Hemogram

Western Pennsylvania Chapter of the National Hemophilia Foundation

Summer 2020
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**

Congratulations Graduates!

Liam Egenlauf

Hopewell Class of 2020

Liam will attend CCBC to obtain his Nursing Degree.

"I am one proud Aunt. None of my own will be nurses so I will embrace my Aunt Kimmy duties." – Kimberly Walsh

Mary Laughlin

Graduating from PA Homeschoolers and Ligonier Valley High School.

Mary is attending WCCC then transferring to IUP for Art Education.

She is the daughter of Cathy and Todd Laughlin.

Kylie Parisi graduated from Duquesne University on May 8, 2020. She graduated with a major in Early Elementary Education with a minor in Psychology and 3 years of Occupational Therapy experience. She is the daughter of Fred and Melanie Parisi and the sister of Gavin Parisi who are very proud of her.

Matthew Hiller graduated from Seton LaSalle High School. He will be attending the University of Pittsburgh in the fall. He is the son of Lenore and David Hiller.

(Continued on page 2)

Congratulations Graduates!

(Continued from page 1)

Erek J. Domowicz graduated with high honors from Seneca Valley Senior High. He is a National Honor Society and National Technical Honor Society member. Erek will be attending Mercyhurst University in the Fall for a dual major in Cyber Security and Data Analytics. He is the son of Scott and Mary Domowicz.

Allie Baker graduated from IUP in May 2020 with a Bachelor of Science degree. Allie was working as an intern at UPMC Altoona as a Nuclear Medical Technologist. Sadly, her internship ended early due to COVID-19. She is expected to graduate from The Nuclear Medical Institute, University of Findlay, Ohio in the Fall of 2020.

Julia Rose Shoemaker graduated from Kiski Area High School with honors on June 3, 2020. Julia plans to attend Ursinus University majoring in Chemistry and minoring in Mathematics.

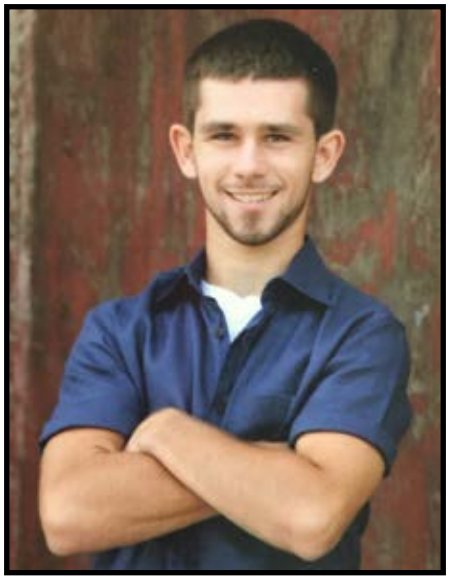
Mason Bobro graduated from Riverside High School (Ellwood City PA). He will be attending Robert Morris University majoring in Biomedical Engineering.

He is the son of Marty Bobro and Heather Kosto-Bobro and brother of Celeste Bobro.

Taylor Covert graduated from Ellwood City School District.

Taylor is enrolled at the Health Academy at the Community College of Beaver County. Her future plans are to be a Nurse Practitioner.

She is the daughter of Michael and Karen Covert.



Christian Covert graduated from the Community College Of Beaver County with a degree in Aviation Science.

Christian is currently enrolled in the Accelerated Business Management program at Southern Illinois University.

He is the son of Michael and Karen Covert.

Best of Luck, Graduates!

Would you like to submit a community announcement for our next issue? Please e-mail jessica@wpcnhf.org.

Calendar of Upcoming Events

July 9, 2020
Understanding Gene Therapy
Virtual Program

July 14, 2020
Understanding von Willebrand Disease
Virtual Program

July 23, 2020
Annual Meeting & Walk Kickoff
Virtual Program

July 25, 2020
Men's Group
Virtual Program

July 30, 2020
Drag Queen Bingo
Virtual Event

August 11, 2020
Family Paint Night
Virtual Program

August 18, 2020
Constructive Conversations for Caregivers
Virtual Program

August 29, 2020
Education Day
Virtual Program

September 12, 2020
Run for Their Lives 5K
Virtual Event

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

October 10, 2020
Unite for Bleeding Disorders Walk and Unite Day
Virtual Event

November 6, 2020
New Parent Network
Erie, PA

November 7, 2020
Fall Program
Erie, PA

November 14, 2020
Take A Bough
Pittsburgh, PA

December 6, 2020
Winterfest
Location TBD

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

11th Annual Run for Their Lives 5K

RUN FOR THEIR LIVES

Virtual 5K Race

WPCNHF

Join us for the 11th Annual Run for Their Lives Virtual 5K happening September 12, 2020 through October 10, 2020!

Whether you're a seasoned runner, a virtual event first-timer, or excited to support the bleeding disorders community of Western PA - this is one virtual event we know you'll love. From the ease of your own treadmill to your local trail, the Run for Your Lives Virtual 5K takes place anywhere you'd like, whenever you'd like.

Cost to participate is $20 and includes a digital race bib and finishers certificate. Runners can add a race medal for $5 and an event shirt for $10. Items will be mailed out the week of September 7th. Register by August 14th to qualify for a race medal or shirt.

GCXC RACE TIMING & MANAGEMENT PROBIKE+RUN

All proceeds benefit the bleeding disorders community of Western Pennsylvania!

Register today at:
bit.ly/runfortheirlives2020

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

Ask us about sponsorship opportunities and how you can help!

Thank you to our supporters:

Barbara Young
Carol Goldstein in honor of Mary Jean Speer
Christina Miller
Derick Stace-Naughton
Elizabeth Patrick
Emily Nikithser
Gary Farro
Jarred and Karen Slater
John Yunghans
Kim Zoella
Kimberly Walsh
Lisa Peduzzi
Michael Clancy
Robert Boyle
Ronald Weisser
Sanford and Carole Darling
Susan Eyrolles
Susie Cohen
Tracy Sethman

Letter from the Executive Director

Dear Community Members & Friends,

Since March 11, when the World Health Organization declared the novel Coronavirus (COVID-19) outbreak a global pandemic, our lives and lifestyles have changed dramatically. We conducted a survey asking how the Chapter can support you during this time. You shared the need for financial support due to lay off and wage cuts. You want us to check in on you, connect you with the community, and continue to provide educational programming. I want you to know we heard you. Janet, Jessica, and I have been working tirelessly to provide enriching educational programs, social activities, and secure additional funding for our emergency patient assistance program. The health, safety, and wellbeing of the bleeding disorders community is our highest priority.

In the past three months we have held 8 virtual events. This included a Bingo Night emceed by former Steelers player, Yancey Thigpen, a Family Fun Pizza and Game Night emceed by three incredible teens in our Teen Group: Allison, Ethan, and Julia, and two advocacy events held with the Eastern PA Chapter. This fiscal year, we have awarded over $20,000 in emergency patient assistance to our members in need. During this complex and difficult time, I am so grateful for the generosity of the community. We have held numerous successful fundraisers via email and social media campaigns and received grants from community foundations to support our Emergency Assistance Program.

We are excited to share that our advocacy efforts have paid off! Pennsylvania has passed a five month budget with the Hemophilia line fully funded, and language included to ensure the funds will be distributed to the treatment centers the same way they have been distributed in the past! Congratulations and thank you to all our incredible Advocacy Ambassadors for their great work on this.

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

Sincerely,

Kara Dornish

Kara Dornish
Executive Director

Letter from the President

Hello Chapter Members,

As we venture through the many obstacles we are facing, there is one thing to remember, we will get through this. We will come out better than before and all it takes is positive thoughts and common sense. I am always reminded of the saying, "Never look down on someone unless you are helping them up." We may be the one who needs the help someday.

Here at the chapter, we have begun to offer new ways to engage our community through video chatting and virtual programing. It is a new change (an interesting one to say the least), but I am glad that our sponsors have welcomed the changes needed to allow our programming to proceed as best as we can. I ask for everyone's patience during this process and to know that behind the scenes, the Chapter is working hard to ensure the quality of care and support you've come to expect does not change during these uncertain times.

I would also like to add that the chapter staff is just a phone call away. If you need any assistance, feel free to reach out to Kara, Janet or Jessica to get the help needed.

Kind Regards,

Michael Covert
WPCNHF Board President

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.

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.

Letter from HCWP

Dear HCWP Patients and Families,

Our nation continues to experience significant challenges in light of the COVID-19 pandemic. As many of you may be aware, this has caused us to cancel Camp Hot-to-Clot this summer, which is sad news to all of us. We are hoping to still bring some sort of opportunity for connection to the youth that would have participated, and are continuing to explore this possibility.

Our center continues to do all that we can to provide safe and comprehensive care to you. Presently, Dr. Ragni continues to offer telehealth appointments. Dr. Seaman and Dr. Xavier are available for patient appointments either in person or via telehealth, depending upon your comfort level and need. Please discuss your options when you call for your appointment. We do request that you bring the minimum amount of people necessary to appointments in order to help us maintain effective social distancing, as well as that you wear a mask. All who enter the building do go through a brief screening process, which includes questions about exposure to COVID-19 and having a temperature check. Although these measures may be somewhat uncomfortable, they are there to protect the well-being of our patients and our staff. Please continue to contact us with your questions and concerns, and know that we are here to continue to provide treatments, education, and meet urgent needs. Additionally, please continue to contact us if you have an urgent bleeding concern, as we may be able to help you avoid an ER visit.

We know that COVID-19 has affected many people financially. The bleeding disorder community does have resources available, such as through the state patient assistance program, WPCNHF, and a dedicated Hemophilia Federation of America fund. Please contact the center and ask to speak with social work in order to be connected with these resources and other supports that may be available to you. We are glad to help connect you. Additionally, if the pandemic has caused challenges to you in terms of job or insurance insecurity please let us know so that we can offer any resources we may have.

As you may know, the HCWP does have Vitalant as its parent organization and we now have a website established through them. The link is https://hcwp.vitalant.org. The new website has been technologically updated and features a more user-friendly method of factor ordering as well as online submission of home treatment records. We are hopeful these features will allow for improved and streamlined care. The website also continues to offer information on the center's services, ongoing research, and staff. Please let us know if you have any questions, suggestions or comments by messaging us on the contact page of the website.

When you face a medical emergency or a bleed and need to take your child to UPMC Children's Hospital, please make sure to always call (412) 209-7280. Your call will trigger a new work flow that will flag CHP emergency room providers, and ensure that your child will receive appropriate care promptly. We also want to remind you to always communicate with the hemophilia center in the event you or your child need ANY invasive procedure to make sure appropriate care is provided during the procedure and to avoid bleeding complications.

Since our last newsletter, we have continued to grow our staff. We have welcomed Juliana Sheline to our research staff, Bruce Haas as a genetic counselor, as well as Devera Hoblak and Patricia Linn to our administrative team. Please join us in welcoming them aboard!

As always, we remain dedicated to caring for you as best as we are able. Please reach out to us with any concerns or questions, and we'll be glad to talk with you.

Wishing you peace and health,

Your HCWP Staff

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

ADVATE has over 15 years of treatment experience in the real world and provides clinically proven bleed protection* for patients with hemophilia A.[1]

ADVATE
[Antihemophilic Factor (Recombinant)]

REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

Prophylaxis with ADVATE prevented bleeds[1]

The ability of ADVATE to treat or prevent bleeds was evaluated in a clinical study using a standard prophylaxis, pharmacokinetic driven prophylaxis, and on-demand treatment.

53 previously treated patients (PTPs) with severe to moderately severe hemophilia A were analyzed. For the first 6 months of the study, patients received on-demand treatment. For the following 12 months of the study, patients received either standard prophylaxis every 48 hours or a pharmacokinetic-driven prophylaxis every 72 hours. The primary goal of the study was to compare annual bleeding rates between those receiving prophylaxis treatment and those receiving treatment on-demand. The number of bleeds per year for the 2 prophylaxis regimens were comparable.

- Those patients experienced a median of 1 overall bleed per year on either prophylaxis treatment vs 44 overall bleeds per year with on-demand treatment.† This represented a 98% reduction in overall bleeds per year.
- Zero bleeds were reported in 42% of patients (22 out of 53 patients) during 12 months on prophylaxis

†Median is the middle number in a group of numbers arranged from lowest to highest.

ADVATE Important Information

What is ADVATE?

- ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia).
- ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider (HCP) may give you ADVATE when you have surgery.
- ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

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

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

What should I tell my HCP before using ADVATE?

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 ADVATE passes into your milk and if it can harm your baby.

What should I tell my HCP before using ADVATE? (continued)

- Are or become pregnant. It is not known if ADVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADVATE may not work for you).

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP 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 ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE and Hemophilia A?

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

- Side effects that have been reported with ADVATE include: cough, headache, joint swelling/aching, sore throat, fever, itching, unusual taste, dizziness, hematoma, abdominal pain, hot flashes, swelling of legs, diarrhea, chills, runny nose/congestion, nausea/vomiting, sweating, and rash. Tell your HCP about any side effects that bother you or do not go away or if your bleeding does not stop after taking ADVATE.

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

Please see Important Facts about ADVATE on the following page and discuss with your HCP.

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

Reference: 1. ADVATE Prescribing Information.

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ADVATE
[Antihemophilic Factor(Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

This leaflet summarizes important information about ADVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADVATE. If you have any questions after reading this, ask your healthcare provider.

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

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

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

What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). The product does not contain plasma or albumin. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

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

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

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

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

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

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

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

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

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

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

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

You should tell your healthcare provider if you:

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

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

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

Side effects that have been reported with ADVATE include:

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

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

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

What else should I know about ADVATE and Hemophilia A?

Your body may form inhibitors to factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA-approved product labeling can be found at www.ADVATE.com or 1-877-825-3327.

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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Gene Therapy Research

Dr. Tammuella (Tami) Singleton, Children's Hospital New Orleans, presented the program *Gene Therapy Research: Understanding the Science*, on June 9. Dr. Singleton presented a complex topic in a way that was engaging and easy to understand. She started with the basics of DNA, using a food recipe and menu as analogies. She built on her introduction and explained how gene therapy is designed to work, types of gene mutations, types of gene therapies that are being researched, different stages of clinical trials, and why some people are better candidates for research.

Although great advances have been made over the years, gene therapy research isn't new; it has been taking place for the past 50 years. More than 2,500 gene therapy projects have been initiated and have either been completed, are ongoing, or are in preclinical trials. Gene therapy research in humans began in the 1990's and the first Hemophilia B gene therapy clinical trial took place in 1999. In 2015, the first Hemophilia A clinical trial began.

As different therapies continue to be researched and emerge, we encourage our members to stay informed and take advantage of opportunities to learn about the science behind them. We thank Michelle Beeler, from BioMarin, for sponsoring this virtual event and bringing this incredibly informative program to our Chapter members.

Proclamation

WPCNHF is proud to share this proclamation from Governor Tom Wolf proclaiming April 17, 2020 World Hemophilia Day in Pennsylvania.

Commonwealth of Pennsylvania

Governor's Office

PROCLAMATION

WORLD HEMOPHILIA DAY
April 17, 2020

WHEREAS, hemophilia is a rare genetic bleeding disorder in which one of the proteins that causes the blood to clot is missing or there is not enough of it to work properly, causing people to bleed longer; and

WHEREAS, without effective blood clotting, cuts and internal injuries have difficulty healing, and internal bleeding into the joints can result in pain and permanent damage; and

WHEREAS, hemophilia is typically a lifelong condition that is primarily treated with infusions of a protein involved in blood clotting; and

WHEREAS, it is estimated that more than 400,000 people worldwide are living with hemophilia; and

WHEREAS, approximately 20,000 people in the United States – and more than 2,000 people in the commonwealth – are living with hemophilia; and

WHEREAS, hemophilia is found in all populations; and

WHEREAS, people living with hemophilia, and those caring for and serving them, are strongly united in advocating for access to treatment and care.

THEREFORE, I, Tom Wolf, Governor of the Commonwealth of Pennsylvania, do hereby proclaim April 17, 2020, as WORLD HEMOPHILIA DAY. I strongly encourage all citizens to increase their awareness of hemophilia diagnosis and treatment.

GIVEN under my hand and the Seal of the Governor, at the City of Harrisburg, this seventeenth day of April two thousand twenty, the year of the commonwealth the two hundred forty-fourth.

Tom Wolf
TOM WOLF
Governor

Blood Brotherhood Virtual Meeting

John Yunghans – Men's Group Coordinator

On April 23, a few men in our Chapter's Blood Brotherhood group gathered virtually to connect and support each other. It was awesome to hear everyone's voice again. We discussed the challenges facing our community and how we were each working to stay healthy and help others. Our call ended looking forward to how our small group can make a larger positive impact. Stay tuned for more details to follow about our next virtual meeting!

Advocacy Update

Pennsylvania Passes 5 Month Budget with the Hemophilia Line Item Fully Funded

House Bill 2387

Signed in House, May 28, 2020

Signed in Senate, May 28, 2020

Presented to the Governor, May 28, 2020

Approved by the Governor, May 29, 2020

We are happy to let you know on Friday, May 29, 2020 a 5-month budget was passed with the hemophilia line item fully funded at $400,000 (5/12th). The Hemophilia line can be found on page 45 (lines 2 and 3) of HB 2387.

```
2      For hemophilia services.
3          State appropriation.....                    400,000
```

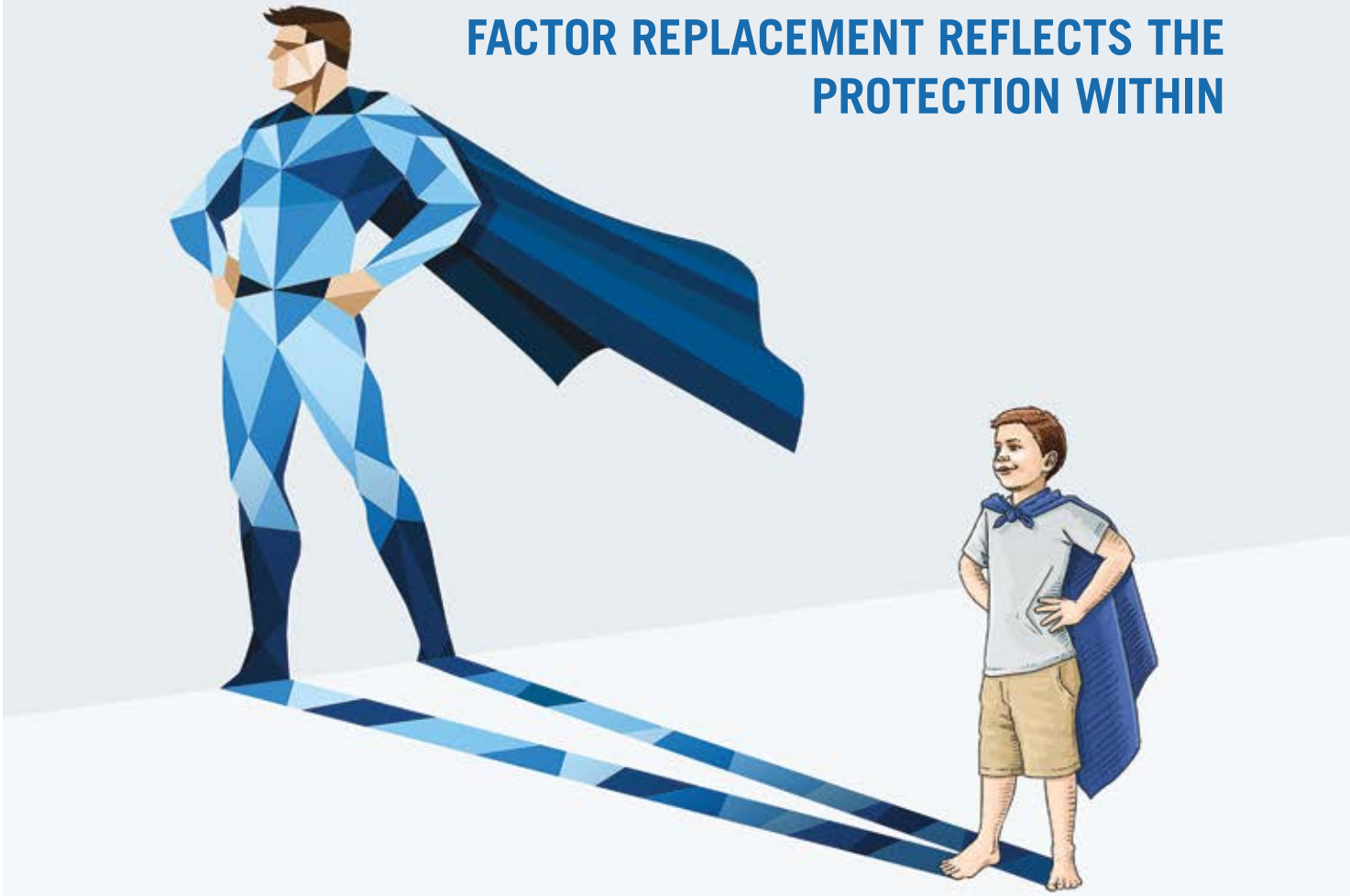
In addition, the language in the fiscal code reads as follows: This ensures hemophilia funding in the budget must be distributed to the 7 Hemophilia Treatment Centers in the same way it was last fiscal year (no regional approach). The hemophilia language can be found on page 20 (lines 40-42) in House Bill 1083.

```
40         (B)  Funds appropriated for hemophilia services shall be
41     distributed to grantees in the same proportion as distributed
42     in fiscal year 2019-2020.
```

A special thank you to our Advocacy Ambassadors for contacting legislators and sharing the importance of the Hemophilia Treatment Centers in Pennsylvania.

If you would like to become an Advocacy Ambassador please contact Kara at kara@wpcnhf.org. Visit wpcnhf.org/advocacy-ambassador-program for more information.

FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN



For people with hemophilia, Factor treatment temporarily replaces what's missing.[1,2] With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.[2-6]

Brought to you by Takeda, dedicated to pursuing advancements in hemophilia for more than 70 years.[7]

Stay empowered by the possibilities.

References: 1. Peyvandi F, Garagiola I, Young G. The past and future of haemophilia: diagnosis, treatments, and its complications. *Lancet*. 2016;388:187-197. **2.** Canadian Hemophilia Society. Factor replacement therapy. http://www.hemophilia.ca/en/bleeding-disorders/hemophilia-a-and-b/the-treatment-of-hemophilia/factor-replacement-therapy/. Accessed May 18, 2018. **3.** Franchini M, Mannucci PM. The history of hemophilia. *Semin Thromb Hemost*. 2014;40:571-576. **4.** Hvas AM, Sørensen HT, Norengaard L, Christiansen K, Ingerslev J, Sørensen B. Tranexamic acid combined with recombinant factor VIII increases clot resistance to accelerated fibrinolysis in severe hemophilia A. *J Thromb Haemost*. 2007;5:2408-2414. **5.** Antovic A, Mikovic D, Elezovic I, Zabczyk M, Hutenby K, Antovic JP. Improvement of fibrin clot structure after factor VIII injection in haemophilia A patients treated on demand. *Thromb Haemost*. 2014;111(4):656-661. **6.** Berg JM, Tymoczko JL, Stryer L. Many enzymes are activated by specific proteolytic cleavage. In: *Biochemistry*. 5th ed. New York, NY: WH Freeman; 2002. https://www.ncbi.nlm.nih.gov/books/NBK22589/. Accessed May 18, 2018. **7.** Shire. Shire's 70+ year commitment to the hemophilia community. https://www.shire.com/en/newsroom/2018/january/7sossj. Accessed June 6, 2018.

Takeda

Answering Girls' Questions on Puberty and Bleeding Disorders

A new educational book from NHF tackles everyday issues

Author: Liz Krieger

The onset of adolescence can be sudden or slow, but regardless, it comes with a host of physical changes. And for girls who have bleeding disorders, there are extra considerations. Thankfully, there's a new National Hemophilia Foundation (NHF) book that addresses these issues in an approachable and clear way.

The 48-page book, Time to Talk Puberty: A Guide for Girls with Bleeding Disorders, provides a comprehensive overview of bleeding disorders, how they are affected in puberty, treatment options, and tips and tricks. While it's important that girls with bleeding disorders have an open dialogue with their doctors, the book will be a nice accompaniment to those face-to-face discussions, says Robert Sidonio Jr., MD, MSc, director of hemostasis and thrombosis clinical operations at the Aflac Cancer and Blood Disorders Center at Emory University in Atlanta.

What is the right age to talk about puberty?

Talking about puberty with your daughter should start earlier than you may think—by age 8 or 9 at the latest, says Sidonio, who helped create the book. "The average age of a girl's first period is around 10 to 11 years of age, so it is important to provide some anticipatory guidance," he says.

This new publication is particularly impactful because it's visually appealing—with a format and verbiage geared for adolescents. There's a section on "real" questions that covers everyday problems tween and teenage girls with bleeding disorders face, such as what to do if you have a nosebleed when you're at a sleepover and how to manage cramps. "Many of these questions are ones I hear in my clinic, but I think some teenage girls may be afraid or feel uncomfortable asking their providers about these issues," Sidonio says.

It can be difficult for young women with bleeding disorders to know what is and is not normal, says Christine Guelcher, RN-BC, MS, PPCNP-BC, the HTC program coordinator at Children's National Hospital in Washington, DC, who was also involved in developing the book. "There may be other female family members who are affected but don't realize it because heavy bleeding is the 'norm' in their family. This book addresses these issues in an age-appropriate way."

"The book helps girls understand that there are lots of ways to manage heavy menstrual bleeding and that there are even apps that can be used to keep track of what is working and allow providers to make individualized adjustments," Guelcher says.

To receive a PDF of Time to Talk Puberty: A Guide for Girls with Bleeding Disorders contact HANDI by phone at 800.424.2634 or by email: handi@hemophilia.org

Article Courtesy of HemAware copyright 2020

Let's Get!

COTTRILL'S PHARMACY, INC.

In response to the COVID-19 quarantine, Cottrill's Pharmacy created a series of videos to help patients and their families stay active and keep healthy. *Let's Get Moving* is a series of seven videos with licensed Physical Therapist, Dr. Mike Zolotnitsky, that are designed for all ages and do not require any equipment. *Let's Get Creative: Nature Edition* – is a series of videos which demonstrate creative projects that viewers can participate in using only items that are found in their environment. Projects include creating terrariums from objects found in your yard or around the house. Did you miss the videos or would you like to watch them again? You can find seven of the *Get Moving* exercise videos, led by Mike Zolotnitsky, PT, DPT, along with the DIY Terrarium video, led by Josh Tezak, from the *Let's Get Creative* video series, in the video section of the Chapter's Facebook page.

WPCNHF's Winning Women

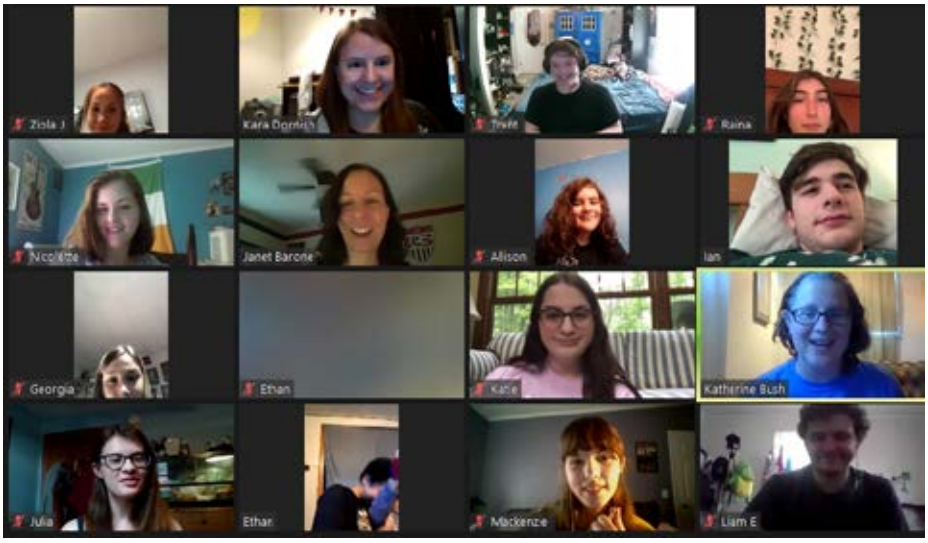
Maria Steele-Voms Stein – Women's Group Coordinator

On Saturday, May 16th, the Western PA Chapter's Winning Women's group hosted our first Virtual education event. The webinar, "Taking Care of You," moderator was Yota Dermatis, Helping Hands Coordinator for the Hemophilia Federation of America. The presentation and interactive discussion included information on how change and stress impacts both our physical and psychological well-being, a timely subject especially with the recent events that are impacting each of us in many ways. Yota provided the webinar participants with many tips on stress management and the importance of self-care.

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 issues related to bleeding disorder management and to have a lot of FUN! I hope to see you at an upcoming WPCNHF Winning Women's group or chapter event soon.

The Chapter thanks the Hemophilia Federation of America for sponsoring this program.

Teen Zoom Event



By Julia S. – Teen Group Co-coordinator

On May 30th, 2020, the WPCNHF Teen Group held their first virtual meeting on Zoom. Janet Barone and Katherine Bush started planning the meeting early in May with help from teen leaders, Nicolette Cloutier and Julia Shoemaker. A total of 13 teens attended the meeting and each one got their own deck of Uno cards mailed to them. Once everyone got on the chat, we discussed what was happening with camp this year (before we learned that it was unable to be held in person). All the teens agreed that if we could not see each other in person, we would do video chats in order for everyone to be together.

Some of the teens volunteered to help with the Family Game Night by making questions and reading them during the virtual event. Then, Janet and Katherine talked about some of the resources available to the teens, such as educational scholarships. The links to the programs were shared with everyone through the chat.

The teens were then put into two groups. Each group had either Janet or Katherine and Nicolette or Julia in it. We played some Pictionary, discussed how we were dealing with the current situation, and if anyone needed anything. They recommended reaching out to the Hemophilia Treatment Center. Once we came back together, we discussed future game ideas that we can do during a virtual meeting. At the end of the chat, we were able to take a group picture with all the teens who attended.

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

Genentech
A Member of the Roche Group

Unite
for Bleeding Disorders

WPCNHF

The Western Pennsylvania Chapter of the National Hemophilia Foundation

UNITE for Bleeding Disorders Virtual Walk

In order to properly fulfill our mission and provide the best possible experience for our community, we have made the tough decision to move this year's Unite for Bleeding Disorders Walk virtual. We are teaming up with the National Hemophilia Foundation to celebrate Unite Day on October 10, 2020! Stay tuned for more information!

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

www.uniteforbleedingdisorders.org/event/wpa

Let's make today brilliant.

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.

bleedingdisorders.com

Takeda

Fun and Games

Sometimes it is all fun and games! Recognizing that many of us were looking for a break from online meetings, education programs, and classes, but still desired to get together and stay connected, the Chapter began hosting online game nights.

On May 20, Medexus Pharma and Factor One Source Fast Pharmacy sponsored a bingo night. Instead of bingo numbers, the game was played with words which were a mix of bleeding disorder-related words and fun, Pittsburgh-related words! What made this night even more special was the guest who called out the bingo words—former Pittsburgh Steelers player Yancey Thigpen! A lot of fun was had, and prizes were awarded to the winners. We thank Nora Latcovich from Medexus Pharma and Bill Jamison and Rusty Kuchta from Factor One Source Fast Pharmacy for the much-needed break.

On June 16, the Chapter hosted a Family Game Night, sponsored by the National Hemophilia Foundation and dinner sponsored by Drug Co. Our members engaged in three competitive trivia games through Kahoot, plus a fun practice game that was full of Camp Hot-to-Clot trivia. Three teens from our Chapter stepped up and volunteered to read the trivia questions and create the questions for the practice game. Allison S., Ethan W., and Julia S. all did an outstanding job!

The three competitive games were created by the National Hemophilia Foundation and each game focused on a set of trivia questions relating to either von Willebrand Disease, Rare Bleeding Disorders, or Hemophilia. Random trivia questions were sprinkled throughout each game. It was an entertaining night testing our knowledge on everything from the number of clotting factors our bodies produce to the height of the Eiffel Tower! Prizes were awarded to the top scorer in each game.

We thank Jasmine Pauldurai and Nikole Scappe from the National Hemophilia Foundation for creating and running the bleeding disorders trivia game. We thank Ryan Melton and E.J. Villegas from Drug Co. for sponsoring dinner gift cards.

Getting to Know HCWP Staff

Kara Moore, HCWP Nurse

Birthplace: Bullskin, Pennsylvania

First job: Waitress at a pizza shop

Accomplishment you're proudest of: Having the opportunity to practice as a Sexual Assault Nurse Examiner in the Emergency Department

What three words describe you best? Empathetic, independent, and optimistic

Dream vacation: Travel to Ireland

Things you can do without: Social media, soda, and video games

Person you'd most like to have dinner with: Forensic Pathologist Dr. Cyril Wecht

Movie you could see anytime: Sweet Home Alabama

TV show you try not to miss: The Bachelor/The Bachelorette

Three things that can always be found in your refrigerator: Avocados, craft beer, and cheese

Secret vice: Huge bargain shopper, i.e. Goodwill, Gabes, Salvation Army

Who would play you in the movies? Sandra Bullock

Your pet peeve about Pittsburgh: Saying yinz….my family uses y'all

People may be surprised to know that: I am a volunteer firefighter.

Virtual Annual Meeting

WPCNHF

July 23, 2020
6:00 PM

Join us virtually for our Annual Meeting and Walk Kick-Off! Learn more about the services the Chapter offers, help us recognize our top volunteers, hear from our sponsors, and help us kick off the Unite for Bleeding Disorders Walk!

Dinner Gift Cards and Event Boxes with sponsor giveaways will be sent to those who register by July 16th.

This event is open to members of our Chapter with bleeding disorders and their immediate family.

RSVP with your first and last name and the number of people in your household attending by emailing rsvp@wpcnhf.org by July 23rd at 3pm to receive a dinner gift card. You must RSVP by July 16th to receive an event box. Please include Annual Meeting in the subject line. The Zoom link and call in information will be sent to those who register.

Thank you to our sponsors: Accredo, Bayer, BioMarin, CSL Behring, CVS Specialty, DrugCo, Factor One Source Fast Pharmacy, Genentech, Medexus Pharma, Novo Nordisk, Octapharma, Sanofi Genzyme, Spark, and Takeda.

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