



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

Spring 2020
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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

Bowling for Bleeding Disorders

The Seventh Annual Bowling for Bleeding Disorders fundraiser was held at Paradise Island Bowl in Neville Island, Pennsylvania on Sunday, February 9, 2020. The cost to attend was \$25 per participant which included an event t-shirt, shoe rental, bowling, pizza, wings, and unlimited soft drinks.



All 16 lanes were filled as 75 bowlers competed for the prize of highest score and best style.



Congratulations to Brian Esser from team Rolling for Ryker who won the award for highest score!

Congratulations to Robert Boyle who won the award for Best Style!

We are extremely grateful for everyone who participated in this event. We are

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Saturday, September 12, 2020

**North Park Pool Loop
S. Ridge Drive
Allison Park PA 15101**

Check in begins at 7:30 a.m.
Race begins at 8:30 a.m.

Registration fee: \$25 (until September 11th) | Race Day Fee: \$30
Registration includes race bib, technical race shirt, race goody bag, and access to virtual race results.

This race is timed electronically by:

GCXC PROBIKE+RUN

All proceeds benefit the
bleeding disorders community
of Western Pennsylvania!

Register today at:
bit.ly/runfortheirives11



Questions? Email jessica@wpcnhf.org or call 724-741-6160

Communication Notice

During this time of uncertainty, things are changing rapidly and a lot of the information that is being distributed is time-sensitive. The best way to receive up-to-date information about programs, events, last minute webinars, and issues affecting the bleeding disorders community is to sign up to receive email and text messages.

If you are not currently receiving email and text messages from the Chapter or have opted out of either one in the past and would like to subscribe, please send an email to info@wpcnhf.org or call the Chapter office at 724-741-6160 and give us your email address and/or cell phone number.

For those who don't have access to email and/or text messages, we will do our best to mail important information to you, when able to do so.

Bowling for Bleeding Disorders

(Continued from page 1)

excited to report that nearly \$10,000 was raised! All the money raised went towards emergency and medical patient assistance, educational programs, and support groups to benefit the bleeding disorders community in Western PA. The sponsors of the event included The Hemophilia Center of Western Pennsylvania, Novo Nordisk, Octapharma, CSL Behring, and Bayer.

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



RED TIE CAMPAIGN™
FOR ALL BLEEDING DISORDERS

Thanks for participating in the Red Tie Campaign!



Calendar of Upcoming Events

June 7, 2020
Axe Out Bleeding Disorders
Cranberry Twp., PA

June 9, 2020
Gene Therapy Dinner Program
Erie, PA

July 8, 2020
Gene Therapy Dinner Program
Robinson Township, PA

July 9, 2020
Gene Therapy Dinner Program
Murrysville, PA

July 14, 2020
VWD Dinner Program
Location TBD

July 18, 2020
New Parent Network Picnic
Ligonier, PA

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

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

August 11, 2020
Constructive Conversations
Dinner Program
Location TBD

August 29, 2020
Education Day
Wexford, PA

September 12, 2020
Unite for Bleeding Disorders
Walk, Run for their Lives 5K,
and WPCNHF's 9th Semi-
Annual Cornhole Tournament
Allison Park, PA

September 20, 2020
Ballers for Bleeding
Disorders
Freedom, PA

September 25-27, 2020
Young Adult Retreat
Clinton, PA

October 3, 2020
Men's Group
Bridgeville, PA

November 6, 2020
New Parent Network
Erie, PA

November 7, 2020
Fall Program
Erie, PA

December 6, 2020
Winterfest
Location TBD

Update to Chapter Events and the Coronavirus

In an effort to make decisions with the wellbeing of our community and patients in mind, we have continued to monitor the rapidly changing information surrounding the Coronavirus (COVID-19) outbreak; including guidelines from federal, state, and local authorities.

We have decided to postpone or cancel all upcoming events in March and April.

March 21- Education Day is Postponed to August 29th

March 21- New Parent Network is Postponed

March 24- Harrisburg Day is Cancelled

March 25- Dinner Program (Amish Only) is Postponed

April 4- Cornhole Tournament is Cancelled

April 16- Healthy Joints – World Hemophilia Day Event is Cancelled

April 18- Men's Group event is Postponed

Our primary concern is, and has always been, the health and wellness of the people and community we serve.

We appreciate your understanding during a very dynamic situation. We will continue to follow guidance from the CDC and public health officials. We will provide updates on when we can reschedule these events or any future rescheduling or cancellation of additional planned events. Please follow us on social media and check our website (wpcnhf.org) for live updates. As always, should you have questions, please contact us directly at: 724-741-6160 or info@wpcnhf.org.

Visit wpcnhf.org for more information on our upcoming events.

Thank you to our supporters:

Aline Briz in honor of Sebastian Pace	Jamie Rosborough	Mary Boyle	Sara Mahoney in honor of Elizabeth Glance	The Robert F. and Joan Marie Klein Fund of the Pittsburgh Foundation
Ashley Thompson	John and Brenda Raphael	Michael Clancey	Sharon Boone	Tracy Sethman
Cathy Aniszewski	Joseph and Yvonne Silipo	Raymond L. DeFazio	Susan Eyrolles	UPMC
Dani's Hair Loft	Karen Cook-Vujevich	Robert Boyle	The Endowment for Butler County of the Pittsburgh Foundation	
Dawn Rotellini	Kim Zoella	Robert Walsh		
Dominique Murray	Laura Zinski in honor of Elizabeth Glance	Ron Weisser		
Emily Erimias	Mary and John Long	Sam's Cleaners		

Ask us about sponsorship opportunities and how you can help!

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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 Executive Director

Dear Chapter Members and Friends,

I know things may seem a bit uncertain and scary right now. Please know our primary concern is the health and wellness of the individuals, families and communities we serve. We encourage everyone to take this public health emergency seriously and continue following the guidelines of both the CDC and local public health officials. It is important that we all follow the guidance of medical experts — by washing our hands, avoiding contact with those who may be feeling sick, practicing social distancing by avoiding large crowds, and contacting medical professionals if you have signs of the coronavirus.

Being connected with each other is more important than ever. While we

may be practicing social distancing, staying healthy means not falling into an unhealthy pattern of social isolation. Taking care of our emotional well-being, prioritizing self-care and staying engaged with the important people in your life are among the most critical things we can do during this time.

While many Chapter events have been postponed or cancelled, there are still ways to be involved. Check out our advocacy update in this newsletter and visit the advocacy section of our website (wpcnhf.org) to see how you can create an impact by writing letters and making phone calls to legislators. We will keep you updated through our social media pages on free webinars you can participate in. We will continue to monitor guidelines set by local

public health officials and the CDC and will reschedule postponed events as soon as it is safe to do so. In the meantime, don't hesitate to contact us with any questions or concerns. While the chapter office is closed to the public at this time, all staff is available by phone or email and we love hearing from you.

Thank you for all that you do on behalf of the bleeding disorders community.

Sincerely,


Kara Dornish
Executive Director

Letter from the President

As we get ready for the Spring and Summer season, I am reminded of the extraordinary people I get to meet through our work with the WPCNHF. This offers me an opportunity to remind myself what I am thankful for; my family, faith and our community.

I am honored to serve and feel sincere gratitude for the teams and volunteers that make it all possible. I am thankful for all the wonderful resources brought to our community by the hard-working chapter staff. Kara Dornish, Janet Barone and Jessica Lee ensure the success of all events and programs.

I am going to be chairing a new committee for the senior members of our Chapter, this focus group will have get togethers just like all of the other focus groups, however we will focus on the needs of our senior members. We will be emailing everyone within this age group for their input and suggestions for future talks and locations of those talks.

As we look forward to 2020, we prepare for many changes in the industry. It is critical that we focus our efforts from a Board standpoint towards a common goal, 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, Melinda Perry-Stern, 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 as our top priority.

Kind Regards,

Michael Covert
WPCNHF Board President

WPCNHF Emergency Assistance Fund

The WPCNHF Emergency Assistance Fund is available to help families and individuals in the bleeding disorders community in unusual, emergency situations. It is supported by generous contributions from individuals and corporations committed to the bleeding disorders community.

Examples of appropriate grants are for food, utility bills, transportation to

treatment, rent support, medical ID jewelry, medical supplies not covered by insurance, etc.

The WPCNHF Emergency Assistance Fund should be used as a payer of last resort and is not meant to be used to remedy chronic financial problems.

Process:

To assist in the review and validation of applications for aid, we accept requests from the Hemophilia Treatment Center of Western Pennsylvania and its affiliated social workers.

These individuals typically know the candidates, understand their current financial state, and are better suited to determine the severity of the need for emergency funds. They then submit the individual's application for emergency aid supported by proper documentation.

If the person needing assistance is not a patient of the Hemophilia Center of Western Pennsylvania, the Chapter will handle the request directly with the third party or the referring physician's

(Continued on page 7)

GO SEEK. GO EXPLORE.
GO AHEAD.

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Explore more at HEMLIBRAjourney.com



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 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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Genentech
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WPCNHF Emergency Assistance Fund

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office. In this case, the patient must provide proof of medical condition or

recommendation from his/her physician. They must also complete all paperwork to become a member of the Chapter if they have not already done so.

Follow-up calls may be necessary when information is missing or to discuss the

specific case when the need is unclear. Whenever possible, the payment will be made directly to the provider.

HCWP Corner

Kathleen Schnur, LSW

Dear HCWP Patients & Families:

I must say my initial “happy spring” corner shifted drastically in the past week. What a surreal state of the nation and world at this time amidst the COVID-19 pandemic. Our doctors sent out a letter that most of you should have received by now. The Chapter has also included this letter as an insert to the newsletter. The big picture is that things are changing rapidly. Things will be significantly different when this newsletter makes its way into your hands. We are available, we are here, call us.

During these uncertain times, individuals can experience stress and anxiety. There is a significant halt to our usual activities as well as a substantial and perhaps profound impact to many aspects of our lives. Let’s talk about some ways to address these emotions and anxiety. One way is stick to the facts. There is an abundance of information accessible to anyone, but much of it creates a sense of fear because it’s either totally false or in isolation of the bigger picture. Facts can minimize fear. Stick to sites like the World Health Organization (<https://www.who.int/>), the Centers for Disease Control (CDC <https://www.cdc.gov/>), and the PA Dept. of Health (<https://www.health.pa.gov/topics/disease/coronavirus/Pages/Coronavirus.aspx>) that are sharing updates and accurate

information as it is available. You want to stay informed, but avoid excessive exposure to the media coverage.

It can be helpful to develop a new routine. Remember to eat, move, and sleep; take care of yourself. Try to stay connected to those you might need to be social distancing from: call, text, video chat. Remember it is okay to take a break, acknowledge your feelings and emotions, have a moment, and take a breath. I like to categorize things I CAN control vs. the things I CANNOT control, so I can let go of the things that I cannot control (ex. I cannot predict what will happen, I cannot control the amount of toilet paper available at the stores vs. I can turn off the news, I can find fun things to do at home). If you need help, there are a few options for support. Substance Abuse and Mental Health Services Administration’s (SAMHSA’s) Disaster Distress Hotline: 1-800-985-5990 or text TalkWithUs to 66746. People with deafness or hearing loss can use their preferred relay service to call 1-800-985-5990. Additionally, at this point myself and Katherine are still in the office and can be reached at 412-209-7267 or 412-209-7286 respectively.

Some additional resource websites that have updates for resources for individuals, businesses, families, and schools include the Commonwealth of PA website (<https://www.pa.gov/guides/responding-to-covid-19/>) and the PA Association of Community Health Centers (<http://www.pachc.org/Health-Center-Operations/>

COVID-19-Resources). Also check your specific county’s health department website for additional support. If access to the internet is a barrier, please reach out to us (social work) as we are available in the office at this time.

To our families with children, there are plenty of guidelines and suggestions available through the above resources when talking to your kiddos about COVID-19. Some common themes include to not be afraid to discuss the coronavirus. Kiddos are observant and between the visual changes in the community (face masks and gloves), changes in school, social distancing, and even the news, they will already be aware that something is going on. Be developmentally appropriate. Don’t give too much information, be honest, and be comfortable in not having all the answers sometimes. Be aware of your own emotions and anxiety, and wait until you feel a bit calmer before talking with your kiddos. Follow their lead, allow them to ask questions, and ask them how they’re feeling about this. Kiddos need reassurance without false hope as well as some control, maybe discuss how you as a family are trying to keep safe and how you can include the kiddos. Keep the dialogue going and try to keep a routine. Recognize what you CAN control and try to let go of what you CANNOT control.

Stay safe and be well.

Dinner with Vaughn Ripley

On February 11th, we had the pleasure of welcoming Vaughn Ripley to Western PA and hearing his personal story about some of the major challenges he had faced and overcome. Vaughn has hemophilia

and is one of the longest surviving persons with HIV. He’s an author, speaker, fitness trainer, coach, and motivator! We appreciated Vaughn sharing his experiences with us and we left feeling encouraged and inspired.

In 2010, Vaughn published his first book, *Survivor: One Man’s Battle with HIV, Hemophilia, Hepatitis C*. The book,

including a Kindle edition, is available on Amazon. Vaughn enjoys writing and is currently working on a series of fiction novels. More information can be found on his website: vaughnripley.com

We thank Dan Bull, Novo Nordisk and Shelia Biljes, BioMatrix for sponsoring this event.

Statement from Len Valentino on COVID-19

As we continue to monitor the COVID-19 outbreak in the US and around the world, we understand the uncertainty that it may bring to our community. I know that first and foremost on your mind is the health and safety of you, your family, and others around you. In general, people with inherited bleeding disorders are neither immune compromised nor at greater risk for viral infections such as COVID-19. People living with hemophilia and inhibitors have an altered immune system and greater care should be taken to avoid exposures to others who are sick, especially those with fever and/or a cough. Those who take particular drugs (e.g., steroids such as prednisone) that depress the immune system are at heightened risk for infections including viral infections. These individuals should take heightened precautions to keep space between them and others, avoid crowds as much as possible, wash hands frequently – especially after going out and limiting contact with others who are sick to avoid exposure.

As the situation and understanding of COVID-19 is rapidly evolving, we will continue to monitor and reevaluate the appropriateness of the decisions made previously. We encourage you to closely follow the recommendations made by your state and county health departments, along with information from the Centers for Disease Control and Prevention (CDC) and the World Health Organization (WHO).

We know you may have concerns about upcoming spring walks, chapter events, and chapter advocacy days. We have asked our chapters to follow all directives from their local governments and departments of health regarding large gatherings and social distancing. If you have a question or concern about a specific chapter event, please contact your chapter directly.

NHF's annual Bleeding Disorders Conference on August 6th – 8th in Atlanta, GA is still scheduled to take place as planned, however as we continue to monitor the COVID-19 outbreak, this



may change. We will continue to keep you informed of its status.

NHF's NYC staff continues to work remotely until further notice. All NHF employees will be available via cellphone and email to support our community. All NHF staff travel has been suspended until the end of April, but we will be monitoring the situation daily, and this could change. Nonetheless, we will continue to work to serve the bleeding disorders community and our mission during this period.

Additionally, I want you to know that NHF

is here for you. Please feel free to contact us with any questions or concerns you may have regarding the bleeding disorders community and the COVID-19 outbreak by calling our HANDI helpline at 800.424.2634. We will provide the community with information as it becomes available.

Sincerely,

A handwritten signature in black ink.

Leonard A. Valentino, MD
President and CEO
National Hemophilia Foundation

A flyer for a cornhole tournament. The background is a green grass texture. At the top, it says "WPCNHF's 9th Semi-Annual CORNHOLE TOURNAMENT" in large black letters, with "Saturday, September 12, 2020" below it. On the left, it lists the location: "North Park Swimming Pool, S. Ridge Drive, Allison Park, PA 15101". It also lists registration and tournament times: "Registration: 8 am, Tournament: 9 am". Below that, it lists team costs: "Team Cost: (per Team of Two), Early Bird: \$50, Regular: \$60". At the bottom left, it says "Sign Up at give.classy.org/cornhole9". On the right, there is a graphic of a white cornhole board with black bags and a red WPCNHF logo. At the bottom, a white box contains text: "This double-elimination tournament, run by Steel City Cornhole, will be held in conjunction with the Unite for Bleeding Disorders Walk and the Run for Their Lives 5K. Register online or in person the day of the tournament." Below that, it lists prizes: "Prizes: 1st Place - \$500, 2nd Place - \$200, 3rd Place - \$100". At the very bottom, it says "All proceeds stay local to benefit the individuals living with bleeding disorders in Western Pennsylvania."

Teen Retreat

By Makenzie C.

The Teen Group had a great time at the Teen Retreat that was held in January! Held over the weekend of the 10th, the Teen Group attended an abundance of educational and group bonding activities. On Friday night, Teen Group coordinators, Julia S. and Nicolette C., hosted group bonding games.

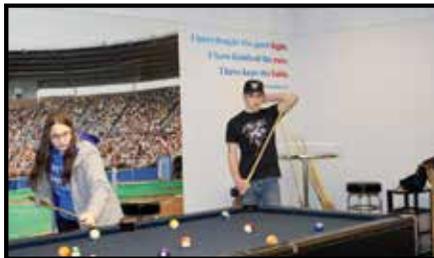
Saturday morning, the Teen Group attended the *Breaking Through! Art Therapy Workshop*, a program that works with Chapters to teach young members of the bleeding disorders community how to use the creative arts as a form of self-expression. During the program,

the Teen Group explored how to harness the arts to express oneself by singing, discussing art, and creating self-portraits.

Saturday afternoon, a CPR certification class was held, where the teens learned how to perform CPR on both children and adults. Then, the Teen Group prepared and cooked their own dinner. To finish up the night, they enjoyed a viewing of “BOMBARDIER BLOOD”, a documentary about Chris Bombardier and his journey on climbing the seven summits as a hemophiliac.

On Sunday, the group enjoyed one last breakfast together, and a short reflective session was conducted to finish up the weekend.

The Teen Group hopes to see you at the next event!



One Lucky Night at Bingo for Bleeding Disorders

On February 6, 2020, Unite for Bleeding Disorders Walk Team, Rolling for Ryker, with support from the Western Pennsylvania Chapter of the National Hemophilia Foundation, hosted a bingo fundraiser at Red Fox Winery in Hickory, PA.

Red Fox Winery ran the bingo games, selling bingo cards for \$2 per card, and generously donated 10% of their wine sales from the night back to the Chapter. There were even more chances to win with a 50/50 raffle and multiple raffle baskets. The basket items included a Rivers Club one-month membership, an Italian Dinner for Two, a beautiful diamond earring set, and a Bath and Body basket. We are thankful for our generous community members and supporters for donating such amazing items for the baskets!



In total, \$1,050 was raised! These funds will support our emergency and medical patient assistance fund, educational programs, and support groups that benefit the bleeding disorders community in Western PA. A huge thank you to Mindy, Steve, Ryker, Michelle, Mike, the whole Rolling for

Ryker Team and everyone who came out to support WPCNHF. We hope to see you at our next bingo night! If you are interested in holding a fundraiser for your Unite for Bleeding Disorders Walk Team and would like support, please reach out to Jessica Lee at jessica@wpcnhf.org or 724-741-6160.



Save the Date

Saturday, November 14, 2020
Gaetano's Banquet Center and Restaurant
1617 Banksville Rd, Pittsburgh, PA 15216

Holiday Tree and Wreath Auction and Wine Tasting Event

Doors Open: 6:30pm

Wine Tasting Tickets: \$25

Non-Tasting (Designated Driver) Tickets: \$10

More information at: WPCNHF.ORG

We Need Your Help

There are many ways to participate in this event and we need your help. We need help acquiring donations, decorating trees and wreaths, and making the onsite event inviting, festive, and fun for all to enjoy.

How can you help?

1.) Volunteer - Volunteers will be needed to help decorate trees and wreaths at the Chapter Office starting on November 1st. We will also need volunteers to help transport auction items from the Chapter Office to Gaetano's and help set up on November 14th.

2.) Donate - Donations of artificial trees and wreaths, holiday decor, gift cards, raffle basket items, and monetary donations are needed.

3.) Attend this Event - Come and enjoy this fun and festive event! We invite you to attend this event and encourage you to invite your friends, family, and co-workers. It's a great way to kick off your holiday season! We will also have all of the auction items available for bid online, so even if you can't attend the event in person, we encourage you to participate in the online auction. The online auction will open on November 9th, one week before the in-person event.

To sign up to volunteer or to coordinate donation drop offs, contact Jessica at jessica@wpcnhf.org

Needs Assessment Results

We've heard you and we are responding! Thank you to those who took the time to complete the Chapter needs assessment and provide us with specific details about your

challenges; the type of programs you desire; what you feel the Chapter is doing well; and ways you think the Chapter could increase support. Your feedback is critical to helping us ensure we are meeting your needs.

While we are working hard to address your needs as quickly as possible, some of the changes and requested programs

will take time to fully implement. Here's a peek at the results for the program topics that were of interest to at least 50% of the people who responded, along with actions we are currently taking. Please note: due to the uncertainty surrounding the coronavirus (COVID-19) outbreak, some of the programs are being rescheduled and others may need to be.

Topic	Percentage of Respondents	Action
New Products & Therapies	68.4%	Three Gene Therapy dinner programs are currently scheduled: June 2020 – Erie July 2020 – Murrysville July 2020 – Robinson Township In addition, the theme of our 2021 Education Weekend will be Emerging Therapies: April 2021 – Seven Springs
Family Camp or Retreat	60.7%	January 2020 – Teen Retreat September 2020 – Young Adult Camp/Retreat April 2021 – Education Weekend (all ages) Other retreat and camp programs are being considered.
Research & Clinical Trials	57.8 %	April 2021 - Education Weekend
Aging and Bleeding Disorders	56.6%	August 29, 2020 - Education Day In addition, we plan to add more programming and social events specifically for our aging members.
Women with Bleeding Disorders	53.3%	We will continue to provide education and support through our Women's Group events, as well as hold other programs and social events that are specifically for women who have a bleeding diagnosis.
Stress Management	50%	Stress management and mental health are the topics for upcoming Men's Group and Women's Group events, which are being rescheduled, due to COVID-19. We will also keep you posted on any upcoming stress and mental health webinars.

Please know that although we have first responded by scheduling programs with topics that will have the greatest impact on meeting the needs of our members, we are looking into all of the requests and comments and will continue to address them.

Another area we want to address immediately is awareness of the

Chapter's Emergency Financial Assistance program. Through the needs assessment results, we've learned that only 50% of the respondents were aware of the Chapter's Emergency Financial Assistance program and just 17.3% of those people knew how to apply for assistance if they would need to do so. Please see the article on page 4 to learn more about this program!

In response to feedback on the number of emails our members receive, we've recently sent out (via email ☺) an interactive form that allows you to select the specific types of email that you would like to receive from the Chapter.

We also greatly appreciated the positive feedback that we received and we will continue to work hard to serve you!



The Hemophilia Center of Western Pennsylvania clotting factor program was established in 2000 as a complement to the Center's other comprehensive care services. The clotting factor program allows the Center the opportunity to offer clotting factor to its patients, thereby supplementing its comprehensive treatment care model and providing the best possible care for its patients.

Please contact the Center at (412) 209-7280 for more information about how this program can benefit you and the entire bleeding disorder community.

The Hemophilia Center of Western Pennsylvania supports patient choice consistent with the Veterans Health Care Act of 1992 and maintains a freedom of choice policy where patients are informed of their choices regarding factor replacement products.

Factor Program Services

- All factor product brands available
- Online factor ordering available
- 24 – 48 hour delivery
- Same day courier service for emergent needs
- On-call services, 24/7
- Home treatment supplies
- Lot tracking for recall notification
- Online home treatment records
- Insurance benefit information assistance

Patient Benefits

- Direct communication and service from the Center's treatment team
- Support of the Center's operations
- Expansion of patient services

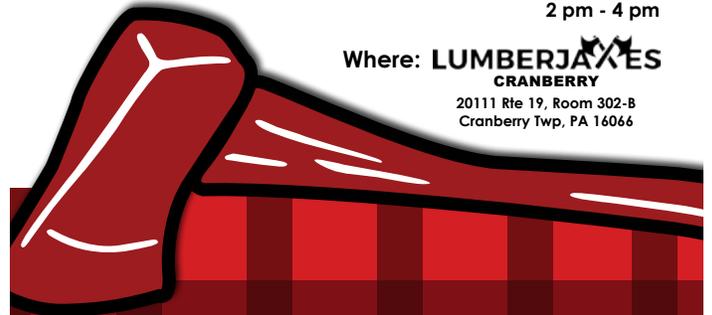


Axe Out Bleeding Disorders

A badaxe tournament to support the Western PA Chapter of the National Hemophilia Foundation

When: Sunday, June 7, 2020
2 pm - 4 pm

Where: LUMBERJAXES
CRANBERRY
20111 Rte 19, Room 302-B
Cranberry Twp, PA 16066



Registration starts at 1:30 pm.

Cost is **\$40 per person** and includes entry into tournament (2 hours of axe throwing), pizza, snacks, and raffles. Each lane can hold 12 throwers. Prizes will be given to top throwers, including a trophy for the Grand Champion! This event is BYOB - no hard liquor.

Book Online and click on "Fundraisers" at: bit.ly/axeoutbleedingdisorders
Questions? Contact Jessica at 724-741-6160 or jessica@wphnf.org

To me, it's personal.

As a Community Relations and Education Manager for Sanofi Genzyme, I'm here to help provide support and resources for you and the Western Pennsylvania community.

Jacose Bell
CoRe Manager for Pennsylvania

Let's connect.

Call, text, video chat: 857-529-4994
Email: jacose.bell@sanofi.com
Facebook: @HemophiliaCoRes



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HEM-US-7108 3/20



Washington Days

Matthew Hiller

Prior to Washington Days, I wasn't typically involved in the Bleeding Disorder Community and felt as though I ought to contribute to the movement. My high school required service hours for graduation, and I saw this event as a unique opportunity toward advancing advocacy on behalf of all members of the Bleeding Disorder Community. As a result, I became more grateful to have been selected to represent Western Pennsylvania.

I have not attended any advocacy programs before, nor did I believe it was possible to attend. It was an invigorating experience yet intimidating upon entering the offices of the representatives. The first meeting with representative Mike Doyle went quite well, though it was an overall example of how to structure the presentation of my story in the following meetings. I was nervous throughout my first



meeting as I thought I had inadequately communicated my account with hemophilia. However, upon completing the session, I began to gain confidence in expressing my story and experiences.

The best part of the day was meeting with representative Mike Kelly. He was personal and seemed genuinely interested to learn more about the everyday life of a hemophiliac. It was perhaps one of the most touching engagements of the day as Mr. Kelly immediately inquired about what occurs in a hemophiliac's life and the process of receiving an infusion. He related the process to the similar manner in which diabetics treat insulin through a subcutaneous needle. This relation made an impact on his perspective of the struggles associated with having a bleeding disorder. This was my first-time attending Washington Days, and I hope to attend next year.



During Washington Days, we asked our legislators to co-sponsor the Hemophilia SNF Access Act (Senate: S. 3233, House: HR 5952) to improve access to skilled nursing facility care for Medicare beneficiaries with bleeding disorders. We also asked our legislators to support federal hemophilia programs at CDC, HRSA and NIH that provide funding for comprehensive care, research, surveillance, and prevention activities that benefit the bleeding disorders community. Over 450 individuals from around the country participated in NHF's Washington Days!

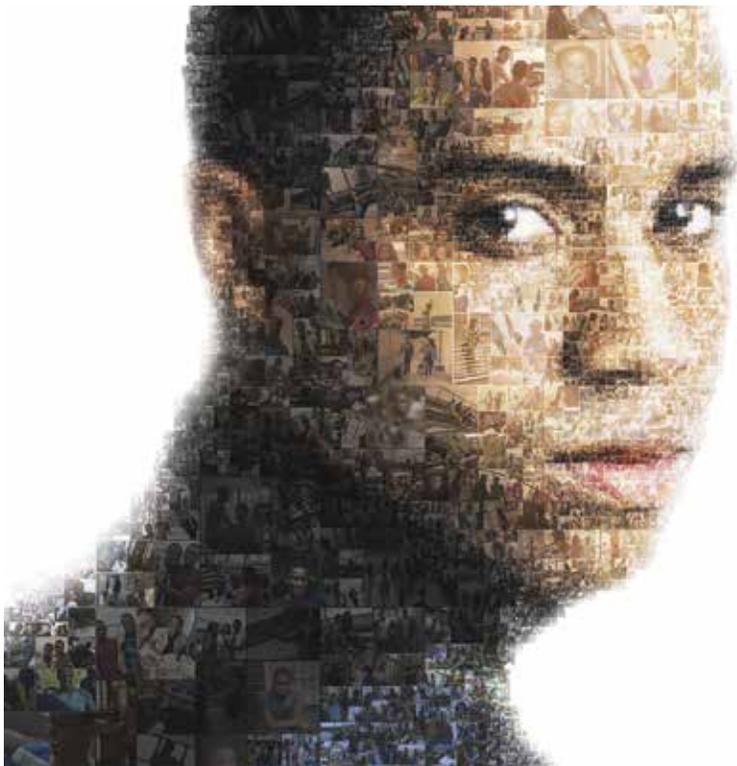
NACCHO

By John Yunghans

I am so thankful I was able to attend the North American Camping Conference for Hemophilia Organizations (NACCHO) this year. It was my first time at NACCHO, and I wasn't sure what to expect. What I found was incredible people from all over the world dedicated to making hemophilia camp the most transformational and informational experience it can be for our community. We kicked off with a session on Fred Rogers' approach to child development and how we can enhance the sense of belonging for campers. There was an amazing sense of camaraderie that propelled collaboration and networking

between us. I felt every day was filled with new ideas and lessons to write down as fast as I could in my notebook! These learning moments happened in sessions, at the lunch table, and, yes, even on the dance floor. When the last day of NACCHO came, it felt like I was leaving my last day of camp. I cannot wait to return next year and share how we have integrated and iterated what we learned this year!






ADYNOVATE
[Antihemophilic Factor
(Recombinant), PEGylated]

REAL LIFE. REAL BLEED PROTECTION.*
AdynovateRealLife.com

HEMOPHILIA A IS A PIECE OF YOU. NOT ALL OF YOU.

ADYNOVATE® is a treatment that can be personalized to fit your lifestyle so you have more time to spend doing the other things that also make you, you. It has a simple, twice-weekly dosing schedule on the same 2 days every week.^{1,2}

*In clinical trials, ADYNOVATE demonstrated the ability to help prevent bleeding episodes using a prophylaxis regimen.

No actual patients depicted.

ADYNOVATE twice-weekly prophylaxis prevented or reduced the number of bleeds²

ADYNOVATE was proven in 2 pivotal clinical trials to prevent or reduce the number of bleeding episodes in children and adults when used regularly (prophylaxis)²

- **Children Under 12 Years:** This study evaluated the efficacy of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months in 66 children under 12 years old who received 40–60 IU/kg of ADYNOVATE prophylaxis treatment²
 - During the 6-month study in children under 12, those receiving twice-weekly prophylaxis treatment experienced a median¹ overall ABR¹ of 2.0
 - 0 bleeds in 38% (25 out of 66 patients) during 6 months on twice-weekly prophylaxis

¹Median is defined as the middle number in a list of numbers arranged in numerical order.

²ABR=annualized bleed rate, the number of bleeds that occur over a year.

³Per-protocol patients were assigned to the prophylactic group and treated with their originally assigned dose for the entire duration of the study.

ADYNOVATE Important Information

What is ADYNOVATE?

- ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital factor VIII deficiency).
- Your healthcare provider (HCP) may give you ADYNOVATE when you have surgery.
- ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADYNOVATE?

Do not use ADYNOVATE if you:

- Are allergic to mouse or hamster protein.
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)].

Tell your HCP if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

What should I tell my HCP before using ADYNOVATE?

Tell your HCP 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 ADYNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

- **Adolescents and Adults 12 Years and Older:** This study evaluated the efficacy of ADYNOVATE in a 6-month study that compared the efficacy of a twice-weekly prophylactic regimen with on-demand treatment and determined hemostatic efficacy in the treatment of bleeding episodes in 137 patients. These adolescents and adults were given either ADYNOVATE prophylaxis twice-weekly at a dose of 40–50 IU/kg (120 patients) or on-demand treatment with ADYNOVATE at a dose of 10–60 IU/kg (17 patients). The primary study goal was to compare ABR between the prophylaxis and on-demand treatment groups²
 - 95% reduction in median overall ABR (41.5 median ABR with on-demand [17 patients] vs 1.9 median ABR with prophylaxis [120 patients])
 - 0 bleeds in 40% (40 out of 101 per-protocol³ patients) during 6 months on twice-weekly prophylaxis

What important information do I need to know about ADYNOVATE?

- You can have an allergic reaction to ADYNOVATE. 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.
- Do not attempt to infuse yourself with ADYNOVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADYNOVATE 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 ADYNOVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

What are possible side effects of ADYNOVATE?

- The common side effects of ADYNOVATE are headache and nausea. These are not all the possible side effects with ADYNOVATE. Tell your HCP about any side effects that bother you or do not go away.

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 Important Facts about ADYNOVATE on the following page and discuss with your HCP.

For Full Prescribing Information, visit www.adynovate.com.

References: 1. Valentino LA. Considerations in individualizing prophylaxis in patients with haemophilia A. *Haemophilia*. 2014;20(5):607-615. 2. ADYNOVATE Prescribing Information.

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ADYNOVATE

[Antihemophilic Factor
(Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

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

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

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 ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

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

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE 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 ADYNOVATE by themselves or with the help of a family member.

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

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

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

How should I use ADYNOVATE? (cont'd)

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

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

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 ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

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The common side effects of ADYNOVATE are headache and nausea. 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 ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE 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 ADYNOVATE 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 ADYNOVATE for a condition for which it is not prescribed. Do not share ADYNOVATE 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 ADYNOVATE. The FDA-approved product labeling can be found at www.ADYNOVATE.com or 1-877-825-3327.

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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Issued 05/2018

Advocacy Update

Advocacy Ambassadors

We are pleased to announce that 16 Chapter members are now official Advocacy Ambassadors! Our first group of ambassadors attended the advocacy retreat that was held on February 22nd and received their certificate of completion for the Advocacy Ambassador training program. Miriam Goldstein, JD, Director of Policy, Hemophilia Federation of America and Nathan Schaefer, MSW, Vice President of Public Policy, National Hemophilia Foundation were our guest speakers. Topics included national and local issues, advocacy ambassadors, speaking with your legislator, and telling your story.



Days later, several of the Advocacy Ambassadors joined us on Capitol Hill, in Washington D.C., for NHF's Washington Days. (See the NHF Washington Days article, on page 13, written by one of our new Advocacy Ambassadors, Matthew Hiller.)

We are excited to have a dedicated group of individuals who are willing to volunteer their time to speak with and write their legislators about issues that impact the bleeding disorders community. In addition to meeting with their own legislators, many of the ambassadors are willing to join you on visits to your local legislative offices. When you see someone at a Chapter event wearing their red Advocacy Ambassador t-shirt, please be



sure to ask them about their involvement in the program!

National Issues

On February 27th over 450 advocates from all across the United States went to Washington DC to meet with legislators and staff to discuss federal funding for bleeding disorder programs and access to Skilled Nursing Facilities (SNFs). Twelve (12) advocates from Pennsylvania attended nine (9) meetings with legislators and/or their staff. Our advocates from Pennsylvania included: Janet Barone, Kara Dornish, Lindsay Frei, Matthew Hiller, Lenore Hiller, Heather Kosto, Christopher Templin, Curt Krouse, Scott Miller, Jessica Lee, Marty Tully, and Joe Pugliese.



We asked our legislators to co-sponsor the Hemophilia SNF Access Act. People with bleeding disorders may need access to skilled nursing facilities after a hospitalization related to surgery for joint disease or a co-morbidity like HIV or hepatitis, when their doctor thinks it is the best setting for them to access nursing care to help them recover more quickly.

SNFs typically won't accept Medicare beneficiaries with bleeding disorders because the daily payment isn't high enough to cover treatment costs. Treatment costs could be as high as \$10,000 per day right after surgery. There are about 1,000 people with bleeding disorders on Medicare and a much smaller number need access to SNF care each year. People who can't access SNFs often stay in the hospital longer - costing Medicare and taxpayers more money - or may go home where their families are unable to properly care for them and then often return to the hospital.

The Hemophilia SNF Access Act adds bleeding disorders treatments to the list of high cost, uncommon services that SNFs may separately bill for under Medicare Part B. This change to the Medicare law will allow people with bleeding disorders to receive care in SNFs, often the most medically-appropriate rehabilitative setting. This bill will not increase Medicare costs as the policy is budget neutral.

We also asked Congress to continue to support the following Federal Bleeding Disorders Programs:

- National Institutes of Health (NIH): Fund biomedical research on bleeding disorders. NIH is working to implement a national blueprint for research on inhibitor prevention and eradication.
- Centers for Disease Control and Prevention (CDC): Funds HTC surveillance and prevention activities, and supports outreach and education programs provided by national bleeding disorders patient organizations.
- Health Resources and Services Administration (HRSA): Provides funding for HTCs to provide multi-disciplinary services not typically covered by insurance, such as physical therapy and social work services. Also, as HRSA grantees, most HTCs participate in the 340B Drug Discount Program, which supports comprehensive care offered to all of their patients.

Local Issues

On January 16th and 17th, staff from WPCNHF, Eastern PA Hemophilia Foundation, and Dr. Elaine Eyster from Penn State Hershey Hemophilia Treatment Center met with the

Department of Health and members of the House and Senate Appropriations Committees, in Harrisburg, to address concerns regarding state funding to the 7 comprehensive hemophilia treatment centers (HTCs) in Pennsylvania. Previously, the Specialty Care Programs



funds have been distributed to the hemophilia treatment centers through a state procurement process known as a Sole Source request. This ensured that if the hemophilia line item was in the state budget, all 7 hemophilia treatment centers in Pennsylvania received state funding. This will end on June 30, 2020. In its place is a new grant process called Request for Applications (RFAs). The RFAs will use a regional approach, based on the Pennsylvania HealthChoices five regions.



Problems with this model:

- There are 7 federally supported hemophilia treatment centers (HTCs) but only 5 HealthyChoices regions, with 4 HTCs located in Philadelphia.
- While applicants may apply for multiple regions, having only one grant awarded per region is problematic when four world class HTCs are in one region (Philadelphia). As proposed, the four HTCs in Philadelphia will be pitted against each other competing for funding.
- When we voiced this concern in the meeting with the Department of Health they told us they expect the Treatment Centers to team up to apply for funding. But this only creates more problems as who will

be responsible for the administrative burden and how will the funding be divided between them?

This one-size fits all approach that the Department of Health is requiring for all specialty care programs clearly doesn't work for hemophilia and will only jeopardize our HTCs funding. Lost funding can result in staff positions being eliminated, which can result in loss of comprehensive care.

We are asking the General Assembly to keep the Hemophilia Program as a separate line item at the current fiscal year amount of \$959,000. In addition, we request that the funding continue to be distributed, as in previous years, to all seven hemophilia treatment centers in Pennsylvania.

In addition, the Chapter continues to monitor activity on the bills that were introduced in 2019 to preserve patient protections, should the court case from Texas rule the Affordable Care Act unconstitutional.

How You Can Help

While Harrisburg Day has been cancelled due to Coronavirus (COVID-19), there are still ways you can make an impact. Visit wpcnhf.org/get-involved/advocacy/ for sample letters, phone call scripts, and resources to download.

- Write Letters to your Legislators - Be sure to customize your letter to include the HTC you are treated at and include personal stories why funding for the Hemophilia Treatment Centers is important to you.
- Make Phone Calls - Don't hesitate to reach out to us



at the Chapter at 724-741-6160 if you would like to practice a call or go over talking points before your call.

Let us know how it went. Be sure to let us know the results of your call and if you sent a letter. The more details you can provide us with the better. Please email info@wpcnhf.org or call us at 724-741-6160 and let us know.



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► **Pharmacokinetics** is the study of the activity of drugs in the body over a period of time.

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LET'S GO

Getting to Know HCWP Staff



Kari Stepanik, Nurse

Birthplace: Pittsburgh, PA

First job: Dairy Queen

Accomplishment you're proudest of:
My 2 beautiful children, Mason and Ellie

What three words describe you best?
Loyal, Entertaining, Compassionate

Dream vacation: Tour of Europe

Things you can do without:
Traffic, alarm clocks, and smelly seafood

Person you'd most like to have dinner with: Melissa McCarthy

Movie you could see anytime:
The Lion King

TV show you try not to miss: Law and Order: SVU

Three things that can always be found in your refrigerator: Diet Mountain Dew, at least 3 different types of cheese, and leftovers

Secret vice: Nancy B's Cookies and Cheap Wine

Who would play you in the movies?
Probably the sidekick of the hero that needs a babysitter

Your pet peeve about Pittsburgh: The way people drive on the parkway

People may be surprised to know that:
I have never shopped at Aldi's, although I should start.

Dear Hemophilia: Finding Hope Through Chronic Illness

Cazandra Campos-MacDonald

Our stories are powerful. Our experiences are unique. And sharing our lives can transform the world. Cazandra Campos-MacDonald's new book, *Dear Hemophilia: Finding Hope Through Chronic Illness*, is her story of raising two sons with Severe hemophilia A with inhibitors. Her journey is filled with despair and heartache, yet hope is always the center of her world. Cazandra invites the reader into her life as she raises her sons and uncovers the truth about her older brother's untimely death. With raw, even painful honesty, she shows us that even those with the strongest faith can lose sight of what is



important. For more information and to follow Cazandra's journey, visit www.cazandracmacdonald.com. Her book is now available at Amazon.

"Travel with Cazandra and share her love, even anger, and above all commitment to God as she boldly confronts a rare bleeding disorder, and eventually finds peace with it in the end." –Laureen A. Kelley, author, *Raising a Child with Hemophilia*

"The two most powerful warriors are patience and time" said Leon Tolstoy. He must have never met the mother of a child with a chronic health condition and certainly not Cazandra Campos MacDonald. Behold the warrior! If we could all be as brave, as determined and as undaunted as Cazandra this world would be a significantly better place. Cazandra bares her soul and her plight for herself and for her children in this superbly written account of her story. –Jorge de la Riva, Former Chairman of the Board, National Hemophilia Foundation

KT Taping with Mike Zolotnitsky

We had a full house at the March 7th KT Taping Program with Mike Zolotnitsky, PT, DPT! Dr. Mike began with a discussion on the benefits of Kinesiology Tape (KT Tape), an elastic athletic tape that is applied to help reduce pressure and pain. The event was held at Clearfield Bowling Lanes, in Clearfield, PA and because most of the program attendees would be bowling that day, Dr. Mike guided everyone through a taping technique to help protect their wrist and thumb. Dr. Mike also demonstrated taping techniques to relieve swelling and pain for shoulders, elbows, knees, and ankles.

When applied correctly, it is believed that KT tape can help reduce swelling by lifting the skin and allowing fluid to move away from the injured area. KT tape can also be used to support muscles. It's important to note that while one might benefit from using KT tape, Dr. Mike cautioned that improper taping techniques can have an adverse effect. Therefore, it's best to check

with your Hemophilia Treatment Center or other specialist before using KT tape.

Following the program, participants enjoyed bowling, pizza, wings, and sub sandwiches! We thank Melissa Kendrick and Cottrill's Pharmacy for sponsoring this event.



Unite

for Bleeding Disorders



The Western Pennsylvania Chapter of the National Hemophilia Foundation UNITE for Bleeding Disorders Walk

Saturday, September 12, 2020 | Registration at 9 a.m. | Walk Starts at 10 a.m.

North Park Swimming Pool Loop
S. Ridge Drive
Allison Park, PA 15101

For more details, contact Jessica Lee at jessica@wpcnhf.org | 724-741-6160

www.uniteforbleedingdisorders.org/event/wpa

Western Pennsylvania Chapter of the National Hemophilia Foundation

20411 Route 19, Unit 14

Cranberry Township, PA 16066

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

info@wpcnhf.org

