



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

**Winter 2020**  
*Inside this issue*

**Camp Hot-to-Clot**  
*See Page 3*

**8th Semi-Annual  
Cornhole Tournament**  
*See Page 5*

**7th Annual Bowling for  
Bleeding Disorders**  
*See Page 13*

**Bingo for Bleeding  
Disorders**  
*See Page 14*

## **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

## **Oktoberfest**

October 19 was the day of our annual Oktoberfest event. The day began with sponsor exhibits and donuts & cider in the Fellowship Hall at Trinity Evangelical Lutheran Church, in Wexford.

When the program was ready to begin, the children headed to a supervised room to work on fall crafts. The rest of us were fortunate to participate in the program *Keep those Joints a Movin' & a Groovin'*, which was created by Cheri McShea PT, DPT specifically for this event! Cheri, Physical Therapist at the Hemophilia Center of Western PA, covered a wide range of topics around joint health. This was not your typical joint health presentation! Many found it interesting to learn about the positive and negative impacts of certain foods, herbs, spices, and beverages (see page 18); how footwear choices can impact your joints; the benefits of managing stress; and of course, how to recognize & treat bleeds and protect joints.

*(Continued on page 2)*

### **What did your fellow members have to say?**

**"Excellent presentation filled with lots of information"**

**"Very thorough"**

**"Simplified, rational explanation"**

**"Interesting and helpful"**

**"Very beneficial & informative"**



## **Teens vs. Zombies**

By Nicolette C.,  
Teen Group Co-Coordinator

On October 20th, WPCNHF hosted a teen event during their Zombies of the Corn fundraiser in Freedom, PA. This gave teens the opportunity to catch up and plan events. Everyone caught up with friends over refreshments and then we started planning the teen retreat, a two-day event in January for teenagers involved in the Chapter or Camp Hot-to-Clot.

We discussed activities and meal ideas for the upcoming retreat before going to the zombie shoot. During the zombie shoot, we rode around in a truck/tractor hybrid equipped with paintball guns. The group traveled through the zombie shoot arena,



shooting zombies and saving Western PA from an infestation!

*(Continued on page 2)*

# Oktoberfest

(Continued from page 1)

We thank the following companies for supporting our Oktoberfest program: Accredo Health, Cottrill's Pharmacy, CSL Behring, DrugCo, Factor One Source, Genentech, Hemophilia Center of Western PA, Novo Nordisk, and Octapharma.

We also thank our many members who helped to make the day a success. Whether it was helping with the room setup, working the registration table, supervising the younger children, or helping to clean up and rearrange the tables & chairs, your time and effort was greatly appreciated! We were so impressed with how quickly the room returned to the way we found it!

It was a beautiful fall day and when the program was over many headed to Soergel Orchards to enjoy their Fall Festival.



## Teens vs. Zombies

(Continued from page 1)

Afterward, we returned to our pavilion to discuss final plans and determined the winners of the Chapter sponsored costume contest. The costumes ranged from Sully from Monsters Inc. to some kind of ghoulish creature. We awarded prizes and then gathered for a group photo to commemorate the night. Overall it was a night of reconnecting with friends, planning future endeavors and most importantly, having fun!



## Zombies of the Corn Fundraiser

**For every person who purchased a ticket to the haunted attraction and signed-in at the Chapter's pavilion, Three Rivers Paintball donated \$5 back per person to WPCNHF. In total, we raised \$450 dollars and raised critical awareness for the bleeding disorders community. Thank you to everyone who came and supported WPCNHF!**

**The Chapter thanks My Hero's Sub Shop in Rochester, PA for providing dinner for the teens.**

# Calendar of Upcoming Events

January 10 - 12, 2020  
Teen Retreat  
Clinton, PA

February 6, 2020  
Bingo for Bleeding Disorders –  
To support Rolling for Ryker  
Hickory, PA

February 9, 2020  
Bowling for Bleeding Disorders  
Pittsburgh, PA

February 11, 2020  
Dinner Program with  
Vaughn Ripley  
Cranberry Township, PA

February 22, 2020  
Advocacy Ambassadors Retreat  
Robinson Twp., PA

February 26-28, 2020  
Washington Days  
Washington D.C.

March 7, 2020  
Dinner Program with Dr. Zolo  
Clearfield, PA

March 21, 2020  
Education Day  
Location TBD

March 25, 2020  
Dinner Program with  
Dr. Guerrera  
Punxsutawney, PA

April 4, 2020  
WPCNHF's 8th Semi-Annual  
Cornhole Tournament  
Wildwood, PA

April 23-26, 2020  
HFA Symposium  
Baltimore, MD

July 23, 2020  
Annual Meeting &  
Walk Kickoff  
Pittsburgh, PA

August 9-15, 2020  
Camp Hot-to-Clot  
Fombell, PA

## Camp Hot-to-Clot Important Dates

**Camp:**  
August 9-15, 2020

**Registration opens:**  
May 1, 2020

**Registration closes/Forms due:**  
June 15, 2020

**Please note:** The registration window is shorter this year to allow more time to prepare for camp.

Camp Hot-to-Clot 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.



\* Visit [wpcnhf.org](http://wpcnhf.org) for more information on our upcoming events.

Ask us about sponsorship opportunities and how you can help!

## Board of Directors

**President**  
Mike Covert

**Secretary**  
John Yunglans

**Board Members**  
Brittani Spencer  
Melinda Perry  
R. Scott Domowicz  
Jennifer Smith

## Staff

**Executive Director**  
Kara Dornish

**Program Director**  
Janet Barone

**Development Director**  
Jessica Lee

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.

## 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.



# Letter from the President

As we move into the holiday season and gather again to celebrate with family and friends, I am reminded of the extraordinary people I get to meet through our work with the WPCNHF. The holiday season offers me an opportunity to remind myself what I am thankful for; my family, faith and our community.

I reflect on this incredible opportunity to serve and feel sincere gratitude for the teams and volunteers that make it all possible. I am thankful for all of the wonderful resources brought to our community by the hard-working chapter

staff. Kara Dornish, Janet Barone and Jessica Lee never cease to amaze me. They make everything appear so effortless but we all know there is a lot of work being done to ensure the successful execution of all events and programs.

As we look forward to 2020, we prepare for changes in the industry. It is critical that we work as one team toward our mutual goals and to ensure that our chapter provides nothing short of the best for our community. With the support from our dedicated board members, Brittani Spencer, Mindy Perry,

Jennifer Smith, John Yunghans and R Scott Domowicz, we will continue adapting to the industry and making any changes necessary for the needs of our chapter members.

Happy holidays and a happy new year to all!

Kind Regards,

Michael Covert  
WPCNHF Board President

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## Letter from the Executive Director

Dear Community Members & Friends,

Thank you for a great 2019! I remember writing my very first letter (then as Interim Executive Director) exactly one year ago and thinking of all the things we would like to accomplish in the year to come. It's crazy how fast the year went by and just how much the Chapter has accomplished!

We held 19 educational events at no cost to our members including a very successful Education Weekend which included 2 days of educational programming and 18 sessions. We had our most successful Walk fundraising year, raising a grand total of \$72,741, and were awarded the 2019 Rising


Star Chapter Award from the National Hemophilia Foundation. We brought back a very beloved fundraiser, Take A Bough, which was a great success, raising over \$16,000 to support the community! We held our first volunteer recognition event at our Annual Meeting in July where we recognized 13 incredible individuals for their hard work and dedication not only to the chapter, but the entire bleeding disorders community.

We continued to work 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 are excited to bring our advocacy to the next level in 2020 by implementing an Advocacy

Ambassadors Program in February. We hope you will join us in this endeavor as your participation is what will make a real difference in ensuring patient protection and affordable healthcare for the entire bleeding disorders community.

I am truly honored to be leading this organization into 2020. I look forward to continuing to serve this community and I hope to see you at many of our upcoming events! Wishing you good health and happiness in the coming year and always.

Sincerely,

  
Kara Dornish  
Executive Director

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## Health Insurance Roadmap

Understanding coverage options is essential for making informed decisions about your health insurance. On November 20, our members were invited to learn more about this important topic. Andrew Fleming, Takeda's Reimbursement and Access Manager for Pennsylvania, presented the program *Health Insurance Roadmap*. One of the topics that was of particular interest to those in attendance was co-pay accumulators.

Andrew gave helpful tips such as calling the insurance company before enrolling to ask if the plan contains co-pay accumulators or co-pay adjusters; asking if the policy excludes drug manufacturer coupons or co-pay assistance from counting toward your annual out-of-pocket (OOP) maximums; and being sure to keep record of their call. It's important to ask these questions, as the language insurance companies use in their policies varies and the name they give to their copay accumulator/co-pay adjuster might be something that actually sounds like a benefit to the insured!

If your health insurer or PBM (Pharmacy Benefit Manager) has implemented a co-pay accumulator program, please contact the Chapter with the details (which insurer or PBM, what medication, etc.). The Chapter supports proposed legislation that seeks to end the discriminatory practice of co-pay accumulator programs being implemented by health insurers and PBM's by requiring them to count discounts enrollees get through drug payment assistance programs as paying off their out-of-pocket obligations.

WPCNHF's 8th Semi-Annual

# Cornhole Tournament

Saturday, April 4, 2020

North Park Sports Complex

2330 Wildwood Road

Wildwood PA 15091

Registration: 1:00 p.m.

Tournament Begins: 1:30 p.m.



**CASH PRIZES!  
& RAFFLES!**

## Social Division:

**Team Cost (Per team of Two):**

**Early Bird: \$40**

Now through March 20th

**Regular: \$50**

**Social Division Prize:**

1st Place - winner take all - \$100

## Competitive Division:

**Team Cost (Per team of Two):**

**Early Bird: \$50**

Now through March 30th

**Regular: \$60**

**Competitive Division Prize:**

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. All of the proceeds stay local to benefit the members of the Western PA Chapter of the National Hemophilia Foundation.

**Register at [give.classy.org/Cornhole8](https://give.classy.org/Cornhole8)**

Questions? Contact Jessica at [jessica@wpcnhf.org](mailto:jessica@wpcnhf.org) or call 724-741-6160

# HCWP Corner

By Kathaleen Schnur, LSW

To Our Patients and Families of HCWP:

One of my favorite traditions is singing Auld Lang Syne with my loved ones as we ring in the New Year while clanging pots and pans on our front porch and placing quarters on all of the window sills in our home (please feel free to share your own traditions with me). “We two have run about the slopes, And picked the daisies fine; But we’ve wandered many a weary foot, Since auld lang syne.” The title, translated literally into standard English, is Old Long Since and can be interpreted as for old times’ sake. While the song has no specific reference to the new year, the song

has two friends recalling adventures of long ago. When the clocks hit midnight and the calendars change over to a new year, it’s a wonderful time to reflect on the highs and lows, successes and struggles, moments to appreciate and opportunities to grow. Whether you spent your January 1st sleeping, working, or celebrating, I hope you took a moment to reflect on your own year and set a refreshing tone for 2020.

At the Center, we welcomed Kara Moore, a new nurse, in October. Kara’s background is emergency medicine, and she is excited for the opportunity of developing long-term patient relationships as well as being challenged in new and different ways. Kara enjoys skiing and belongs to an off-roading Jeep club. Kara also enjoys writing poetry.

We have confirmed our Camp Hot-to-Clot

dates for this year (August 9-15). Make sure your kiddo is current on their clinic appointment. If you are not sure, give us a call. More information will follow by USPS and email blasts. If you do not receive anything or have additional questions, please contact me or Kit at the Center.

We look forward to seeing you in the clinic and at community events. Please remember that your visit doesn’t end when you walk out the doors here. We are here to support you on your path of life with a bleeding diagnosis and sometimes those questions and concerns happen between visits or after your visit when reviewing the information, so give us a call and let’s work together.

Wishing you and your families all the best in 2020!

## Your Health: It’s Worth Fighting For

By Laurie Kelley

**Q** I feel like I’m not really getting what I need from my healthcare coverage. What should I do if I’ve already received a denial of service or medication?

**A** Here are examples of denials that may happen:

- Your health insurance company won’t let you be seen at a hemophilia treatment center (HTC) for comprehensive care because the HTC isn’t “in-network.”
- You can’t go to an HTC because you’re in a health maintenance organization (HMO). Your managed care company doesn’t have any physical therapists in-network experienced with bleeding disorders.
- Your HTC doctor prescribed a brand of factor replacement therapy, and your insurance company won’t approve it.

### What can you do about these denials?

Typically, people tell me they’ve just accepted the insurance company’s decision and denial. But you need to be proactive. Did you or your healthcare provider ask the insurance company to reconsider? Did you file a complaint? You have a right to challenge the decision. You’ll

likely get help from your provider, and you may enlist the help of your local hemophilia organization. Consider asking for an appeal even if you have Medicaid. Sometimes, people with Medicaid feel they are getting “free” healthcare and don’t want to rock the boat. *No matter what type of healthcare coverage you have, you have the right to ask the company to reconsider.*

**Q** How about a few ideas to get me started on an appeal?

**A** Here are some ideas on getting what you need:

- Insurance companies are in the business of providing care that leads to good medical outcomes for their members. If you and your healthcare providers can show why something is medically necessary, your chances of getting the insurance company to cover it will increase.
- If an HTC isn’t in-network, ask the insurance company to make an exception. When you call the number on the back of your insurance card, be prepared to tell them why you need this service. You’ll probably have to ask the HTC or provider to write a letter to the insurance company. If the insurance company still says no, you can file an appeal.
- If your insurance company doesn’t agree with the treatment plan that you and your healthcare provider have

agreed on, you may need a letter of medical necessity. For example, if your treatment plan includes a prescription for a different factor replacement therapy than you currently use, a prior authorization may be required. If the insurance company still doesn’t approve it, you can appeal that decision.

- You’ll need to follow the processes for complaints and appeals that your insurance company requires, so keep good records of phone calls and correspondence (emails, letters, forms).
- You can get the details on the company’s process by calling the number on the back of your insurance card or going to the insurer’s website.

**Bottom line:** If you and your healthcare team think that you’re not getting medically necessary treatment approved, you’ve got to speak up!

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Column: Ask the Expert



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Discover your sense of go. Discover HEMLIBRA®.

#### 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**.





**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,  
1 DNA Way, South San Francisco, CA 94080-4990  
U.S. License No. 1048

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For more information, go to [www.HEMLIBRA.com](http://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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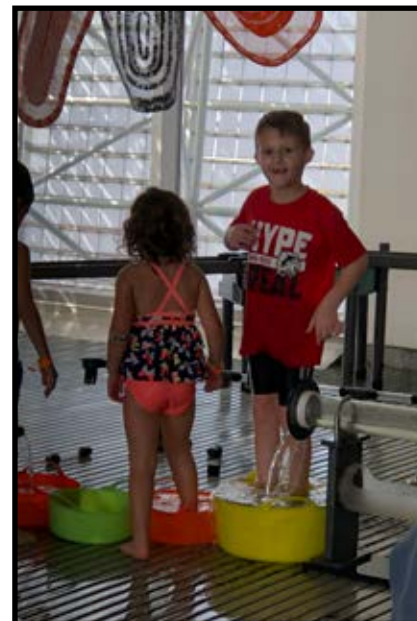
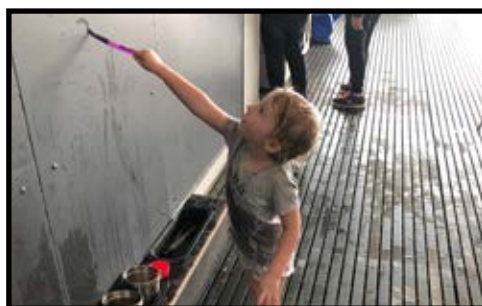
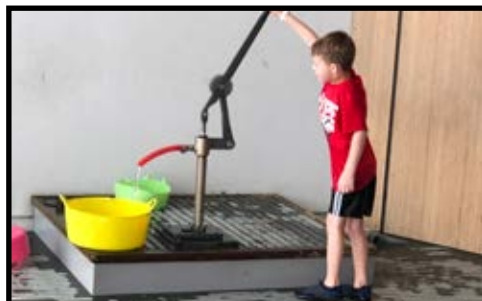


## New Parent Network

Children's Museum of Pittsburgh was the location for our final event in the 2019 New Parent Network series. On November 2, we held a social event where families could mingle with each other and meet our program sponsors. We gathered for food, welcomed some new members, and caught up with old friends! It never ceases to amaze us how quickly time flies and how quickly the children grow up. Several of our families have children who are aging out of the program this year and we hope to see their kids next summer at Camp Hot-to-Clot!

Kathaleen Schnur, LSW, Mental Health Professional, from the Hemophilia Center of Western PA and Janet Barone, WPCNHF Program Director, partner on New Parent Network events, which are open to families who have a young child with a bleeding diagnosis.

We thank the sponsors of our 2019 New Parent Network series of events: CSL Behring, Genentech, Novo Nordisk, Sanofi Genzyme, and Takeda.



## Advocacy Update

WPCNHF and the Eastern PA Hemophilia Foundation jointly hosted an advocacy stakeholders meeting, on November 12, 2019, in Harrisburg, PA. The retreat was attended by members of the PA Advocacy Committee, which is comprised of Chapter staff, representatives from the seven Hemophilia Treatments Centers in PA (including HCWP), National Hemophilia Foundation, Hemophilia Federation of America, Industry, and a Government Relations firm. Our special guest speaker was Meaghan Abbott, Director of Intergovernmental Affairs at the Department of Health. Issues discussed included the Pennsylvania takeover of the health insurance exchange, PA Department of Human Services statewide preferred drug list, prior authorization legislation, and advocacy programming for the Chapters.



The PA Chapters are working closely together on advocacy efforts and are forming an Advocacy Ambassadors program. We are looking for individuals who are interested in supporting advocacy efforts throughout the year. On February 22, the WPCNHF will host an advocacy retreat to train members who are willing to share their stories and

meet in person with legislators and/or write letters and make phone calls to ask them to support legislation that benefits those living with bleeding disorders. If you are interested in becoming a volunteer Advocacy Ambassador, please contact Chapter staff.



## 7th Annual Take A Bough Returns as a Huge Success!

The 7th Annual Take A Bough was held at Gaetano's Banquet Center on Banksville Road. This year marked the return of the beloved Chapter event after four years!

Thanks to the support from our sponsors, donors, and patrons, we raised over \$16,000! We are extremely grateful for everyone who participated in Take A Bough this year, as this fundraiser would not have had a successful return without them.

This year's auction opened online on November 11th, one week prior to the live event that took place on November 16th. Unlike previous years, the live auction was a one-day event that featured a wine tasting from three local Pittsburgh wineries. Deer Creek Winery of South Hills Village, Arsenal Cider, and Refucilo Winery generously donated their time to Take A Bough and provided samples of their most popular wines and ciders. Bottles were also available for attendees to purchase at anytime during the night.

Planning and preparation for this event began months before November 16th. Our co-chairs, Mindy Perry-Stern and Maria Steele-Voms Stein, helped gather trees, decorations, gifts, and raffle items leading up to the event. From November 1st through November 13th, volunteers came into the office to help decorate trees, wrap gift baskets, and make wreaths. We had a total of seven trees, 25 wreaths, and 16 centerpieces available for bid.

At the event, there were 14 raffle baskets donated by community members and a










50/50 raffle ran by Michael Perry. Maria ran a reverse raffle using small blood drop ornaments our Camp-Hot-to-Clot campers made in August. Tickets were sold for \$10 each and participants had the chance to win \$200! Maria was the last number standing at the end of the night and donated her winnings back to the Chapter. Her raffle raised a total of \$340!

The auction ended online and in-person at 9 p.m. Participants were able to take their winnings home that night, while online participants could pick them up at the Chapter office starting Monday November 18th. The Western Pennsylvania Chapter of the National Hemophilia Foundation would like to thank Mindy and Maria for co-chairing the event, our amazing sponsors and wineries, and the many volunteers who



decorated in the office, transported items to Gaetano's, set up the venue, and helped during the event. Successful fundraisers like Take A Bough allow the Chapter to continue to carry out the mission of enriching the lives of those with bleeding disorders in Western Pennsylvania and responding to the needs of the community in a dynamic environment.

 <b>2019 Take A Bough Sponsors</b> 	
<b>Silver Sponsor</b>	
	
<b>Bronze Sponsor</b>	
	
<b>Supporting Sponsor</b>	
	
<b>Patron Sponsor</b>	
	
<b>Media Sponsor</b>	
	



## NHF's 71st Bleeding Disorders Conference

By Guy Law

My name is Guy Law and my fiancé's name is Miranda. I am a hemophiliac and was a camp counselor at Camp Hot-to-Clot. When we were given the opportunity to go to the Bleeding Disorders Conference, we were ecstatic. It was Miranda's first time attending and she experienced, firsthand, how bleeding disorders have affected me and saw how far our community has advanced. We even took some time to have fun in California!

I've been surrounded by Hemophilia my whole life but getting to see someone experience it for the first time was amazing. When you try to explain what a bleed is, or how your medication works, it's hard to understand until you see it for yourself (like we did at the conference). It's crazy to see how far we have come, especially in treatment therapy. Thinking back to when I was a kid, I'd have to go to



the hospital constantly, but now I do an injection every two weeks.

We attended many sessions, including one lead by Dr. Ragni, and this proves the bleeding disorders community shines bright as we move into the future. We

explored Disneyland and California adventure theme park (ears and all), decorated for their Halloween party, and had such a magical time. I got to see some old friends and make new ones. Thank you WPCNHF for this amazing opportunity!

## Chapter Launches Blood Brotherhood Program

By John Yunghans,  
Men's Group Coordinator

Our chapter launched our first Blood Brotherhood Meeting. Blood Brotherhood exists to provide a support network to men affected with bleeding disorders. We gathered together over delicious steaks and a great talk from HFA about legal rights for individuals with bleeding disorders in the workplace and beyond. I really enjoyed our discussion and getting to know these awesome guys. We are excited to meet again in February. This group is open to any man with a bleeding disorder in our chapter. Stay tuned for more information about our next gathering. We also thank WPCNHF and HFA for sponsoring this event and making these connections possible.



## WPCNHF's Winning Women Create Stunning Pieces of Art

By Maria Steele-Voms Stein,  
Women's Group Coordinator

On Thursday, October 24th, the Winning Women's group of the Western PA Chapter hosted a "Women's Night Out" event at the Pittsburgh Glass Center located on Penn Avenue in the Garfield neighborhood of Pittsburgh. We dined on a delicious meal prepared by the Cooked Goose Catering Company while Kimberly Walsh, a Common Factors® Advocate, led an interactive discussion on the importance of self-advocacy. Afterward, the craftsman at the Pittsburgh Glass Center guided us on a tour of the center's various glass making studios. A step-by-step demonstration of the glass blowing process was led by the extremely talented and knowledgeable glass artists, Daniel Kilbride and Zach Layhew. Last but not least, we had the opportunity to participate in a "hands on" glass making

experience crafting our own keepsake blown glass pumpkin.

The WPCNHF Winning Women's group is a great opportunity for the women of our chapter to network with other women in our community, learn about important issues related to bleeding disorder management and have a lot of FUN. I hope to see you at an upcoming WPCNHF Winning Women's group and chapter event soon!

The Chapter thanks CSL Behring for sponsoring this program.



## Getting to Know HCWP Staff



Walt Livingston, Nurse

**Birthplace:** New Kensington

**First job:** Fire Department Bingo Worker

**Accomplishment you're proudest of:**  
Serving in the US Army

**What three words describe you best?**  
Honesty, Protector, Believer

**Dream vacation:** Ruskin Florida

**Things you can do without:** Gossip

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

**Movie you could see anytime:** Not a big Movie watcher

**TV show you try not to miss:** Voice or Americas Got Talent

**Three things that can always be found in your refrigerator:** Diet Peach Tea, Milk, Cheese

**Secret vice:** Bowling, Numismatic

**Who would play you in the movies?** No one, they live in a make-believe world.

**Your pet peeve about Pittsburgh:** Route 28

**People may be surprised to know that:** I trained in boxing and Martial arts



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Western PA Chapter of the National Hemophilia Foundation

**SUNDAY  
FEBRUARY 9TH  
2020**

**2 P.M. - 5 P.M.**

# **7TH ANNUAL BOWLING FOR BLEEDING DISORDERS**



**REGISTER TEAMS ONLINE  
AT [GIVE.CLASSY.ORG/  
BOWLING4BLEEDING](http://GIVE.CLASSY.ORG/BOWLING4BLEEDING)**

**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!**



# BINGO for BLEEDING DISORDERS

Thursday, February 6, 2020

7 p.m. - 9 p.m.

Red Fox Winery and Lounge  
80 Red Fox Road  
Hickory, PA 15340

Join us at the Red Fox Winery and enjoy drinks, play bingo, and give back to the Western Pennsylvania Chapter of the National Hemophilia Foundation! Cost is \$2 per card, per bingo game from 7 p.m. - 9 p.m. In addition to the game, the Red Fox Winery will donate 10% of their wine sales from the evening back to the Chapter! There will also be awesome raffle baskets and a 50/50 for even more chances to win! WPCNHF will be there to provide additional information about bleeding disorders and our community. There is no registration required to attend this event.

For more information, contact Jessica Lee at [jessica@wpcnhf.org](mailto:jessica@wpcnhf.org) or call the chapter office at 724-741-6160.





## Emotional Wellness as a Mature Adult: Discussing the Unique Challenges of Living With Hemophilia



For more information, visit  
[b2byourvoice.com](http://b2byourvoice.com) to download  
*Learn from Experience: A Guide for  
Mature Adults*.

This content is brought to you by Pfizer.

### How Hemophilia Affects Mature Adults

Mature adults may look back and recognize how living with hemophilia has influenced who they are today. Persevering through the challenges of being a child diagnosed with hemophilia when less was known about the condition, and navigating the issues of being a young adult with a bleeding condition can shape one's perspective. Knowledge and wisdom are some of the benefits that accrue with age, but along with these can also come additional health concerns such as high blood pressure, diabetes, and arthritis; depression and stress; and financial planning and retirement concerns. For those who have lived with hemophilia for many decades, the task of managing these concerns of older age may seem to be less important. However, there are some key points to keep in mind when addressing the effect hemophilia can have on mental health.

### The Risk of Clinical Depression

Mature adults living with hemophilia typically have experienced substantial challenges related to their disease throughout their lives. In some instances, hardships may contribute to the development of clinical depression, which is more common among people living with hemophilia than the general population. The results from one study conducted at a hemophilia treatment center showed that 37% of a sample of patients met the criteria for depression. Of that 37%, 20% had moderate to severe symptoms, and 66% reported having functional impairment due to their depressive symptoms.<sup>1</sup> The authors of the study concluded that the comprehensive care of adults with hemophilia should include depression screening for the potential to improve overall health outcomes.<sup>1</sup>

Education and support for people living with bleeding disorders and their families is one component of managing psychological wellness. Having control over life decisions and self-advocacy can also be important. For some living with hemophilia, past experiences may serve as a motivator to continue to work toward personal objectives. Others may find the journey more difficult to navigate. Self-help seminars and support groups are some of the resources that may help adults set and attain realistic goals.

**"[A reminder to] older adults that there is always  
somewhere to turn, even in times of immense hardship. All  
you need to do is ask, and you should never feel ashamed  
for doing so."**

**— Judy Bagato**

RN, BSN, Hemophilia Specialist

### Finding Support for Complex Issues

For people who acquired human immunodeficiency virus (HIV) and/or hepatitis C (HCV) from virally contaminated blood products, there may be feelings of anger and resentment. The adversity caused by a lack of family or social support during younger years or changes later in life, such as changes in one's capacity for employment or altered family dynamics, may also contribute to these feelings. Learning effective ways to cope with the stresses of living with hemophilia in older age may help an individual to be resilient to these challenges. If you are experiencing stress that is affecting your day-to-day outlook, it is important to seek help. Reach out to your treatment team to discuss your situation and learn about what help and support may be available.

**Reference:** 1. Iannone M, Pennick L, Tom A, et al. Prevalence of depression in adults with haemophilia. *Haemophilia*. 2012;18:868-874. doi: 10.1111/j.1365-2516.2012.02863.x.



Patient Affairs Liaisons are Pfizer employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to [hemophiliavillage.com/support/patient-affairs-liaison-finder](http://hemophiliavillage.com/support/patient-affairs-liaison-finder) or call Pfizer Hemophilia Connect at 1.844.989.HEMO (4366).

# ADVOCACY RETREAT

FEBRUARY 22

9:00 – 1:00



**YOUR STORY  
MATTERS!**

**BECOME AN  
ADVOCACY  
AMBASSADOR.**

## Advocacy Ambassadors

We are looking for individuals who are interested in supporting the advocacy efforts of the Chapter throughout the year. Do you have a desire to meet with legislators to help influence decisions on policies that affect individuals and families living with bleeding disorders? Are you willing to make phone calls or write letters to your legislators asking them to support legislation that could have a positive impact on the bleeding disorders community and vote against legislation that could have a negative impact? If you've answered yes to any of the above questions, we would like you to consider becoming a Volunteer Advocacy Ambassador for the Chapter!

## Registration

To register or ask questions, call 724-741-6160 or send an e-mail to [RSVP@wpcnhf.org](mailto:RSVP@wpcnhf.org). Open to adults and teenagers. Babysitting can be provided with advanced arrangements.

## Training

Learn about the following:

- Current issues that impact the bleeding disorders community
- Effectively talking with legislators
- How to tell your story
- Perfecting your elevator speech
- Phone calls & letter writing

## Location

Hilton Garden Inn Pittsburgh Airport  
South-Robinson Mall  
303 Park Manor Dr.  
Robinson Township, PA 15205

A limited number of hotel rooms are available for Friday, February 21, for those who are traveling two hours or more.





## How to Stay Active, Have Fun and Be Safe in Winter: A Few Precautions and Tips Can Help You Remain Active and Engaged All Season Long

Author Denise Schipani

### Fitness & Nutrition

If you love the idea of winter sports—think skiing, sledding/tubing, ice skating—but wonder if your bleeding disorder means you’re consigned to the indoors for the season, hold on: Your enjoyment of the winter wonderland doesn’t have to be limited to watching from the window.

Physical therapists Angela Forsyth, PT, DPT, and Alice Anderson, PT, DPT, PCS, co-authors of the National Hemophilia Foundation’s (NHF’s) *Playing It Safe: Bleeding Disorders, Sports and Exercise* guide, say that the best advice is to check with your treatment team before you engage in any winter sports. Don’t automatically assume a sport isn’t for you, notes Forsyth: “Your treatment team can help you come up with a strategy before you try a sport and find commonsense

ways to make it safer, such as wearing the proper equipment.”

No matter what outdoor winter activity you engage in, some general safety advice applies. Be sure those who are with you (or staff at a facility) know what to do in case of an accident or injury. If there’s any risk of collision, wear a helmet. Also, check the weather report, and dress appropriately for the elements.

### Get Outside—Safely

Before you grab your sled, skis or skates, make sure you’re prepared.

### Sledding/Tubing/Tobogganing

These can be gentle family fun—or turn into high-velocity downhill activities, with the potential for collision and injury.

- Ask your treatment team if you should adjust your prophylaxis or infusion regime before jumping in.
- Choose a commercial course rather than a local hill. Why? “You’re probably safer on an organized slope where there are safety provisions in place, over the free-for-all that a hill near your home might be,” says Forsyth. Emergency personnel can more quickly be summoned on a commercial course.
- Avoid the activity if the terrain is particularly icy or has too many obstacles, like trees or excessive crowds.

### Skiing

- Skiing carries the risk of collision and

falls, and it can be tough on joints, so approach it smartly.

- Get in fighting shape first. Ask a physical therapist to work with you on strengthening the muscles that support your knees and ankles.
- Keep in mind your history of joint issues. People who have already had knee bleeds, which make the joint weaker, are at more risk of another, says Anderson.
- Assess your balance and proprioception, which is the sense we have of where our limbs and joints are without having to look. People with bleeding disorders may have trouble with that, leaving them more vulnerable to injury.

### Ice skating

- Lacing up and gliding along can be great fun; just take proper precautions first.
- Make sure your skates fit properly. Skating can be tough on the ankles, so the first step is well-fitting skates that won’t put pressure on your joints.
- See a physical therapist first. A PT can work with you on strengthening as well as range-of-motion exercises for the ankle joint.
- Go skating at less crowded times to reduce the risk of colliding with other skaters.

*Article Courtesy of HemAware copyright 2019*

# Community Outreach

Dr. Michael Guerrero, Director of the hemophilia treatment program at Children's National Hospital, presented *Learning from Experiences of Living with*

*Hemophilia B*. This program provided an overview of results from B-HERO-S study, which took an in-depth view at how Hemophilia B affected the lives of those who participated in the study.

The dinner program was held in Punxsutawney, on October 16. We appreciate the information Dr. Guerrero

shared with us and we thank Novo Nordisk for sponsoring this program.

## Impact of Food Choices on Joint Health

Food choices can have both positive and negative impacts on joint health. As many of us renew our goals at the start of the year for a healthier lifestyle, we want to take this opportunity to pass along some of the tips Cheri McShea shared with us during her recent presentation.

### Eat Healthy!

- Choose foods that are 'anti-inflammatory'. These are foods that stabilize insulin and minimize 'bad fats', such as:
  - o Colorful fruits and vegetables including carrots, tomatoes, leafy greens, peppers and sweet potatoes, blueberries, cherries, oranges, papaya and strawberries
  - o Foods with 'good fat' such as olive oil, canola oil, soybean oil, corn oil, salmon, mackerel, tuna and sardines
  - o Whole grains like amaranth, barley, brown rice, buckwheat, corn, oats, rye and wheat



- Avoid foods that are 'pro-inflammatory'. These foods contribute to chronic inflammation and pain, such as:
  - o Foods made with refined sugar including candy, cookies, cakes, pies, pastries, etc.
  - o Beverages such as soft drinks, energy drinks, sweetened tea and large glasses of juice
  - o Fried foods
  - o Foods with unhealthy fats such as red meat, full fat dairy products, shortening, lard, heavy gravies/sauces
  - o Foods with a lot of added chemicals or processing like lunch meat, white flour/rice, and pre-packaged snacks
- Tips for making changes:
  - Making improvements in your nutrition starts at the grocery store:
    - o Most of the healthier food is around the outside of the store; most of the processed foods are in the middle of the store. So, try to stay away from the middle of the grocery store as much as possible.
    - o Read labels – look for foods that are lower in cholesterol, salt and sugar and higher in whole grains, fiber, and protein
  - Start with one or two changes, then as these become habit, make more changes. Ideas:
    - o Substitute water for soda pop
    - o Reduce red meat to once or twice a month
    - o Reduce coffee/tea 'add ins' such as regular/flavored creamers, sugar, etc.
    - o Eat salmon once a week
    - o Cut up fruit and veggies and store them in the refrigerator for quick, on-the-go snacks
    - o Or, fill small containers with a tablespoon of walnuts, almonds, pistachios and/or cashews as an alternate quick, on-the-go snack
  - Weigh yourself regularly.
    - o Regular weigh ins will help you to stay on track.
    - o Weigh yourself at least once a week.
    - o Always weigh yourself in the morning, right after getting up and after you have gone to the bathroom
  - A supportive partner/family greatly improves your chances of success!
- Added benefits:
  - Losing weight not only helps your heart, lungs, energy level and self-esteem, it also significantly reduces the stress on your joints. For every 1 lb. of weight that you lose, there will be 4 to 5 lbs. less pressure on your joints. This means less pain, and better mobility!
  - After a joint or muscle bleed, fruits, vegetables, whole grains, low fat sources of protein and water provide the nutrients critical to tissue repair!

Source: *Keep Those Joints a Movin' and a Groovin'*, by Cheri McShea, PT, DPT



## Winterfest 2019

Our 2019 Winterfest was the final program of the year and educated the community on the importance of proper dental care, especially as the holidays were approaching! Over 50 people gathered at the Wyndham Pittsburgh University in Oakland to discuss oral health and how to prepare for dental visits or surgeries with our guest speaker, Jean Marandola, Senior Clinical Specialist, Takeda. All ages were welcome. We thank Takeda for sponsoring this educational program.

After the program ended, the Chapter, along with a grant provided by the Colburn-Keenan Foundation, sponsored admission to the Phipps Conservatory Holiday Magic! Winter Flower and Light Garden show. It was truly a magical evening and a great way for our families to catch up. A special thanks to Pat and Paul Sabo for running the registration table and handing out Phipps tickets!



**We are always  
thankful to you  
for choosing us,  
for trusting us,  
and for giving us the  
opportunity to serve you.**

*May your cup of happiness always be filled,  
your path always bright,  
and your heart always light.*

*All the best to you and yours in 2020 from your  
team at the Hemophilia Center of Western PA.*

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

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