# Hemogram

Western Pennsylvania Chapter of the National Hemophilia Foundation

Summer 2019

Inside this issue



## 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**

## Washington Days

Hi, my name is Cassandra Miller and I was lucky enough to be chosen to go to this year's Washington Days. In the past I have done other advocacy events, but this one took the cake. It was such a different experience to be able to go around the Capital to talk to our different legislators about my story and to teach them about bleeding disorders. It was amazing to see how many people, around 400, gathered together to accomplish such a big goal.

Overall I think the legislators that we met with were very supportive of the bleeding disorder community and were very receptive to the two main asks that we presented to them. We asked our legislators to oppose short-term insurance plans and support people with pre-existing conditions by co-sponsoring HR 1010 or introducing companion legislation to rescind the 2018 regulation that expanded short-term plans. We also asked for continued support for federal hemophilia programs at CDC, HRSA, and NIH that support bleeding disorder communities. I am so thankful for the opportunity that I was given to continue to advocate for our community in Washington.

## Hemophilia Carriers

**By, Craig Seaman, MD**

Over the past several years, the hemophilia community has become increasingly aware of the needs of hemophilia carriers. We know that carriers experience bleeding related symptoms, too. Symptoms mainly include easy bruising, prolonged bleeding with minor wounds, heavy menstrual periods, abnormal bleeding with childbirth, and prolonged bleeding following invasive procedures, such as dental extractions and surgery. Unlike hemophiliacs, joint and muscle bleeds are uncommon. Not all carriers experience bleeding symptoms, which is largely dependent on factor levels, which can vary from normal to low. Symptomatic hemophilia carriers should receive clotting factor concentrates, similar to hemophiliacs, to treat and prevent bleeding.

At HCWP, we are aware of the above issues, and recommend any hemophilia carrier with bleeding symptoms call to schedule an appointment. A physician will perform a detailed bleeding history and physical examination then obtain necessary blood tests to determine factor levels. Sometimes, if carrier status is unknown, genetic testing may be needed. Based on these results, the physician will determine the best treatment plan moving forward.

# Unite for Bleeding Disorders

WPCNHF

## UNITE FOR HOPE.
## UNITE FOR COMMUNITY.
## UNITE TO MAKE A DIFFERENCE.

### WHEN

Saturday, September 7, 2019
Registration: 9am - Walk Start: 10am

### WHERE

North Park, Harmar Pavilion
S Ridge Drive
Allison Park, PA 15101

### HOW

www.uniteforbleedingdisorders.org/event/wpa

### CONTACT

**Kara Dornish at**
**kara@wpcnhf.org**
**(724) 741-6160**


Takeda is here to support you throughout your journey and help you embrace life's possibilities. Our focus on factor treatments and educational programs, and our dedication to the bleeding disorders community, remain unchanged. And our commitment to patients, inspired by our vision for a bleed-free world, is stronger than ever. **Let's make today brilliant.**

bleedingdisorders.com

Takeda

BAXALTA AND SHIRE ARE NOW PART OF TAKEDA

# Letter from the Executive Director

Dear Chapter Members and Friends,

I hope everyone is having a wonderful summer. I am officially back from maternity leave and am so excited to be leading the Chapter forward! The Chapter hosted many great educational programs, support groups, and fundraisers over the past few months. We made several advocacy trips and will continue to keep you up to date on policies and legislation that can impact you and your family.

The Cornhole Tournament Fundraiser was so much fun and a great success! It was one of our biggest attended tournaments yet and raised over $8,000 for the bleeding disorders community. I loved seeing all the photos of everyone who participated in the Red Tie Campaign. We surpassed our fundraising goal, raising $2,025 all of which went to our Emergency and Medical Patient Assistance Program. Thank you to everyone who participated!

The Unite for Bleeding Disorders Walk is coming up on Saturday, September 7th and I encourage all of you to attend! The Unite Walk is a celebration and time for all of us to Unite for one common purpose; to make the world a better place for those with bleeding disorders. I hope to see you all there!

As always, please contact the office with any questions or concerns. It is truly an honor to be leading this organization. I look forward to seeing all of you at future Chapter events.

Sincerely,

Kara Dornish

Kara Dornish
Executive Director

# Letter from the President

Hello Chapter Members:

I am pleased to announce that Kara Dornish has accepted the full-time Executive Director Position for the Western Pennsylvania Chapter of the National Hemophilia Foundation. Kara has been with the Chapter for nearly 6 years. She was the Marketing and Events Manager and was most recently the Interim Executive Director. She has a master's degree in Public Relations from Montana State University-Billings and is very passionate about the bleeding disorders community.

I am also pleased to announce that Janet Barone has been promoted to the Program Manager on a full-time basis. Many of you know Janet well. Janet has been with the Chapter for over 10 years and brings a lot of knowledge in bleeding disorders programming, services, and advocacy.

I am also pleased to announce that Jessica Lee has been promoted to the Fundraising and Events Manager position on a full-time basis. Jessica has been with the Chapter for the past 7 months as the Marketing and Events Intern. She is a 2019 graduate of LaRoche College with a bachelor's degree in Writing with a minor in Marketing.

I look forward to working with this great team and all the excitement they bring to the Chapter.

The Western Pennsylvania Chapter of the National Hemophilia Foundation has recently added some new Board Members. Please welcome them and feel free to ask them any question you may have about the Board and the Chapter.

The new Board Members include Brittani Spencer, Mindy Perry-Stern, John Yunghans, and R. Scott Domowicz.

Kind Regards,

Michael Covert
Board President

**Inserted in this edition of the Hemogram is a copy of the article, Solving the Puzzle of Mental Health. This article, written by Rita Colortio and illustrated by Ulla Puggaard, was originally featured in the National Hemophilia Foundation's Bleeding Disorders Magazine, Hemaware. If you are struggling with mental wellness, please know you're not alone. We hope that you take the time to read this article and pass it on to your friends and family members.**

# Calendar of Upcoming Events

**July 13, 2019**
**New Parent Network**
**Pittsburgh, PA**

**July 25, 2019**
**Annual Meeting & Walk Kickoff**
**Homestead, PA**

**August 4-10, 2019**
**Camp Hot-to-Clot**
**Fombell, PA**

**August 24, 2019**
**Summer Program**
**Erie, PA**

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

**September 21, 2019**
**Infusion Day (Amish Only)**
**Punxsutawney, PA**

**October 19, 2019**
**Oktoberfest**
**Wexford, PA**

**October 24, 2019**
**Women's Group**
**Pittsburgh, PA**

**November 2, 2019**
**New Parent Network**
**Pittsburgh, PA**

**November 16, 2019**
**Take A Bough**
**Oakdale, PA**

**December 8, 2019**
**Winterfest**
**Oakland, PA**

**January 10-12, 2020**
**Teen Retreat**
**Clinton, PA**

**February 9, 2020**
**Bowling for Bleeding Disorders**
**Pittsburgh, PA**


Ask us about sponsorship opportunities and how you can help!

## Board of Directors

***President***
Mike Covert

***Board Members***
Brittani Spencer
John Yunghans
Melinda Perry
R. Scott Domowicz

***Emeritus Trustee***
Scott Miller, CPA, Esq., DBA

## Staff

***Executive Director***
Kara Dornish

***Program Manager***
Janet Barone

***Fundraising and Events Manager***
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.

## WPCNHF Wish List

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

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

## Mission Statement:

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

# HCWP Corner

**By Kathaleen Schnur, LSW**

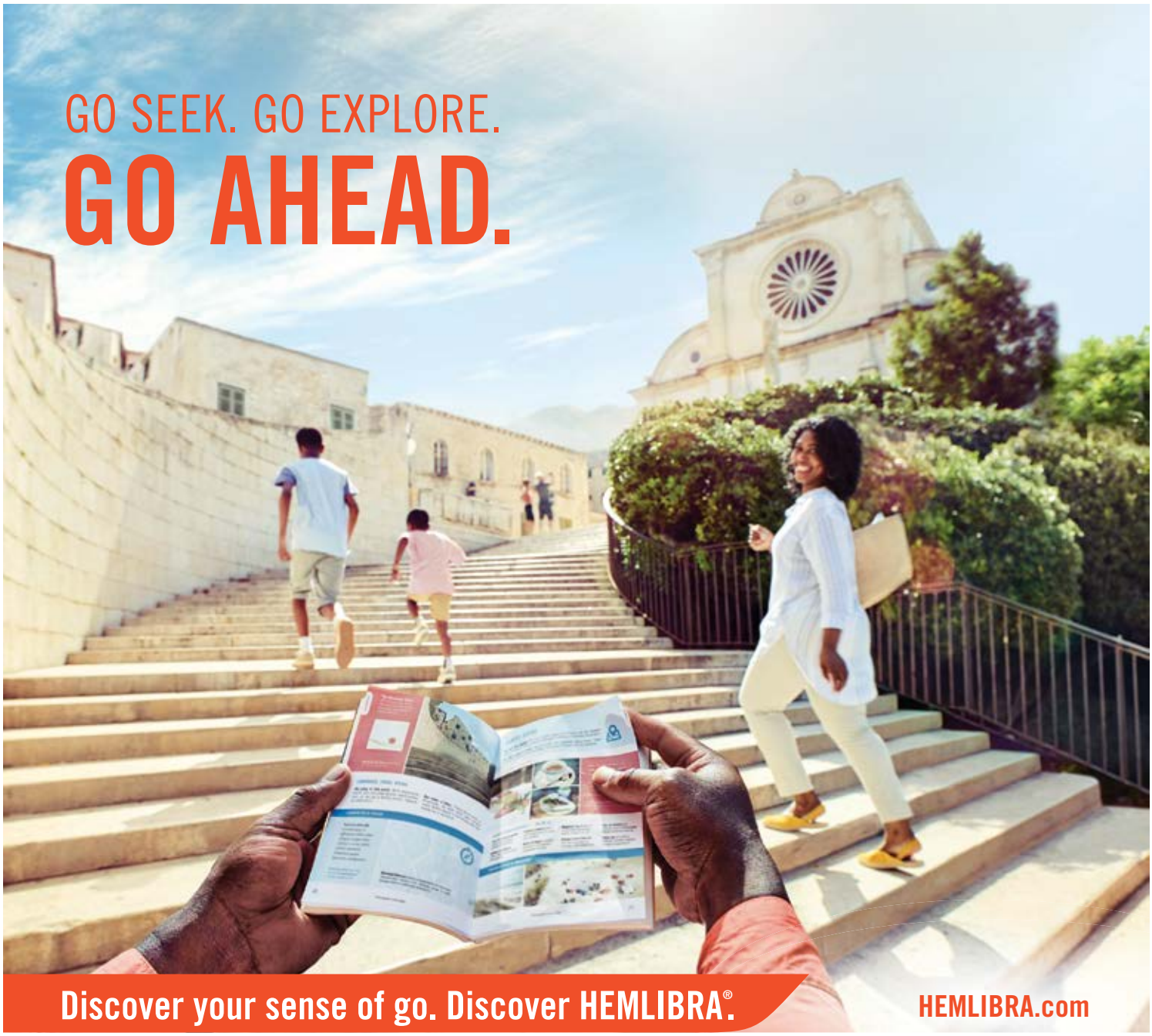
Salutations to our patients and their families:

Suddenly, summer has arrived. The kiddos are done with school, families and individuals are planning summer vacations, picnics, and outings, physical activities tend to increase (outdoor adventures, yard work, more opportunities to be outside), and new routines are surfacing. Protect your skin from the sun, your body from the bug bites, drink plenty of water, be active, and rest. As activities increase, listen to your body.

Check your go-bag, do you have an updated travel letter? This travel letter is not just for airports, it's a layer of support from your MD that states your diagnosis and treatment in an emergency situation if you need to go to an unfamiliar emergency department (or even your local department). Speaking of emergency situations, one of our families attended a conference and shared a resource called http://dannysdose.com/. We make efforts to educate our newer families with younger kiddos to connect with their local EMS to make them aware that a child with a bleeding diagnosis lives in the area. Some families create a plan, some families just want it noted through dispatch (someone at the address has a bleeding diagnosis), etc. Please know that the EMS will transport the child/person to the hospital with the medication, but cannot administer the medication, unless a critical care paramedic. EMS works under state protocols and have an approved drug list. The above link offers ideas for when contacting your local EMS. Remember relationship building is important, so regardless of age of patient, it's not a bad idea to connect with your local EMS provider. We are always appreciative when our families share their experiences!

We at the Center are busy as usual; we just finished our Amish Outreaches and are in full swing of preparing for camp. We continue to collaborate with the Chapter for programming and look forward to seeing all of you at the upcoming events. Additionally at the Center, we welcomed a new nurse, Kari Stepanik. She worked as an apheresis nurse and also in an emergency department. Kari discovered her passion for nursing early on as she watched and supported her grandmother through her grandmother's fight with ALS. She is a proud Momma of two little ones. Kari is excited to be part of the HCWP team.

Kari Stepanik




### What is HEMLIBRA?

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

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

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

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

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

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

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

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

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

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

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

See "**What are the possible side effects of HEMLIBRA?**" for more information about side effects.

## What is HEMLIBRA?

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

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

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

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

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

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

## How should I use HEMLIBRA?

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

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

## What are the possible side effects of HEMLIBRA?

- See "**What is the most important information I should know about HEMLIBRA?**"

**The most common side effects of HEMLIBRA include:**

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

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

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

## How should I store HEMLIBRA?

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

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

## General information about the safe and effective use of HEMLIBRA.

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

## What are the ingredients in HEMLIBRA?

**Active ingredient:** emicizumab-kxwh

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

Manufactured by: Genentech, Inc., A Member of the Roche Group,
1 DNA Way, South San Francisco, CA 94080-4990
U.S. License No. 1048

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

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



Genentech
*A Member of the Roche Group*

# WPCNHF's 6th Semi-Annual Cornhole Tournament

WPCNHF's Sixth Semi-Annual Cornhole Tournament was held on April 6, 2019 at The Cornerstone at Tonidale. This double elimination tournament was managed by Steel City Cornhole. Warm up and registration started at 1:00pm and the tournament began at 2:00pm. Each participant received an event t-shirt and each participant over 21 years received a drink ticket.

It was a full house as nine Competitive Teams and 23 Social Teams competed for the first place prize in their division. A Chinese Auction was held and we raffled off some great items including an overnight stay at the Mountaineer Grande Hotel, a private escape room for eight people, a variety of amusement center and park tickets, and tickets to the Washington Wild Things and the Altoona Curve.

WPCNHF would like to thank everyone who participated in the event, sponsored the event, donated items, and volunteered their time to help make the event a success! Special thanks to Joe Castellano of Steel City Cornhole for doing an amazing job running the tournament, Lindsay McNany for literally recruiting a bus full of participants, Michael Perry for running our 50/50 raffle, Matt Zandier for donating his winnings from the 50/50 back to the chapter, Michelle from The Cornerstone at Tonidale, and our amazing volunteers Holly, Ryan, and Allie!

Thank you to our sponsors: Corn in the Hole Sponsor: The Hemophilia Center of Western Pennsylvania, Corn on the Cob Sponsors: CSL Behring, Novo Nordisk, and Takeda, Woody Boarder Sponsor: Bayer. We are excited to report that over $8,000 was raised! 100% of this money will stay local to support the members of the Western PA Chapter of the National Hemophilia Foundation. Please be sure to save the date for WPCNHF's Seventh Semi-Annual Cornhole Tournament which will be held on Saturday, September 7, 2019 at the North Park Harmar Pavilion in conjunction with the Unite for Bleeding Disorders Walk and Run for Their Lives 5k. We hope to see you there!


## Congratulations to the winners of the Cornhole Tournament!

***Competitive Division***
First Place -
Trey Burchfield and Brandon Corwin

Second Place
Dennis Cottrill and Seth Cottrill

***Social Division***
First Place –
Holly Corwin and Kylie Corwin

# Advocacy Update

Although legislative advocacy continues year-round at the Chapter, spring is especially a busy time! Within the last couple of months we've participated in the National Hemophilia Foundation's Washington Days, our State Legislative Day in Harrisburg, and the Hemophilia Federation of America's Patient Fly-In.

**Washington Days – March 27-29, 2019**
Over 400 people participated in Washington Days, including eight people from our Chapter.

We asked congress to support the federal programs that support people living with bleeding disorders:

- National Institutes of Health (NIH) funds biomedical research on bleeding disorders and is currently developing a national blueprint for research on inhibitor prevention and eradication.
- Centers for Disease Control and Prevention (CDC) funds Hemophilia Treatment Center 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 to Hemophilia Treatment Centers for multi-disciplinary services not typically covered by insurance.

We also asked congress to ensure access to insurance by opposing the proliferation of short-term plans. We explained how protections put in place by the Affordable Care Act, such as the elimination of lifetime annual caps, the elimination of pre-existing conditions exclusions, creation of essential health benefits, and limits on out-of-pocket expenses are critical to those with bleeding disorders and shared our personal stories on how loss of the protections would impact our families.

**Harrisburg State Advocacy Day – April 9, 2019**
Approximately 30 people from across the state participated in the State Advocacy Day, in Harrisburg, with eight people representing Western PA. The Hemophilia Program line item had be zeroed out in the proposed state budget and had been combined with four other disease states. We asked for the Hemophilia Program line item to be reinstated in the budget as a separate line item that is at least level-funded at $959,000. In late June, we learned that the hemophilia line item was reinstated!

We also asked our legislators to protect patient access to care by supporting three bills that were introduced:

- HB 470 to amend the Insurance Company Law to place the ACA's prohibition on annual and lifetime limits into state law.
- HB471 and SB50 would preserve pre-existing condition protections if the ACA is invalidated by the courts.

We shared personal stories on how our families have benefited from the care received at one of the seven hemophilia treatment centers in the state of Pennsylvania, and why funding is so

important. We also explained how the above bills are critical to people with bleeding disorders.

**HFA Patient Fly-in – June 10, 2019**
Twenty-four community members from 14 states attended HFA's Patient Fly-in and met with members of congress and their staff. In addition, 188 connections were made through calls, tweets, or e-mails for the Virtual Hill Day.

Insurers try to limit costs by adopting formularies and step therapy protocols. Step therapy is not appropriate when it comes to treating people with bleeding disorders, because the consequences of not having access to essential medications can be serious, even life-threatening. We asked for support of legislation that would protect patients' access to their prescribed treatments, by establishing patient protections around the use of step therapy protocols in group health plans.

We also asked our legislators to roll back the 2018 federal rule expanding the availability of short-term plans. Lastly, we asked them to support measures to enhance the affordability of health insurance.


The day ended with a congressional reception that was attended by over 100 people. Representative David Schweikert, Arizona and our own Senator Bob Casey, of Pennsylvania were the recipients of the 2019 Champion Awards, recognizing them for the work they do to support people with chronic conditions.

## Congratulations to Noah Proctor, recipient of the Alec James Schake Memorial Scholarship

I was born April 20, 2001. I had a mobile childhood, moving 5 times before settling down in Butler county around 2011. My main interests growing up were reading and music in addition to art. I played the violin for 6 years from 4th to 9th grade, eventually favoring academics to orchestral performance. Math and history were my favorite subjects; however, I approached them in different ways. History became a hobby and interest, resulting in the genre of book I'd often read or the computer game I would play. Math became the shoes I would walk forward with: a future career. I love learning and mathematics fills that need to understand.

I will go to the California University of Pennsylvania (often referred to as Cal U) and become a Bachelor of Science in Electrical Engineering. I may complete a dual major in Electrical Engineering with either Mechanical or Mechatronics Engineering. Mechatronics is a relatively new field and Cal U is the only college in Pennsylvania to offer such a program. It would complement my primary degree, though I hesitate. Mechanical Engineering could be greatly more valuable and is a longer-standing field. Regardless of those pros and cons, I plan to intern with MSA during my studies and to hopefully work with them in developing safety equipment after completing my degree.

# WPCNHF's Winning Women

**By Maria Steele Voms Stein**

In May, the Winning Women's group of the Chapter sponsored a hands on cooking class at Crate in Greentree, PA. Guided by the instructions of Chef Steve Goda and his kitchen staff, we prepared a menu that included Sauteed Lemon Chicken with Artichokes and Capers, Lemon Parsley Farrow Salad and Chocolate-Balsamic Strawberry Trifles with Mascarpone Whipped Cream.

As a part of the evening, we had the educational opportunity to learn about making healthy eating lifestyle choices from the presentation "Food for Thought: Healthy Choices for Those with a Bleeding Disorder." The program was presented by Jean Marandola, Senior Clinical Specialist, Takeda, Inc.,

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 chapter event soon!

# Getting to Know HCWP Staff

**Margaret Ragni, MD**

**Birthplace:** Columbus, Ohio

**First job:** Camp counselor, teaching kids how to swim

**Accomplishment you're proudest of:** The young people I have trained who have been successful in their careers

**What three words describe you best?** Creative, innovative, persistent

**Dream vacation:** A location combining hiking, nature, art museums and music

**Things you can do without:** Inequality by gender, race, and ethnicity

**Person you'd most like to have dinner with:** The first woman president

**Movie you could see anytime:** The Shape of Water

**TV show you try not to miss:** The Rachel Maddow Show

**Three things that can always be found in your refrigerator:** Ice cream, grapes,

Dr. Ragni with Dr. Manno and Dr. High

and olives

**Secret vice:** Dark chocolate

**Who would play you in the movies?** Merle Streep

**Your pet peeve about Pittsburgh:** Too many gray days

**People may be surprised to know that:** I love jazz.

# Where Does Your Factor Come From?

**By Laurie Kelley**

You may know the brand name of the factor concentrate your child or other loved one uses to treat bleeds. And you may have chosen the brand with the help of your hematologist. But where do get your factor? Who provides it? Is your current brand the best way to meet your personal needs? Do you have choice of provider?

Pharmaceutical companies develop and manufacture factor. Then they sell the factor to a licensed pharmacy—a factor provider. You can't buy factor directly from the manufacturer, just as you can't buy a car directly from General Motors, or diapers from Kimberly-Clark. And you can't get factor from your local drug store. Your hematologist supplies a prescription to a factor provider, who delivers it to you. Who are factor providers?

**Hospital Pharmacies**

You want a factor provider that can meet your personal needs; this usually means being cost-effective and speedy, and supplying factor in the correct assay sizes with all the ancillaries (such as needles and syringes) you require. Unless you are a member of a health maintenance organization (HMO) and are required to buy factor from the hospital pharmacy, or your hospital runs a 340B program (see p. 18), obtaining your factor through a hospital pharmacy is usually not a good option. Why not? Hospital pharmacies are the least cost-effective factor provider, and often mark up the cost of factor several hundred percent to cover the high overhead costs of running the hospital. Also, hospital pharmacies are not set up for home delivery and unlike specialty pharmacies, do not offer any additional services, such as a home nurse. Factor is already very expensive without the hospital markup! You'll want a long-term solution, with a factor provider that ships to your home.

**Specialty Pharmacies**

Specialty pharmacies are one of the chief factor providers in the US. If your insurance payer approves a specialty pharmacy based on your physician's prescription, you make a phone call, order your factor, and receive the order at your home within 24 to 48 hours, along with all necessary ancillaries and supplies. Reimbursement specialists handle your insurance paperwork. Specialty pharmacies stock most brands of factor, and usually can provide a size or assay that closely mirrors what you need for your child's infusions. Some specialty pharmacies will send a nurse to your home to perform or assist in the infusion process. There are many specialty pharmacies and home care companies that service hemophilia, and some are devoted only to hemophilia.

**Your HTC**

Did you know your hemophilia treatment center might sell factor? There are about 140 HTCs in

*(Continued on page 15)*

7th ANNUAL

# TAKE A BOUGH

HOLIDAY TREE AUCTION TO BENEFIT WPCNHF

*Save the Date*

SATURDAY
NOVEMBER 16, 2019
CORNERSTONE AT
TONIDALE

# Holiday Tree and Wreath Auction and Wine Tasting Event

DOORS OPEN: 6:30 PM
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 are 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 the Cornerstone at Tonidale and help set up on November 15th, as well as event day volunteers on November 16th.

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

3.) **Participate** - 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.

*To sign up to volunteer or coordinate donation drop offs*
*contact Kara at kara@wpcnhf.org*

# Where Does Your Factor Come From?

*(Continued from page 13)*

America as of this writing, and over 100 participate in the 340B program; all are licensed distributors of factor. So you also have the option—if your payer permits—to purchase factor from your HTC. Why and when would you consider buying from your HTC? Federally funded HTCs can take advantage of the federal Public Health Service (PHS) Act known as the 340B Drug Pricing Program. The PHS Act allows certain federally funded entities and public hospitals to purchase prescription outpatient drugs (including factor) at steeply discounted prices. So federally funded HTCs can buy factor from pharmaceutical companies at rock-bottom prices, and then sell it to you and make a profit.

In theory, 340B pricing is beneficial. It offers competition to help keep prices down, reduces costs for the government, and generates funds for the HTC to use for staff positions or overhead—which is truly needed. But not every eligible HTC uses the 340B program. And even when an HTC does offer factor through 340B, not all the HTC's hemophilia consumers take advantage of this. Why? Sometimes, 340B pricing doesn't guarantee lower prices to the consumer: some HTCs chargethe same price per unit as specialty pharmacies. And some consumers simply prefer the personal relationship they have with their specialty pharmacy reps.

**PBM Pharmacies**

Pharmacy benefit managers (PBMs) are powerful, multi-billion-dollar companies hired by insurance companies to manage the insurance benefits and prescription drug plans of private-sector entities, such as employers and labor unions. PBMs help determine the formulary—a limited list of preferred drugs that the payer will reimburse. PBMs also negotiate and manage contracts with pharmaceutical companies to buy the drugs needed by plan beneficiaries like you. The main function of a PBM is to keep prescription drug costs low for the insurance company.

PBMs are able to make high-volume drug purchases to receive substantial discounts from pharmaceutical companies. With their vast resources and negotiating skills, PBMs such as Express Scripts and CVS Health now serve most of the hemophilia patients in the US. Some PBMs have started their own specialty pharmacies to sell factor; and because they have a direct line to the payer, these PBMs are able to switch families from the factor provider of their choice to the PBM's specialty pharmacy. They have incredible power over pricing, product availability, and your payer.

Based on this, can you even choose a factor provider? Unfortunately, your healthcare payer—insurance company or government program—often chooses for you. Find out if your insurance company reimburses for specialty pharmacy services. Then, learn which companies are in-network for you. Your choices might be limited, because for the payer, working with a single factor provider is one way to lower costs. More and more often, choice is being restricted. You may face a struggle when choosing a preferred factor provider.

If you can choose, use this list of questions to ask your factor provider to make sure your personal needs are met:

- Which brands of factor concentrate do you provide?
- How much product will you provide at one time?
- How are products delivered to me?
- Do you ship during emergencies?
- Do you supply the assay size I need as a single dose?
- How much will I pay per unit of product?
- Do you (the HTC) offer 340B pricing?
- Are you recognized as an in-network provider by my insurance company?
- What are your hours of operation?
- Are a pharmacist and registered nurse available 24/7?
- Can I use your regular HTC services even if I choose to use a specialty pharmacy as my factor provider?
- Do you supply ancillaries: needles, syringes, and bandages?
- Do you provide needle disposal containers?
- Do you contract with local home nursing services?
- Is home nursing service included in the cost of product or billed separately?

Even though choice is being limited, you are not limited! Learn all you can about who supplies your factor, and continue to safeguard your needs. Ask questions, and get the answers that will help you make effective decisions.



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## Medical ID Jewelry

Medical ID jewelry is essential for people with bleeding disorders. Wearing a Medical ID can potentially save your life as well as potentially prevent irreversible damage due to delayed treatment. If you are injured and unable to speak for yourself, or speak for your child with a bleeding disorder, the Medical ID can serve to provide emergency personnel with critical information.

WPCNHF provides Medical ID Jewelry free of charge to our members with bleeding disorders. A variety of styles are available for both adults and children.

# ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated]

**ADYNOVATE® is FDA approved for children and adults with Hemophilia A**

**PROVEN PROPHYLAXIS + SIMPLE,* TWICE-WEEKLY DOSING SCHEDULE =**

*moments* **YOUR WAY**

*ADYNOVATE allows you to infuse on the same 2 days every week. Work with your doctor to determine an infusion schedule that is appropriate for you.

The pediatric study of children <12 years of age (N=66) evaluated the immunogenicity, efficacy, PK (as compared to ADVATE® [Antihemophilic Factor (Recombinant)]), and safety of ADYNOVATE twice-weekly prophylaxis (40-60 IU/kg) and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.[1,2]

The pivotal trial of children and adults ≥12 years (N=137) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis (40-50 IU/kg) vs on-demand (10-60 IU/kg) treatment, and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.[1]

+Children (<12 years) experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds[1,3]

+38% (n=25) of children (<12 years) experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds[1]

**Talk to your doctor to see if ADYNOVATE treatment may be right for you and visit ADYNOVATE.com**

## ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] 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 mice 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).

## DETAILED IMPORTANT RISK INFORMATION (cont'd)

### 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.** ADYNOVATE Prescribing Information. **2.** Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2017;23(2):238-246. **3.** Data on file; Shire US Inc.



Shire

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).

**What are the possible side effects of 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.

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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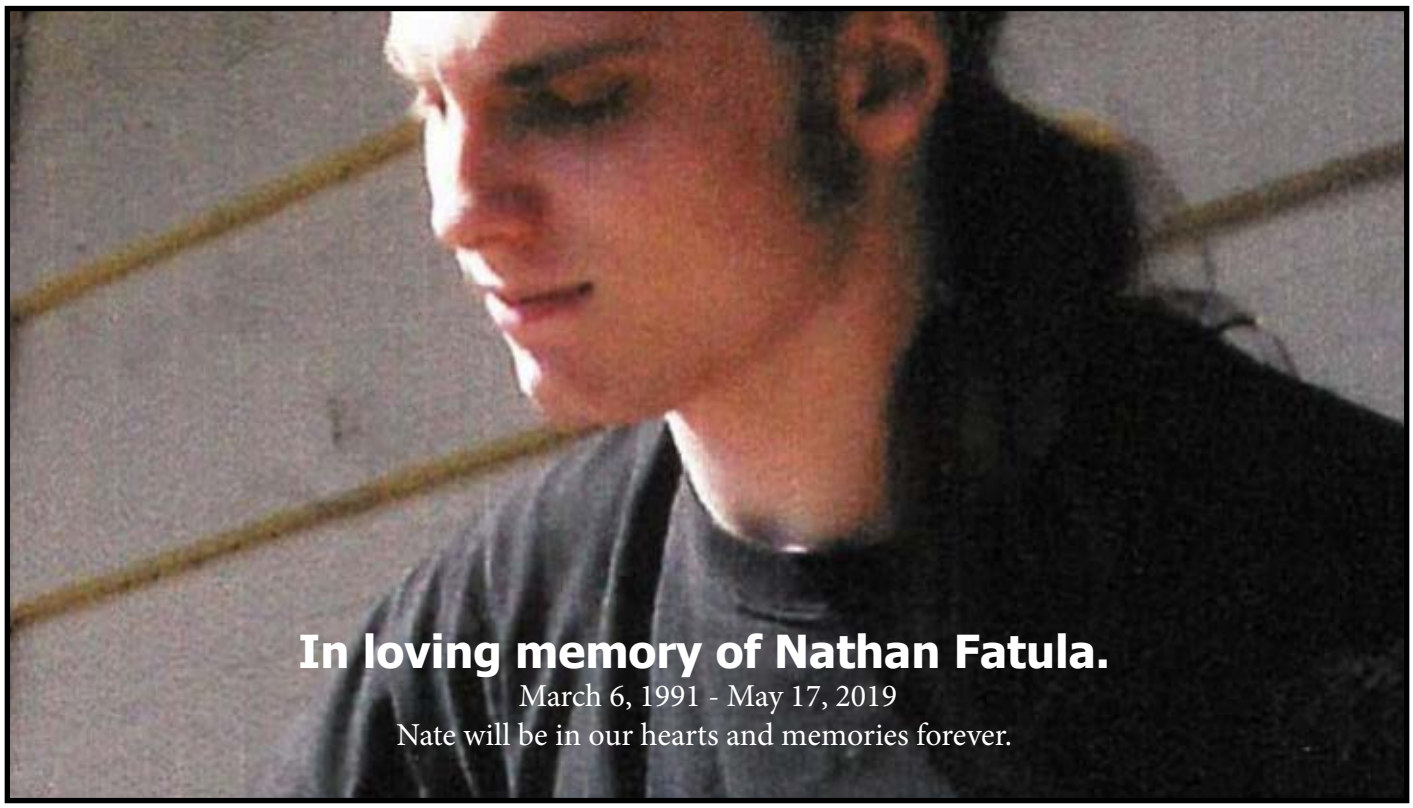
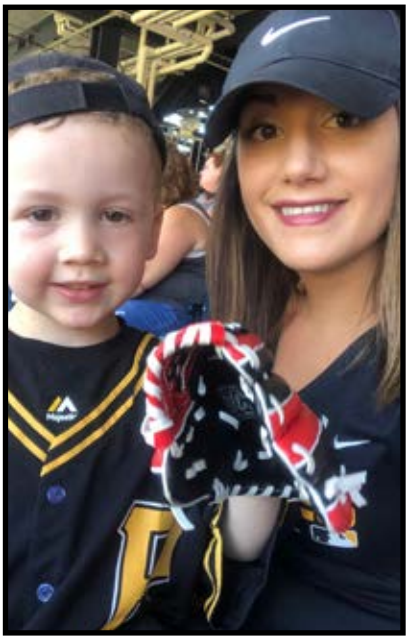


# Meet the New Board Members



## Brittani Spencer

**What influenced you to get involved with the Chapter and join our board of directors?** I have been involved with WPCNHF since college when I was given the opportunity to intern with the Chapter. I then went on to become the Chapter's Fundraising and Events Manager. During my time with WPCNHF, I learned about bleeding disorders, the challenges facing the community and the importance of advocacy. My position allowed me to meet community members and truly see the impact the Chapter has on the lives of those with bleeding disorders and their families. A favorite memory I have from my time as a Chapter employee is attending camp Hot-to-Clot. My role of driving the beverage and snack cart always seemed to put a smile on the camper's faces.

**What is your background or current occupation?** I left the Chapter in 2014 to work as a Development Officer at the University of Pittsburgh School of Medicine. In July, I will be heading to Nashville, TN where I will lead advancement efforts for St. Bernard Academy.

**What are you looking forward to as a new board member?** I decided to join the Board of Directors to help further enhance the fundraising efforts and increase the Chapter's visibility to the local community. I look forward to the upcoming walk/run and Take A Bough events and also seeing and interacting with Chapter members.

**What do you like to do for fun?** Aside from my work in development, I enjoy traveling, camping, exploring new restaurants and spending time with my family.

## John Yunghans

**What influenced you to get involved with the Chapter and join our board of directors?** I have been positively impacted by the hard work of the chapter throughout my life by the support my family and I have received. When I was approached about joining the board to serve, I was ecstatic about the opportunity to serve others the same way this organization supported me.

**What is your background or current occupation?** My degree is in church ministry, but my first job in Pittsburgh was at the Pittsburgh Post-Gazette in advertising. More recently have been working full time in Apple retail stores.

**What are you looking forward to as a new board member?** Our new partnership with Hemophilia Federation of America's Blood Brotherhood program has got me excited. The content is fantastic and super relevant to the men in our chapter. This is definitely something I am looking forward too!

**What do you like to do for fun?** I really enjoy games, books, Frisbee, and corn hole :)

# Donations Needed for Raffle Baskets

We are in need of donations for baskets we will be raffling off at the Unite for Bleeding Disorders Walk. Donations such as themed gift baskets or gift cards are great contributions. You can also sponsor a basket with a monetary donation. If you would like to help please e-mail Jessica Lee at jessica@wpcnhf.org, call 724-741-6160, or stop by the office during business hours 9am-4pm Monday through Friday. All donations are greatly appreciated!

# 10th Annual Run for Their Lives 5K Run

## September 7, 2019

RUN FOR THEIR LIVES

*Bleeding disorders can't stop us.*

**North Park**
**Harmar Pavilion**
**S. Ridge Drive**
**Allison Park, PA 15101**

**Check in begins at 7:30 am**
**Race begins at 8:30 am**

**Register Online at wpcnhf.org**
**Questions? Email kara@wpcnhf.org or call 724-741-6160**

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