

Western Pennsylvania Chapter of the National Hemophilia Foundation

Fall 2019 Inside this issue

WPCNHF vs. Zombies of the Corn!
Join Us

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7th Annual Take A Bough

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# DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

If your company is participating in the United Way campaign, you may designate all or a portion of your gift to the Chapter.

WPCNHF Contributor Agency Code Number is: 83

## <u>Hemogram</u>

# Lights... cameras... camp!: Camp Hot-to-Clot 2019

The adventure was larger than life this year at Camp Hot to Clot! The campers and staff all enjoyed a great week centered around some great Hollywood hits. We bounced on a Jurassic Park inspired inflatable, had our

own TriWizard Tournament, and enjoyed Vader-ade at our Star Wars dance party! Our older campers even had the chance to make their own short film.

It wasn't all fun and games, though. The youth also did a lot of learning about bleeding disorders and self-advocacy while building meaningful relationships with each

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## 2019 Annual Meeting

Thanks to a grant provided by the Hemophilia Alliance, WPCNHF was able to recognize thirteen volunteers at our 2019 Annual Meeting. These volunteers received a jacket with the chapter logo and an award. The individuals were: Glenn Balog, Linda Balog, Ryan Balog, Michael Clancey, Eileen Nikithser, Emily Nikithser, Melinda Perry-Stern, Michelle Perry, Robert Sethman, Tracy Sethman, Julia Shoemaker, Maria Steele Voms Stein, and Ron Weisser. Melinda was recognized as the "Volunteer of the Year" and received a glass blood drop award along with her jacket. Thank you again to our wonderful

volunteers for their hard work and dedication, not only to the chapter, but to the entire bleeding disorders community!

The Annual Meeting was held at Dave & Buster's in Homestead and over 120 people attended. We thank the following for supporting the Annual Meeting: Accredo, Aptevo, BioMatrix,

Cottrill's Pharmacy, CSL Behring, CVS Specialty, Diplomat, DrugoCo, Factor One Source, Grifols, the Hemophilia Center of Western Pennsylvania, Novo Nordisk, Octapharma, Takeda, and UniQure.





## Lights... cameras... camp!: Camp Hot-to-Clot 2019

(Continued from page 1)

other and their counselors. For the first time, camp staff have begun to track the knowledge of our campers about bleeding disorders, and we will continue to do so from year to year. This will help us to demonstrate concretely how our youth benefit from camp and ideally help secure funding for camp in an ever-changing health care landscape. This will also help us identify knowledge gaps that we need to fill.

Our 65 campers also spent a morning focused on making many beautiful cards for the residents of a skilled nursing facility. Many of our campers put focused time and effort into making meaningful, touching, and cheerful cards that are sure to be treasured.

We enjoyed our campers, and we sincerely hope they enjoyed their camp experience. Well, that's a wrap!

Now on to planning next year...

Sincerely,

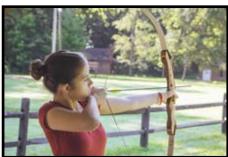
Your camp directors and camp planning committee



























# Calendar of Upcoming Events

October 16, 2019 Dinner Program (Amish Only) Punxsutawney, PA

October 19, 2019 Oktoberfest Wexford, PA

October 20, 2019

WPCNHF vs. Zombies of the Corn Freedom, PA

October 20, 2019

Teen Group vs. Zombies of the Corn Freedom, PA

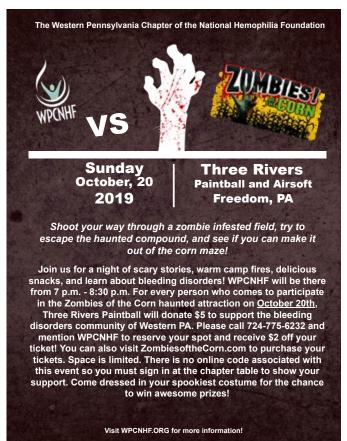
October 24, 2019 Women's Group Pittsburgh, PA November 2, 2019 New Parent Network Pittsburgh, PA

November 16, 2019 Take A Bough Pittsburgh, PA

November 20, 2019 Insurance Dinner Program Robinson Twp., PA

December 8, 2019 Winterfest Oakland, PA

January 10 - 12, 2020 Teen Retreat Clinton, PA



## Ask us about sponsorship opportunities and how you can help!

## **Board of Directors**

**President**Mike Covert

Secretary
John Yunghans

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

Emeritus Trustee Scott Miller, CPA, Esq., DBA

## **Staff**

Executive Director
Kara Dornish

**Program Director**Janet Barone

**Development Director**Jessica Lee

## **Mission Statement:**

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

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

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

## **Letter from the President**

Hello Chapter Members, a lot has been happening at the Chapter and the staff have been very busy putting together the wonderful programs we all get to enjoy. The Walk was a great success and I want to thank everyone for their participation.

We are currently looking for people

interested in serving on Chapter Committees for Fundraising and Advocacy. Please reach out to me or Kara if you are interested.

The next few months are filled with many great Chapter events. I look forward to seeing you and your family at many of

them. Please do not hesitate to contact me, or the Chapter staff, if you have any questions or concerns.

Kind Regards

Michael Covert Board President

## **Letter from the Executive Director**

Dear Chapter Members and Friends,

Happy Fall! I am thrilled to continue serving the bleeding disorders community in our area as I begin my 7th year with the Chapter.

The Unite for Bleeding Disorders Walk had its best year ever! Over \$72,000 was raised for the bleeding disorders community in Western PA! I hope you all had a great time and enjoyed the new location. Thanks to everyone who worked hard to make this year's Walk a success! I am so thankful for everyone who joined us this year – this event couldn't succeed without you!

We had a great week at Camp Hot-to-Clot! I am so glad I got to be a part of it again this year. Kit, Kat, and Janet put their heart and soul into the planning of Camp each year and it shows! We have lots of educational programs and opportunities for community members to come together in the next few months. Updated information can also always be found on our website at www.wpcnhf.org. As we begin to plan for next year, if there's a topic you'd like to learn more about, or something you think would be interesting to others, please let us know and we'll do our best to bring those programs to you.

I hope to see you all at Take A Bough this year! In addition to bidding on beautiful holiday trees, wreaths, and centerpieces there will be wine tasting from local wineries in the area. It will be a fun evening as we raise awareness and funds for the bleeding disorders community.

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

Sincerely,

## Kara Dornish

Kara Dornish Executive Director



Gus had a great time attending his very first Unite for Bleeding Disorders Walk!

## Don't Be Scared; Be Prepared!

Hopefully, Western PA won't experience a natural disaster anytime soon, but should one strike, many of us will be prepared, thanks to the great advice given by Sharon Meyers, Hemophilia Federation of America (HFA), Interim President & CEO! Sharon presented the HFA program *Don't Be Scared; Be Prepared: Creating an Emergency Plan*, at the Ambassador Banquet & Conference Center, in Erie, PA.

Sharon Meyers was a nationally certified EMT for seven years and has first-hand experience working on an ambulance and answering 911 dispatch calls. She has also taught disaster preparedness, disaster management, and CPR classes. In addition, she has experienced a natural disaster, in which she had minutes to collect her belongings before evacuating the area. She recommends planning ahead what you will need/ want to take with you if you have only 15 minutes to gather your belongings and evacuate. Valuables and irreplaceable documents and photos can be kept in a lockbox that you can quickly grab on your way out. Keep a list of the things

you want to take with you in convenient place. Remember, things can quickly become chaotic in an emergency and it could be easy to forget that lockbox or important medication, if you are rushing around trying to get yourself or your loved ones ready to leave in just minutes—a checklist can be invaluable.

Make a list of important documents,

medications, and valuable items to take with you in the event of evacuation. What should your



Emergency Packing List include? Here

are suggestions to get you started:

- Family Photos
- Medical Records
- Legal Documents
- Anything Irreplaceable

Create an **Emergency Supply Kit** to last a minimum of 72 hours (3 days)

- Water (1 gallon per day, per person)
- Food
- Basic Kitchen Items
- Clothing And Bedding
- First Aid Kit



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## Donations Needed for Take A Bough

We are in need of donations for Take A Bough! Donations such as Christmas trees (pre-lit or unlit), ornaments, string lights, wreaths, holiday décor, and themed gift baskets or gift cards are great contributions. You can also sponsor a tree or wreath with a monetary donation. If you would like to help, please e-mail Jessica Lee at jessica@wpcnhf.org, call 724-741-6160, or stop by the office during business hours 9am-4pm Monday through Friday. All donations are greatly appreciated!



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

bleedingdisorders.com



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## **HCWP Corner**

Dear HCWP patients and families:

I'm not sure how it happened, but summer has come to an end. Schools are in session, vacation-mode has ended, and the colors, scents, and flavors of Fall have arrived!

We at the Center have been busy traveling around to provide in-service education to the schools and child care facilities our kiddos attend by request of the families and schools. Please let us know if you would like us to work with you and your child's school. We can provide documentation and support as well as share tools. We are committed to helping you and your kiddos navigate life with a bleeding diagnosis. We are here for you beyond your clinic visit, so please call us.

We had a fantastic week at camp. We were grateful to have the clinical support of three industry nurses who added to our wonderful health center staff throughout the week:
Nora Latcovich (Aptevo Therapeutics),
Beth Moir (Accredo), and Trish Underland (Cottrill's Pharmacy). Additionally, the support of the larger community by way of grants, education, collaboration, working, and volunteering throughout the process of planning, prepping for, and executing the week of camp is invaluable to the kiddos and the knowledge and relationships they gain and develop. Thank you all.

Please note that there are two open enrollment periods coming for health insurance. If you purchase your plan through the Marketplace (healthcare.gov) (ACA) the 2020 Open Enrollment Period runs from Friday, November 1 through Sunday, December 15, 2019. If you don't purchase a plan by December 15, you can't get 2020 coverage unless you qualify for a Special Enrollment Period (SEP). The annual Medicare Open Enrollment period begins on October 15 and continues until December 7. For 2020 coverage, open enrollment will run from October 15 through December 7, 2019. During the annual enrollment period (AEP) you can make changes to various aspects of your coverage. Please reach out to the social workers at the Center if you have questions or need clarification.

Have a wonderful season, we look forward to seeing you and hearing from you!

Warmly,

Kathaleen

## **Infusion Day**

In response to requests for infusion training, the Chapter hosted an Infusion Day training program, in Punxsutawney, on Saturday, September 21. The event began with Kathaleen Schnur, LSW giving an overview on the process for ordering factor; information to have ready when placing an order; and the benefits of home infusion. Next, Nancy Stinely, RN, talked

about the infusion process including necessary supplies; preparing the infusion area; important step-by-step information regarding the infusion technique; helpful tips for home infusion; and the importance of infusion tracking logs.

After the instructional overview, Kimberly Walsh, RN, led the group in hands-on training, where they were able to practice the infusion process, using fake veins. When everyone was finished practicing,

Nurse Nancy and Nurse Kim provided stepby-step guidance for those who wanted to practice the infusion process on themselves.

We thank Sanofi Genzyme for sponsoring this event.

Is there an educational program that you would like to see the Chapter offer? Please feel free to contact the Chapter to let us know. Also, be sure to participate in our needs assessment!



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

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

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

### **Factor Program Services**

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

### **Patient Benefits**

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



### 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 microanglopathy (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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## 2019 Unite for Bleeding Disorders Walk, Run For Their Lives 5K, and Cornhole Tournament

This year, our 11th Annual Unite for Bleeding Disorders Walk, 10th Annual Run for their Lives 5K, and 7th Semi-Annual Cornhole Tournament all moved to a brand new location! The festivities took place at the North Park Swimming Pool Lot! These events brought friends and families together to raise over \$75,000 to support the bleeding disorders community in Western Pennsylvania.

Snow White, Rapunzel, Sleeping Beauty, and Anna visited us at our KidsZone. They talked, colored, and did crafts with the children and families who stopped by. The KidsZone featured a face painter, a balloon artist, crafts, and fun games provided by Main Event. There was also a DJ and a photo booth, so everyone could capture their favorite memories from the day. Thank you to: First Class Entertainment for the DJ and Photo Booth services, Face Paint Pittsburgh, Dragonfly Balloons, Kona Ice Pittsburgh, WISH 99.7 Street Treat Patrol, Main Event, and our very talented princesses volunteers.

This day would not be possible without the support of our many team captains who





rallied their runners and walkers and went above and beyond in all that they did. Thank you to all 24 of our Walk Teams! A special shout out to the teams who really went above and beyond and raised \$1,000 or more:

Rolling for Ryker - \$9,300 Conor's Clan - \$9,160 Luke's Lineup - \$8,098 Team Jaxson - \$3,603 Kramer's Gamers - \$1,595 Charlotte's Hemo Heroes- \$1,445 Cameron's Walking Sticks - \$1,415 Clotting Cavaliers - \$1,315 Red N Plenty - \$1,182 Maxwell House - \$1,120

Congratulations to our top fundraising team, Rolling for Ryker, who raised an incredible \$9,300! Thank you to the Team Captain of Rolling for Ryker, and this year's Walk Chair, Mindy Perry-Stern! This year marked the second walk Rolling for Ryker has participated in. Mindy has been an active member of the Chapter ever since her one-year-old son, Ryker, was diagnosed with Hemophilia A in 2017. She appeared on Wish 99.7 FM with WPCNHF's Executive Director, Kara Dornish, and shared her story with Cris Winter. She also secured an interview on Star 100.7 FM with Kelly where she was able to promote the walk again! This year, Mindy's walk team raffled off a pair of Steelers home game tickets and a Juju Smith-Schuster jersey. They sold tickets staring in February, 2019 and raised over \$3,000! At the walk, Mindy recognized her father, Michael Perry, for selling a huge portion of the teams raffle tickets. We are so thankful for all of Mindy, and her team's, hard work and dedication to the entire bleeding disorders community.



This year's Top Individual Fundraiser was Emily Nikithser, who individually raised an amazing \$2,000. Emily is the team captain of Conor's Clan and won the Top Individual Fundraiser award last year. This year was their fourth walk to support Emily's 4 year-old son, Conor. Emily did an incredible job holding two very successful fundraisers this year including Conor's Clan's Car Wash and Get Crafty with Conor's Clan! On top of fundraising, Emily is an active member and volunteers her time at the Chapter. We are so incredibly thankful for Emily and her amazing team.



Finally, a big congratulations to the winner of the Awesome John Eyrolles Top Youth Fundraiser Award, Luke Miller, who raised an amazing \$1,695! Luke is the inspiration for his walk team, Luke's Lineup. This year marked their seventh walk. We are so thankful for Luke's Lineup and everything they accomplished this year! Luke was diagnosed as a baby with severe hemophilia A, but his parents and his big brother are always there for him. This year, Luke's Lineup had 66 people on their team! They also ran their first ever raffle, a wildencounter trip to the zoo! They started selling tickets a month before the walk and were able to raise over \$500.



Thank you to all of our Factor Club Members who have raised \$500 or more for the Unite for Bleeding Disorders Walk! Medals were awarded to the following Factor Club Members:

Brooke Aberegg of Aberegg Army, Cooper Aberegg of Aberegg Army, Finleigh Alkins of Luke's Lineup, Gwen Austin of Clotting Cavaliers, Analise Baker of Team Jasson, Jasson Baker of Team Jasson, Josh Baker of Team Jaxson, Kelly Baker of Team Jaxson, Janet Barone of Cameron's Walking Sticks, Kara Dornish of Kara's Walkers, Nikki Micholas of Kramer's Gamers. Luke Miller of Luke's Lineup, Marie Miller of Luke's Lineup, Sam Miller of Luke's Lineup, Reagan Bayne of Luke's Lineup, Andrew Moravek of Luke's Lineup, Ava Moravek of Luke's Lineup, Emma Vernon of Luke's Lineup, Mya Vernon of Luke's Lineup, Joseph Vernon of Luke's Lineup, Lynda Maxwell of Maxwell House, Conor Nikithser of Conor's Clan, Eileen Nikithser of Conor's Clan, Emily Nikithser of Conor's Clan, Patrick Nikithser of Conor's Clan, Barbara O'Connor of Luke's Lineup, Charlotte Rosborough of Charlotte's Hemo Heroes, Marilin Rosborough of Charlotte's Hemo Heroes, Gabbie Rose of Clotting Cavaliers, Dawn Rotellini of Gino's Gang, Tracy Sethman of Red N' Plenty, Bob Sethman of Red N' Plenty, Allison Smith of Luke's Lineup, Liam Smith of Luke's Lineup, Jen Werme of Conor's Clan, Russell Werme of Conor's Clan, and Michael Perry of Rolling for Ryker.

This year's event had fabulous t-shirts designed by many of our walk teams. Thank you to Jamie and Darin from Printeesweet for the printing of them, and for the many families that took the time to vote for their favorite t-shirt the day of our Walk. Congratulations to Luke's Lineup as the official Team T-shirt Winner, raising nearly \$250!



for Their Lives 5k and to everyone who participated in the run. We are excited to announce that over \$6,000 was raised from the Run and will stay local to support the members of WPCNHF.

they did managing the Run

Congratulations to the winners of the Run for Their Lives 5k!!

**Top Youth Finisher** Sam Miller



**Top 3 Female Finishers** 1st Place: Lisa Samangy 2nd Place: Amy Bayne 3rd Place: Jodie White







**Top 3 Male Finishers** 1st Place: Douglas Basinski 2nd Place: Bernard Fertall 3rd Place: Jon Kozik

Thank you to Joe Castellano from Steel City Cornhole for running our 7th Semi-Annual Cornhole Tournament! The Cornhole Tournament brought in over \$2,000, all of which will stay local to support individuals with bleeding





disorders in Western PA. Congratulations to the winners of the tournament! First Place went to Chuckie Love and Trey Birchfield, second place went to Dennis Cottrill and Seth Cottrill, and third place went to Joe Castellano & Joey Castellano!













Lastly and most importantly, thank you to each and every one of you who came together with us to Unite for Bleeding Disorders. 100% of the money raised from the Walk, Run, and Cornhole Tournament stays local to promote patient advocacy and blood safety for everyone, support families in need by offering assistance with medical bills, travel, knee/elbow braces and other medical devices, provide medical ID jewelry to our members at

no cost to them, provide local educational programming throughout the year, provide a support network to all our community members, and create and increase awareness about bleeding disorders.

Mark your calendar now for next year's Unite for Bleeding Disorders Walk, Run For Their Lives 5k, and Cornhole Tournament taking



place at the North Park Pool on Saturday, September 12, 2020!

# First Annual Ballers for Bleeding Disorders Fundraiser

On September 15, 2019, Erek Domowicz hosted a paintball tournament, Ballers for Bleeding Disorders, at Three Rivers Paintball to support the Western Pennsylvania Chapter of the National Hemophilia Foundation. Erek is a senior at Seneca Valley and this was his senior graduation project.

Twenty-two 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. Erek designed a logo for this event and it was printed on t-shirts for each participant. There was also a raffle basket full of coupons and other goodies, plus snacks for sale. Chapter staff also stopped by to share information about bleeding disorders. In total, Erek raised over \$850 for the Chapter with his event! He and his father, Scott Domowicz, plan to host a 2nd Annual Paintball Tournament next year with an even bigger turnout. The scheduled date for next year's tournament is September 20, 2020. Great job on a successful fundraiser, Erek!





# The Push for a New Charity Skin: Riot Games and the Bleeding Disorders Community

Colin Domowicz is a nineteen year old affected by Von Willebrand Disease (VWD). VWD is an inherited bleeding disorder that prevents the blood from

clotting properly, like hemophilia, but is due to a deficient or defective blood protein known as von Willebrand factor. As a child and preteen, he was an avid soccer player. He loved the game and loved his team; however, there were many practices, games, and tournaments where Colin would get hurt, and after a while, it became difficult for him to play. As he got older, those injures became worse, and you can't play soccer when you're injured. "I had to find ways to occupy myself while recovering, and that's when I started to play video games more," Colin said.



Video gaming has been a part of Colin's life for a little over a decade. Since Colin (Continued on page 17)

## New Parent Network Summer Program

Just when you think things couldn't get any cuter at the zoo, in walk our New Parent Network families with their adorable children! Our summer New Parent Network program was held on July 13th, at the Pittsburgh Zoo & PPG Aquarium, where the families gathered in the Water's Edge conference room. Talk about a room with a view—a polar bear was right outside the window!

Our guest speakers were four young adults living with a bleeding disorder:



























Heather, Haley, Cameron, and RJ. Parents of young children had the opportunity to ask them questions and hear about their experiences including challenges they had growing up with a bleeding disorder; what they would tell their younger selves; and what their parents did for them to help prepare them for life with a bleeding disorder.

After the question & answer session

with the young adults, the families had some refreshments and then went on a scavenger hunt. They soon found many zoo attractions and our guest speakers waiting for them with bleeding disorder trivia questions! The families collected puzzle pieces along the way and collectively assembled the puzzles when they returned.

Kathaleen Schnur, LSW, Mental Health

Professional, from the Hemophilia Center of Western PA and Janet Barone, WPCNHF Program Director, facilitated the program. New Parent Network events are for families who have a young child with a bleeding diagnosis.

We thank the sponsors of our 2019 New Parent Network series of events: CSL Behring, Genentech, Novo Nordisk, Sanofi Genzyme, and Takeda.

## Better You Know Campaign Introduces Bleeding Disorders Literature to Aid Diagnosis in Women and Men

The Better You Know Campaign was launched in 2016 with the goal of raising awareness about bleeding disorders in women and men who may experience symptoms, but had not been diagnosed, and to connect these undiagnosed individuals to their local chapters and treatment centers.

These new materials, developed in cooperation with the Centers of Disease Prevention (CDC) and Better You Know, are now available for woman, girls, and health care professionals. All the materials are also available in Spanish. These materials include:

- Booklet for teen girls
- Brochure for primary care physicians, pediatricians, dentists, and ENT providers on bleeding disorders in women
- Brochure specifically for OB/GYNs on bleeding disorders in women
- Lab test booklet for women and girls
- Lab test log for patients
- Menstrual chart
- Doctor Prep Visit Guide
- Healthcare diary
- Signs & symptoms postcards

The BYK website (www.betteryouknow.org) will house these newly revised materials and educational resources for women and men in addition to:

- An online assessment tool that will let individuals know if they are at risk for a bleeding disorder
- Information on bleeding disorders, where to go if they are at risk, and how to prepare for doctor's appointments
- Videos from women about living with a bleeding disorder, symptoms, and a path to diagnosis
- Tools and guidelines for how to

- spread awareness about bleeding disorders via social media, press releases, etc
- Accredited webinars for healthcare providers on the signs and symptoms of bleeding disorders and steps to take toward diagnosis

All publications are also on the BYK site under "resources" and are now available for printing or downloading!

Jhon Velasco, Manager of Education and Training at NHF, encourages you to continue to raise awareness of bleeding disorders, and hopes this kit provides you with the useful materials to do so.

Together we can truly make an impact so that more and more individuals can receive the educational information available to them, get tested and get the care they deserve. If you need any information about the BYK program, want to find out how to get more involved, or need additional materials free of charge, please contact Jhon Velasco, jvelasco@hemophilia.org, 212.328.3702.

# Vaccines for Adults with Bleeding Disorders

Just as with kids, having a bleeding disorder is not an excuse for adults to opt out of immunizations. Here's what you may need.

Flu season is just around the corner, and you know that means - it's almost time to get your annual flu vaccine. You might need other immunizations, too. Ask your doctor if you should have any of these adult vaccines:

**Tdap (Tetanus, Diphtheria and Pertussis)** Adults should receive the Tdap vaccine if they did not receive it as a child, and every

adult should receive a Td (tetanus and diphtheria) booster shot every 10 years. The Centers for Disease Control and Prevention (CDC) also recommends that pregnant women get the Tdap vaccine to protect them and their babies from pertussis, also known as whooping cough.

#### Varicella

If you never had chickenpox or you didn't get the vaccine as a child, you can still catch chickenpox as an adult, so it's a good idea to get immunized. If you're not sure if you had chickenpox, your doctor can do a blood test to check.

### **Shingles**

If you did have chickenpox as a child, the virus can lie dormant in your body and then flare up again as shingles—a severe rash with blisters and nerve pain. The CDC says almost 1 in 3 Americans will develop

shingles. The vaccine is recommended for adults ages 50 and older. However, it is not recommended for pregnant women, people with weakened immune systems and those with HIV or AIDS, leukemia or lymphoma.

### Pneumococcal

Pneumonia can be debilitating, especially in older people. The CDC recommends the pneumococcal vaccine for adults ages 65 and older and for adults younger than 65 who have health conditions such as liver disease, HIV, asthma or diabetes. There are two types of pneumonia vaccine, so ask your physician which one is appropriate for you.

### **HPV (Human Papillomavirus)**

HPV is usually transmitted through sexual contact, and it causes warts on the genitals, mouth and rectum. HPV often

(Continued on page 19)





FDA approved for dosing 2 to 3 times a week



Regardless of age and dosing schedule



In previously treated people

AFSTYLA was studied in 258 adults, adolescents, and children the largest hemophilia A pivotal trial program to date

\*AsBR=Annualized spontaneous bleeding rate.

## Important Safety Information

AFSTYLA is used to treat and control bleeding episodes in people with hemophilia A. Used regularly (prophylaxis), AFSTYLA can reduce the number of bleeding episodes and the risk of joint damage due to bleeding. Your doctor might also give you AFSTYLA before surgical procedures.

AFSTYLA is administered by intravenous injection into the bloodstream, and can be self-administered or administered by a caregiver. Your healthcare provider or hemophilia treatment center will instruct you on how to do an infusion. Carefully follow prescriber instructions regarding dose and infusion schedule, which are based on your weight and the severity of your condition.

Do not use AFSTYLA if you know you are allergic to any of its ingredients, or to hamster proteins. Tell your healthcare provider if you previously had an allergic reaction to any product containing Factor VIII (FVIII), or have been told you have inhibitors to FVIII, as AFSTYLA might not work for you. Inform your healthcare provider of all medical conditions and problems you have, as well as all medications you are taking.

## Ask your doctor if twice-weekly dosing is right for you

Immediately stop treatment and contact your healthcare provider if you see signs of an allergic reaction, including a rash or hives, itching, tightness of chest or throat, difficulty breathing, lightheadedness, dizziness, nausea, or a decrease in blood pressure.

Your body can make antibodies, called inhibitors, against FVIII, which could stop AFSTYLA from working properly. You might need to be tested for inhibitors from time to time. Contact your healthcare provider if bleeding does not stop after taking AFSTYLA.

In clinical trials, dizziness and allergic reactions were the most common side effects. However, these are not the only side effects possible. Tell your healthcare provider about any side effect that bothers you or does not go away.

### Please see full prescribing information at AFSTYLA.com.

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.



## On Time Can Be Too Late

By Michael Joshua

I have hemophilia, but it doesn't have me. And it won't hold me back as I prepare to head off to college in August.

On time can be too late when preparing to transition from high school to college. Because I have a diagnosis of severe hemophilia B, my mother always started preparing for the next school year before the end of the current school year. During that time she would meet with the school nurse or administrative staff for a medical packet and to schedule an in-service if necessary. My mom always told me that my medical history is my personal business, and it's up to me to decide to share with others. However, it's very important that I inform those who need to know about my hemophilia and educate them on what's necessary in case I require medical attention and assistance.

Waiting until you graduate from high school is too late to prepare for college. When you grow up with a bleeding disorder, you learn that your normal is different from the normal of people without a bleeding disorder. I researched and determined which schools were the best options for me to attend. After campus visits, I began the application process and was able to discuss my medical needs with an admissions counselor. By October, I had submitted an application for early action admission and completed the FAFSA (Free Application for Federal Student Aid). Immediately after receiving acceptance in November, I reached out to an accessibility counselor at the Office of Accessible Education to discuss available resources and what I will need to manage my disorder. I got the necessary paperwork via email, and had it in hand to present to the hematologist during my six-month visit to the hemophilia treatment center. During this visit, I was able to get my hematologist involved and discuss what I will need to move out on my own and have access to care. In January, I also met with a rehabilitation counselor at the Office of Workforce Development Rehabilitation Services regarding available resources for college.

In February, I attended the admitted student visit. Not only did I participate in the activities scheduled, I also took the time to personally meet the counselor at the Office of Accessible Education. Among other accommodations, it was confirmed that I would receive a private dormitory room with no additional cost. Next, I familiarized myself with the location of Student Health Services, and met the staff there. I informed the nurse about my treatment schedule and learned about their hours, their services, and campus emergency numbers. Because factor is

shipped by motorized delivery service and not by the US Postal Service, there is a specific process that has to be followed in order for the package to be received.

When preparing to transition from high school to college, it's very important to plan ahead, be assertive, know available resources, and establish a support network. Although it didn't take a long time to navigate this situation, if I had waited until orientation, after move-in, then the time of a shipment or an emergency would not have been the best moment to learn. A new chapter of my life begins this August, but I am ready and not afraid of the challenge. I have always challenged the limits rather than limiting the challenges. As Malcolm X once said, "The future belongs to those who prepare for it today."

Michael is set to graduate from Baton Rouge Magnet High School in 2019, with plans to study political science and English at Loyola University in New Orleans in the fall. He aspires to practice law or become a sports analyst. Michael has a strong passion for helping others and enjoys spending time with family and friends, volunteering in the community, watching sports, and participating in competitive swimming and weight lifting.

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Publication: PEN 8.19 Column: as i see it

## **Advocacy Update**

On July 2, 2019, Governor Tom Wolf signed into law House Bill 3, a historic reform to health insurance that creates an online exchange operated by the state in lieu of the federal government. The legislation provides for lower premiums and increased access to health insurance by developing a state-based health insurance exchange and a new reinsurance program. The state-based exchange is expected to save money for those purchasing plans on the exchange. The state-based exchange will allow consumers to enroll in coverage starting during open enrollment for 2021.

On July 18, 2019, WPCNHF and the Eastern PA Chapter of NHF submitted letters in support of Senate Bill 731 (J.Ward-R), which was referred to the Senate Banking & Insurance Committee on June 7, 2019.

To help individuals with rare and chronic illnesses afford special prescription medications, drug manufacturers have offered co-pay assistance programs that alleviate a person's out-of-pocket obligation. Such co-pay coupons or discounts for chronic diseases (i.e., hemophilia, primary immunodeficiency diseases (PI), cancer, kidney disease, multiple sclerosis, HIV, rheumatoid arthritis) represent a lifeline by making medications more affordable for individuals and increases access to prescribed treatments.

Under the practice known as "co-pay accumulator programs," the health insurer or Pharmacy Benefit Manager (PBM) prevents a drug manufacturer's payments from counting toward an enrollee's deductible. Therefore, after using the entire amount of the co-pay card or coupon, enrollees are forced to pay their full deductible; thereby defeating the purpose of the drug manufacturer's co-pay

assistance program.

Senate Bill 731 seeks to end the discriminatory practice of copay accumulator programs being implemented by health insurers and PBM's by requiring them to count discounts enrollees get through drug payment assistance programs as paying off their out-of-pocket obligations. Virginia, West Virginia and Arizona recently enacted laws allowing drug discounts to count towards an enrollee's deductibles and out-of-pocket limits.

If your health insurer or PBM has implemented a co-pay accumulator program, please contact the Chapter with the details (which insurer or PBM, what medication, etc.). Also, as you renew your benefits and select your health insurance plan, remember to check and see if the health plan you are choosing has a co-pay accumulator program.

## **Young Adults and Insurance**

## Considerations When Deciding on a Health Coverage Plan



For more information, visit b2byourvoice.com to download *Young Adults and Hemophilia B.* 

This content is brought to you by Pfizer.

For young adults with hemophilia, having insurance is a crucial step in becoming independent; the annual costs of treating hemophilia can make access to health care coverage a necessity. Appropriate health insurance can be provided through an employer and is an important factor to consider during a job search, but there are other options to explore for purchasing insurance outside of employment as well.

Timing can be key: There may be a waiting period before a recently hired employee is covered under a new policy, or there may be open-enrollment dates to keep in mind for other health insurance options.

### **Questions to Ask About Health Insurance Plans**

When deciding on a health care plan, here are some of the important points to consider, as well as the definitions of some key terms in understanding health insurance.

What are the plan's exclusions and/or limitations? Exclusions are health care services for which your health insurance or plan doesn't pay.<sup>2</sup>

Is clotting factor covered?

Does the plan offer product choices for clotting factor?

Does the plan cover visits to your primary care provider and your hemophilia treatment center?

Are referrals required, and if so, for which services? A referral is a written order from your primary care doctor for you to see a specialist or get certain medical services.<sup>2</sup>

Is there a lifetime or yearly limit or cap? A limit or cap is the maximum benefit paid by the insurer; some insurance companies have caps on certain costs.

What are out-of-pocket costs for the in-network providers versus the out-of-network providers? Out-of-pocket costs are your expenses for medical care that aren't reimbursed by

insurance. Out-of-pocket costs include deductibles, coinsurance, and co-pays for covered services, plus all costs for services that aren't covered.<sup>2</sup>

What is the annual deductible for in-network providers versus out-of-network providers? A deductible is the amount you pay for covered health care services before your insurance plan starts to pay.<sup>2</sup>

How much is the monthly premium? A premium is the amount paid for the insurance coverage.<sup>2</sup>

"It is important for [young adults], especially those with a chronic condition, to realize the necessity of having health insurance, as well as knowing what it takes to maintain that insurance."

— Joy Mahurin

Reimbursement Specialist

## **Maintaining Health Insurance**

People living with hemophilia should keep in mind the potential for a lapse or gap in health insurance. In most cases, young adults may stay on their parents' policies until age 26.3 However, it's important to be aware of the potential for a lapse in coverage after age 26 and prior to having a policy of one's own through an employer or the Health Insurance Marketplace. One option to retain medical coverage is Consolidated Omnibus Budget Reconciliation Act (COBRA) coverage. Other options may be state-sponsored individual Health Insurance Portability and Accountability Act (HIPAA) insurance plans and even Medicaid (for those who are disabled or who meet income requirements). In addition, for those who struggle to keep up with health care costs, some National Hemophilia Foundation (NHF) chapters have programs that can assist with paying deductibles, co-pays, and premiums.

References: 1. Chen SL. Economic costs of hemophilia and the impact of prophylactic treatment on patient management. *Am J Manag Care*. 2016;22(suppl 5):S126-S133.

2. US Centers for Medicare & Medicaid Services. Glossary. Healthcare.gov Web site. https://www.healthcare.gov/glossary/. Accessed March 28, 2019.

3. US Department of Health & Human Services. Young adult coverage. HHS.gov Web site. https://www.hhs.gov/healthcare/about-the-aca/young-adult-coverage/index.html. Accessed March 28, 2019.



Patient Affairs Liaisons are Pfizer hemophilia 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).

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## The Push for a New Charity Skin: Riot Games and the Bleeding Disorders Community

(Continued from page 11)

could no longer participate in sports, he began to feel alone and disconnected from his peers. He gravitated toward gaming as an outlet, a community, and an adventure. He said, "Gaming allows you to explore many new "worlds" and stories that you wouldn't be able to experience anywhere else. Because sports weren't really an option, I was able to be engaged with my friends off the field." Colin has made life-long friends, some half-way across the world, through the gaming community (although, most of them know him as Draagaxs, his gamer tag.) Colin was able to feel connected to his peers and his bleeding disorder no longer felt so isolating.

Colin's favorite game is League of

Legends and he started playing six years ago. "I enjoy playing League of Legends because it's a competitive game," Colin said, "and being a competitive person who can't really play sports, it's great." Starting his second year in college, League of Legends has become an important way for his friends to stay connected as well. "... All my friends play the game, and it's a great way for all of us to get together and do something without leaving our houses. It isn't always easy to do because of people's schedules or distances." You can find Colin playing, and winning multiple championships, as Zoe, Sylas, or Xerath.

The gaming community has been a staple through Colin's adolescent years, and even into the next chapter of his life. He is consistently blown away by the help and support the friends he's made through video games provide and strongly believes he would not be the person he is today without this community.

Riot Games, the creators of League of Legends, have rallied this large community in the past by supporting nonprofit organizations that mattered to League Players. In 2018, they were able to raise 6.1 million dollars through their Dark Star Cho'Gath charity skin. This money was divided among 21 nonprofits all over the world. The Western Pennsylvania Chapter of the National Hemophilia Foundation, along with Colin, has reached out to Riot Games and asked them to create another charity skin that would benefit the bleeding disorders community. While Riot Games has not yet responded to their outreach, they are hoping more individuals in the gaming community living with bleeding disorders will come forward and unite with Colin and his push for a charity skin.

Most people have a limited understanding of hemophilia, and a lot less even know what Von Willebrand's Disease is. Bleeding Disorders are more than getting a cut on the arm and bleeding to death, because that simply isn't the case. Bringing awareness to this small, but important, community of individuals is necessary to help affected kids and teens feel a little more connected to their peers. Colin adds, "Riot has helped other foundations greatly, and I hope they continue."

## Don't Be Scared; Be Prepared!

(Continued from page 4)

- Household Documents & Contact Numbers
- At least ½ Tank Gas in the Car
- Special Items Fully charged cell phone and a portable radio with extra batteries

Pack a **Travel Bag** (**To Go Bag**) that's always ready for an emergency or a long trip, to include your medication and related supplies, such as:

- Factor
- Syringes

- Saline
- Heparin (if patient has a port)
- Alcohol
- Wipes
- Huber Needles
- Butterfly Needles
- Adhesive tape
- Gauze
- Co-Ban or Co-Flex
- Sharps Container
- Sterile dressing changing kits / Port kits with sterile gloves & mask
- Infusion log
- Hand soap & sanitizer
- Travel letter from HTC
- Band-Aids
- Ace Bandage
- Tourniquet

An emergency supply checklist, "to go bag" list, and other materials can be downloaded from HFA's website: https://www.hemophiliafed.org/for-patient-families/resources/toolkits/be-prepared-toolkit/. If you don't have access to a computer or printer, contact the chapter and we will be glad to print and mail these resources to you.

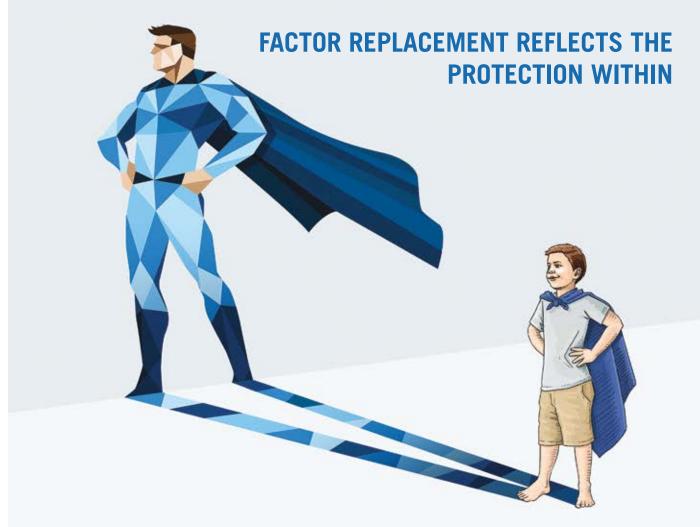
We thank the following for sponsoring our summer education program: BioMatrix, CSL Behring, Genentech, Hemophilia Center of Western PA, Hemophilia Federation of America, Noro Nordisk, Takeda, and Spark Therapeutics.



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## **Needs Assessment**

In October, Need Assessments were mailed to all 700+ households on our mailing list. Be sure to complete the assessment and return it to the chapter so we can better serve the community and be sure we are meeting your needs.



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

Brought to you by Takeda, dedicated to pursuing advancements in hemophilia for more than 70 years.<sup>7</sup>

## Stay empowered by the possibilities.

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

Takeda

## **Meet the New Board Members**



## Melinda Perry

What influenced you to get involved with the Chapter and join our board of directors? My son Ryker was diagnosed on Christmas of 2017 with Hemophilia A. We wanted to do everything we could to learn about his bleeding disorder and what we can do to help him and other families like us.

What is your background or current occupation? I am a Senior Paralegal and

Office Manager for a law firm in Pittsburgh.

What are you looking forward to as a new board member? To be able to do things to help families and raise money for an amazing foundation.

What do you like to do for fun? My son Ryker, husband Steve and myself love to go to our camp, and swim, and let Ryker play with his camp friends who adore him so much.



## **Scott Domowicz**

What influenced you to get involved with the Chapter and join our board of directors? I joined the board to contribute back to an organization that has provided so much to me and my family over the past 20 years.

What is your background or current occupation? I am currently the Principal Management Consultant at Great Lakes Management Consulting. I was also a former firefighter with the Monroeville VFD.

What are you looking forward to as a new board member? My goals, as a board member, are to promote growth and fiscal stability for the chapter so that it may meet the growing need for services as the availability of funding sources shrinks and to provide an increase in the number of opportunities to engage with other members of the bleeding community in fun, family oriented activities.

What do you like to do for fun? I spend time with my family, scuba dive, kayak, fish, travel, garden, and go on winery tours. :)

## Getting to Know HCWP Staff



Karen Cononie, Administrative Assistant

Birthplace: Pittsburgh PA

First job: Waitress at Pizza Hut

Accomplishment you're proudest of: my son

What three words describe you best? Loyal, compassionate, funny

**Dream vacation:** Sicily, where my family came from

Things you can do without: lazy people, anyone that abuses animals, liars

Person you'd most like to have dinner with: my mom

**Movie you could see anytime:** I don't really go to movies

TV show you try not to miss: CSI

Three things that can always be found in your refrigerator: water, cheese, tea

**Secret vice:** having a lot of dogs to take care of but everyone already knows that!!

Who would play you in the movies? Hmm, I really don't know

**Your pet peeve about Pittsburgh:** potholes, bad drivers

**People may be surprised to know that:** My son and I did a commercial for Animal Friends years ago on families that volunteer together

## Vaccines for Adults with Bleeding Disorders

(Continued from page 13)

goes away on its own, but it can sometimes develop into cancer. HPV is a major cause of cervical cancer in women and of anal cancer and genital warts in women and men. HPV vaccination is recommended through age 26 for women and age 21 for men if they were not vaccinated when they

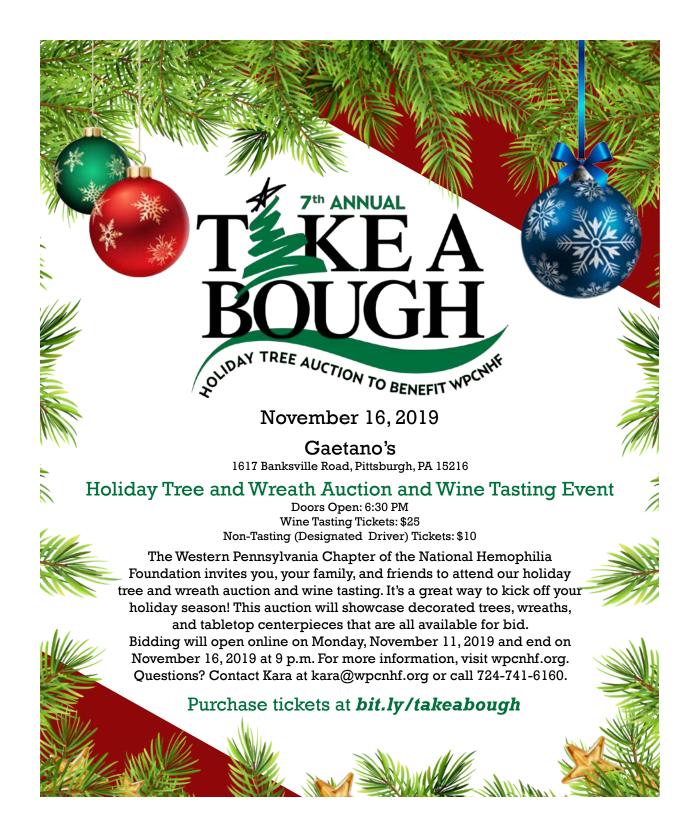
were younger.

### Hepatitis A and B

Hepatitis A and B cause inflammation of the liver and can lead to serious complications for people with bleeding disorders. Although the National Hemophilia Foundation's Medical and Scientific Advisory Council strongly urges vaccinations for hepatitis A and B, some people with hemophilia still may not have been immunized. Consult your hemophilia treatment center team or primary care physician about getting the hepatitis A and B vaccines, which are given in a series.

To reduce the risk of a muscle bleed, many vaccinations can be given subcutaneously, or under the skin, instead of intramuscularly, or into the muscle. However, some healthcare providers may prefer to give intramuscular injections using a small-gauge needle in a larger muscle, like the thigh. Your hemophilia treatment center can instruct you on whether factor infusion is needed before an intramuscular injection, and treating the area with ice afterwards can help reduce bruising and ease discomfort.

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## Western Pennsylvania Chapter of the National Hemophilia Foundation

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