



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

Fall 2020
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Annual Meeting

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Calendar of Upcoming Events

October 10, 2020
Unite for Bleeding Disorders Walk
Virtual

October 24, 2020
Women's Group - Winter Wreath
Making Workshop
Virtual

October 25, 2020
Zombies of the Corn Fundraiser
Freedom, PA

November 7, 2020
Fall Program
Virtual

November 16-21, 2020
Take A Bough
Virtual

December 1, 2020
World Aids Day and Giving Tuesday

December 6, 2020
Family Winter Program
Virtual

Hemogram

11th Annual Run for Their Lives 5K!

The annual Run for Their Lives 5K looked a little different this year as it turned into a virtual 5K instead of an in-person race. For \$20, participants could sign up online for a digital race bib and digital finishers certificate. They could add a race medal for \$5 or a t-shirt for \$10. They could run, walk, or skip 3.1 miles between September 12, 2020 and October 10, 2020. Participants could submit their times online and could print out their finisher's certificates.

We are excited to report that nearly \$5,000 was raised! All the money raised went towards emergency and medical patient

assistance, educational programs, and support groups to benefit the bleeding disorders community in Western PA.

The sponsors of the event included: The Hemophilia Center of Western Pennsylvania, CSL Behring, and Bayer.

WPCNHF would like to thank all who participated in and sponsored this event. Next year's Run for Their Lives 5K is scheduled for September 18, 2021 at the North Park Pool Autocross. We can't wait to see everyone there!



Second Annual Ballers for Bleeding Disorders

On September 20, 2020, WPCNHF hosted their second annual Ballers for Bleeding Disorders paintball fundraiser at Three Rivers Paintball in Freedom, PA.

Twelve people played in the tournament. The cost was \$40 per person and included admission, rental paintball gun, all day air, goggles, and 200 paintballs. Registration began at 11:30 a.m. and the players were on the field by 12:30. The tournament lasted until 4:30 p.m. Spectators were able to get in on the action and try their hand at target practice for \$10 per person.

Thank you to Erek and Scott Domowicz for their great working planning and putting on this fundraiser and Three Rivers Paintball for hosting this event. Thank you to Dye Paintball, courtesy of Dangerman, Carbon,

Gatormaille, and Dunedain for supporting the event and providing multiple items to our raffle!

The Ballers for Bleeding Disorders logo was updated this year as the Chapter introduced new tiered supporter levels for our paintball players. With each level, individuals can earn a Ballers for Bleeding Disorder T-Shirt, Velcro patch, or discount code for the next

tournament. You can check out the supporter levels at give.classy.org/ballers-for-bleeding-disorders.

This year, over \$3,000 was raised to support emergency and medical patient assistance, educational programs, and support groups to benefit the bleeding disorders community in Western PA. The sponsors of the event included The Hemophilia Center of Western Pennsylvania, Novo Nordisk, CSL Behring,

and Bayer. We hope to see everyone at our next Ballers for Bleeding Disorders fundraiser taking place this Spring.



SAY HELLO TO JAMES

He has hemophilia A and has gone through two major surgeries while keeping to his factor regimen with the support of his hemophilia care team

"RECOVERY WAS TOUGH,
BUT I LEARNED I HAD
MORE SUPPORT THAN
I THOUGHT POSSIBLE."



Read stories like James' in
Hello Factor magazine:
BleedingDisorders.com



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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.

Letter from HCWP

Dear HCWP patients and families,

The pandemic continues to challenge our world, our nation, our state, our communities, and our personal lives. Our daily life experiences have greatly shifted in how we work, for some schooling, shopping, connecting to others, and how we celebrate milestone events. However even during these moments of grieving the normalcy of life six months ago, amidst the stress and frustration, we continue to make attempts to adapt and find new ways to connect with each other. We are grateful to witness so much virtual connection among our bleeding disorders community. Many events and conferences have transitioned to virtual formats to keep the community supported and engaged. Many of the bleeding disorder organizations are offering additional support to the patients and families financially impacted during the

pandemic. We encourage our families to keep connected and call us for assistance.

Our Medical Director, Dr. Ragni, wants to share that there appears to be no greater risk of COVID among patients with hemophilia. The symptoms and management of hemophilia patients who do develop COVID is the same as those without hemophilia, except for continuing factor/or nonfactor therapies during standardly used anticoagulation to prevent thrombosis related to COVID.

Our clinic is seeing patients both in person and through telehealth. Dr. Ragni continues to only do telehealth appointments with her patients. Doctors Seaman and Xavier are offering both in-person and telehealth to meet the needs of our patients and their families. In-person visits require a phone screening and an in-person screening (fever, exposure, and any symptoms), we also require masks of both patients, supports, and staff. Additionally, when doing telehealth, the complete team

will be outreaching to you to assess your needs and support you as needed. HCWP is working with our parent company Vitalant to formalize a video conferencing format for our patients and families to use in the future.

Our doctors are moving forward with many research projects. Some of them include an array of VWD studies, inhibitor studies, joint disease studies, and the genetics and bleeding in rare bleeding disorders. Many of these are listed on our website; <https://hcwp.vitalant.org>. We encourage interested patients to ask about these in clinic.

On a final note, you are our patients and families, your appointment is ongoing even when you leave the office. We strongly urge you to call us with concerns and needs. Stay safe and stay well.

~Kathleen Schnur

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



For more information, visit
b2byourvoice.com to download
*Learn from Experience: A Guide for
Mature Adults*.

This content is brought to you by Pfizer.

How Hemophilia Affects Mature Adults

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

The Risk of Clinical Depression

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

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

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

— Judy Bagato

RN, BSN, Hemophilia Specialist

Finding Support for Complex Issues

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

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



**PATIENT
AFFAIRS
LIAISONS**

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

Letter from the Executive Director

Dear Chapter Members and Friends,

Happy Fall! Can you believe it is October already?! I am thrilled to continue serving the bleeding disorders community as I begin my 8th year with the Chapter.

Fall is an exciting time at the Chapter! The virtual Unite for Bleeding Disorders Walk will be held on October 10th and our virtual Fall Program will be held on November 7th. This year looks different, but we hope it is still a time for us to learn, unite and celebrate.

I know this has been tough! Work and school are so much different this year. We are all feeling a bit zoomed out and maxed out. With mandates and guidelines changing all the time, it is easy to feel overwhelmed by our own anxieties. Please remember we are all in this together—

think of others, reach out however you can, and remember to ask for help if you need it.

I hope to see you all at our virtual Take A Bough event this year! In addition to bidding on beautiful holiday trees, wreaths, and centerpieces there will be special appearances from local wineries in the area to teach us how to make different drinks. It will be a fun evening as we cheer each other on and raise awareness and funds for the bleeding disorders community.

Thank you for all that you do on behalf of WPCNHF.

Much Love and Appreciation,

Kara Dornish

Kara Dornish
Executive Director

Letter from the President

Hello Chapter members,

What a challenging year this has been for all of us, including the staff at the Chapter office. Their ability to adapt to change and make progress into new programming and overall functions of the Chapter is truly appreciated. I have to say, I am enjoying these virtual events. They are interesting and are more accessible to many of our members.

Our fundraising activities have been impacted by the pandemic. We are extremely grateful to our sponsors and members who have continued to support the Chapter during this difficult time. If your means allow, please consider making a donation or supporting an upcoming fundraiser. For those who are experiencing

financial hardships due to COVID, please remember that there are various patient assistance programs available to people living with a bleeding disorder. If you are in need, please contact the Chapter for more information.

Lastly, I want to thank the board members for their continued efforts to make the chapter better for our members. There is a lot of hard work going on behind the scenes that you might not be aware of. Thank you for your continued dedication and commitment to the bleeding disorders community.

Regards,

Michael Covert
WPCNHF Board President

Community Announcements



Guy Law graduated from Full Sail University with a Master's in Entertainment Business on June 26, 2020.

Guy and Miranda Law were married June 20, 2020, in Erie, PA.



Elijah and Stephanie Shropshire gave birth to a baby boy on September 9, 2020. His name is Lev Hunter Shropshire and weighed 6 lbs 7 oz.

Board of Directors

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

Mission Statement:

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

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

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



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

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

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

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

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

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

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

What is HEMLIBRA?

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

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

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

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

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

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

How should I use HEMLIBRA?

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

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

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

What are the possible side effects of HEMLIBRA?

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

The most common side effects of HEMLIBRA include:

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

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

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

How should I store HEMLIBRA?

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

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

General information about the safe and effective use of HEMLIBRA.

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

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

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

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

HEMLIBRA® is a registered trademark of Chugai Pharmaceutical Co., Ltd., Tokyo, Japan

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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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Advocacy Update

State

On Friday, May 29, 2020 a 5-month budget was passed with the hemophilia line item fully funded at \$400,000 (5/12th). In addition, the language in the fiscal code reads: Funds appropriated for hemophilia services shall be distributed to grantees in the same proportion as distributed in fiscal year 2019-2020. 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.

We have been meeting with legislators to ensure this remains in place in the Pennsylvania state budget for the rest of the year.

Background: There are approximately 20,000 patients with bleeding disorders in the United States. More than 3,000 of these patients reside in Pennsylvania and are treated at one of the seven federally funded treatment centers in Pennsylvania. These seven centers are recognized as centers of excellence federally and by the commonwealth. The seven Pennsylvania Hemophilia Treatment Centers include:

1. The Children's Hospital of Philadelphia (Philadelphia)
2. St. Christopher's Hospital for Children (Philadelphia)
3. Hospital of the University of Pennsylvania (Philadelphia)
4. Penn State Hershey Medical Center (Dauphin County)
5. Thomas Jefferson University Hospital (Philadelphia)
6. Lehigh Valley Hospital (Lehigh County)
7. The Hemophilia Center of Western Pennsylvania (Allegheny County)

In 1974, Pennsylvania became one of the first states in the U.S. to establish a state hemophilia program to improve patient medical outcomes, providing annual state funds to support comprehensive hemophilia treatment centers in Pennsylvania. Since then, these programs have provided care to individuals with hemophilia and other inherited bleeding disorders, such as von Willebrand Disease,



through a comprehensive model of care.

Each year we advocate that the funding for hemophilia in the state budget is maintained at \$959,000.

This year we ran into trouble. In previous years, these funds have been distributed through something called a Sole Source Request. This ensured that if the hemophilia line item was in the budget that all 7 hemophilia treatment centers in Pennsylvania would receive funding.

The Department of Health tried to put an end to this with a new grant process called Request for Applications or RFAs. The RFAs will use a regional approach developed by the Department of Health based on the Pennsylvania Health Choices Five Regions.

On this map, you can see the five regions which are in different colors and stars showing where each of our seven hemophilia treatment centers are.

As soon as this information was released, we were contacted by many of the treatment centers with concerns. We had a lot of questions about why this model was chosen, who will get the funding for the two northern regions where no treatment centers are and how will funding be broken up between the eastern regions where there are multiple centers? So both the Western and Eastern PA Hemophilia Foundations compiled the questions that our HTCS had and scheduled a meeting with the Department of Health.

On January 16th Kara and Jessica along with Curt and Lindsay from the Eastern PA Chapter and Dr. Eyster from the Penn

State Hershey Hemophilia Treatment Center met with the Department of Health to get answers and voice our concerns.

What we found out is...

- There will be one grant awarded per region.
- Applicants may apply for multiple regions. So, in our case in Pittsburgh, The Hemophilia Center of Western PA will be able to apply for both the southern and northern regions on the western side of the state.

However, even though our center is recognized as a world class HTC with a multidisciplinary team of experienced care providers, this model allows the potential for other entities that may not be as qualified to receive funding that should be going to our HTC just because of where they are located on the map.

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

be responsible for the administrative burden and how will the funding be divided among them? The Department of Health did not have answers for this.

It became very clear to us that this one-size fits all approach that the Department of Health is requiring for all specialty care programs clearly doesn't work for hemophilia and will only jeopardize our HTC's funding.

Our ask to legislators is to:

- 1) Keep the Hemophilia Program as a separate line item in the budget
- 2) Maintain the funding at the current fiscal year amount of \$959,000
- 3) Keep the distribution of funds, as in previous years, to all seven-state supported hemophilia treatment centers and not based on the 5 PA HealthChoice Regions

Federal

We are asking legislators to co-sponsor The Hemophilia SNF Access Act (S. 3233 / H.R. 5952): Improve Access to Skilled Nursing Facility Care for People with Bleeding Disorders

Why do Patients with Bleeding Disorders Need Access to SNFs?

- People with hemophilia and other bleeding disorders are referred to skilled nursing facilities (SNFs) to aid recovery and ensure appropriate management of complications after a hospitalization due to surgery related to joint damage caused by internal bleeding episodes or due to co-morbidities, such as HIV/AIDS and hepatitis.
- SNFs are the medically appropriate setting because they provide short-term, intensive, inpatient rehabilitative services and have the medical and nursing expertise to provide a higher level of care than what patients can access at home.
- The number of Medicare beneficiaries with bleeding disorders is relatively small – estimated at fewer than 1,000 people and a much smaller number need access to a SNF in any given year.

Why Are There Access Problems?

- SNFs are paid a set daily rate for all services provided to patients covered under a Medicare Part A stay. This bundled payment includes nursing and therapy components, drugs, supplies, and equipment, in addition to a room/board and administration component to cover the cost of typical patients.
- People with hemophilia use clotting factor and other treatments to manage their chronic condition and allow the blood to clot. Bleeding disorder treatment costs alone following a surgery can be extremely expensive, exceeding \$10,000 per day.
- Costs for a person with a bleeding disorder will far exceed the daily rate for a highest-level SNF stay. Accordingly, it is extremely difficult to find a SNF that accepts patients with bleeding disorders due to the significant losses the SNF will incur as a result of treatment costs.
- Without access to SNF care, most patients stay in the acute inpatient setting longer, which increases costs for Medicare. Some patients are sent home, which has resulted in bad outcomes or hospital readmission since they are not able to access the level of coordinated, skilled care necessary for a successful recovery.

How will the Hemophilia SNF Access Act Solve this Problem?

- The Hemophilia SNF Access Act (S. 3233 / H.R. 5952) is bipartisan legislation that will allow SNFs to bill separately for bleeding disorders treatments and their administration.
- The bills add bleeding disorders treatments to the small list of costly, infrequent, and specialized services that SNFs can bill separately under Medicare Part B, which includes chemotherapy, radioisotopes, and certain prosthetic devices.
- This change to the Medicare law will remove the existing financial disincentive for SNFs to care for people with bleeding disorders.
- The bill will not increase Medicare costs as the policy is budget neutral.

Become an Advocacy Ambassador

Advocacy Ambassadors are volunteers in a leadership position responsible for helping to establish and build a strong grassroots network of bleeding disorders advocates within Pennsylvania. The goal is to increase awareness of Hemophilia, von Willebrand disease, and other factor deficiencies and the challenges persons affected and their families face. Ambassadors serve as liaisons between the Pennsylvania Hemophilia Foundations and the public, state agencies and officials working towards improving the quality of life of individuals and their families who are affected by bleeding disorders.



Why Should I Join?

Members of the Hemophilia Foundations of Pennsylvania Advocacy Ambassador Program are part of the hundreds of bleeding disorders community members throughout the nation working towards improving the lives of individuals with Hemophilia, von Willebrand disease and other rare bleeding disorders and assuring their access to affordable care and treatment. The opportunity to be an Advocacy Ambassador enables you to:

- Connect with other community members, caregivers, and stakeholders within our state and nation through calls, webinars, and in-person meetings and events
- Participate in local and national events to connect, learn and address the bleeding disorders leading issues
- Develop relationships with key decision-makers and opinion leaders
- Share your story to help other community members by raising awareness
- Address issues of access to treatment and care at the state and national level
- Increase the awareness of those challenges to key decision-makers and elected officials in the state that can take action to make essential changes

Contact Kara Dornish (kara@wpcnhf.org) or Janet Barone (janet@wpcnhf.org) to sign up to be a WPCNHF Advocacy Ambassador.



LIFE HAPPENS

AND ADVATE WILL BE THERE WHEN IT DOES

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

Not an actual patient.

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



[Antihemophilic Factor (Recombinant)]

REAL LIFE. REAL BLEED PROTECTION.*

AdvateRealLife.com

Prophylaxis with ADVATE prevented bleeds¹

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.¹ 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

¹Median 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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[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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Summer Events

Memories of summer 2020: Sunshine, record breaking temperatures, walking barefoot, fresh veggies from the garden, and Zoom meetings—yep, Zoom meetings. I typically feel that summers zoom by, but this year, zoom had a whole new meaning! Until mid-spring, the Chapter had never held an event over a video conferencing platform. By the end of summer, that was all we did!

When the pandemic hit, the Chapter's schedule was already set for the year and planning for many of our events was well

underway. When it became apparent that we would not be returning to the office in two weeks, or even two months for that matter, we started exploring ways to continue to support our community with educational and social opportunities. Like many other organizations, we converted our in-person events to online events and ran them through Zoom video conferencing.

During the months of July, August, and September, the Chapter held 14 virtual events including programs, social events, and fundraisers. While we still have several events on our schedule that will be held over Zoom this year, we recognize that some people are experiencing

“Zoom fatigue” from spending many hours working, schooling children, attending conferences, etc., online and we are exploring other ways to engage the community. We also realize that not everyone has access to the technology needed to participate in online events. The Chapter will hold in-person events again when it is safe to do so.

In this issue, you will find recaps of all the events we held this past quarter, which was the first quarter of the Chapter's fiscal year 2020-2021. We miss you all and hope you can join us for the remaining events on our 2020 calendar.

Understanding Gene Therapy and Its Potential Application to Hemophilia

Laureen Temple, Sr. Patient Education Liaison, Spark Therapeutics, gave an overview of Gene Therapy research, the basics of genetics and the role genetics play in hemophilia, how gene therapy is meant to work, and the challenges of gene therapy research. Gene therapy research has been taking place for more than 50 years and to date over 2,600 gene therapy clinical trials have been planned, are

ongoing, or have been completed.

If you are new to learning about gene therapy, there's a lot of information to absorb. We will continue to offer opportunities to learn about gene therapy research and clinical trials. In the meantime, you can visit www.hemophiliaforward.com to learn more.

We thank Spark Therapeutics for sponsoring this virtual event, which was held on July 9, 2020.



Genetics and gene therapy resources

Genetics Home Reference
<https://www.ghr.nlm.nih.gov>

Mayo Clinic
<https://www.mayoclinic.org>

American Society of Gene and Cell Therapy
<https://www.asgct.org>

Hemophilia Federation of America
<http://hemophiliafed.org/>

Special Issue of Dateline; Learning Central
<http://www.geneticalliance.org>

Genetic Alliance
<http://www.geneticalliance.org>

Global Genes
<https://globalgenes.org>

NORD (National Organization for Rare Disorders)
<https://rarediseases.org>

National Hemophilia Foundation
<https://www.hemophilia.org/>

Insights Innovation in Treatment
<https://www.yourgenome.org>

Your Genome
<https://www.yourgenome.org>

Genes in Life
<https://genesinlife.org>

Understanding von Willebrand Disease

On July 14, we held the program Understanding von Willebrand Disease. This event was planned in response to requests from members for von Willebrand-specific topics. Anyone who wanted to learn more about this bleeding disorder was welcome to attend this session. Jan Martin MSN, Senior Clinical Specialist, Takeda, presented the information. Jan has 37 years of nursing experience, including 15 years in the

Hemostasis and Thrombosis Center at University Hospitals in Cleveland.

The information included symptoms, types of VWD, treatment, and diagnosis. VWD is the most common bleeding disorder and it is estimated that 9 out of 10 people who have VWD aren't yet diagnosed. Unfortunately, diagnosis can be a complicated and frustrating process.

There are three main types of VWD. People who are diagnosed with VWD Type 1 have a quantitative deficiency—they have the von Willebrand Factor, but they have a deficient amount. People

diagnosed with VWD Type 2 have a qualitative deficiency and there are four sub types of VWD Type 2; Jan explained the differences in all of them. VWD Type 3 is typically the most severe form of VWD and people diagnosed with this type have a deficiency in the von Willebrand factor.

Would you like to learn more about VWD or an associated topic? If so, please call the Chapter or send an email to janet@wpcnhf.org

We thank Erik Drotos and Takeda for sponsoring this event.

When it comes to your hemophilia A treatment

Move beyond the threshold^a

A simple switch to Esperoct[®] can give you high factor levels for longer.^b

Extend half-life beyond the standard

22-hour average half-life in adults^c

High factor levels in adults and adolescents

At or above 3% for 100% of the time^{a,d}

At or above 5% for 90% of the time^{a,e}

Flexible on the go^c

The only extended half-life product with stability up to 104°F^f

^aTrough level goal is 1% for prophylaxis.

^bCompared with standard half-life products.

^cData shown are from 42 adults who received a pharmacokinetic (PK) assessment around the first Esperoct[®] 50 IU/kg dose.

^dData shown are from a study where 175 previously treated adolescents and adults received routine prophylaxis with Esperoct[®] 50 IU/kg every 4 days for 76 weeks. Pre-dose factor activity (trough) levels were evaluated at follow-up visits. Mean trough levels for adolescents (12-18 years) were 2.7 IU/dL.

^eSteady-state FVIII activity levels were estimated in 143 adults and adolescents using PK modeling.

^fFor up to 3 months.

What is Esperoct[®]?

Esperoct[®] [antihemophilic factor (recombinant), glycopegylated-exei] is an injectable medicine to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A. Your healthcare provider may give you Esperoct[®] when you have surgery

- Esperoct[®] is not used to treat von Willebrand Disease

IMPORTANT SAFETY INFORMATION

Who should not use Esperoct[®]?

- You should not use Esperoct[®] if you are allergic to factor VIII or any of the other ingredients of Esperoct[®] or if you are allergic to hamster proteins

What is the most important information I need to know about Esperoct[®]?

- Do not attempt to do an infusion yourself unless you have been taught how by your healthcare provider or hemophilia treatment center
- Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as: hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face

What should I tell my healthcare provider before using Esperoct[®]?

- Before taking Esperoct[®], you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII
- Your body can make antibodies called "inhibitors" against Esperoct[®], which may stop Esperoct[®] from working properly. **Call your healthcare provider right away if your bleeding does not stop after taking Esperoct[®]**

What are the possible side effects of Esperoct[®]?

- Common side effects of Esperoct[®] include rash or itching, and swelling, pain, rash or redness at the location of infusion

Please see Brief Summary of Prescribing Information on the following pages.

Discover more at [Esperoct.com](https://www.esperoct.com).



Novo Nordisk Inc., 800 Scudders Mill Road, Plainsboro, New Jersey 08536 U.S.A.

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esperoct[®]

antihemophilic factor (recombinant), glycopegylated-exei

esperoct®

antihemophilic factor (recombinant),
glycopegylated-exei

Brief Summary information about ESPEROCT® (antihemophilic factor (recombinant), glycopegylated-exei)

This information is not comprehensive.

- Talk to your healthcare provider or pharmacist
- Visit www.novo-pi.com/esperoct.pdf to obtain FDA-approved product labeling
- Call 1-800-727-6500

Patient Information

ESPEROCT® (antihemophilic factor (recombinant), glycopegylated-exei)

Read the Patient Information and the Instructions For Use that come with ESPEROCT® before you start taking this medicine and each time you get a refill. There may be new information.

This Patient Information does not take the place of talking with your healthcare provider about your medical condition or treatment. If you have questions about ESPEROCT® after reading this information, ask your healthcare provider.

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

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

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

What is ESPEROCT®?

ESPEROCT® is an injectable medicine used to replace clotting Factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder in all age groups that prevents blood from clotting normally.

ESPEROCT® is used to treat and prevent or reduce the number of bleeding episodes in people with hemophilia A.

Your healthcare provider may give you ESPEROCT® when you have surgery.

Who should not use ESPEROCT®?

You should not use ESPEROCT® if you

- are allergic to Factor VIII or any of the other ingredients of ESPEROCT®
- if you are allergic to hamster proteins

If you are not sure, talk to your healthcare provider before using this medicine.

Tell your healthcare provider if you are pregnant or nursing because ESPEROCT® might not be right for you.

What should I tell my healthcare provider before I use ESPEROCT®?

You should tell your healthcare provider if you:

- Have or have had any medical conditions.
- Take any medicines, including non-prescription medicines and dietary supplements.
- Are nursing.
- Are pregnant or planning to become pregnant.
- Have been told that you have inhibitors to Factor VIII.

How should I use ESPEROCT®?

Treatment with ESPEROCT® should be started by a healthcare provider who is experienced in the care of patients with hemophilia A.

ESPEROCT® is given as an infusion into the vein.

You may infuse ESPEROCT® 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 hemophilia treatment center or healthcare provider. Many people with hemophilia A learn to infuse the medicine by themselves or with the help of a family member.

Your healthcare provider will tell you how much ESPEROCT® to use based on your weight, the severity of your hemophilia A, and where you are bleeding. Your dose will be calculated in international units, IU.

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

If your bleeding is not adequately controlled, it could be due to the development of Factor VIII inhibitors. This should be checked by your healthcare provider. You might need a higher dose of ESPEROCT® or even a different product to control bleeding. Do not increase the total dose of ESPEROCT® to control your bleeding without consulting your healthcare provider.

Use in children

ESPEROCT® can be used in children. Your healthcare provider will decide the dose of ESPEROCT® you will receive.

If you forget to use ESPEROCT®

If you forget a dose, infuse the missed dose when you discover the mistake. Do not infuse a double dose to make up for a forgotten dose. Proceed with the next infusions as scheduled and continue as advised by your healthcare provider.

If you stop using ESPEROCT®

Do not stop using ESPEROCT® without consulting your healthcare provider.

If you have any further questions on the use of this product, ask your healthcare provider.

What if I take too much ESPEROCT®?

Always take ESPEROCT® exactly as your healthcare provider has told you. You should check with your healthcare provider if you are not sure. If you infuse more ESPEROCT® than recommended, tell your healthcare provider as soon as possible.

What are the possible side effects of ESPEROCT®?

Common Side Effects Include:

- rash or itching
- swelling, pain, rash or redness at the location of infusion

Other Possible Side Effects:

You could have an allergic reaction to coagulation Factor VIII products. **Call your healthcare provider right away or get emergency treatment right away if you get any signs of an allergic reaction, such as:** hives, chest tightness, wheezing, dizziness, difficulty breathing, and/or swelling of the face.

Your body can also make antibodies called "inhibitors" against ESPEROCT®, which may stop ESPEROCT® from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all of the possible side effects from ESPEROCT®. Ask your healthcare provider for more information. You are encouraged to report side effects to FDA at 1-800-FDA-1088.

Tell your healthcare provider about any side effect that bothers you or that does not go away.

What are the ESPEROCT® dosage strengths?

ESPEROCT® comes in five different dosage strengths. The actual number of international units (IU) of Factor VIII in the vial will be imprinted on the label and on the box. The five different strengths are as follows:

Cap Color Indicator	Nominal Strength
Red	500 IU per vial
Green	1000 IU per vial
Gray	1500 IU per vial
Yellow	2000 IU per vial
Black	3000 IU per vial

Always check the actual dosage strength printed on the label to make sure you are using the strength prescribed by your healthcare provider.

How should I store ESPEROCT®?

Prior to Reconstitution (mixing the dry powder in the vial with the diluent):

Protect from light. Do not freeze ESPEROCT®.

ESPEROCT® can be stored in refrigeration at 36°F to 46°F (2°C to 8°C) for up to 30 months from the date of manufacture until the expiration date stated on the label.

ESPEROCT® may be stored at room temperature (not to exceed 86°F/30°C), for up to 12 months within the 30-month time period. Record the date when the product was removed from the refrigerator. The total time of storage at room temperature should not exceed 12 months. Do not return the product to the refrigerator.

Do not use this medicine after the expiration date which is on the outer carton and the vial. The expiration date refers to the last day of that month.

After Reconstitution:

The reconstituted (the final product once the powder is mixed with the diluent) ESPEROCT® should appear clear and colorless without visible particles.

The reconstituted ESPEROCT® should be used immediately.

If you cannot use the reconstituted ESPEROCT® immediately, it must be used within 4 hours when stored at or below 86°F (30°C) or within 24 hours when stored in a refrigerator at 36°F to 46°F (2°C to 8°C). Store the reconstituted product in the vial.

Keep this medicine out of the sight and out of reach of children.

What else should I know about ESPEROCT® and hemophilia A?

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

Revised: 02/2019

ESPEROCT® is a trademark of Novo Nordisk A/S. For Patent Information, refer to: <http://novonordisk-us.com/patients/products/product-patents.html>

Manufactured by:
Novo Nordisk A/S
Novo Allé
DK-2880 Bagsværd, Denmark

More detailed information is available upon request. Available by prescription only.

For information about ESPEROCT® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA
1-800-727-6500

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US19ESP00010 August 2019



Blood Brotherhood

By: John Yungahans, Men's Group Coordinator

On Saturday, 7/25, the Blood Brotherhood gathered virtually to educate ourselves on current trends in the insurance marketplace. We are thankful for HFA supporting this event

and providing an amazing presenter, Miriam Goldstein, J.D., Policy Director & Principal Legal Counsel, HFA. As affected members of our community, concerned about taking care of ourselves and our families, this topic was especially meaningful to us. We learned about how the pandemic has affected the insurance landscape, current legislation, and its potential impact. We left this event with a renewed focus on advocacy. We

looked into next steps, getting involved with the chapter's advocacy efforts, and supporting HFA's Project Calls. I am thankful for all the

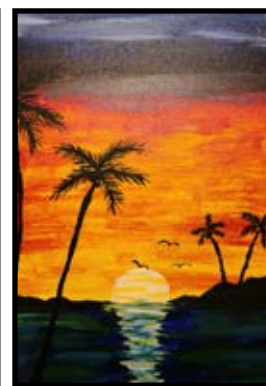
guys who joined our virtual meeting and I am excited to see them again at our next event. If you would like to join us for our next event or would like to connect with me, please email info@wpcnhf.org.



Paint Night

We were excited to offer our members a chance to gather virtually and enjoy a night of painting on August 11. Who knew we had so many talented artists among us? This night was enjoyed by painting enthusiasts and first-time painters alike.

The event began with a brief talk by Cody K., a young adult with a bleeding disorder. He talked about the importance of taking charge of your health care and not living life on the sidelines. We appreciated Cody sharing his personal story with us.



Next, we picked up our paint brushes and followed a pre-recorded demonstration with instructions for painting a tropical scene. Canvas boards and other painting supplies were mailed in advance to everyone who had registered. This was

our first attempt at this type of virtual program, and we were pleased to have so many people participate!

We thank Kelly Devito, Jessica Graham, and CSL Behring for sponsoring this event.

Teen Pizza Party

By: Nicolette C. – Teen Group Co-Coordinator

The WPCNHF teen group met on Wednesday, August 12, at 7:00pm for a virtually held pizza party. Before the party started, Domino's Pizza gift cards were sent out so the teens could order pizza and eat during the party. We started out with an icebreaker, asking what our favorite pizza or food from camp was.

We then held a moment to recognize our graduating seniors and LITs (for whom this would have been their last eligible year to be a leader-in-training). Days prior, the graduating seniors and LITs were sent a giftbox with instructions to not open them just yet, so they could be opened on camera at the virtual event. The seniors and LITs opened their boxes, which revealed a green blanket with the

Camp Hot-to-Clot logo on it.

Then the games began; the first game we played was UNO. The teens were split into two groups and played for 15 minutes, in which multiple intense games were held. The second game we played was a "Sentence at a Time" story building game. This is where one person starts off a story by saying something like "Once upon a time..." and everyone adds on one sentence as the story gets more and more wacky and nonsensical.

This game was a hit and was played until the end of the event, when announcements about future teen events were made. Any ideas for events that could be held virtually were encouraged to be shared. The teen



group chatted among themselves for a brief time, then the meeting subsequently ended after 8:30 PM.



Exploring the science behind gene therapy research

Gene therapy research has the potential to bring an entirely new option to people with specific genetic conditions. Many gene therapies are in clinical trials to evaluate the possible risks and benefits for a range of conditions, including hemophilia. HemDifferently is here with gene therapy education, providing accurate information on the basics and beyond.

What questions do you have? Get them answered. Explore gene therapy at **HemDifferently.com**.

No gene therapies for hemophilia have been approved for use or determined to be safe or effective.

BIOMARIN

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THE 5 STEPS OF INVESTIGATIONAL GENE TRANSFER

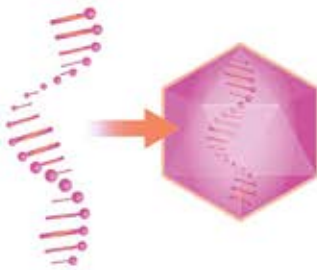
One method of gene therapy currently being explored in clinical trials is called gene transfer. This approach aims to introduce a working gene into the body to determine if it can produce a needed protein.



STEP 1

CREATING A WORKING GENE

A working copy of a mutated gene is created in a laboratory.



STEP 2

BUILDING A THERAPEUTIC VECTOR

A therapeutic vector is used to protect the working gene and serves as a transport vehicle for the gene to enter the body. The therapeutic vector is created from a neutralized virus, meaning no viral genes remain inside.



STEP 3

DELIVERING THE WORKING GENE

A single, one-time infusion delivers large numbers of therapeutic vectors into the body.



STEP 4

MAKING PROTEINS

Once in the body, the new working gene is designed to provide instructions for the body to make the protein it needs on its own.

 = Proteins.



STEP 5

MONITORING AND MANAGING HEALTH

Clinical trial participants are regularly monitored to better understand the safety of the gene transfer and to evaluate its effect on the body.

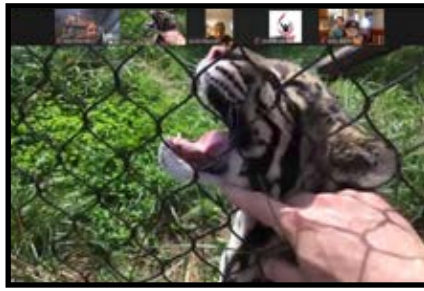
Our Road to the Walk



This year marks the twelfth year WPCNHF has held their annual Unite for Bleeding Disorders Walk. To celebrate, we launched our 2020 Road to the Walk Challenge! This challenge has participants walk 1.2 miles over the course of 10 weeks to celebrate 12 years of uniting. The Road to the Walk started on Monday, August 3rd. Each week, aside from getting those miles in, our community is challenged to do anything from making a self-donation, sharing their favorite walk memory, or recruiting new teammates! All the proceeds raised during our Road to the Walk supports the 2020 Unite for Bleeding Disorders Walk.

Clouded Leopard Virtual Encounter

During the week of September 4th, we challenged our community to raise \$50 by the end of the week! The first five families who reached the week's goal were invited to attend a virtual encounter with baby clouded leopards! This virtual encounter was hosted by the Pittsburgh Zoo and



PPG Aquarium on Sunday, September 6th. Thank you to everyone who donated and attended this virtual experience!

Unite Trivia Night



On Thursday, September 10th, the Chapter held a Unite Trivia Night. The cost was \$10 per device and participants were able to choose which walk team they wanted their donation to support. The first round

of the night tested how well everyone remembered last year's walk! The second round focused on pop culture questions and the third round was all about general knowledge. The winner at the end of the night received a prize and their very own pair of blood drop Unite socks! Thank you to everyone who participated and thank you to John and Christina for guest hosting the game!

Unite Yoga Night



On Wednesday, September 16th, the Chapter held a relaxing yoga night! There was no cost to register for this event, but participants were encouraged to donate to support one of the amazing Unite for Bleeding Disorders Walk teams. No experience in yoga was necessary. Beginners to advanced were welcome to attend. Our yoga instructor, Laura Jackson, generously donated her time to lead a session for the community. She provided multiple versions of each stretch and position, so everyone was able to participate, regardless of comfort level. Thank you to everyone who attended and thank you to Laura for leading the session!

Drag Queen Bingo

WPCNHF held their first Drag Queen Bingo night fundraiser virtually over Zoom, on July 30, 2020. 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 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. The first basket was exercise and sports themed and included 4 reserved level seats to a 2020 Washington Wild Things Game. The second basket was a relaxation basket and included everything necessary to destress, like candles, lotions, tea, and most importantly, a gift card for Sarris Candy.

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. WPCNHF 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!

A photograph of three young adults camping at night. A man on the right is playing an acoustic guitar and smiling. A woman on the left is also smiling. A third person in the middle is roasting marshmallows over a campfire. A red heart shape is drawn around the man playing the guitar. In the background, there are trees, a tent, and a lantern.

**WE'RE IN THIS
TOGETHER.**

Friday 6:26 pm

Sharing stories by the
campfire with friends

Isaac, living with
hemophilia B

Not an actual patient

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



2020 Virtual Annual Meeting and Walk Kick-Off

On July 23, we held our 2020 Annual Meeting and Walk Kick-Off virtually. Over 103 individuals joined us via Zoom to hear our annual report, help us recognize top volunteers, congratulate scholarship winners, kick off the Unite for Bleeding Disorders Walk, and hear about all the programs the Chapter offers throughout the year.

At the Western Pennsylvania Chapter of the National Hemophilia Foundation, we are lucky to have many hard working and passionate volunteers who are willing to donate their time and resources so that the Chapter can fulfill its mission. Volunteers are the lifeblood of our organization; we would not be able to succeed in our mission without them. In total this past year, volunteers have donated over 650 hours to help with various Chapter events and tasks. The following volunteers were recognized at the Annual Meeting:

Thank you to our board members: Michael Covert, Brittani Spencer, John Yunghans, Christina Miller, Melinda Perry, Scott Domowicz, and Jennifer Smith.

Thank you to our committee members: Victoria Baker, John Yunghans, Melinda



Perry, Maria Vom-Stein, Nicolette Cloutier, and Julia Shoemaker.

Thank you to our top volunteers: Adam Boyle, Cameron Cedeno, Delaine Lee, Diane Standish, Erek Domowicz, Heather Kosto-Bobro, Jim Cedeno, Judy Walsh, Lenore Hiller, Marty Bobro, Mason Bobro, Matthew Hiller, Michael Perry, Michelle Perry, Robert Sethman, Ronald Weisser, Steve Stern, Susan Eyrolles, and Tracy Sethman.

Thank you to our volunteer of the year, Eileen Nikithser. Eileen always goes above and beyond for the Chapter and is always willing to lend a helping hand. She participates in nearly every office volunteer opportunity we have, often also providing food and snacks. She has been a top fundraiser for her grandson's Walk team, Conor's Clan for the past 4 years. She is also a strong advocate for the community participating in Harrisburg Day. We cannot thank her enough for everything she does for the bleeding disorders community.



We are very grateful to our sponsors for their flexibility and support during this time. Thank you to the the following for supporting the 2020 Virtual Annual Meeting: Accredo, BioMarin, CSL Behring, CVS Specialty, DrugCo, Factor One Source Fast Pharmacy, Genentech, The Hemophilia Center of Western PA, Medexus Pharma, Novo Nordisk, Octapharma, Sanofi Genzyme, Spark Therapeutics, and Takeda.

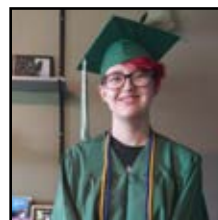
June for Joint Health

June for Joint Health is an initiative through a joint partnership between the National Hemophilia Foundation and Sanofi Genzyme. The goal is to encourage people to build life-long habits that promote safe, joint building activities through the month of June and beyond. Nearly 80% of bleeds occur in joints and clinical studies have shown that conditioning, stretching, exercising, and treatment can help improve joint health. For more information visit www.juneforjointhealth.org.

Jeffrey LeBlanc, a physical therapist and Clinical Director for professional physical therapy in Havervill, MA, led a presentation demonstrating exercises that are beneficial for improving joint health. After the session, all participants had the opportunity to receive a free booklet on stretches and a free yoga mat for stretching.

We thank Jacose Bell from Sanofi Genzyme and the National Hemophilia Foundation for sponsoring this event, which was held on August 13, 2020.

Congratulations to the 2020 WPCNHF Scholarship Winners



Mason Bobro



Christian Covert



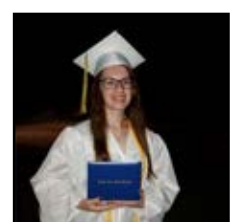
Taylor Covert



Colin Domowicz



Erek Domowicz



Julia Shoemaker

Jivi[®] Extension Study

Explore the study design and see the safety and efficacy data from patients who were part of the study.

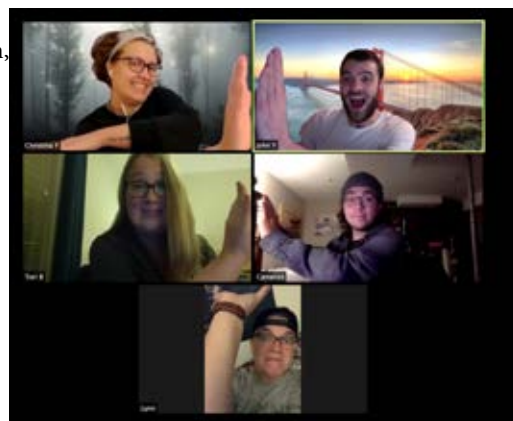
► Dive in at [JiviExtensionStudy.com](https://www.JiviExtensionStudy.com)

Strength in the Journey

Planning for our first young adult event began a year ago, when we conducted a survey with young adults to gauge their interest in participating in a retreat, in a camp-like setting. The response was positive, and planning proceeded. The arrangements for the event, Strength in the Journey Weekend, were nearly finalized when it was decided that we needed to postpone the in-person event, due to COVID-19. The committee, which includes three young adults (Victoria (Tori) Baker, John Yunghans, and Christina Yunghans) immediately switched gears and planned an event to take place over Zoom. The in-person event will be rescheduled when it is safe to do so and the facility reopens.

The Zoom event was held on Saturday, September 26. It was a mix of education, social time, and fun! The event began with the program Evaluating Your Insurance Options, led by Jacose Bell, Community Relations and Education Manager, Sanofi Genzyme and supported by Keira Hobbs, Case Manager for Western PA, Sanofi Genzyme. Jacose and Keira gave clear, easy to understand descriptions and explanations on insurance terms and practices that can often be confusing.

The event ended with an energetic Trivia Slam game, led by Watson Adventures, a company that runs scavenger hunts and trivia games. We split into teams and had a fun, competitive game—young adult participants vs. WPCNHF staff! We worked together in our teams to come up with answers to the trivia questions—it was quite challenging



to restrain ourselves from looking up the answers on the internet! The game also incorporated photo challenges and it was entertaining to see what each team submitted. The winning team is pictured here!

We thank Sanofi Genzyme for sponsoring the educational insurance program for this event.

World Aids Day

World AIDS Day takes place yearly, on December 1. It was first observed in 1988 and was the first-ever global health day. It's an opportunity for people worldwide to unite in the fight against HIV, to show support for people living with HIV, and to commemorate those who have died from an AIDS-related illness.

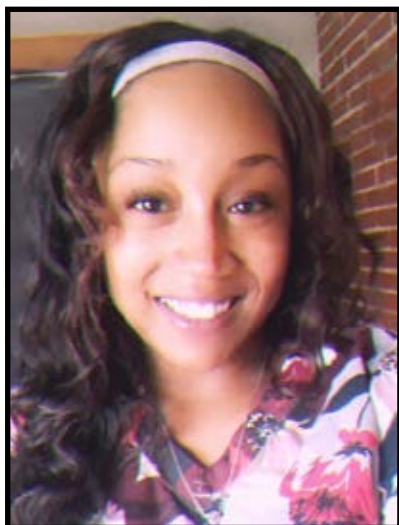
From the late 1970s to the mid-1980s, about half of all people with hemophilia became infected with HIV after using contaminated blood products. An estimated 90% of those

with severe hemophilia were infected with HIV. Many developed AIDS and thousands died. There have been no transmissions of HIV through factor VIII or IX products in the US since 1987. That's when viral inactivation (viral killing) methods were first used to treat blood products. (<https://www.hemophilia.org/Bleeding-Disorders/Blood-Safety/HIVAIDS>)

Locally, the Pitt Men's Study will observe World AIDS Day virtually this year, through online presentations and activities. (The Pitt Men's Study is a confidential research study of the natural history of HIV/AIDS, funded

by the National Institutes of Health, that has been ongoing in Pittsburgh since 1984.) In preparation, they are asking the community to submit names (first name, last initial) of those who have passed, in remembrance, as part of the traditional Circle of Love. The deadline for submitting names is November 1. Information regarding participation in the Circle of Love is posted on the Pitt Men's Study World AIDS Day page. For more information, or to submit a short description of, or tribute to, the person you would like to commemorate, visit www.pittmensstudy.com/world-aidsday/.

Getting to Know HCWP Staff



Deja Johnson, Medical Assistant

Birthplace: Forbes Hospital Monroeville, PA

First job: Nigros restaurant

Accomplishment you're proudest of: My family

What three words describe you best? Caring, Motivated, Independent

Dream vacation: Paris

Things you can do without: News

Person you'd most like to have dinner with: My father, I want to know what heaven is like.

Movie you could see anytime: Mean Girls

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

Three things that can always be found in your refrigerator: Seagrams wine coolers, Hawaiian Punch, Pepsi

Secret vice: Going grocery shopping without my children

Who would play you in the movies? Tiffany Haddish

Your pet peeve about Pittsburgh: The pot holes

People may be surprised to know that: I have a set of natural Triplets.

Constructive Conversations for Caregivers

Many of us take on a role that we didn't always see coming—the role of a caregiver for someone with a medical condition.

Who are we? We are parents, spouses, children, friends, siblings, grandparents, aunts, uncles, etc. Sometimes this transition happens suddenly, due to a major incident; other times we gradually

take on responsibility that increases over time. A caregiver's contributions and influence on positive health outcomes cannot be underestimated. However, the role can be exhausting and there can often be unproductive conversations with your loved one that can leave you feeling helpless or frustrated.

On August 18, we held a program that was designed specifically for caregivers, called Constructive Conversations. This program was presented by Michael Sager, Senior Manager, Patient Affairs, Pfizer.

The program helped caregivers gain a better understanding and learn techniques for effective conversations, such as the motivational interviewing technique. The skills learned can not only help us when speaking with someone regarding their bleeding disorder, but in other conversations as well. We thank Michael Sager and Pfizer for sponsoring this event.

Are there other topics that are of interest to caregivers? Please call or send an e-mail to janet@wpcnhf.org to let us know! We are here to support you!

Education Day

This year's Education Day underwent a major transformation! We were originally looking forward to a large, in-person event in March. The pandemic hit and we postponed the event until August 29 and ultimately converted it to an online event. We are so thankful that all 15 sponsors continued to support us even though we could no longer meet in person. Instead, they provided logo items and literature that the Chapter shipped to the homes of those who registered. In addition, they each had an opportunity to speak to our members during the virtual event.

Participants had a choice to take part in one of two educational programs: Healthy Aging and Bleeding Disorders or Coping with COVID. Jan Martin, MSN, Clinical Specialist, Takeda, presented the program on Healthy Aging and Bleeding Disorders. The program provided information on building a healthy body, mind, and future, and provided tips and techniques for healthy aging. Coping with COVID was a custom program developed and presented by Kathaleen Schnur, LSW, Social Worker,

Hemophilia Center of Western PA. Kathaleen provided information on the importance of one's well-being while navigating this fluid situation and the impact it has on our mental health. She reviewed strategies for coping and communication; and she spoke about the importance of validating your own experiences with your own emotions and losses (events, routines, experiences, etc.), during this time. We thank our speakers, Takeda, and the HCWP for providing these important programs.

Since we were unable to meet in person, all participants received a gift card to buy lunch after the event. In addition, we held gift card drawings during the event and five lucky participants received an additional gift card of their choice!

We thank the following sponsors for making this event possible: Accredo, CVS Specialty, Cottrill's Pharmacy, Drugco Health, Factor One Source Fast Pharmacy, Hemophilia Center of Western PA, Option Care, BioMarin, CSL Behring, Genentech, Novo Nordisk, Octaparma, Pfizer, Sanofi Genzyme, and Takeda.



Mentor Parent Training

We are excited to formalize the parent mentoring component of the New Parent Network program. The New Parent Network is a program that offers support and a series of events each year to families who have a child age 0-7, who

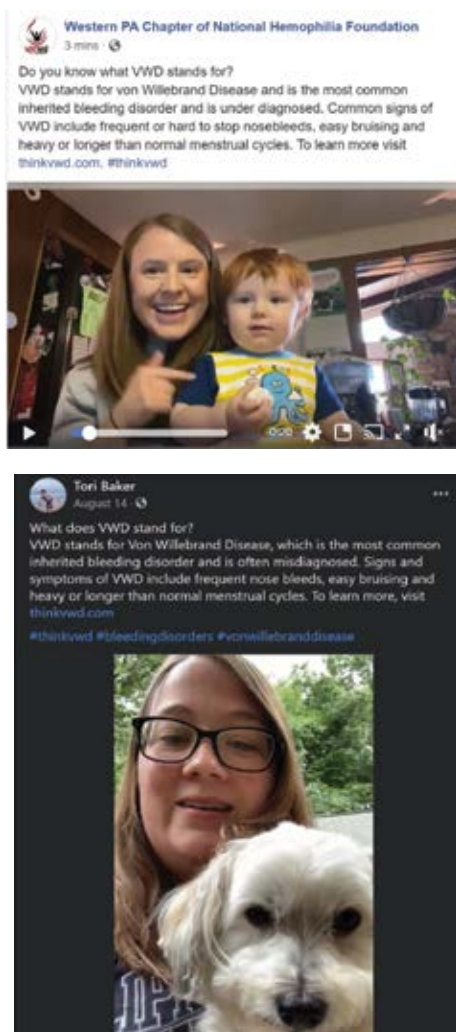
has a bleeding diagnosis. On Sunday, September 27, parents from six different families participated in our mentor parent training program. The training program was facilitated by Janet Barone, WPCNHF and Kathaleen Schnur, LSW, HCWP. If you have a child, newborn to age 7, who has a bleeding diagnosis and would like to be connected with another parent of child with a bleeding diagnosis, please reach

out to either Janet (janet@wpcnhf.org / 724-741-6160) or Kathaleen (kschnur@vitalant.org / 412-209-7267).

We thank the following for sponsoring the 2020 New Parent Network series of events: CSL Behring, CVS Specialty, Hemophilia Center of Western PA, Novo Nordisk, Sanofi Genzyme, Takeda.

VWD Awareness

The website thinkvwd.com has been launched with a PSA featuring Alex Borstein to help raise awareness of VWD. VWD, or von Willebrand disease, is the most common inherited bleeding disorder caused by a deficient or defective clotting protein called von Willebrand factor. Some people may never know they have VWD unless they experience a serious accident or undergo surgery. While VWD affects men and women equally, women have more symptoms due to heavy bleeding during menstrual periods. People with VWD experience symptoms such as excessive bleeding from a small wound, prolonged bleeding after a surgery or dental procedure, easy bruising from small bumps or injuries, frequent nosebleeds, and heavy menstrual bleeding in women. If you think you could have VWD, review your medical and family history with your healthcare provider. He or she may order a variety of blood tests to confirm a diagnosis or refer you to a bleeding disorder specialist. The good news is, there are treatment options available if you are diagnosed with VWD.



Zombies of the Corn Fundraiser

Purchase tickets to Zombies of the Corn for October 25th and use code WPCNHF and TR Paintball will donate \$5 to the Chapter!

zombiesofthecorn.com



Western Pennsylvania Chapter of the National Hemophilia Foundation

20411 Route 19, Unit 14
Cranberry Township, PA 16066
Phone: 724-741-6160 Toll Free: 800-824-0016 Fax: 724-741-6167
info@wpcnhf.org

THE NATIONAL HEMOPHILIA FOUNDATION & TAKEDA PRESENT

THINKVWD.COM Social Challenge Video

HERE ARE THE 5 STEPS TO PARTICIPATING IN THE CHALLENGE

- 1.) COME UP WITH A FUNNY ACRONYM FOR VWD.**

Once you come up with a funny acronym, be sure and tell people what VWD actually stands for, which is von Willebrand Disease.

"Velociraptors with Dentures"
- 2.) PROVIDE PEOPLE WITH A FACT ABOUT VWD**

Please use one of the following facts:

 - VWD is the most common inherited bleeding disorders and is underdiagnosed.
 - VWD affects 1 out of every 100 people.
 - Common signs of VWD include frequent or hard to stop nosebleeds, easy bruising & heavy or longer than normal menstrual cycles.
- 3.) ENCOURAGE PEOPLE TO VISIT THINKVWD.COM**

Be sure to say "To Learn More, visit thinkvwd.com!"
- 4.) RECORD A SHORT VIDEO WITH ALL ABOVE ELEMENTS**

Try to make your video short and sweet - no more than 50 seconds.
- 5.) POST TO YOUR SOCIAL MEDIA AND CHALLENGE OTHERS TO DO THE SAME.**

Post your video on Facebook, Twitter, or Instagram, and call out and tag your friends to take the challenge. Let's make this go viral!



REMEMBER TO #THINKVWD ON ALL YOUR SOCIAL MEDIA CHALLENGE POSTS!

You can help spread awareness by making a **THINKVWD.COM** Social Challenge Video.

