so grateful for the help I got—in a foreign country. My second year in Israel, I had a spontaneous bleed. Over a few days, I watched a bruise spread from quarter-sized to over half my calf. So I asked for a referral to a local hematologist. Coincidentally, I was referred to Professor Seligsohn, MD, who happened to be head of the hemophilia treatment center (HTC) in Israel. He asked about my history and became very animated when he learned that hemophilia A ran in my family. He pulled out a sheet of paper and mapped all the people in my family with hemophilia. He ran my factor VIII level, and found it was 20% (it has remained at that level ever since).

When my factor VIII level came back, Dr. Seligsohn asked what my treatment plan had been in the States. Treatment plan? What on earth was he talking about? He explained to me that I had mild hemophilia A and that I needed a plan for day-to-day injuries and surgeries. I questioned the need: "I'm a symptomatic carrier, so I have an X chromosome that compensates for the one my father passed to me. Do I really need a treatment plan?" The doctor put a fist on his desk and said, "Shellye, your factor VIII is 20%. When we have a person with severe hemophilia A who is hurt or needs surgery, we make sure his factor VIII is brought up to between 50% and 100%, depending on what the procedure is. If we are bringing a person with severe hemophilia up to at least 50% factor VIII, why would it be okay to leave you at 20%?"

A light bulb went off. For years I had been labeled a carrier, then a symptomatic carrier, and both of these terms had prevented my healthcare providers and me from making sure that I had the medical plan necessary to properly address bleeding issues. Even though I was a woman, I needed factor VIII too! I had a bleeding disorder as much as any man did.

My eyes were open. It took a move to Israel to understand how the US uses discriminatory labels that undermine

(Continued on page 12)

SAVE THE DATE

The 2017 WPCNHF Education Weekend is for both individuals and families living with a bleeding disorder. Spouses/partners and children are welcome. Programs will be provided for adults with bleeding disorders and parents of children with

EDUCATION WEEKEND

SEVEN SPRINGS MOUNTAIN RESORT • Saturday, April 29, 2017

bleeding disorders. Programs and activities will also be provided for all school-age children whether they have a bleeding disorder or are the child or sibling of someone with a bleeding disorder. Babysitting will be provided for infants

and pre-school age children. Hotel room and meals will be provided.

For more information, contact Janet Barone: 724-741-6160 or janet@wpcnhf.org

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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:

Subjects	Dose (IU/kg)	Frequency of infusions
Adolescents [12-17 yrs] and adults	30-40	Every other day
Children [2-11 yrs]	30-50	Every other day or three times per week

Manufactured by:

Octapharma AB
Elersvägen 40
SE-112 75, Sweden
U.S. License No. 1646

Distributed by:

Octapharma USA, Inc.
121 River Street, Suite 1201
Hoboken, NJ 07030

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Issued September 2015.

- 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.

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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A FOND FAREWELL Diane S. Standish, LSW

You may have already heard my news, that after 25 years with the Hemophilia Center, I have decided it's time to leave. "Retirement" is how our Human Resources department categorizes it, but I see it as a temporary break. I'm giving myself a year off to attend to my family and figure out what career to pursue next – real retirement is still far off!

May 6, 1991 was my first day at HCWP, which was such a different place then. We had 8 employees and about 300 patients; now we have 23 staff members and over 1,000 patients. Everyone got their factor from one specialty pharmacy back then; now, there is a multitude. There was only one medication for HIV-positive patients in 1991, and all factor was plasma-derived.

The "dark days" of hemophilia were still upon us when I started at HCWP. HIV/AIDS, then a terminal illness, affected a significant number of patients, and sometimes we functioned like hospice staff. What a sad time. I will always remember the dozens of people whom we lost, as well as their families. Their courage in fighting this awful disease still inspires me and gives me perspective when I am facing something difficult.

But I am leaving with many more good memories. It has been such a gift to watch babies grow into children, and then

teenagers, and then adults (and if you are wondering if I'm talking about you, I am!). It's also exciting to witness the development of improved factor products and medications firsthand through the research program that Dr. Ragni has built and many of you have participated in.

One highlight of my time at HCWP was my involvement with Camp Hot-to-Clot, starting with a few visits to the original Camp Judson site in Erie, then serving as a camp counselor, then Leaders-in-Training (LIT) Director, then Camp Director for the past two years. As a Mom, I am humbled by the camp parents' absolute trust in our staff. Camp Hot-to-Clot is in the very capable hands of our seasoned camp veterans, and will continue to grow and get even better every year!

Dr. Ragni's tireless efforts to advance treatment for bleeding disorders, HIV/AIDS, and hepatitis C have contributed more to these fields than probably anyone knows. She has always supported my being involved in committees, programs, and conferences. Sometimes Dr. Ragni had more confidence in my abilities than I did and pushed me to try new challenges, and guess what? She was right! I've been so fortunate to have such a bold, respected, and trusting mentor.

One more highlight has been the treasured friendships that I have formed with colleagues, past and present. Some really smart, dedicated, talented, and fun people have come through the doors of HCWP and the Chapter. We have had



some memorable madcap adventures! If Janet Barone asks you to help out with a project, say YES! I promise that you will learn from it and have a great time along the way. Thank you to all of my colleagues who have made me a better social worker and a better person.

So what now? I am going to take some time off to enjoy the remainder of my twin daughters' senior year of high school (yes, they're really 17 now), and spend time with my Mom, who needs more help these days. I'm interested in the areas of public policy and legislative advocacy, so I plan to learn more about those fields. Ideally, I will find a way to use my knowledge of bleeding disorders in some way to benefit this community.

Be kind to the new Mental Health Professional, and to all of the HCWP staff. Keep asking questions until you get answers, but know that our staff really does care about you.

Thank you to those who have called or sent cards and emails to wish me well – it is so meaningful to know that you care. I want to say thank you to ALL of you for teaching me some valuable life lessons: how to cope with the stressful things that life throws at you; how to put aside your own worries to care for an ailing spouse, child, or other family member; and how to keep finding hope that things will get better. I will miss all of you but I will never forget you. I hope that our paths will cross again.

Wishing you good health, peace, and joy in 2017,

Diane

**WPCNHF'S
2nd Annual**

April 1, 2017

CORNHOLE TOURNAMENT

**Cornerstone at Tonidale
7001 Steubenville Pike
Oakdale, PA 15071**

**Check In & Warm Up: 1:00pm
Tournament Begins: 2:00pm**

This double elimination cornhole tournament will be managed by Steel City Cornhole. Each participant will receive one drink ticket and an event t-shirt. All of the proceeds stay local to benefit the members of the Western PA Chapter of the National Hemophilia Foundation. Questions? Contact Kara at 724-741-6160 or Kara@wpcnfhf.org.

Cost

Individual:
\$25 Now through March 31
\$30 Day of Event

Team of Two:
\$45 Now Through March 31
\$55 Day of Event

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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.



Get to know us: BiogenHemophilia.com/CoRes

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Meet Christine, your CoRe Manager



Hello! I'm Christine Rowe, and I have a son with severe von Willebrand disease. I'm also a CoRe Manager for Biogen. It is my job to connect you with others in the community, share insights taken from my personal experience, introduce our educational programs, and to support you on your journey. I am here so we can take action together!

Contact me!

Christine.Rowe@biogen.com | 267.249.8372



Get to know us: BiogenHemophilia.com/CoRes

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as i see it: My Journey from Carrier to Hemophilia A

(Continued from page 6)

women's ability to get proper hemophilia treatment and care. The discrimination was not orchestrated; it was an evolution of knowledge about what hemophilia is and how it is inherited. As our understanding evolved, the term assigned to women with hemophilia changed from carrier to symptomatic carrier—when it should have changed to mild hemophilia A.

Because I met Dr. Seligsohn and got the correct label of mild hemophilia A, I am now connected with an HTC. I have had mole and wisdom teeth removals safely with factor VIII concentrates. After these procedures I healed in days, not months. I even formed scabs!—something I'd never done in the past. I continue to unlearn the years of accepting incorrect understandings of women with hemophilia.

I have also learned that I must remain a vigilant self-advocate. Just last week I met a new local hematologist. She was very sweet, but did not understand why a woman with 20% factor VIII levels would need to use "expensive meds" because 20% should be enough for me to heal. She was taught that idea in medical school many, many years ago.

Too many doctors are walking around with this misinformation. Even websites of some hemophilia organizations still refer to women as symptomatic carriers, which creates barriers to obtaining proper treatment.

It's critical that women receive accurate diagnostic labels that rid the medical establishment of false assumptions about women and hemophilia. Lives depend on it.

Shellye Horowitz has an MA in school counseling from Humboldt State University and a certificate in educational administration from Gonzaga University. She is a middle school principal in Eureka, California, and lives among the redwood trees of Northern California with her two teenaged daughters.

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Oktoberfest

The Pittsburgh Zoo & PPG Aquarium was the place to be on for this year's Oktoberfest! Over 100 members attended this event. Everyone gathered in the Education Complex to start the day off with displays by Factor Manufacturers and Home Healthcare Companies. Next, lunch was served and the participants took part in the program *You Got This: The Art of Speaking Up*, which was presented by Edward Kuebler, LCSW and Laurel Pennick MSSW, LCSW. Edward is employed at the University of Texas Gulf States Hemophilia and Thrombophilia Treatment Center, Houston, TX, as the Senior Social Worker. He has worked in the bleeding disorders community for 23 years. Laurel is the Clinical Social Worker at the Arizona Hemophilia and Thrombosis Center at the University of Arizona Health Science Center. She has spent over 20 years in the

social work profession, including nine years in Pediatric and Adult Hemophilia Care.

The program *You Got This: The Art of Speaking Up* is one of the modules in the Collaborating with Care series, which up is offered by the National Hemophilia Foundation. This training module offers insight and sample scenarios on how to educate others and ask for support in areas such as education, the workplace, social life, dating, sports, child care, and health care. The attendees choose which topics they want to learn about.

During the program, there was an informative discussion on emergency situations. As a result, the Chapter has obtained copies of two guides: Emergency Care for Patients with Hemophilia and Emergency Care for Patients with von Willebrand Disease (instructional manuals for medical professionals). Any Chapter

member, whether or not they attended the program, can obtain a copy by contacting the Chapter office. When the program was over, our members enjoyed the afternoon at the zoo and aquarium!

We thank the following for supporting this event:

Accredo
Affinity Biotech
Bayer Healthcare
Biogen
BioRX
Cottrill's Pharmacy
CSL Behring
Hemophilia Center of Western PA
National Hemophilia Foundation
Novo Nordisk
Pfizer
Shire

Getting to Know the HCWP Staff: Michael Andromalos- Dale, HCWP Nurse

Birthplace: Dayton, Ohio

First job: Teaching in Wyoming

Accomplishment you're proudest of:
Raising my family & Nursing Degree at age 60

What three words describe you best?
Patient, Hardworking, Loyal

Dream vacation: River cruise through Europe

Things you can do without: Small minded people

Person you'd most like to have dinner with:
Living: President Obama, Dead: Woody Hayes

Movie you could see anytime: Dances with Wolves

TV show you try not to miss: Blue Bloods

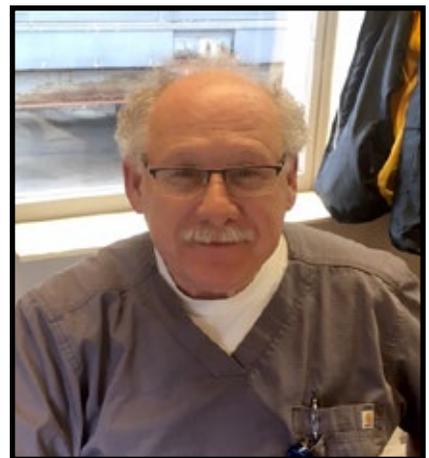
Three things that can always be found in your refrigerator: Liberté yogurt, Almond Milk, & Cruciferous vegetables

Secret vice: No time for a secret vice

Who would play you in the movies: Gene Hackman

Your pet peeve about the city: One way streets

People may be surprised to know that: I lived in Saudi Arabia

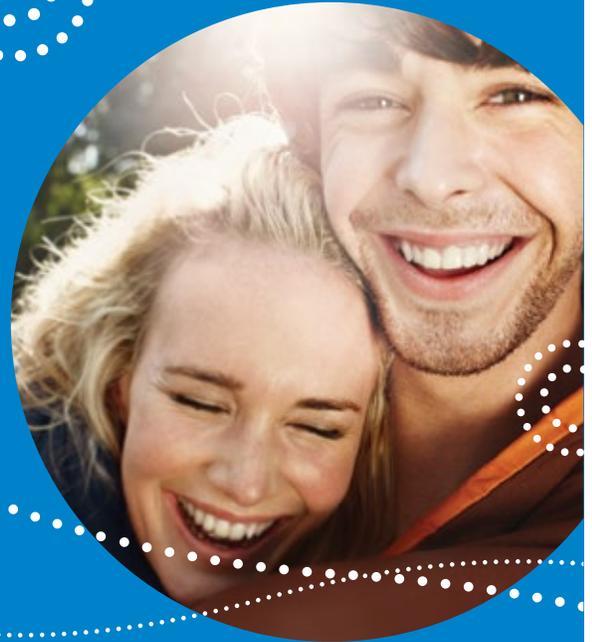




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Thank You for allowing us to serve

You during 2016

Wishing you a happy and healthy

New Year for 2017

*From the staff at the
Hemophilia Center of Western Pennsylvania*

New Parent Network: Social Media

A thought-provoking discussion on Social Media, wrapped up the 2016 New Parent Network Series. Beth Marshall, Director of Communications at the National Hemophilia Foundation, facilitated the Social Media program on November 11, in Erie, PA.

The group discussed both the benefits and potential risks of posting information on social media. Notable topics included considerations for mentioning bleeding disorders, posting personal stories for



fundraising or advocacy purposes, and giving and receiving advice in online discussion groups. We don't know how the digital footprint we are leaving will impact our children in the future. We also don't know how they will feel in the future about the information we have shared about them.

As children get older, it is recommended that parents discuss social media with them. Parents can ask what type of information their child is comfortable being posted about them and how often. Parents can also get permission from their child before posting photos of them online. Being aware of potential risks and keeping an open dialogue with your child is the best option.

The New Parent Network Series was introduced in 2016 as an initiative 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 and we plan to offer a new series of events in 2017.

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

Aptevo
Bayer Healthcare
Biogen
CSL Behring
Novo Nordisk
Shire

Erie Fall Program

Have you ever wondered whether you should disclose your (or a family member's) bleeding disorder? That was the topic of discussion at the Chapter's fall program, in Erie, PA. Cathy M. Tiggs, MSSA, LISW, from the Hemostasis and Thrombosis Center at University Hospitals of Cleveland, presented the program *To Reveal or Conceal: Navigating Disclosure of a Bleeding Disorder*. Deciding when and how to talk about a bleeding disorder can be challenging, but it is an important part of life for people with bleeding disorders and caregivers. This program explored ways to communicate about bleeding disorders in real-life situations.

To Reveal or Conceal: Navigating Disclosure of a Bleeding Disorder is one of the modules in the Collaborating with Care series, which is offered by the National Hemophilia Foundation. We thank the National Hemophilia Foundation for bringing this program to Western Pennsylvania.

The event included exhibits by Factor Manufacturers and Home Healthcare Companies and a buffet lunch. Over 35 families attended. When the event was over, many of the families headed to Splash Lagoon to enjoy the rest of the afternoon at the indoor water park.

We thank the following for supporting the Erie Fall Program:

Bayer Healthcare
Biogen
BioRX
Cottrill's Pharmacy
CSL Behring
CVS/Caremark
Grifols
Hemophilia Center of Western PA
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