



HEMOGRAM

WESTERN PENNSYLVANIA CHAPTER OF THE NATIONAL HEMOPHILIA FOUNDATION

SPRING 2021



THANK YOU
FOR BAKING
WITH US!

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BOARD OF DIRECTORS

Interim President

Brittani Spencer

Secretary John Yunghans

Treasurer Christina Miller

Board Members

R. Scott Domowicz

Melinda Perry

Jennifer Smith

STAFF

Executive Director Kara Dornish

Program Director Janet Barone

Development Director Jessica Lee

Staff office hours are Monday-Friday from 9 a.m. until 4 p.m. Every attempt will be made to return calls received during regular office hours on the same day.

MISSION STATEMENT

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

Hemogram is published quarterly by the Western Pennsylvania Chapter of the National Hemophilia Foundation. The material in this newsletter is provided for your general information only. WPCNHF does not give medical advice or engage in the practice of medicine. WPCNHF under no circumstances recommends particular treatments, and always recommends that you consult your physician or treatment center before pursuing any course of treatment.

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

EVENTS CALENDAR

April 17, 2021

World Hemophilia Day
Virtual Program

April 24, 2021

WPCNHF's Murder
Mystery Night
Virtual Fundraiser

May 9, 2021

Mother's Day Paint 'N Sip
Virtual Fundraiser

May 23, 2021

Strategies to Better
Manage Stress
Virtual Program

June 26, 2021

Young Adult Retreat
Seven Springs, PA

July 22, 2021

Annual Meeting & Walk
Kick-Off
Virtual Program

August 26-28, 2021

NHF Bleeding Disorders
Conference
Virtual Program

September 18, 2021

Unite for Bleeding
Disorders Walk and
Run for their Lives 5K -
Fundraiser

October 9, 2021

Fall Program
Erie, PA

October 18-28, 2021

HFA Symposium
Virtual Program

November 5, 2021

New Parent Network
Seven Springs, PA

November 5, 2021

Teen Program
Seven Springs, PA

November 6-7, 2021

Education Weekend
Seven Springs, PA

November 20, 2021

Family Program
Pittsburgh, PA

November 23, 2021

Advocacy Stakeholder Retreat
Virtual Program

December 4, 2021

Take A Bough - Fundraiser
Pittsburgh, PA

VISIT WPCNHF.ORG FOR MORE INFORMATION ON OUR UPCOMING EVENTS.

COMMUNITY ANNOUNCEMENTS

Matt and Bekah Quigley gave birth to their second child, a baby girl, on December 15, 2020. Her name is Keely Brooke Quigley and weighed 7 lbs. 3 oz. Congratulations!



Would you like to submit a community announcement for our next issue?

Please e-mail jessica@wpcnhf.org

Virtual Murder Mystery Night

Saturday, April 24th
at 7:00 PM

More information and to register:
give.classy.org/wpcnhfmurdermystery
Register by April 18th to receive an event box!

YOU'RE INVITED!

Join us in celebrating Mother Fates' 100th birthday at the Fates Motel! Due to social distancing, all family members will video call in from different rooms of the motel.

When: Saturday, April 24th at 7:00 PM
Cost: \$25 per device

CONTACT US

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Hemophilia Foundation

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LETTER FROM THE EXECUTIVE DIRECTOR

Dear Chapter Members & Friends,

Spring is finally here! I hope everyone takes some time to enjoy the fresh air and sunshine. We made it through a challenging year, and I cannot express how thankful I am for this amazing community. While I cannot wait to see everyone in person, I am so proud of everyone for their ability to adapt and come together this year in unique ways.

March was Bleeding Disorders Awareness Month, and we started off the month advocating for the community by participating in NHF's Virtual Washington Days. We played Bleeding Disorders Awareness Month Bingo which encouraged writing letters to your local legislator and spreading awareness of bleeding disorders by sharing facts posted on the Chapter's social media pages. We are continuing to meet local legislators virtually and

would love your participation. If you would like to get more involved in advocating for the bleeding disorders community, please get in contact with me.

We have increased our ability to provide emergency financial assistance, particularly to those who are struggling with food insecurity, with the WPCNHF COVID-19 Grocery Assistance Program. During the 2020-2021 fiscal year, we have been able to assist 178 members, granting over \$22,000 through our patient assistance program. If you need assistance, please do not hesitate to reach out. We are here to help.

We are continuing to monitor guidelines set by local public health officials and the CDC with hopes we can resume in-person events soon.



In the meantime, we will continue to provide at-home and virtual activities to educate and keep us connected. Our top priority is your health and wellness.

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

Kara Dornish

Kara Dornish
Executive Director

LETTER FROM THE BOARD PRESIDENT



Hello Chapter Members,

It's a privilege to serve as the Interim President of our Board of Directors. I am eager to continue enhancing the meaningful work being done by this organization.

I want to thank the Chapter Staff for their tireless effort. Every day, they go above and beyond to support our community. This year has brought plenty of new challenges; however, their focus has remained consistent. Our Chapter continues to thrive, and support from our industry and donors remains strong. We've held numerous virtual events and have more scheduled in the months to come. The events have been nothing shy of entertaining! I encourage you to register for the upcoming programs and events. I also encourage you to take part in World Hemophilia Day on April 17. This is a global day that brings together

everyone in the bleeding disorders community.

Please know that we're here for you. We have a new program titled, the WPCNHF COVID-19 Grocery Assistance Program. This program is in place to help those who are suffering from financial hardship due to COVID-19. If you qualify and require assistance, please apply.

On behalf of the Board of Directors, I would like to extend an invitation to anyone interested in serving on our Board to help us formulate new ideas, bring your expertise, and make a difference in the lives of others. Please reach out to Kara Dornish if you are interested and she will guide you through the process.

Wishing you all the best,
Brittani Spencer
WPCNHF Interim Board President

ADVOCACY UPDATE

Western PA Advocacy Ambassadors

LOCAL ISSUES

We have made it a priority to meet virtually with newly elected state representatives and state senators in the first quarter of 2021. We are introducing ourselves to them, educating them on bleeding disorders, our organization, the needs of the community, the importance of Pennsylvania's seven Hemophilia Treatment Centers and the multidisciplinary

care patient's receive, and the importance of maintaining the hemophilia line item in the state budget. So far, we have met with: Representative Josh Kail, Representative Nick Picciottano, Representative Austin Davis, Representative Jessica Benham, Senator Devlin Robinson, Senator Jay Costa, and Representative Dan Frankel.

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



Representative Austin Davis

Allegheny County

Advocacy Ambassadors: Delores Johnson & Kyrie Holliday



Representative Dan Frankel

Allegheny County

Advocacy Ambassadors: Janet Barone and Kara Dornish



Senator Devlin Robinson

Allegheny County

Advocacy Ambassadors: John Yunghans, Christina Yunghans, Melinda Perry & Ryker Stern



Senator Jay Costa

Allegheny County

Advocacy Ambassador: Kathaleen Schnur



Representative Jessica Benham

Allegheny County

Advocacy Ambassador: Cassandra Miller



Representative Josh Kail

Beaver County

Advocacy Ambassadors: Janet Barone and Kara Dornish



Representative Nick Picciottano

Allegheny County

Advocacy Ambassadors: Melinda Perry, Ryker Stern, Delores Johnson, & Kyrie Holliday

NHF WASHINGTON DAYS

On Thursday, March 4th the Western Pennsylvania Chapter of the National Hemophilia Foundation participated in the National Hemophilia Foundation's Virtual Washington Days. Thirteen (13) advocates from Pennsylvania attended seven (7) meetings with legislators and/or their staff. Our advocates from Pennsylvania included: Janet Barone, Kara Dornish, Lindsay Frei, Kyrie Holliday, Delores Johnson Huber, Curt Krouse, Jessica Lee, Scott Miller, Joe Pugliese, Dylan Rooney, Nikole Scappe, Chris Templin, and Ethan Webb.

THE PROBLEM WITH CO-PAY ACCUMULATORS

89% of insured Pennsylvanians have a deductible on their plan and 65% of these are a high deductible (which is considered \$1,450 or more). The deductible cap for 2021 is \$8,550 for individuals and \$17,100 for families. The average deductible in Pennsylvania is \$2,429 per person and \$4,751 per family. People with bleeding disorders are hitting their out-of-pocket maximum right at the beginning of the year and rely on copay assistance to afford the high upfront cost for medication. Insurance companies have implemented what they call co-pay accumulator programs which do not count the use of co-pay assistance toward the patient's deductible or out-of-pocket (OOP) maximum.

WHAT ARE CO-PAY ACCUMULATOR ADJUSTOR PROGRAMS AND HOW DO THEY IMPACT PATIENT ACCESS?

- Co-pay accumulator programs say that co-pay assistance does not count towards a patient's deductible or OOP max.
- Co-pay accumulator programs harm people with bleeding disorders and other conditions who need co-pay assistance to

CONTINUED ON PAGE 6...



(Top) Team PA prepares for their first meeting of the day.

(Right) Western PA meets with Rachel Hugman of Representative Conor Lamb's office.



NHF'S VIRTUAL WASHINGTON DAYS

ETHAN WEBB

Hi, my name is Ethan Webb. I am 14 years old and I am diagnosed with Hemophilia A, severe. This year, I participated in the National Hemophilia Foundation's (NHF) Virtual Washington Days. The first meeting I attended was with Senator Pat Toomey's staffer, Tom. I attended my second meeting with my mom and little brother, and we met with U.S Representative Conor Lamb's staffer, Rachel. I was very nervous, but it was good to see people I knew and grew up with. I've always enjoyed the trip down to D.C and Harrisburg for state days. The hemophilia community has always been helpful and kind.

In my meetings, I talked about the

many complications I had with my port when I was two. This was before the Affordable Care Act. I also talked about Camp Hot-to-Clot and how they taught us how to medicate ourselves. I learned how to infuse myself at 7.

I shared how important the HCWP is to my family and other families as well. The center in Oakland has been really helpful and has taught me a lot. I recently talked with my doctor and social worker privately about mental health and lack of school due to COVID. Having the full staff on speed dial means so much. I am grateful for my hemophilia community and enjoyed attending these meetings virtually! ■



ADVOCACY UPDATE

CONTINUED FROM PAGE 5...

afford their treatments.

- Without assistance, patients who cannot afford treatments may stop taking them or reduce the prescribed dosage. This leads to complications (i.e., increased ER visits, joint bleeds/damage, and missed days from work/school) that harm patients and increase overall costs.

- Private plans should be required to count all co-pays (regardless of who pays) towards a person's OOP max.

The Biden administration can put an end to co-pay accumulators by reversing the 2021 Notice of Benefit and Payment Parameters (NBPP) which allows health insurance issuers and pharmacy benefit managers to use co-pay accumulators. The US Department of Health and Human Services' own regulation defining "cost-sharing" states it: "includes payments made by or on behalf of an insured." This should include co-pays paid by assistance programs. We've asked members of the House to sign the McEachin-Davis letter asking the Biden Administration to make sure that all co-pays count for patients. We've asked members of the Senate to support this letter and to consider drafting a similar letter asking the Biden Administration to make sure that all co-pays count for patients.

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

- National Institutes of Health (NIH): Funds biomedical research on bleeding disorders. NIH is working to implement a national

blueprint for research on inhibitor prevention and eradication.

- Centers for Disease Control and Prevention (CDC): Funds HTC surveillance and prevention activities and supports outreach and education programs provided by national bleeding disorders patient organizations.

- Health Resources and Services Administration (HRSA): Provides funding for HTCs to provide multi-disciplinary services not typically covered by insurance, such as physical therapy and social work services. Also, as HRSA grantees, most HTCs participate in the 340B Drug Discount Program, which supports comprehensive care offered to all of their patients. We've also asked Congress to support COVID relief provisions being considered that make it easier for people to get coverage, including:

- Financial incentives for states to expand Medicaid

- Subsidies for people to maintain employer-sponsored coverage via COBRA

NHF urges Congress to pass these provisions into law and to enact permanent policies to make coverage more accessible for people with bleeding disorders and others with chronic conditions.

HOW YOU CAN HELP

- Schedule virtual meetings with your local legislators. We will work with you one on one to go over talking points and tips on how to share your story, and we will join you for your meeting. Contact Kara at kara@wpcnhf.org or 724-741-6160 if you are interested.

- Sign up for action alerts and find your legislators at - <https://p2a.co/2rCTRxm>

Do you use copay assistance to afford treatment for your bleeding disorder? Have you faced high out-of-pocket costs for your treatment? If you answered yes to either of these questions, we want to hear from you! Please take our survey at:
<http://bit.ly/accadj21>

BECOME AND ADVOCACY AMBASSADOR

Advocacy Ambassadors are volunteers interested in helping to lead our state's grass root advocacy efforts and promote the importance of being an advocate within our community. Advocacy Ambassadors participate in the following in-person and online activities:

- Help recruit new advocates to join our ambassador program

- Help to develop state-based advocacy events and campaigns for increasing awareness on the issues of importance to the families and caregivers

- Contribute to our state and national campaigns

- Represent our state at advocacy events

- Develop relationships with key decision-makers on state and national policy issues

- Help mobilize our state in advocacy throughout the year, especially during March, the Bleeding Disorders Awareness Month

- Represent both PA Foundations positively

If you would like to become an Advocacy Ambassador please contact Kara or Janet for more information. Kara Dornish - kara@wpcnhf.org Janet Barone - janet@wpcnhf.org ■

PROCLAMATION

WPCNHF is proud to share this proclamation from Governor Tom Wolf proclaiming April 17, 2021 World Hemophilia Day in Pennsylvania. ■



Governor's Office

PROCLAMATION

WORLD HEMOPHILIA DAY
April 17, 2021

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 3,000 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, 2021, 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 eighth day of March two thousand twenty-one, the year of the commonwealth the two hundred forty-fifth.

Tom Wolf
TOM WOLF
Governor

2020 UNITE RALLY

The National Hemophilia Foundation hosted their annual Unite Rally virtually on February 1st – 4th. Each year, chapter leaders from across the country come together to celebrate the success of the previous walk year and kickoff the new walk season. Because this event moved virtual, NHF was able to extend the invitation to team captains, volunteers, and committee members from each chapter. Throughout the week, we heard from engaging speakers and gained many helpful fundraising tips.

The week opened with an Awards Ceremony on Monday night. Mindy Perry, chapter board member and team captain of Rolling for Ryker, was one of the winners of NHF's Volunteer Awards! Mindy had the chance to record a video and share her fundraising tips and goals with other team captains.

Congratulations, Mindy! Thank you for everything you do for the Chapter! Thank you to all our team captains and volunteers who attended the Unite Rally!

Registration is now open for the 2021 Unite Walk! You can register yourself or create a team at: <https://uniteforbleedingdisorders.org/event/wpa>. ■

Unite
for Bleeding Disorders



HCWP CORNER

KATHALEEN SCHNUR, LSW

Dear HCWP Patients and Families,

The HCWP welcomed two new hires to our Center, Mike Traeger and Christiana Ekekwe. Mike is a clinic nurse. He spent the last six years working at AGH emergency department. He works part time as a paramedic in his local community. Mike is married and has three grown children. He enjoys staying active for his overall health and wellbeing. Christiana Ekekwe is a research nurse. She was a clinical research coordinator at Magee Women's Hospital. Christiana is married and has two lovely boys. She loves to make friends and claims to be the pickiest human alive.

The clinic continues to offer both in-patient and telehealth clinic appointments to meet the needs of our patients. Our adult patients need to be seen every year or at least every other year depending on your doctor's recommendation.

Our pediatric patients need to be seen at least yearly or twice per year depending on diagnosis and treatment. The center mails reminder cards when it is time to schedule. Additionally, we are sending letters and outreaching by phone. Regular appointments with your hematologist and team is best practice to give you the best care. Please reach out to the center if you are having difficulty getting to your appointment. If you aren't sure when your last clinic visit was, please call and ask, we enjoy hearing from you.

Contact the center with any upcoming procedures, including dental, to minimize potential delays or even a need to reschedule. If you're reading this, check your home storage. Do you have a few unexpired doses of factor on hand? If not, give us a call! The center has an updated website that patients can use to order factor and submit treatment records; <https://hcwp.vitalant.org>. Please feel free to call with any questions.

Many of you are aware that the HCWP research team approaches

patients in clinic to share current studies. Dr. Ragni is part of an NHF research initiative to simplify the research approach with our community. Research plays an important role in patient care. It discovers new treatments, expands opportunities with current treatments, and can identify new information. Identifying and supporting patient needs and concerns around research can offer more opportunities moving forward. One of the current studies happening is exploring human microbiomes. We want to understand how the microbiome is involved in health and disease, especially regarding Hemophilia and inhibitor formation. Please reach out to the research team if interested.

Sending warm and healthy spring thoughts your way! Between the impact of COVID for the last year and a particularly long-feeling winter, I am ready to embrace the warmth and dance in the sun over the next few months. Take care and stay well! ■



WOMEN WITH BLEEDING DISORDERS: HOW TO BE YOUR OWN BEST PATIENT ADVOCATE

EMPOWER YOURSELF TO SPEAK UP AND GET THE CARE YOU NEED | AUTHOR: LIZ KRIEGER

For years, doctors dismissed Lisa Webb's heavy bleeding as just something that women in her family had to endure. Despite multiple miscarriages, two harrowing childbirth experiences, multiple surgeries and countless unexplained bruises, the cause of her problems remained unknown.

Finally, when she was 37, this

Texas homemaker was diagnosed with the rare bleeding disorder factor XI deficiency. While in a way all the pieces of her life came together, she also simultaneously fell apart. "I went down a rabbit hole and into a deep depression," says Webb, feeling deeply angry that she had gone so long without adequate testing, and that the medical professionals had simply

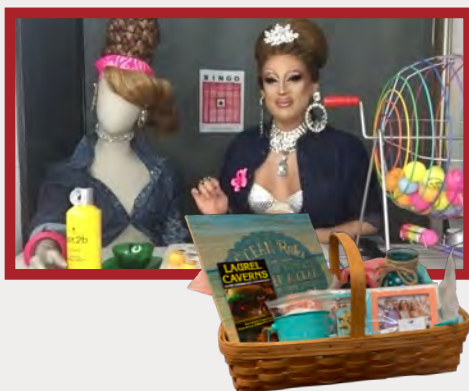
not believed that she could have a bleeding disorder.

Today, a decade later, Webb has become a passionate advocate not just for herself but also for other women with bleeding disorders—so they find the care they need.

Being an empowered patient is

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VIRTUAL DRAG QUEEN BINGO



WPCNH held a second Drag Queen Bingo Night fundraiser virtually over Zoom, on Thursday, January 28th. Over 30 people joined local Pittsburgh Drag Queen, Alora Chateaux, for an evening of entertainment and prizes. The cost to participate was \$15 per person and included the Zoom link to watch Alora's performance, a bingo card, and three rounds of bingo. Additional bingo cards were available for purchase for \$2 per card. Prizes included a spring-cleaning basket, a self-care basket, a beach basket, and a Neora Holistic Wellness basket. Prizes

were awarded to the first person to call out or type BINGO in the chat box for the first two rounds, while the final round winners needed to cover every space on their bingo board!

There were even more chances to win with two raffle baskets! Raffle tickets were sold online leading up to the event.

We are extremely grateful for everyone who participated in this event and are pleased to announce over \$700 was raised! All the money raised will support our emergency and medical patient assistance fund, educational programs, and support groups that benefit the bleeding disorders community in Western PA. WPCNH would like to thank everyone who participated in this event and are truly grateful for your continued support during these uncertain times. We hope to see you at our next bingo night! ■

TALKING ABOUT HEMOPHILIA



On March 28, Skye Peltier, MPH, PA-C, presented the program Talking About Hemophilia: How It Can Help, which was sponsored by Novo Nordisk. Skye is the Physicians Assistant at The Center for Bleeding and Clotting Disorders, University of Minnesota Medical Center, Fairview Medical Center and Faculty, Physician assistant Program, Augsburg College. The



program was held over Zoom for both patients and caregivers. After the presentation, Destinee Diprima, led us in a cookie decorating activity. Destinee is the mother of twin girls, one of whom has hemophilia; and she has a special talent for decorating cookies! Each family who registered was shipped a cookie kit prior to the event. The cookie kits included 12 pre-baked sugar cookies, 4 colors of frosting, and sprinkles from Confections of

a Cake Lover, in Meadville, PA. Destinee's cookie decorating demonstration was sponsored by Optum. Photos of Destinee's impressive, decorated cookies can be found on her Instagram page: @sweethillcookies

We thank Rita Wintermoyer, from Novo Nordisk, and Alicia Unger, from Optum for sponsoring this event. ■



WOMEN WITH BLEEDING DISORDERS: HOW TO BE YOUR OWN BEST PATIENT ADVOCATE

CONTINUED FROM PAGE 4...

always important, but when you're a woman with a bleeding disorder, having confidence that you can speak up and get the care you need is essential.

Even in 2020, long-standing gender, racial, ethnic and religious biases often make it difficult for female patients to be fully heard, says Christie VanHorne, MEd, MPH, a public health consultant based in Poughkeepsie, New York, who specializes in patient empowerment and in women with bleeding disorders.

"Bias in healthcare presents itself when women and those from marginalized groups are ignored, misdiagnosed, dismissed or are the recipients of systemic bias within the healthcare system," says VanHorne, founder of How to Talk to Your Doctor, a project that inspires and educates people to be more active participants in their healthcare.

"Women are sometimes not trusted by medical professionals to understand the symptoms they experience, or they're made to feel that those symptoms are all in their heads."

A TROUBLING HISTORY

History plays a role in why this bias has continued, VanHorne says. For years, women of childbearing age were left out of clinical research for fear that it might harm a fetus or interfere with fertility. Plus, the idea that medical problems are all in a woman's head stems from the history of the term "hysteria," which was a mental disorder attributed to women only. "The term was removed from the diagnostic manual in the 1950s, but women

are still stereotyped as being hysterical or 'crazy,'" VanHorne says.

Then there are the systemic barriers that women can face. These include problems securing transportation for appointments, finding qualified, well-informed doctors in certain areas, difficulty getting child care and sparse insurance coverage. "The more intersectional a woman's identity is (i.e., the more societal groups she belongs to that are discriminated against), the more likely it is that she will encounter these sorts of biases and issues," VanHorne says. Women with bleeding disorders face other unique barriers, since many providers still view bleeding disorders as affecting only men.

"Many women are dismissed because of a lack of knowledge of the conditions by physicians, and some doctors may brush off their patients' symptoms as just a family history of heavy periods," VanHorne says.

Webb says primary care doctors she sees often either don't believe it's possible for women to have bleeding disorders or are woefully undereducated about them, because little is taught about bleeding disorders in medical school.

WHAT YOU CAN DO TO BE MORE EMPOWERED

To be a more empowered patient, here's what VanHorne and Webb recommend:

Find a doctor who will act as a partner in your care.

"That means someone who will listen and believe your lived experiences and symptoms," VanHorne says. "This is key for a proper diagnosis, treatment

and long-term management. If you don't trust your doctor, you won't go to that doctor when you really need to." You want to feel comfortable asking as many questions as you need to. Some specific tips:

- If you live in a rural area where providers are scarce, or you've tried various doctors and continue to feel dismissed, VanHorne recommends asking your hemophilia treatment center if there's a doctor you can connect with through telemedicine. "This technology is helping women have more options when it comes to finding a provider," she says.

- If you have private insurance or Medicaid, do not let your insurance force you into a specific provider. Reach out to advocacy organizations such as the National Hemophilia Foundation (NHF) or local communities to help navigate the system.

Know your family history, but also know your own body.

"You don't have to accept that this is just 'how it is' for women in your family or that you are just a 'heavy bleeder,'" VanHorne says. "If you feel like something is wrong, then it's so important to find a doctor who will listen and trust your lived experiences and symptoms."

Use your voice, and tap your resources.

"It is not your job to be liked," Webb says. She routinely brings informational pamphlets about women and bleeding disorders to doctor and dentist appointments to enlighten and educate providers. You may find it helpful to bring a trusted friend or relative with you, especially if that will help you better advocate for yourself. Webb

says you can—and should—walk away from a medical practice or doctors who are dismissive of you or are resistant to the information you give them. “That’s something I’ve had to do numerous times,” she says.

Bring detailed notes with you to appointments.

For women who menstruate, data is your friend, Webb says. “Keep a detailed journal of your periods—how long they are, how heavy, how many sanitary products you use. Having information like that can be critical when you see a new provider, but it will also help you feel more empowered with a provider you’ve been seeing for a while,” she says.

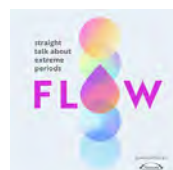
Stay up to date on your bleeding disorder.

“Keep educating yourself, because

that can truly improve the quality of your life,” Webb says. “While I don’t recommend turning to Google to seek out reputable information, there’s plenty of information online that’s verified and from good organizations,” including NHF and scientific journals.

Article Courtesy of HemAware copyright 2020 ■

CHECK IT OUT: PODCASTS FROM BELIEVE LIMITED!



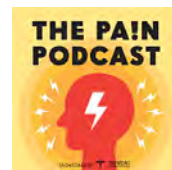
FLOW - STRAIGHT TALK ABOUT EXTREME PERIODS

A monthly show for women with bleeding disorders,

menstruating individuals who experience extreme bleeding, and those looking for more access to menstruation-health information!

Hosted by Christie VanHorne (HowToTalkToYourDoctor.com; formerly NHF and HFA) and Jessica Richmond, speak with experts

about extreme menstrual bleeding. Subscribe to FLOW wherever you listen to pods, or find the show via BloodStreamMedia.com.



THE PAIN PODCAST

A show dedicated to the massive topic of “chronic pain.” In Season 1 (released 2020), we heard

from expert surgeons, pain medicine specialists, chiropractors, and others to better understand the current clinical consensus around chronic pain. In Season 2 (out now!), we hear from patients with hemophilia, fibromyalgia, and a wide-range of conditions to learn more about the pain experience of living with chronic pain. The Pain Pod is also available everywhere you’ll find podcasts and on BloodStreamMedia.com. Please listen and subscribe today! The Pain Pod is made possible thanks to Tremeau Pharmaceuticals. ■

DEDICATION AND PERSONAL SUPPORT



Introducing your **Pfizer Patient Affairs Liaison**, a professional dedicated to serving the rare disease community by connecting patients, caregivers, and patient advocacy organizations with Pfizer Rare Disease tools and resources. A Patient Affairs Liaison’s work is guided by the principles of **compassion**, **commitment**, and **connection**.

Michael Sager

WV, Western PA, Western NY, Northern and Central Ohio

I’m here to:



Provide compassion by understanding the needs of patients, caregivers, and patient advocacy organizations and serving as a point of contact for questions they may have



Maintain commitment by educating patients and caregivers about Pfizer Rare Disease patient support resources



Facilitate connection by providing educational programs that bring patients, caregivers, and patient advocacy organizations together to share experiences and support advocacy for their communities

“
I’m dedicated to connecting you with the resources and information you need. Feel free to contact me at any time in English, Spanish, or Portuguese. I look forward to serving you!
”



To get in touch with Michael:



330-413-9755

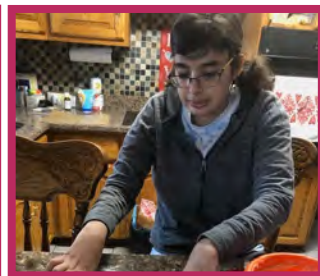


michael.sager@pfizer.com



LET'S GET BAKING!

In February, the Chapter partnered with Cottrill's Pharmacy to bring our member's a fun and educational project that could be done on their own schedule. Kits with just about everything needed to bake and decorate homemade cookies were mailed to each family who registered, and a gift card to purchase a few fresh ingredients was also included. Melissa Kendrick, Cottrill's Pharmacy, assembled the amazing cookie kits which included pre-measured dry ingredients, a variety of sprinkles, parchment paper, oven mitt, and a heart-shaped and a blood drop shaped cookie cutter. Melissa also recorded a video with instructions for making the cookies. Katherine Bush, Hemophilia Center of Western PA, was also featured in the video. Katherine explained the



blood clotting process in terms that could be easily understood. We really enjoyed the photos that everyone shared of their cookie creations! If you would like to view the video, it can be found on the Chapter's website: <https://www.wpcnhf.org/baking/>

We thank Melissa Kendrick, from Cottrill's Pharmacy, for sponsoring this program. ■



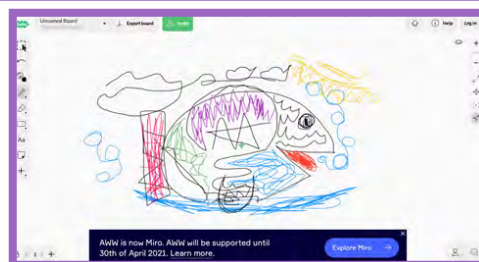
TEEN GROUP

RAINA S., TEEN GROUP CO-COORDINATOR

To kick off the beginning of Spring, the Teen Group attended a virtual Leading Edge program with GutMonkey. Leading Edge programs are experiential programs that are implemented by GutMonkey and sponsored by Pfizer. Teens participated in a series of activities to stay connected, during this time of separation.

As an icebreaker, GutMonkey instructors Tom Hamm and Haelynnne Barron started with asking the teens, "If you could make one small animal big, and one big animal small, what would that animal be and why?" After each teen got an opportunity to share, Tom led the group in a more interactive activity – a scavenger

hunt! He asked the teens to find something that correlated to a category such as, "something you have from a vacation," or "something that smells," and teens would be given an amount of time to find something that fits. After the scavenger hunt, Haelynnne guided the teens through a personality quiz. They were asked to name their three favorite animals and qualities they liked about them. The first animal listed represented how you see yourself, the second animal was how others see you, and the third animal was how you truly are. Our last activity of the night was virtual drawing! Partners were given a challenge to draw one singular line, and let the other person build

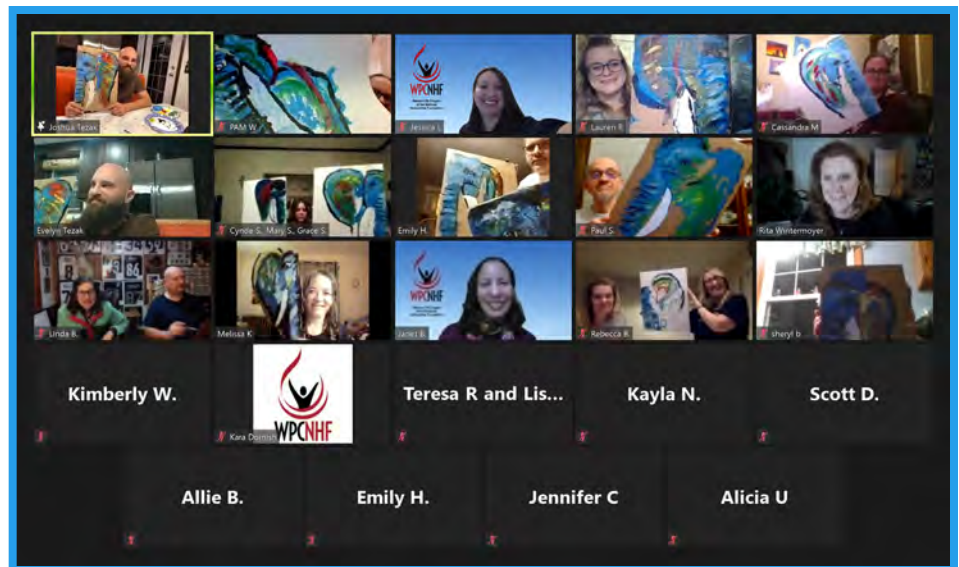


off of it. Eventually, it would make a work of art! To wrap up the event, we took a virtual group picture. ■



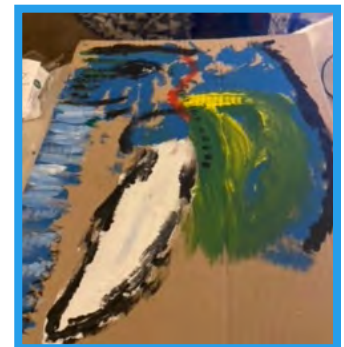
COPING WITH ANXIETY AND DEPRESSION

The Chapter continues to recognize the need for mental wellness programs in the bleeding disorders community and continues to provide educational opportunities. On February 25, 2021, we held our second program of the year that focused on mental well-being. Jennifer Maahs, RN-BC, MSN, PNP presented the program Coping with Anxiety and Depression. This program was sponsored by Novo Nordisk and it provided an overview on anxiety and depression in the bleeding disorders community. After the program, Cottrill's Pharmacy sponsored a painting activity. Josh Tezak, Cottrill's Pharmacy, guided us in creating a painting using both our fingers and paint brushes. The



results were amazing! We enjoyed seeing the variations in everyone's work of art!

We thank Rita Wintermoyer, from Novo Nordisk, and Melissa Kendrick, from Cottrill's Pharmacy, for sponsoring this event. ■



GETTING TO KNOW HCWP STAFF



DANA IVANCO
SENIOR REGULATORY COORDINATOR

Birthplace: Illinois

First job: Gym Trainer Assistant

Accomplishment you're proudest of: Getting to where I am today in life!

What three words describe you best? Outgoing, Caring, Determined

Dream vacation: Hiking across Ireland

Things you can't do without: Makeup and dresses!

Person you'd most like to have dinner with: My husband

Movie you could see anytime: Mamma Mia

TV show you try not to miss: Law and Order

Three things that can always be found in your refrigerator: OJ, Pickles, Milk

Secret vice: Hallmark movies

Who would play you in the movies? Lily James

Your pet peeve about Pittsburgh: Traffic

People may be surprised to know that: I have done an Iron Girl Triathlon

GO SEEK. GO EXPLORE. GO AHEAD.

PEOPLE LIKE YOU. STORIES LIKE YOURS.
Explore more at HEMLIBRAjourney.com



Discover your sense of go. Discover HEMLIBRA.

What is HEMLIBRA?

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

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

HEMLIBRA increases the potential for your blood to clot. People who use activated prothrombin complex concentrate (aPCC; Feiba®) to treat breakthrough bleeds while taking HEMLIBRA may be at risk of serious side effects related to blood clots.

These serious side effects include:

- **Thrombotic microangiopathy (TMA)**, a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs
- **Blood clots (thrombotic events)**, which may form in blood vessels in your arm, leg, lung, or head

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


HEMLIBRA[®]
emicizumab-kxwh | 150
Injection for subcutaneous use mg/mL

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

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

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

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

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

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

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

What is HEMLIBRA?

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

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

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

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

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

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

How should I use HEMLIBRA?

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

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.

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

What are the possible side effects of HEMLIBRA?

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

The most common side effects of HEMLIBRA include:

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

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

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

How should I store HEMLIBRA?

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

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

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

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



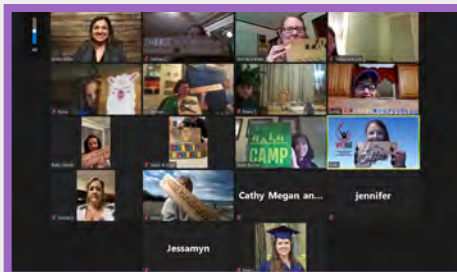
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Genentech
A Member of the Roche Group

BUILDING YOUR SUPPORT SYSTEM

With any chronic condition, having a good support system can make a huge difference on both mental and physical well-being. Benefits can include reduced anxiety, depression, and stress and an increase in overall well-being. It's important to have supportive relationships during both good times and tough times.

On January 16, Krissy M., a patient advocate with CSL Behring, shared her story with us about her experiences building a support network both in-person and online. Afterward, Jessica Graham, CSL Behring, led us in a sign painting workshop. The signs turned out beautiful! It was fun to see everyone's personality shine through in their work!



We thank Kelly DeVito and Jessica Graham, from CSL Behring, for sponsoring this event. ■

CSL Behring



SAVE THE DATE

Unite
for Bleeding Disorders

RUN FOR
THEIR LIVES

13TH ANNUAL UNITE FOR BLEEDING DISORDERS WALK

12TH ANNUAL RUN FOR THEIR LIVES 5K

**SATURDAY
SEPTEMBER
18
2021**

FOR MORE INFORMATION, VISIT:
WWW.WPCNHF.ORG



NEW PARENT NETWORK

The New Parent Network 2021 series of events kicked off with a lively virtual event for children and parents! The event took place on March 7, 2021 and all family members were invited and encouraged to participate. Prior to the event, each family who registered received a package with items for the event.

The focus of this event was to introduce young children, through play, to objects and terminology associated with bleeding disorders. We created a set of flashcards for each family and included them in the event package, along with some snacks and prizes for the kiddos!

Kathaleen Schnur, Social Worker at the Hemophilia Center of Western PA, led the families through the program using the cards to guide a discussion around the common series of events associated with an onset of a bleed to treatment. The kiddos were full of energy and enthusiastically showed us their cards when they matched the card Kathaleen was holding up! The families can use the cards in the future to continue to familiarize children with bleeding disorders terminology and reinforce safety tips, as well as expand on the discussion as their child's level of comprehension increases. The cards can also be used for matching games like Concentration or Go Fish!

We thank the following organizations for sponsoring the 2021 New Parent Network series of events: CSL Behring, Hemophilia Center of Western PA, InfuCareRX, and Takeda! ■



Sunday, May 9, 2021 • 3:00 PM - 5:00 PM

Cost:

Registration with kit pick-up: \$25 | Registration with kit shipping: \$35

Celebrate Mother's Day while supporting the Western Pennsylvania Chapter of the National Hemophilia Foundation! Join us on Sunday, May 9th from 3-5 pm. Local artist, Mickayla Poland, will provide step-by-step instruction on how to create a beautiful spring scene on a wine glass.

Painting kits will include one wine glass, 2 paint brushes, 5 paints, and instructions to care for your glass. Kits can be picked up at the Chapter office or shipped to you.

Our Chapter Office is located at:

20411 Route 19, Unit 14
Cranberry Township PA 16066

Kits can be picked up starting May 3rd between 9 am - 4 pm. More information about coordinating a pick-up will be sent after you register.

The final day to register is Saturday, April 24th.

Don't forget your Sip!

ONEHOPE

WPCNHF is partnering with One Hope Winery to raise additional funds for the bleeding disorders community! 10% of your wine purchase (minus tax and shipping) between April 25th and May 9th will be donated to WPCNHF! More information on how to purchase wine can be found at the link below.

Register Today at: give.classy.org/wpcnhfpaint

MARCH IS BLEEDING DISORDERS AWARENESS MONTH

March is nationally recognized as Bleeding Disorders Awareness Month. During Bleeding Disorders Awareness Month, we invite members, friends, and supporters of the bleeding disorders community to join us in raising critical awareness and funds to improve the lives of those diagnosed with a bleeding disorder.

This year, WPCNHF invited supporters and community members to celebrate online with Bleeding Disorders Awareness Month Bingo throughout the month of March. We challenged you to complete

as many squares as possible on your bingo card and try to get a bingo. We played by standard rules, so that meant 5 across, 5 down, or 5 diagonally. Everyone who got a bingo won a Unite for Bleeding Disorders T-Shirt!

Some of the challenges included making a donation, taking 30,000 steps during March, posting a selfie wearing

red, and posting a photo or sharing a memory from Washington Days! We also shared bleeding disorders facts on our social media pages and shared stories from our Advocacy Ambassadors!

Thank you to everyone who celebrated, advocated, and helped raise awareness for bleeding disorders throughout

the month of March! We hope to see you at our virtual World Hemophilia Day event on Saturday, April 17th! ■

Didn't have a chance to win a Unite Shirt? You can purchase a Unite shirt, baseball tee, or tank top at: give.classy.org/uniteshirts



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

Factor Program Services

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

Patient Benefits

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

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

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

Development Stages, Safety, and Your Child with Hemophilia



For more information, scan the QR code with your smartphone camera to access *Hemophilia B in Early Childhood*.



This content is brought to you by Pfizer.

Parents and caregivers are a child's primary nurturers, teachers, and protectors. Parents and caregivers of a child with hemophilia may find it easier to care for their child if they understand the stages of physical, emotional, and mental growth all children go through and how these stages can impact hemophilia care.

At every developmental stage, there are special considerations for children who live with hemophilia. When a child is about 6 months old, they can start to become more mobile, which may increase the chances for bruising or bleeding. While it's important to allow a child to explore and expand their newly acquired mobility, it's also important that their environment is safe. These are challenging times for caregivers, as there may be a tendency to be overprotective.

Knowing ahead of time how to prepare for a growing child with hemophilia may help in gauging the types of safety measures needed during these life stages. The following are some special considerations and safety suggestions to consider for a child living with hemophilia, but at all ages, be sure to consult with a child's treatment team when making health and safety decisions or in the treatment of injuries.

Infants 6 to 12 Months¹

- Bleeding episodes that need factor concentrate seldom occur during the first year
- Crawling and walking are important for muscle development despite the possibility for a bleeding episode
- Frequent playpen use is discouraged
- Infants with hemophilia may experience more bruising than infants who do not live with a bleeding disorder

- Head injuries should be reported to a health care provider immediately

The Toddler Years

- Lower the crib mattress to its lowest level to discourage climbing out, or consider putting the mattress on the floor²
- Discourage unsupervised climbing and jumping from high places or off furniture¹
- Always use an approved car seat according to your state's laws¹
- Avoid excessive roughhousing²
- Use a helmet when skating, biking, or riding a scooter²

The Preschool Years

- Use ice to help reduce bruising and ease discomfort²
- Encourage a well-balanced diet to assist with staying fit and trim in order to avoid joint stress from excess weight²
- Promote regular flossing and brushing teeth with a soft brush²
- Talk to the dentist about your child's hemophilia diagnosis²
- NHF recommends the hepatitis B vaccine (recommended for all children) and the hepatitis A vaccine (above 2 years old)³

Parenting infants, toddlers, and preschoolers can be a challenge for any family. Families may benefit from the extensive resources offered in the hemophilia community, including printed materials, family get-togethers, educational conferences, emotional support, and comprehensive hemophilia care at a local hemophilia treatment center.

References: 1. Hemophilia of Georgia. Safety Issues. <http://www.hog.org/handbook/section/5/safety-issues>. Accessed July 8, 2020. 2. National Hemophilia Foundation. Caring for your child with hemophilia. <https://www.hemophilia.org/sites/default/files/document/files/Caring%20for%20Your%20Child.pdf>. Accessed May 10, 2020. 3. National Hemophilia Foundation. MASAC recommendations for hepatitis A and B immunization of individuals with bleeding disorders. <https://www.hemophilia.org/Researchers-Healthcare-Providers/Medical-and-Scientific-Advisory-Council-MASAC/MASAC-Recommendations/MASAC-Recommendations-for-Hepatitis-A-and-B-Immunization-of-Individuals-with-Bleeding-Disorders>. Accessed May 10, 2020.



Patient Affairs Liaisons are Pfizer employees who are dedicated solely to providing support to the community. Your Pfizer Patient Affairs Liaison is available to help you access the support and information you need. To find your Patient Affairs Liaison, go to pfizerpalfinder.com or call Pfizer Hemophilia Connect at 1.844.989.HEMA (4366).



WESTERN PENNSYLVANIA CHAPTER OF THE NATIONAL HEMOPHILIA FOUNDATION
20411 Route 19, Unit 14
Cranberry Township, PA 16066

*Happy World
Hemophilia Day*



from WPCNHF's Staff



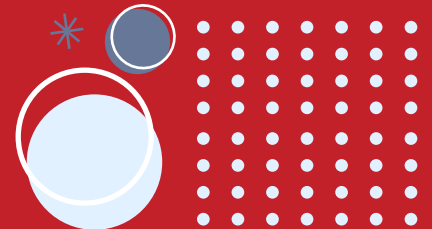
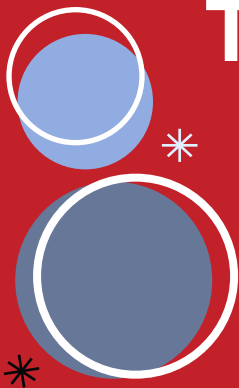
SAVE *the* DATE

WPCNHF'S VIRTUAL ANNUAL MEETING AND WALK KICK-OFF

THURSDAY, JULY 22, 2021

FOR MORE INFORMATION, VISIT:

WWW.WPCNHF.ORG



HEMOGRAM

WESTERN PENNSYLVANIA CHAPTER OF THE NATIONAL HEMOPHILIA FOUNDATION

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

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