



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

Hemogram

Winter 2018
Inside this issue

Chili Cook-Off

See Page 3

**Third Annual
Iced Tees Winter
Golf Classic**

See Page 19

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

BOOling for Bleeding Disorders

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

The Fifth Annual Bowling for Bleeding Disorders fundraiser, called BOOling for Bleeding Disorders for its Halloween theme, was held at Paradise Island Bowl in Neville Island, Pennsylvania on Sunday, October 29, 2017. Dressed in costume, ten 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 Grace Ortenzo who was dressed as a waitress.



(Continued on next page)



BOOLing for Bleeding Disorders

(Continued from previous page)

The scariest costume award went to Will Herndon who as dressed as the Big Bad Wolf.



The prettiest costume award went to Sophia Herndon who was dressed as Little Red Riding Hood.



The funniest costume award went to Nathaniel Brauser who was dressed as a T-Rex.



The best group costume award went to the Brauser Family who dressed up as Ghost Busters.



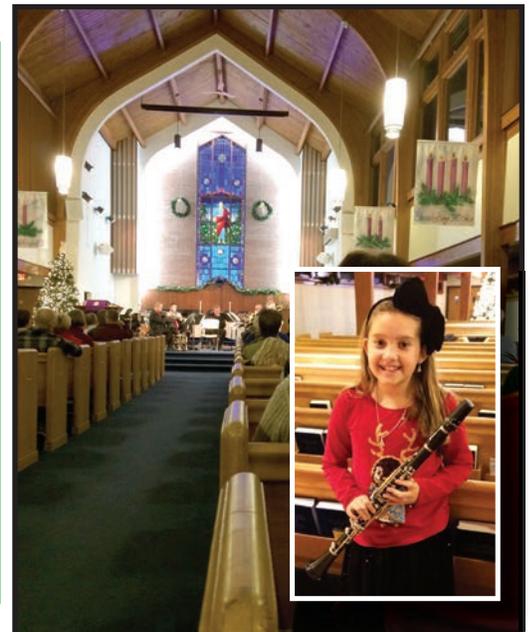
Tony Ortenzo received awards for Highest Score and Most Strikes.



We are extremely grateful for the all *boolers* who participated in this event. We are excited to report that over \$13,000 was raised from this event! All 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: The Hemophilia Center of Western Pennsylvania, Bioverativ, CSL Behring, Bayer, CVS Specialty, Novo Nordisk, Shire, and 91.3 WYEP.

WPCNHF would like to thank all who participated in and sponsored this event. Be sure to save the date for next year's BOOLing for Bleeding Disorders taking place on Sunday, October 28, 2018 at Paradise Island Bowl.

The Western Pennsylvania Chapter of the National Hemophilia Foundation would like to extend a huge thank you to Joe and Sophia Herndon and the Resounding Brass Quintet and Percussion. On Monday, December 11th a Christmas Concert was held at Hampton Presbyterian Church in Gibsonia, PA to raise money for WPCNHF. An incredible \$1,368 was raised to support WPCNHF's programs and services!



Welcome, New Board Member: Sanjay Akut

Hello everyone, my name is Sanjay Akut and I joined the board in the fall of 2017. I am born and raised here in Pittsburgh, PA and I have lived in Pittsburgh my entire life. I have been married to my beautiful wife for 20 years, and we live in Plum, PA with our four sons (1 recently adopted son). Our oldest boy, Zack, is 25 years old and recently got out of the United States Marine Corps. We are so proud of him for serving his country and going overseas to defend our freedoms. Our middle son, Brenden, is 19 and is a freshman at Duquesne University. As I mentioned, we have a recently adopted son, David, who is also 19, from Nigeria and a freshman at Akron University. David attended prep school with Brenden since the 10th grade, and we just kind of took him in and he has become part of the family. Our youngest son, Dylan, is 14 and in the 8th grade. Brenden, David and Dylan are all very skilled soccer players and have been playing since they were really young. Brenden finished his freshman season at

Duquesne, David plays for Akron (made it to the Final Four this year!) and Dylan plays for his club team. It would not be a stretch to say that soccer consumes our lives with a lot of travel and a year-round schedule.

I am an "IT guy" and have been in the IT field for over 20 years. I attended Carnegie Mellon University, where I was bit by the entrepreneur bug. I started my own software company back in the 90's which I ran for the next 11 years of my life. After I left my company, I jumped into the corporate world where I have held various IT leadership positions in the Pittsburgh area. Currently, I am the IT Director of Corporate Applications at Duquesne Light. People often ask me if I would do anything differently, since I went from owning my own business to the corporate world, but I wouldn't have changed a thing. I really do consider my experience running a company as my own personal MBA, just without the fancy paperwork. :)

Earlier in the year, I was approached by a friend and former colleague, Angie Sheppard, about the possibility of joining the WPCNHF's Board. I have a family member who is affected with a bleeding

disorder so I welcome the opportunity to join great staff and board members at this terrific organization. I look forward to helping in any way that I can to grow the Chapter and keep things moving in the right direction as well as continuing to meet more community members at future events. Happy Holidays everyone!

Join Us For WPCNHF'S 2ND ANNUAL
CHILI COOK-OFF
SATURDAY
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1:00 PM
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Letter From The Executive Director, Alison Yazer

Dear Members & Friends,

What a year 2017 was – and I know I'm not alone in looking forward to what 2018 has to offer! It was an incredibly busy year legislatively, both federally and on the state level (see the advocacy corner for more information on the difference). The hemophilia line item in the state budget was reinstated and funded at the same level as previous years, which was a BIG win for the community. Everyone who

worked to make that happen should be very proud of themselves!

While we already have some events planned for 2018, I'd like to ask you to think about your interaction with the Chapter. Are we meeting your needs and expectations? Are there additional services you wish we would offer? Is there a specific educational topic you'd like to see covered, or a region in which you would like us to hold an event? We are only able

to meet a need we are aware of and that's where each of you come in. Please share your ideas with us and help us help you!

I look forward to seeing you at an upcoming event and wish each of you a happy, healthy 2018!

Alison R. Yazer
Executive Director

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

WPCNHF Wish List

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

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

Mission Statement:

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

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.

HCWP Corner

Dearest HCWP Families and Friends:

We are hoping that your season has been merry and bright, and we wish you and yours a happy and prosperous 2018.

The New Year tends to bring refreshed focus on the self. We hope that includes your own health and well-being. See your PCP this year! Don't have one, give us a call, we can help connect you!

We would like to remind you of some important notices for our patients and families. Please remember to keep home treatment records. This is important both clinically and for insurance providers. In addition to those reasons, more of the studies of the novel therapeutics are requiring documentation of dosing and reason to be eligible. Also, have you visited us lately? Regular comprehensive clinic

appointments are critical for optimal care. It is not best practice to prescribe medication to a person we have not seen currently. Please call us to schedule an appointment or find out if you're due.

When you go to the emergency departments or get admitted to a hospital, it is imperative that you let the HCWP know. We want to make sure you are receiving the most up-to-date treatment discussed at your clinic. And because sometimes hospitals do not have clotting factor products, please make sure you have at least one 100% dose of clotting factor at home. Also, please reach out to us if you would like an emergency department letter that outlines your diagnosis and current treatment. Some patients reported that it has been helpful for their self-advocacy efforts at hospitals.

Finally, are you traveling anytime soon? Do you have a current travel letter? Not only can it provide assistance if needed

at the airport, but also when you are in a different city and you need to use a local emergency department. It has the contact information of the closest HTC, too. Please reach out to the HCWP social workers for assistance.

Be on the lookout for our new updated patient satisfaction survey. We will now be mailing them out twice per month to all patients who have had a comprehensive clinic. Please take a moment to complete them and send them back to us. We are also introducing patient reminder cards. We understand life can be busy, but want to remind you to take care of your health.

We are grateful for our patients and their families and look forward to a busy and wonderful 2018 serving you!

Warmly,

All of us at HCWP

Farewell HCWP Family

As some of you may already know, I no longer work at the HCWP. Making the decision to leave was very difficult and emotional. I have no doubt that my career path was supposed to include a stop at HCWP. The impactful relationships that I have developed with families and co-workers within the bleeding disorders

community have made me a better genetic counselor and a better person... for that I will be forever grateful.

My new job will be working in a different specialty, but I will always be a supporter of the bleeding disorders community. Two of my favorite parts of working at HCWP were developing carrier outreach programs and participating in Camp Hot-to-Clot. Although my level of involvement will be different than in past years, I am thrilled to have plans to participate in the

WPCNH's Carrier Retreat this March and to help with Camp Hot-to-Clot 2018. I will eagerly anticipate re-connecting with those of you who may be at these events!

Thank you all for welcoming me into your lives and the bleeding disorders community over the last 5 years. It has truly been a pleasure, and I wish you all the best!

Sincerely,
Michelle Alabek

Advocacy Corner

You hear so much about advocacy, but there's so much about it that's really confusing! Hopefully this will help clarify some aspects of it, but remember, the Chapter is ALWAYS here to help guide you through the advocacy process!

State vs. Federal

This is a tricky one...it's often difficult to tell if an issue is a state issue or a federal one. When the Chapter sends out an alert, we will always identify whether it's for a federal issue or a state issue. Examples of each from this past year are the ACA attempted repeal, which was a federal issue

and the maintenance of the Hemophilia Line Item, which was a state issue.

How do I know who my legislators/elected officials/congressmen (or women) are?

There are websites that can easily help you identify your elected officials, both federal and state.

Federally, Pennsylvania has two senators, Senator Bob Casey and Senator Pat Toomey. Both of them represent the entire state. Pennsylvania has many more Representatives, each of whom represents a specific region within the state. On the state side, both senators and representatives represent specific areas within the state.

This website can help you identify ALL your elected officials:
<https://www.usa.gov/elected-officials>

Remember – anytime we send out an alert, we will include a link to make sure you can easily contact the appropriate office(s).

We know that advocacy can sometimes be overwhelming, but it's critical that each of us contact our elected officials to tell our own stories. If you ever have any questions or need additional information to help contact one of your elected officials, please don't hesitate to contact the Chapter at info@wpcnhf.org or by calling us at 724.741.6160.

Calendar of Upcoming Events

Tuesday, January 16
Dinner Program
Mars, PA

Sunday, January 28
New Parent Network
Winter Social
Mars, PA

Saturday, February 17
Iced Tees Winter Golf Outing
and Chili Cook-Off
Sewickley, PA

Wednesday, March 7 - Friday,
March 9
Washington Days
Washington, D.C.

Sunday, March 11
New Parent Network
Parents & Tiny Tots – Part 1
Oakland, PA

Saturday, March 24
Hemophilia Carriers Retreat
Homestead, PA

Saturday, April 14
Cornhole Tournament
Oakdale, PA

Sunday, April 15
New Parent Network
Parents & Tiny Tots – Part 2
Oakland, PA

Tuesday, April 17
State Advocacy Day
Harrisburg, PA



Combined Federal Campaign

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

WPCNHF CFC Number is: 81343

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



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

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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 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.

Please see adjacent page for Brief Summary of Prescribing Information.

www.nuwiqusa.com

**Want to
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Contact your
Octapharma Representative:

KAREN BOWE

PHONE:
717-395-5887

EMAIL:
Karen.Bowe@Octapharma.com

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

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For all inquiries relating to drug safety, or to report adverse events please contact our local Drug Safety Officer:
Office: 201-604-1137 Cell: 201-772-4546 Fax: 201-604-1141
or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

- 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, 2000, 2500, 3000, or 4000 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 July 2017

Teen Group

Laser Storm Pittsburgh was the location for the last teen event of 2017. Fifteen teens attended and we managed to squeeze in a meeting and something to eat between two competitive games of laser tag! The group also had a chance to play arcade games, before their parents



returned to pick them up.

We were thrilled to welcome nine first-time attendees to this event and look forward to seeing them again in the future. We have been fortunate to have an active group of teens participate in teen events and camp programs over the last several years. While we are sad to see many of them aging out of the teen



group, we are also very proud of them and can't wait to see what the future holds for them!

Hopefully, it won't be too long before we see some of the older teens again... We are excited to announce that we have plans to kick off a young adult group in 2018 for those ages 18-25! Stay tuned for more information!



Spotlight on Fundraising: Luke's Lemonade Stand



Luke. They have a very supportive group of family and friends who want to help and be there for them. The Hemophilia Walk serves as the perfect opportunity for everyone to come together and let Luke know how much they care about him. It has become an event he looks forward to each year.

In order to help Luke raise money for the Hemophilia Walk his cousins Allison and Liam started Luke's Lemonade Stand. The first year they sold just lemonade. Over the years, they have added snacks and hot dogs. This year was the first year Sam and Luke took over running the lemonade stand. They held three lemonade stands this year raising a total of \$275!

In order to get the word out about Luke's Lemonade Stand they put up signs around their neighborhood and used social media.

When asked what advice she would give to others who would like to hold similar fundraiser Jen replied, "Now that Luke is getting older, I wanted to get him more involved in fundraising and advocacy. We've watched his cousins do both for the past 5 years running their lemonade stand and I was proud that Sam and Luke were up for the challenge of running their own this year. We spend so much time educating the community that our kiddos are typical kids and can do most things that other kids can do. A big reason is due to the resources of our HTC and Chapter so I wanted them to know that even as young as 8 and 5 that they can contribute." Luke continued to raise money for the Hemophilia Walk and as the Top Youth Fundraiser raised a grand total of \$3,035.40! Way to go, Luke!

Scott and Jen Miller are the proud parents of Sam (8) and Luke (5). When Luke was 6 months old, he was diagnosed with severe hemophilia A, which came as a surprise to his family because they had no family history of bleeding disorders. While they knew Luke and their family would face some challenges, they continue to be determined to help Luke live the fullest life possible.

For the Millers, the Hemophilia Walk has always been a symbol of support for



Winterfest

Nearly 100 people gathered at the Wildwood Highlands for the Chapter's Winterfest! There was a soft-play area for young children, laser tag for older children & adults, and arcade games for everyone. The event concluded with a buffet dinner. It was nice to catch up with our members and spend time together, as we wrapped up our final event of the year. A special thank you to Linda and Ryan Balog for their help at the registration table.

We spent the final weeks of the year busily preparing for events for the new year. Be on the lookout for Chapter mail—there's a lot in store for 2018!



Congratulations, Kara!

The National Hemophilia Foundation named Kara Dornish, WPCNHF Marketing & Events Manager, 2017 Walk Staff Person of the Year! More than 30 Chapters participated in the 2017 Walk. The announcement was made on December 5, 2017, at the NHF Walk training conference for 2018. Kara received the award from Tracy Earll,

National Director and Katie Cooper (pictured), National Walk Manager. We are proud of Kara and are excited for the changes she will be implementing in 2018, for the newly branded NHF Walk, Unite for Bleeding Disorders!



HOT-TO-CLOT Campers Have a Blast!

Camp Hot-to-Clot 2017 proved to be another successful venture according to the feedback submitted by 26 of our 77 campers! Favorite events included the ‘exhilarating’ zip line, low ropes, high ropes, archery and fishing. Fun and friendship were frequently mentioned as favorite experiences! As an added bonus, our campers noted that they had learned more about bleeding disorders and how to care for themselves with or without a bleeding disorder!

The campers also gave us suggestions for making Camp Hot-to-Clot 2018 even better. Making it longer than one week was mentioned by several campers! Although we won’t be able to make that change, we will be incorporating several of the other suggestions into next year’s camp!

A huge THANK YOU to all of our campers who came to camp with a great attitude, boundless energy, a willingness to try new things and an openness to making new friends! Also, a huge THANK YOU to our amazing volunteers and staff who

worked tirelessly to make camp a rewarding experience for everyone! And, in case you were wondering... congratulations to Sebastian P. for winning the \$25.00 Amazon gift card for responding to the survey!

Dates for next year:

- Camp Hot-to-Clot: **Sunday, August 5, 2018 – Saturday, August 11, 2018**
- Registration: opens **Tuesday, May 1, 2018** – closes **Friday, June 29, 2018**
- Medical forms: Due at the close of registration this year (Friday, June 29, 2018) – please note that this is a change from previous years!!!
- Comprehensive Clinic Visit at an HTC (campers with bleeding disorders) or a Physical Exam at a pediatrician’s or PCP’s office (campers without bleeding disorders) must be performed between **July 1, 2017 and June 29th, 2018**. We are not able to accept Physical Exam forms from Urgent Care or Walk In Clinics.

If you are interested in volunteering to help with Camp, please contact Janet Barone. If you are a Nurse, Nurse Practitioner, Physician’s Assistant, or Physician who is interested in providing support to the Camp’s health services, please contact Katherine Bush or Kathaleen Schnur.



Getting to Know HCWP Staff

Featuring: Kathaleen Schnur, LSW



Birthplace: I was born in Duquesne, PA

First job: Paper route of 75 houses when I was 10yo for the Pittsburgh Press

Accomplishment you’re proudest of: Being a mom of two brilliant little boys

What three words describe you best? Passionate, silly, and committed

Dream vacation: Taking my family on a cross country road trip

Things you can do without: Icy roads

Person you’d most like to have dinner with: Nelson Mandela and the Dalai Lama

Movie you could see anytime: Too many... Legend, Labrynth, Neverending Story, The Dark Crystal, The Princess Bride, any Bill Murray or Robin Williams flick...

TV show you try not to miss: The Good Doctor

Three things that can always be found in your refrigerator: Cheese, vegetables, tofu

Secret vice: Hmm... I don’t think I have any “secret” vices... I have whine and wine nights with my cousins and friends where we enjoy some wine and snacks and get our whine out in a judgement free zone.

Who would play you in the movies? Scarlett Johansson

Your pet peeve about Pittsburgh: Potholes and poor public transportation

People may be surprised to know that: We celebrate half birthdays in my house as an excuse to increase our cake consumption.

Spotlight on Fundraising: Denisa Coblentz of Coblentz Clotters



The Coblentz Clotters were formed around Denisa's oldest son, Gavin, who was diagnosed with Hemophilia at the age of two when his family discovered issues with his ability to walk. Gavin began seeing Dr. Ragni who was able get him on the right track for normal day to day living. As Denisa explained, "Due to job and financial issues we didn't do the best at keeping our center informed and before we knew what target bleeds really were, Gavin's knees had lost a lot of mobility. Soon we were sent for x-rays and MRIs and we were told Gavin was on the verge of double knee replacements." From that moment, Gavin started physical therapy and visiting the center four times a year. As Denisa recalled, "We changed medications and dosing and increased exercise so many times I can't



count. Until one day we had a trough draw that was above 1%." The family was overcome with joy as they started to see Gavin's knees look like knees and not balloons. After a lot of hard work and support, Gavin was able to run like an everyday child. He set a goal to run a 5k and the Treatment Center helped him reach that goal. Gavin has been running ever since. He even won second place in the Youth Division at the Run for Their Lives 5k this past September!

Denisa started Coblentz Clotters as a way to raise money for the Chapter. She explained, "We wanted to show our appreciation for giving Gavin a fulfilled childhood so we started raising money for the foundation." To raise money for the Hemophilia Walk this year, the Coblentz Clotters held a Hemophilia Awareness Bracelet Fundraiser. Denisa explained how she got the idea saying, "The rubber awareness bracelets are a huge thing

right now and we were trying to think of something inexpensive that could be used as a school fundraiser."

Denisa and Gavin got the community involved by talking to peer leaders at the school. They then went door to door selling the bracelets. They also talked to local business owners and got permission to pass out brochures with information about Hemophilia and other bleeding disorders while selling the bracelets. Denisa advertised the fundraiser by first contacting Kara at the Chapter. Ads were put in the Hemogram Newsletter and e-mails were sent to members of the Chapter advertising the bracelets were for sale. Denisa also posted an ad in the Hemophilia Mother's Facebook Page as well her as own personal Facebook Page.



Coblentz Clotter's raised an incredible \$745 for the Hemophilia Walk. When asked what advice she would give others who would like to hold a similar fundraiser Denisa responded, "Talk to everyone. Start with your chapter, your child's school and sports teams, and small and local businesses. Just know the facts and keep talking."

Junior National Championship

By Jessamyn Butler

After a bit of a rocky start checking Craig's bat bag at the Pittsburgh International Airport, we were soon in the air on the way to the CSL Behring-sponsored "Gettin' in the Game" Junior National Championship in Chandler, Arizona. We were all atwitter with dreams of winning the Championship and getting a trophy, and bringing back the CSL Behring donation to Western Pennsylvania Chapter of the National Hemophilia Foundation. About five hours later, we were on the ground in our favorite place on earth, Phoenix, Arizona! There were CSL Behring greeters there to meet us and help us with our bags and retrieving

the infamous bat bag. We boarded the bus and were transported to the Sheraton Wild Horse Pass Resort and Spa, where we checked in and deposited our bags in our room. It was a very long walk, too long for my physical condition, so we sought a closer room from the desk, which we got the following day.

Right away, we went down to the registration area and Craig checked in with the CSL Behring folks. We got name lanyards, a Gettin' in the Game (GIG) baseball cap, and a folder with the agenda and other important papers. Because we are from the East Coast, we were fortunate enough to be able to arrive the day before the Junior National Championship (JNC) practice, and were treated to a special Welcome Dinner on the Beehive Patio, a terrace at the hotel. After dinner, Craig and I walked the beautiful grounds and took many pictures. One of the most



wonderful photos is of the full moon centered between two trees. Another is of

(Continued on page 16)

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ONLY ADVATE® HAS 13 YEARS OF EXPERIENCE IN THE REAL WORLD AS A RECOMBINANT FACTOR VIII¹

- Proven in a pivotal clinical trial to reduce the number of bleeding episodes in adults and children when used prophylactically*²
- Third-generation full-length molecule, similar to the factor VIII that occurs naturally in the body^{1,2}

*Multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20-40 IU/kg every 48 hours, or pharmacokinetic-driven, 20-80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis.²

The market leader in Hemophilia A treatment (as of October 2016)³

Learn more at ADVATE.com

ADVATE [Antihemophilic Factor (Recombinant)] Important Information

Indications

ADVATE 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). ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery.

ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE 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.

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash.

Tell your healthcare provider about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see the following page for the ADVATE Important Facts.

For full Prescribing Information, visit www.ADVATE.com.

References: 1. Grillberger L, Kreil TR, Nasr S, Reiter M. Emerging trends in plasma-free manufacturing of recombinant protein therapeutics expressed in mammalian cells. *Biotechnol J.* 2009;4(2):186-201. 2. ADVATE Prescribing Information. 3. Elsayed M. Hemophilia Treatment. London, United Kingdom: Datamonitor Healthcare; 2016.

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[Antihemophilic Factor (Recombinant)]



[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. 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 ADVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADVATE so that your treatment will work best for you.

What is ADVATE?

ADVATE 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). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A.

Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

- Are allergic to mice or hamsters.
- Are allergic to any ingredients in ADVATE.

Tell your healthcare provider if you are pregnant or breastfeeding because ADVATE may not be right for you.

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

You may infuse ADVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADVATE to use based on your weight, the severity of your hemophilia A, and where you are bleeding.

You may have to have blood tests done after getting ADVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

Call your healthcare provider right away if your bleeding does not stop after taking ADVATE.

What should I tell my healthcare provider before I use ADVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

Side effects that have been reported with ADVATE include:

cough	headache	joint swelling/aching
sore throat	fever	itching
unusual taste	dizziness	hematoma
abdominal pain	hot flashes	swelling of legs
diarrhea	chills	runny nose/congestion
nausea/vomiting	sweating	rash

Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE 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.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA approved product labeling can be found at www.ADVATE.com or 1-888-4-ADVATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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Westlake Village, CA 91362 USA
U.S. License No. 2020
Issued: 11/2016

S32554 06/17



Ask the Expert

Michelle Rice

Senior Vice President, External Affairs,
National Hemophilia Foundation

QUESTION: Recently I received a notice from my pharmacy benefit manager (PBM) stating that the amount paid by my factor manufacturer assistance program does not count toward my deductible and copay. Is this correct?

ANSWER: Unfortunately, yes. Health plans, specifically high-deductible plans offered by self-insured employer groups, have implemented one of two programs designed to drive savings by ensuring that patients personally share in the cost of healthcare. The programs are often called either an “Accumulator Adjustment Program” or a “Copay Maximum Allowance Program.”

QUESTION: Why were these programs implemented?

ANSWER: The PBMs argue that a patient who has no “skin in the game” will potentially choose higher-cost drugs and get unnecessary tests, procedures, and labs. PBMs also worry that a manufacturer’s copay assistance programs can be used to incentivize patients to choose non-preferred drugs (such as the manufacturer’s) without considering cost, because the patients’ out-of-pocket cost would be zero.

QUESTION: But this means that our costs are higher, or that we may not be able to get the drug we want or need. What is NHF’s position on these programs, and what is it doing to help patients?

ANSWER: NHF sees the value of using cost reduction programs or other mechanisms aimed at lowering payer costs only when generic alternatives are available or the medications are considered low value (not necessary). NHF strongly feels that adopting these programs for patients who use high-cost or high-value (lifesaving) drugs with no

generic alternatives, and who have high-deductible plans, have the reverse effect—leading to increased costs for both patients and payers.

NHF is partnering with National Alliance of Healthcare Purchaser Coalitions, a national nonprofit 501(c)(6) that is a membership organization of purchaser-led healthcare coalitions (self-insured employer groups or institutions), to produce and deliver a webinar to its member agencies including self-insured employer groups. The webinar will explain the unintended consequences that cost reduction programs may have on people affected by chronic conditions requiring high-cost, specialty therapies with no generic alternatives.

PEN’s Insurance Pulse 2017
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Let’s get together to talk about IXINITY®

“After many years, I am still so inspired by the strength and sense of family in the bleeding disorder community. It brings me great joy to be a part of it!

—Ellen Rowe, your resource for all things IXINITY



▶ Contact Ellen at 215-908-4276 or rowee@apvo.com



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Junior National Championship

(Continued from page 12)

a tree lit by a red light that makes it look as though it is on fire.

The next day was the practice for the JNC. The JNC is an opportunity given by CSL Behring to kids with bleeding disorders aged 7-17 to compete in the sports of baseball, swimming, and golf. I do not know the exact events the other sports use for competition, but baseball scores for events in pitching, batting, and fielding. The baseball participants boarded buses for Vista Park, where they practiced for the Big Day at the JNC, using their skills in pitching, batting, and fielding. A good time was had by all, I think!

After the practice, Craig talked nonstop about the friends he had made and about how he could not believe that they all had bleeding disorders too. "They all seem just like 'normal' guys playing ball, like at home on my team. You would never know they have a problem. It is really cool."

The next morning started out with a hearty breakfast and an early departure for Scottsdale stadium, spring training home of the San Francisco Giants, where the Championship would be taking place. The weather was great, the participants were ready, and the excitement was almost palpable. CSL Behring had set up a craft station for parents/guardians to make banners for their contestants, so we were furiously coloring pennants for our kids while the emcee was introducing the kids. Soon, we were in our seats for the National Anthem (everyone stood), and the games began!

The kids were grouped according to age,

in three color groups, and the batters were closest to the seats. We did not have much of a view of the pitching event or the fielding event at all, which was a big disappointment, but we got to see some really good batters! Craig's color group was the last to compete; about 15 minutes before the final batter, the sky got dark, the air took on "that" smell, and it started to pour down rain!! The boys were troupers, though, and the games went on...the rain trickled to a stop and the sun came back out just as the Championship wrapped up and we reboarded the buses to return to Wild Horse Pass for lunch.

Everyone was tired, hungry, and more than a little anxious to know the results, but we had more than six hours to wait, so we had lunch, visited the pools, and did homework to pass the time. CSL Behring also had two parent educational sessions and a wrap up session for the kids during the afternoon to help us pass the time; the parent sessions were about insurance coverage and music therapy for pain, and the kids got a Q&A and autograph session with the GIG athletes.

FINALLY, it was time to dress for dinner! We got all dolled up, took a deep breath, smiled, and walked quickly down to the dinner ballroom. We were seated at a table all the way down at the front; in retrospect, it must have been an omen. The golf contestants were the first to be announced. There were so many categories of winners, we lost track...we were SO nervous that we were practically vibrating in our chairs! Finally, it was time to announce the baseball winners. We held



hands nervously. First, they announced the top scorer of the 7-9 age group. It flew by us unnoticed. Next, the Top Scorer, Age Group 10-12 was announced "from Western Penns..." was all we heard, and we were on our feet hugging each other!! Craig had made it; he made Top Scorer in his age group. Now, by a technicality in the way the scoring works, he did not—unfortunately—get the Junior National Championship trophy and the prize money for our Chapter. But he DID get the designation of Top Scorer in his age division, and he got a medal, a cooler, and a certificate from CSL Behring for his accomplishment. We were both very happy. We had many photos taken with people from CSL Behring and the GIG athletes that evening, and we also celebrated together with ice cream sundaes on the terrace, just the two of us.

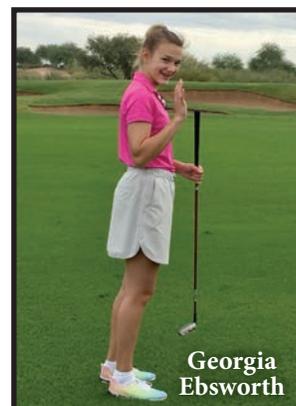
The next morning was kind of melancholy for us because we knew we were about to be leaving our most favorite place on Earth, so we strolled the grounds until it was time to board the bus for the airport. Once again, we had problems checking in the bat bag, so it was lucky that we left early enough to deal with that. Soon we were in the air, heading back to Pittsburgh, with visions of Saguaros dancing in our heads...

Gettin' in the GameSM Junior National Championship 2017

Two Chapter members were selected to participate in CSL Behring's Gettin' in the GameSM Junior National Championship 2017, which was held in Phoenix, Arizona, November 3-5. Georgia Ebsworth competed in the Golf competition and Craig Cushing participated in the Baseball competition. We are very proud of these young athletes!



Craig Cushing



Georgia Ebsworth



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Karen M. Gingrich,
Client Relations Executive
215-595-4863
Karen.mcgoniglegingrich@cvshealth.com



We at the Hemophilia Center of Western Pennsylvania want to thank you for allowing us to serve you through 2017!

We wish you 12 months of success,
52 weeks of laughter, 365 days of fun,
8,760 hours of joy, 525,600 minutes of good luck
and 31,536,000 seconds of happiness in 2018!

Women's Night Out

Twenty-five women gathered at Painting with Twist, in Robinson Township, for a lively women's night out! This fun evening started off with a talk by Suzanne Nash, who is a mother of a 17 year old son with Hemophilia. Suzanne shared her personal experiences and encouraged everyone to find joy in life! Suzanne is an Advocate with CSL Behring's Common Factors® program. We thank CSL Behring for sponsoring this event, which was appreciated by all. In addition, we thank Kelly DeVito and Jessica Graham for all their help coordinating the details.

Here's what some of the women had to say about the evening:

"I absolutely loved the event. I was really happy to get together with other women in a place where I felt that we could take a minute to reflect on us. So often, we are caught up in all of the roles that we have to play, and we often put ourselves last, so this was really just a nice chance to be able to be first. :) It was really nice to catch up with the ladies that I've seen at so many other events, but also to meet others I haven't spoken with before—not that I didn't want to meet them before, but because it was just "us," it's a lot easier to meet a new person that way!"

"I enjoyed having the ladies night to connect with the other women, a night away from the kids to remember who I am, and I loved listening to Suzanne talk. It was almost surreal, actually. One day I am going to have teenagers instead of toddlers and it was so cool to hear her use the phrase "Bloom where you are planted." I have hung up my little postcard from her and look at it each day."

"The event was a wonderful time to connect with other ladies. I've always been hesitant to try painting, but it turns out I really enjoyed it!"

"I had a wonderful time reconnecting with old friends."





Saturday, February 17, 2018
Diamond Run Golf Club
132 Laurel Oak Drive
Sewickley, PA 15143

The Western Pennsylvania Chapter of the National Hemophilia Foundation invites you to participate in the Third Annual Iced Tees Winter Golf Classic! This unique event will take place at Diamond Run Golf Club in Sewickley, PA on February 17, 2018. The outing will include a 9-Hole Shotgun Scramble followed by a Chili Cook-Off and Awards Ceremony.

9:00 a.m. Registration
Coffee & Donuts 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

2:00 p.m. Awards

Your participation includes:

- 9-Holes of Golf
- Gift Bag filled with Golf Goodies
- Iced Tees T-Shirt
- 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: \$30

Interested in competing in the Chili Cook-Off?
Entry fee is \$50 for a chance to win a \$200 grand prize.
E-mail Kara at kara@wpcnhf.org for more information.



Leadership Begins With U

Introducing Leadership U, a paid summer internship* for full-time college students whose lives have been touched by hemophilia. Work alongside leaders at Bayer, meet with advocacy groups in New York City and Washington, DC, and start shaping the future of the hemophilia community.

*Includes lodging and transportation costs

Now Accepting 2018 Summer Internship Applications at

LivingWithHemophilia.com/Lead2018



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Explore Bayer's additional leadership opportunities, Step Up Reach Out and AFFIRM, at www.LivingWithHemophilia.com/Lead

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