



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

Winter 2019
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Register Your Team Today

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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

Winterfest

Our final program for 2019 was both informative and fun! We were excited to have Virginia Kraus, RN, MSN, Senior Clinical Education Manager with Grifols, and Daniela Delgado as guest speakers at our Winterfest program. First, we welcomed Virginia back to Western PA. Virginia gave an informative overview on Hemophilia and von Willebrand Disease and was glad to answer questions both during and after her presentation. Next, we welcomed Daniela to Western PA for the first time. Daniela is an 11-year-old girl who founded Daniela's wish at the age of 4. She makes birthday cakes and delivers them to children with life-threatening

(Continued on next page)



New Parent Network – Fall Program

The final program in our 2018 New Parent Network series of events was held in Erie, on Friday, November 16. The program, Hitting a Home Run at Your Clinic Visit, was presented by Ashley Smith, Development Coordinator for the Hemophilia Federation of America (HFA), to families who have a young child with a bleeding disorder. Ashley talked about the importance of preparing for visits and

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Winterfest

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conditions. Daniela also has a severe bleeding disorder. After sharing her motivational story with us, she taught us all how to decorate adorable melting snowman cupcakes! This was truly a treat (no pun intended)! The room was filled with conversation and laughter as our speakers and participants continued conversations while decorating cupcakes.

We thank Grifols and Biomatrix for sponsoring this event.



New Parent Network – Fall Program

(Continued from previous page)

making the most of your time with all the different people you will see during your appointments (doctor, nurse, physical therapist, social worker, etc.). Participants received a copy of HFA's book, *My Healthy Year*, to document all doctor appointments, bleeds, and other medical conditions, throughout the year.

The Chapter collaborates with the Hemophilia Center of Western PA to determine needs and plan programs to benefit this segment of our bleeding disorders community. The next program will be held on Friday, March 22, 2019. Invitations will be mailed to families who qualify for the



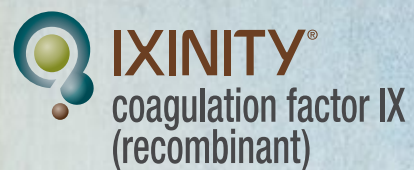
2019 New Parent Network program.

A big thank you to our 2018 New Parent Network sponsors for enabling us to provide these important educational events and networking



opportunities for families:

- Bioverativ
- CSL Behring
- CVS Specialty
- Genentech
- Shire



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Letter from the Interim Executive Director, Kara Dornish

Dear Community Members & Friends,

Thank you for a great 2018! We have accomplished so much and we couldn't have done it without you!

Due to the hard work of the incredible team captains and participants, we had our most successful Walk fundraising year ever, raising a grand total of \$71,251.56 (over \$10,000 more than last year!). We were awarded the 2018 Top Fundraising Award in our tier and the Rising Star Chapter Award from the National

Hemophilia Foundation at the Unite Walk Rally in December.

We worked hard advocating for the community, and the hemophilia line item in the Pennsylvania state budget was reinstated and funded at the same level as previous years! We awarded over \$18,500 in emergency and medical patient assistance and held 18 educational programs at no cost to our members!

I am honored to be leading this organization into 2019. I look forward to

continuing to serve this community and hope to build strong relationships with all of you!

Wishing you good health and happiness in the coming year and always,

Kara Dornish

Interim Executive Director

Board of Directors

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Nathan Rost

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Mike Covert

Board Members

Sanjay Akut

Shannon Howard

Angelica Shepard

Emeritus Trustee

Scott Miller, CPA, Esq., DBA

Staff

Interim Executive Director

Kara Dornish

Member Services Manager

Janet Barone

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.

Calendar of Upcoming Events

January 24, 2019
Young Hope Society
Bridgeville, PA

February 15-16, 2019
Youth Group
Pittsburgh, PA

February 17, 2019
Bowling for Bleeding Disorders
Pittsburgh, PA

March 22, 2019
New Parent Network
Seven Springs, PA

March 22, 2019
Teen Program
Seven Springs, PA

March 23-24, 2019
Education Weekend
Seven Springs, PA

March 27-29, 2019
Washington Days
Washington D.C.

April 4-7, 2019
HFA Symposium
San Diego, CA

April 6, 2019
Cornhole Tournament
Oakdale, PA

April 9, 2019
State Advocacy Day
Harrisburg, PA

July 18, 2018
Annual Meeting & Walk
Kickoff
Homestead, PA

August 4-10, 2018
Camp Hot-to-Clot
Fombell, PA

September 7, 2019
Unite for Bleeding
Disorders Walk
Run for Their Lives 5K
Cornhole Tournament
Allison Park, 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!*

Farewell Letter from Alison Yazer

By now, you are probably aware that I resigned from my role as Executive Director of the Chapter. This was a very difficult decision to make, as it has truly been such an honor to serve this community for the past six years. I learned so much in this role, and I am forever thankful for the opportunity. Much like a Boy Scout, I move on knowing that I am leaving WPCNHF in a better place than I found it, and I have the utmost faith in Kara and Janet's ability to continue moving the Chapter forward in this constantly changing environment.

I wish each of you – and the Chapter – nothing but the best.

Alison R. Yazer

Former Executive Director, WPCNHF

HCWP Corner

Dearest HCWP Families and Friends:

This New Year, we at the HCWP, thank you for allowing us the opportunity to serve you, and we are committed to making your experiences with us satisfying and enriching.

As we move into 2019, we want to remind you that we are here to support you and help you navigate your journey of life with a bleeding disorder. Sometimes it's a very specific part of the journey, and sometimes

it's an unknown that requires keen ears, patience, and guidance.

There's been much chatter about healthcare and transitions regarding health insurance; and many of you have already been reaching out to us for help with breaking down the sometimes overwhelming or confusing jargon used in letters or calls from your insurers. If you have questions or concerns, please reach out to us. We may not know the answers immediately, but we are ready to work together. Please reference the National Hemophilia Foundation website: <https://www.hemophilia.org/>. Under the

Advocacy & Healthcare Coverage tab, you will find numerous resources and updates regarding the advocacy and efforts that are happening in the bleeding disorder community regarding these topics.

We are looking forward to seeing so many of you this year, whether it be at appointments, educational events, Consumer Advocacy Committee meetings, Camp Hot-to-Clot, conferences, or the Walk! We are hopeful that 2019 is a happy and rewarding New Year for you and yours – one that you shall remember for times to come.

Junior National Championship

By Alicia Unger Hutchinson

We are so fortunate to have had the opportunity to attend the Getting in the GameSM Junior National Championship

this year. Landon was overjoyed when we received the call that he was nominated to attend, and what an amazing experience it was!

Landon's sport choice was swimming. The competitiveness was high and the camaraderie

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Campers:

We are hoping to ROLL out a fun week full of ACTION and COMEDY (but not too heavy on the DRAMA or HORROR)!! So, come prepared for your chance to start a scene!

It may be winter, but we are thinking of summer at HCWP! We are beginning to prepare for Camp Hot-to-Clot 2019! Here are some important dates to know:

Camp Dates: August 4-10

Registration opens: May 1, 2019

Registration closes/Forms due: June 30, 2019

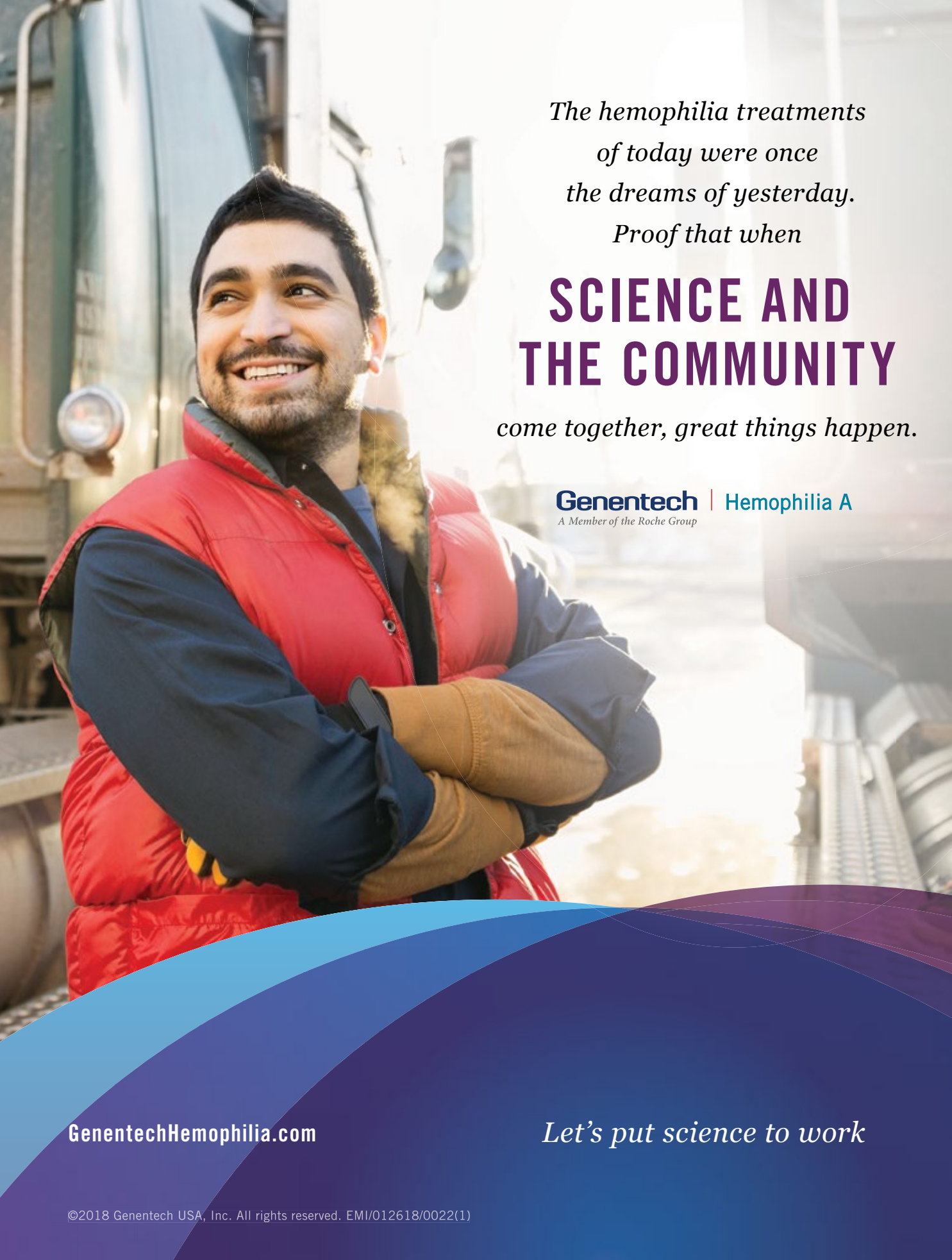
Leader-in-Training (LIT) Info:

Invitations will be sent: May 8, 2019

Applications due: June 12, 2019

On-site LIT training: August 3-4, 2019

Camp is open to anyone between the ages of 7-17 who is either affected by a bleeding disorder or who is the sibling of someone affected by a bleeding disorder. If you have questions about whether you can participate, please contact either Kathaleen Schnur or Katherine Bush (the camp co-directors) at (412) 209-7344.



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come together, great things happen.

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Let's put science to work

WPCNHF'S 6TH SEMI-ANNUAL
CORNHOLE TOURNAMENT

SATURDAY, APRIL 6, 2019
CORNERSTONE AT TONIDALE
7001 STEUBENVILLE PIKE
OAKDALE, PA 15071

REGISTRATION: 1:00PM
TOURNAMENT: 2:00PM



SOCIAL DIVISION
TEAM COST
(PER TEAM OF TWO
INDIVIDUALS)

EARLY BIRD: \$40
NOW THROUGH APRIL 1ST
REGULAR: \$50

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

COMPETITIVE DIVISION

TEAM COST
(PER TEAM OF TWO
INDIVIDUALS)

EARLY BIRD: \$50
NOW THROUGH APRIL 1ST
REGULAR: \$60

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

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.

REGISTER ONLINE AT:

GIVE.CLASSY.ORG/CORNHOLE6

CASH PRIZES!
& RAFFLES!

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

Fall Program

Earlier this year, the Chapter became a member organization of the Hemophilia Federation of America (HFA). We were excited to introduce HFA and the programs and services they provide to our members who attended the Fall Program, in Erie, on Saturday, November 17. For many in attendance, this was their first introduction to HFA.

Ashley Smith, Development Coordinator, reviewed HFA programs, including Blood Brotherhood, Blood Sisterhood, family programs, advocacy, etc., and informed us about other HFA benefits, such as their quarterly magazine, financial assistance program, and scholarships to their annual symposium. Next, we completed a need assessment in eight categories, including aging, advocacy/policy, insurance, and new & emerging therapies. Each category was posted around the room and the participants rotated in groups to each station and noted what they already know and what they want to learn. The Chapter will refer to these lists when planning programs for 2019.

The day also included exhibits by our program supporters. When the needs assessment was completed, we had lunch and everyone had additional time to visit the exhibit displays and network with each other.

We thank the following for supporting this program: Bioverativ, CSL Behring, Hemophilia Center of Western PA, and Hemophilia Federation of America.



Pittsburgh's Bloody Bar Crawl

The Western Pennsylvania Chapter of the National Hemophilia Foundation held its first Bloody Mary Bar Crawl Fundraiser in Pittsburgh's South Side on Saturday, October 13, 2018. Registration began at 2:30pm at the Double Wide Grill. Each participant received an event t-shirt and a wristband to get Bloody Mary and Tito's Handmade Vodka drink specials at the participating bars. The wristbands also granted access to the after-party held at Foxtail. There were 7 participating bars including: Double Wide Grill, Tiki Lounge, Steel Cactus, Local Kitchen+Bar, The Flats on Carson, Super Happy Fun Time Bar and Arcade, and Foxtail.



Participants enjoyed a variety of different Bloody Mary cocktails at each of the participating bars and, at the end, voted for the bar that had their favorite Bloody Mary. Volunteers were stationed at each of the bars, selling raffle tickets and giving out prizes to the participants. Zombies from the Scarehouse were set up at Local Kitchen+Bar with a prize wheel. A Halloween costume contest was held and all of the participants were able to vote for the Most Original, Funniest, and Scariest Costumes.

The after-party at Foxtail included a taco bar catered by Steel Cactus and an assortment of appetizers from Local Kitchen + Bar. Kiss 96.1 Radio DJ, Hughes, was our MC for the night announcing the winners of the Halloween Costume Contest, the bar

with the best Bloody Mary, and the raffle winners.

Congratulations to the Double Wide Grill for being voted the Best Bloody Mary!



Congratulations to the winners of the Costume Contest! The Funniest Costume Award which included 4 VIP tickets to Hundred Acres Manor Haunted Attraction went to Lauren Jeffress. The Scariest Costume Award which included 4 RIP Tickets to the Scarehouse went to Dakota Heth. The Most Original Costume Award which included 4 VIP tickets to Hundred Acres Manor Haunted Attraction went to Samantha Mielo.

WPCNHF would like to thank everyone who participated in the event, sponsored the event, and donated items to help make the event a success! Thank you to our amazing volunteers Melanie Posteraro, Heather Gregori, Adam Boyle, Angie Shepard, and Mike and Karen Covert.

Save the date for our next fundraiser, Bowling for Bleeding Disorders, on Sunday, February 17th! This bowling fundraiser will take place at Paradise Island Bowl. \$25 per person includes 3 hours of bowling, an event t-shirt, shoe rental, pizza, wings, and unlimited soft drinks. Register teams online today at give.classy.org/bowling4bleeding.



Women's Night Out

Once again, we had a wonderful turnout for a women's night out! Over 20 women gathered at Painting with a Twist, in Monroeville, where they could take a break from their busy schedules and spend a little time with each other. The evening started off with dinner and a talk by CSL Behring's Common Factors Advocate, Kristin Prior. Kristen, a social worker and mother of a son with a bleeding disorder, grew up suffering from an undiagnosed bleeding disorder, von Willebrand Disease (VWD), until she was in her thirties.

Kristen talked about the importance of finding support within the bleeding disorders community. She shared her personal story on how friends she's made within the community have supported her and have given her strength, not only with coping with her and her son's bleeding disorders, but in other areas of her life, as well. We often hear our members say that the friends they have made in the bleeding disorders community are their extended family and Kristen's story reminded us of that.

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NHF's Bleeding Disorders Conference

By Michael Baptiste

When we found out we were awarded the trip to the National Hemophilia Foundation's Bleeding Disorders Conference, in Orlando, we were excited! However, most families get excited because it is Florida and hope to spend a day at Disney. Our excitement was that our 16-year-old son would have one last opportunity before leaving for college to attend an incredible educational conference.

Austin was diagnosed with two rare bleeding disorders (factor 5 deficiency & factor 7 deficiency) just two years ago, following a routine appendectomy. We were unaware of his condition, and as a consequence, he almost died due to internal bleeding. Most children are diagnosed young, and parents have many years to educate their child on the fundamental concerns relating to their condition. Discovering his condition so late in his childhood means we need to get as much information into his teenage head as possible before he is out on his own.

The WPCNHF has allowed us to provide Austin with the gift of education. Because of the conference, he can now self-infuse his factor when needed and he is aware of



risks associated with his blood disorder. Not only was the conference educational, it was inspiring and uplifting to connect with so many other families facing similar situations. We attended several incredible sessions during the day on rare bleeding disorders and danced and ate with families at various events hosted by the vendors.

Two weeks ago, Austin had to get his wisdom teeth out and he needed to take his factor one hour before surgery. Because of the training he received at the conference, he was able to self-infuse his factor at home without the help of anyone. Knowing that he now has the confidence and awareness to do this has, in our minds, saved his life! The Baptiste family would like to give a special thanks to the Western PA Chapter of NHF for making the trip possible and giving us the means to educate Austin and the rest of the family.



Junior National Championship

(Continued from page 6)

was second to none! Landon was eager to meet so many new friends, all of which have a bleeding disorder. As we all know, it's not often everyone, or anyone, on your team understands the complexity of living with a bleeding disorder. To top off our incredible weekend, Landon received the good sportsmanship award, which made us all so proud and speaks volumes to his excitement! I hope each of you have the opportunity to attend this event in the future to enjoy swimming, baseball, or golf.

What a genuinely amazing event! We can't say "thank you" enough to CSL Behring and the athletes for their hospitality, guidance, and encouragement!





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OR WITHOUT FACTOR VIII INHIBITORS

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What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.


HEMLIBRA
emicizumab-kxwh | 150
injection for subcutaneous use mg/mL

Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:
 - confusion
 - weakness
 - swelling of arms and legs
 - yellowing of skin and eyes
 - stomach (abdomen) or back pain
 - nausea or vomiting
 - feeling sick
 - decreased urination
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:
 - swelling in arms or legs
 - pain or redness in your arms or legs
 - shortness of breath
 - chest pain or tightness
 - fast heart rate
 - cough up blood
 - feel faint
 - headache
 - numbness in your face
 - eye pain or swelling
 - trouble seeing

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take,

including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.

- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See “What is the most important information I should know about HEMLIBRA?”

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
This Medication Guide has been approved by the U.S. Food and Drug Administration
Revised : 10/2018



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NATIONAL HEMOPHILIA FOUNDATION'S

WASHINGTON DAYS

The National Hemophilia Foundation (NHF) will be hosting its annual Washington Days advocacy event on Wednesday, March 27, through Friday, March 29, 2019, at the Hyatt Regency on Capital Hill.



The Western PA Chapter of the National Hemophilia Foundation has a limited number of travel scholarships available for chapter members who would like to attend.

If you are interested in joining other people from around the country to advocate for issues affecting the bleeding disorders community, please contact the Chapter at info@wpcnhf.org or 724-741-6160 by February 4th for more information.

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- + Chapter and camp program support



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Be a Part of Making Tough Decisions Now

By Steve Place

I have lived for 64 years with mild hemophilia and have voluminous experience, from which I came to my own rock-solid conclusions about how someone with a bleeding disorder can participate in sports and other potentially life-changing activities.

One experience was a significant life change at age 10, when I sustained a serious head injury. I felt able to ride my bike with no hands. Sand and a quick moment of unbalance tossed me off my bike, and my head hit the pavement hard. I got myself up and walked back home with my bike. My sister saw me and screamed. That's when I felt a huge lump on my forehead and knew I was in trouble. Our doctor, who made house calls, wrapped my head with a pressure bandage and told my parents to give me two aspirin every four hours and added that if I made it through the night, I probably would be all right. Aspirin and all, I survived.

All of a sudden, I was prohibited from participating in contact sports. This is tough for a 10-year-old boy. Although I was always the smallest kid in my class and

the last to be chosen at sports, it still hurt. Fortunately, my mom and dad and sister were very supportive, and we got through it together. They steered me to other avenues that led me to a happy, healthy, and productive life. I thank God every day for my hemophilia!

I look back and wish I could have accepted at age 10 what I strongly believe about my bleeding disorder today. I went from "Boo-hoo, I can't do certain things!" to "Drop back, punt, and come up with a new plan."

Now that may sound a bit harsh, but the sooner we accept our limitations in life and pursue the best and safest path, the better off our lives and our families' lives will be. Yes, we must think about our families, too; it's not all about the person with hemophilia. Every person with a bleeding disorder has affected and will continue to affect the lives of those we love most. Our bleeds seem to come at the most inconvenient times, for us and for them!

It was traumatic when at age 10, I had to stop doing the things my buddies were doing. But here I am today, happy, married for 40 years with two daughters, successful, and in excellent health. I am physically active in my daily pursuits. I am a professional handyman and sole proprietor, and I work daily with all types of sharp tools, both power and manual. Safety and thinking through a job are paramount. Knee pads and elbow/forearm

protection are vitally important. The most dangerous tool in my toolbox is a dull blade.

I treat on demand and prior to some potential bleeding situations. I have 95% mobility in all of my joints. The only time I infuse, apart from surgery, is when I make a mistake.

We all want to be the best parents we can be for our kids. Good, tough prodding and steering today can result in a wonderful life later on for them. I made a very strong, positive personal decision that has guided my life for the last 50-plus years. I decided that I will respect my disorder, but I will not be afraid of it. I will determine what I will do, and what I will not do. I basically took charge of my life.

Stephen is 64 and has been married for 40 years. He has two adult daughters, and works 50 hours a week. He is active in his church, both teaching and leading. He believes that life is great, especially when "I respect my disease, but am not afraid of it."
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Column: As I See It

Getting to Know HCWP Staff

Featuring: Cynthia Ventrone,
Medical Assistant



Birthplace: Magee Women's Hospital,
Pittsburgh, PA

First job: Door-to-door sales, office, bank

Accomplishment you're proudest of:
Going to college and working in nuclear medicine for 20 years and continuing in patient care.

What three words describe you best?
Loyal, kind, dependable

Dream vacation: Europe

Things you can do without: Bad attitudes,
taxes, winter

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

Movie you could see anytime: I Can Only Imagine

TV show you try not to miss: Chicagos

Three things that can always be found in your refrigerator: Yogurt, fruit/veggies, dressings

Secret vice: It's a secret...

Who would play you in the movies? Kim Cattrall

Your pet peeve about Pittsburgh: Pot holes and construction

People may be surprised to know that: I just moved into my own condo after living with/caring for my mother for 8 years. They never thought I'd leave.



Happy New Year Welcome 2019 From HCWP

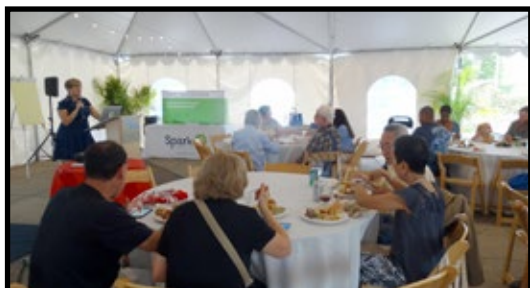
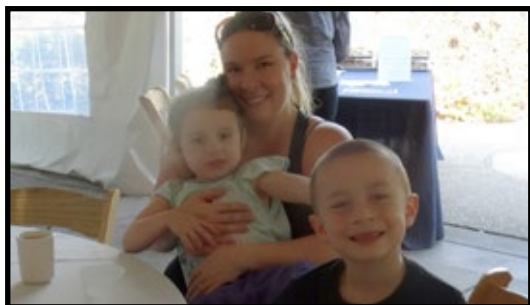
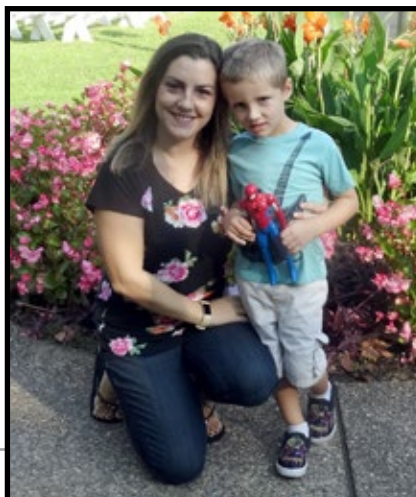
*We at the Hemophilia Center of
Western Pennsylvania thank you for
allowing us to serve you through 2018!*

*May this year give you the
opportunity to
follow your dreams,
love like there is
no tomorrow,
and smile unconditionally.
Happy New Year!*

Oktoberfest

Gene therapy, a technique that uses genes to treat or prevent diseases, has been evolving over the past 50 years and has been making the news headlines more and more frequently. Naturally, it's on the mind on many people living with bleeding disorders—some are even participating in clinical trials. To help our members better understand gene therapy and its potential application to hemophilia, we invited Lauren Temple, Sr. Patient Advocacy & Community Outreach Specialist with Spark Therapeutics, to speak about gene therapy at our Oktoberfest event. While the information answered many of our questions, more time is needed before long-term data is available for answers to other questions.

This educational event was held on October 6, at the National Aviary. We thank the following for supporting this event: Spark Therapeutics, Accredo, Biomatrix, Cottrill's Pharmacy, CSL Behring, CVS Specialty, Hemophilia Center of Western PA, and Shire.



Women's Night Out

(Continued from page 11)

The women spent the remainder of the evening talking, painting, and enjoying each other's company. Although everyone painted the same winter scene, the completed works of art were as unique as each of the women! We thank CSL Behring for sponsoring this event.

The Chapter is in the process of planning women's educational and social events for 2019. If you have a suggestion for an educational topic or event, please contact Janet Barone at janet@wpcnhf.org.





Bowling for Bleeding Disorders

Sunday, February 17th
2PM-5PM

A Bowling Fundraiser to benefit the Western PA Chapter of the
National Hemophilia Foundation.

Paradise Island Bowl
7601 Grand Avenue
Pittsburgh, PA 15225

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

Register Teams Online at:
give.classy.org/bowling4bleeding

Western Pennsylvania Chapter of the National Hemophilia Foundation

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Cranberry Township, PA 16066

Phone: 724-741-6160 Toll Free: 800-824-0016 Fax: 724-741-6167

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