



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

Spring 2018
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Unite for Bleeding Disorders Walk

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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.

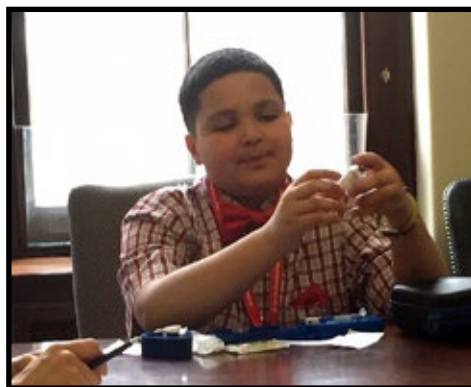
WPCNHF Contributor
Agency Code Number
is: **83**

Hemogram

Washington Days

Over 500 people from across the county joined the National Hemophilia Foundation (NHF), in Washington D.C., to advocate for people living with bleeding disorders. Twelve advocates from Pennsylvania participated in the NHF's largest Washington Days event, to date. Western Pennsylvania was represented by Delores Johnson-Huber and her children Ethan and Kyrie, Dawn Rotellini, Scott Miller, Elizabeth Molnar, Kara Dornish, and Janet Barone.

We shared our stories on how bleeding disorders have affected our lives and why access to Hemophilia Treatment Centers and the comprehensive care we receive from them is so critical—and not available elsewhere. We asked our legislators to support federal standards for public and private insurance so that patient protection and access to insurance is maintained. We gave examples on how protections such as pre-existing conditions policies, the ban on lifetime and annual limits, and federal standards for Essential Health Benefits, impact individuals and families living with bleeding disorders.



We also asked our legislators to support federal hemophilia programs at the Health

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Carrier Retreat

The Chapter collaborated with the Hemophilia Center of Western PA (HCWP) to hold our first-ever Carrier Retreat! Carriers, potential carriers, and mothers of carriers gathered for this important women's event. Michelle Alabek, MS, CGC, (former Genetic Counselor at the HCWP, currently with the UPMC Eye and Ear Institute) started off the day with an informative presentation on Genetics and Genetic Testing. We appreciated her detailed answers to our many questions on the complex topic of genetics.

Next, we were excited to welcome Robert F. Sidonio, Jr. MD, MSc of Emory University and Children's Healthcare Atlanta. Dr. Sidonio is a Clinical Director



of Hemostasis/Thrombosis and Clinical Research, Assistant Professor of Pediatrics, and a die-hard Pittsburgh Steelers fan! Dr. Sidonio presented Women and Girls with Bleeding Disorders which included topics such as inheritance, types of carriers, factor levels and classification, as well as bleeding

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Washington Days

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Resources and Services Administration (HRSA) and the Center for Disease Control (CDC). HRSA provides funding to hemophilia treatment centers (HTC) to provide multi-disciplinary services not typically covered by insurance (such as

physical therapy assessments and social work) and the CDC Division of blood disorders provides funding for HTC surveillance and prevention activities.

One of our younger advocates, Ethan (11 years old), brought his factor and infusion supplies to each meeting and explained step-by-step how he infuses himself twice a week. He did a great job talking about

hemophilia and the infusion process and answering questions!

Please stay on the lookout for communications from NHF and the Chapter. It's critical that we ALL contact our legislators when legislation that can impact our lives and health care--either positively or negatively-- comes up for vote.

Carrier Retreat

(Continued from previous page)

tendencies and symptoms in carriers vs. non-carriers. He later answered all our questions on carriers, during an Ask the Doctor session. It was interesting and reassuring to learn about research projects for women with bleeding disorders, including carrier-specific research studies. We look forward to hearing the results on current and future research, as well as results on proposed terminology related to hemophilia carriers.

During the afternoon, everyone had an opportunity to ask the other women questions about their carrier status and decisions they've made based on being carriers or mothers of carriers/ children with bleeding disorders, during a discussion led by Kathaleen Schnur, LSW, from the HCWP. The women shared their experiences and supported each other during this open and honest discussion.

Before the day was over, we welcomed another speaker to our retreat—Chelsea Frimpong, Education Specialist, with the National Hemophilia Foundation. Chelsea specializes in education and support for women and girls with bleeding disorders. She helped empower us with the program Advocating for Yourself as a Woman.



After enjoying a delicious meal and great company at Mitchell's Fish Market, we returned to our hotel for an entertaining and fun evening with PlantNite! We had a great time creating plant arrangements to take home. They will serve as a wonderful reminder of the Carrier Retreat and the friends we have made. We will also take home with us a better understanding of how bleeding disorders affect carriers; and we will be better prepared to have conversations with our medical providers regarding current/



future conditions and procedures for ourselves and/or our daughters.

We thank the Colburn-Keenan Foundation for making this retreat possible.

WPCNHF Recognized as Bleeding Disorders Champion!

WPCNHF is honored to be recognized as a Bleeding Disorders Champion by the National Hemophilia Foundation.

WPCNHF was recognized for providing members with opportunities to advocate at the state level through state legislative day events; for demonstrating dedication to generating awareness of bleeding disorders at the state and local levels through the Red Tie Challenge activities; and for generating awareness by procuring a proclamation and/or resolution designating March as Bleeding Disorders Awareness month elevating awareness of inheritable bleeding disorders to the general public.



HCWP Corner

Greetings from HCWP:

Happy Spring to all of our patients and their families! We are anticipating warmer weather and the countdown to camp!

Speaking of camp, some important dates to remember:

Registration opens:	May 1, 2018
Registration closes:	June 30, 2018
Medical forms due	June 30, 2018

Please note that the medical form date is changed from last year. The forms are now due at the close of registration.

LIT Dates

Invitations will be sent:	May 7, 2018
Applications due:	June 11, 2018
Notification of decision:	July 9, 2018
On-site LIT training:	August 4-5, 2018

If you have any questions, please reach out by phone 412-209-7344 or email CampH2C@itxm.org

From the clinic:

Patients at HCWP have begun to take Hemlibra. This is a once-weekly subcutaneous (under the skin) drug for those with hemophilia A and inhibitors. It is a factor VIII mimic that prevents the inhibitor from binding to factor VIII, so that bleeds are prevented. To learn more, make an appointment or contact an HCWP nurse at 412-209-7411.

There are many exciting new therapies in clinical trials, including Hemophilia A Gene Therapy studies. To be considered, up-to-date home treatment records are required. To learn more, make an appointment or contact an HCWP nurse at 412-209-7411.

Please make sure you are current on your appointments at the center. It is critical for proper treatment and procedures that you have had a recent exam. Please call HCWP if you are not sure or know you need to schedule an appointment. If there are barriers to you attending your annual appointment, please reach out to the social workers who can assist you.

The school year is coming to an end, and many of our kiddos are finishing up their senior years and considering their next step. If you are considering post secondary education or training please visit the NHF website (<https://www.hemophilia.org/Community-Resources/Scholarships>) to find a list of available scholarships. Also, please feel free to reach out to your Center's social workers to discuss options and strategies as many of you transition to the next level of independence. Whether you are living in dorms, off campus housing, traveling about, or moving out on your own, your social workers can offer support as you begin to navigate on your own.

To our parents with kiddos who are school age, if you would like to set up an in-service (HCWP representatives provide education to your schools, child care centers, after school programs, etc), please call the social workers who can work with you and your schools to set that up between now and next fall.

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Let's get together to talk about IXINITY®

“After many years, I am still so inspired by the strength and sense of family in the bleeding disorder community. It brings me great joy to be a part of it!

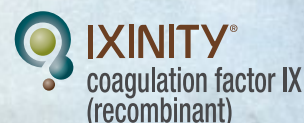
—Ellen Rowe, your resource for all things IXINITY



► Contact Ellen at 215-908-4276 or rowee@apvo.com



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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.

WPCNHF Wish List

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

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

Mission Statement:

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

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.

HCWP Corner

(Continued from page 3)

To everyone, warmer weather sometimes means vacations and getaways. Whether

you are flying, driving, taking a train, or riding a boat, please make sure you have a current travel letter. If you know where you are going, we can also list nearest HTC's and local emergency departments.

We look forward to seeing many of you in the clinic and at programming with the Chapter.

Cheers to a warm and pleasant spring!

Letter From The Executive Director, Alison Yazer

Dear Chapter Members and Friends,

I hope that our spring newsletter finds you and your family well. It has been a busy few months for the Chapter as we continue to plan events and actively advocate for the community. Please see the Advocacy Corner for easy ways you can help the community without even leaving your house!

Later this month, Janet and I will be heading to Cleveland for the Hemophilia Federation of America's Annual Symposium. We thought that since it was so close, we would go check it out and we're hoping to bring back some exciting new ideas and information. We'll definitely report back to you in the next newsletter.

As always, please contact the staff of WPCNHF with any questions or concerns. Thank you for all that you do on behalf of the bleeding disorders community.

Sincerely,

Alison R. Yazer
Executive Director

New Patient Insurance Premium Assistance Program for People with Hemophilia

The Patient Access Network (PAN) Foundation has opened a new patient insurance premium assistance program for individuals with hemophilia. PAN is an independent, national 501(c)(3) organization dedicated to helping federally and commercially insured people living with life-threatening, chronic and rare diseases with out-of-pocket costs for their

prescribed medications.

The program was announced in a PAN press release on January 9, 2018. Since its establishment in 2004, PAN has provided nearly one million underinsured patients with over \$2.6 billion in financial assistance through over 60 disease-specific programs, hemophilia being the newest. Patients who qualify for the PAN Foundation's Hemophilia Premium Assistance Program are eligible to receive \$4,500 per year in financial assistance. Eligible patients need to be residing and receiving treatment in the U.S., and have health insurance.

To learn more about the new program, including additional eligibility criteria and

frequently asked questions, visit the PAN Foundation at www.panfoundation.org.

"The PAN Foundation is excited to alleviate the financial strain of the out-of-pocket premium costs for people living with hemophilia," said PAN President and CEO Daniel Klein. "Thanks to our generous donors, many patients living with hemophilia will be able to access the treatment they need to best manage their conditions and focus on improving their health and quality of life."

Source: PAN Foundation press release dated January 9, 2018

Advocacy Corner

Once again, the Hemophilia Line Item in the Pennsylvania state budget is threatened. This money - \$959,000 - goes directly to patient support! It helps fund things at the seven hemophilia treatment centers in Pennsylvania that insurance may not cover such as social workers and physical therapists and we ALL know how important they are! Even if you're unable to join us for Harrisburg Day this month,

you can still contact your state legislators to ask for their support in maintaining this funding and keeping it a separate line item.

We are also asking state legislators to support HB 2113. This critical legislation will protect YOU from your insurance company switching coverage mid-year. Imagine booking a vacation, endlessly researching hotels to make sure the one you pick will have exactly the amenities you want, only to get to the hotel to find out your beach-front resort is actually a

tent in someone's parking lot. HB 2113 will prevent insurance companies from changing the coverage a plan offers mid-year - if you can't change your plan, why should your insurance company be able to make changes to the plan you choose?

Need help contacting your legislators? Not sure exactly what to say? Visit www.wpcnhf.org/get-involved/advocacy/ to find out how to get started or call the office and we'll be happy to help!

Calendar of Upcoming Events

Sunday, April 15
New Parent Network
Parents & Tiny Tots – Part 2
Oakland, PA

Tuesday, April 17
State Advocacy Day
Harrisburg, PA

Saturday, April 21
Infusion Day
Cranberry Township, PA

Saturday, July 14
Annual Meeting & Walk Kickoff
Pittsburgh, PA

Sunday, August 5 – Saturday, August 11
Camp Hot-to-Clot
Fombell, PA

Saturday, August 25
New Parent Network
Ligonier, PA

Saturday, September 15
Unite for Bleeding Disorders Walk
North Park
Allison Park, PA

Saturday, September 15
Run for Their Lives 5K
North Park
Allison Park, PA

Saturday, September 15
Cornhole Tournament
North Park
Allison Park, PA

Saturday, October 6
Oktoberfest
Pittsburgh, PA

Friday, November 16
New Parent Network
Erie, PA

Saturday, November 17
Fall Program
Erie, PA

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



Combined Federal Campaign

WPCNHF is an approved charitable organization for the Combined Federal Campaign (CFC). If you participate in the CFC, please consider designating all or a portion of your donation to the Chapter.

WPCNHF CFC Number is: 81343

Learn. Explore.
Connect With
Our Hemophilia
Community
on **Facebook**.

Our
Hemophilia Community



Find us on **Facebook.com/OurHemophiliaCommunity**

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Unite
for Bleeding Disorders

**SAVE
THE DATE**

Saturday,
September 15, 2018

Registration Check-In Time: 9:00am
Walk Start Time: 10:00am
Distance: 5K (3.1 miles)
Location: North Park Boat House
10301 Pearce Mill Rd
Allison Park, PA 15101
Walk Chair: Tracy Sethman

Join us to support the Unite for Bleeding Disorders Walk! We will walk to raise critical funds and awareness for the bleeding disorders community! We hope you can join us!

For more information, please visit
uniteforbleedingdisorders.org/event/pitt
or contact: Kara Domish, Local Walk Event Manager,
at 724-741-6160 or kara@wpcnhf.org

Run For Their Lives 5K Run

To Register or Donate visit,
wpcnhf.org/event/runfortheirives
or e-mail
kara@wpcnhf.org

Benefiting the Western Pennsylvania Chapter of
the National Hemophilia Foundation

September 15, 2018

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

North Park Boat House
10301 Pearce Mill Rd
Allison Park, PA 15101



Unite

for Bleeding Disorders

2018 Volunteer Opportunities



Run Bags & Pinwheel Assembly- Volunteers are needed during office hours (9am-4pm) the week of August 27th to assist with stuffing run bags and assembling Unite Pinwheels.

Packet Pick Up- Volunteers are needed on Thursday, September 13 from 6pm-8pm and Friday, September 14 from 4pm-8pm to work Run for Their Lives 5k packet pick up at Pro Bike + Run in Robinson Twp.

Walk Day Volunteers Opportunities – Saturday, September 15th

Set up- Arrive at 6:30am- Help set up tables, chairs, and signage.

Direct Parking/Traffic- Arrive by 7:15am- Wave in and direct vehicles to parking lot, assist pedestrians with safely crossing the street to the Boat House.

Run Registration & Check-In- Arrive at 7:30am- Help register onsite individuals and check-in already registered individuals.

Cornhole Registration & Check-In- Arrive at 7:45am- Help register onsite individuals and check-in already registered individuals

Photographer- Arrive at 8:00am- Capture candid moments and important parts of the day. Must have own equipment and share all rights to photos after the event.

Race Water- Arrive at 8:00am- Stand along the race route to direct runners and walkers and pass out water to the runners and walkers.

Race Medals- Arrive at 8:15am- Hand out race medals to runners as they cross the finish line.

Chinese Auction & Food Table- Arrive at 8:30am- Sell tickets for the Chinese auction. Help set up food table and make sure area is kept clean.

Walk Registration & Check-In- Arrive at 8:30am- Help register onsite individuals and check in already registered individuals.

Unite Table - Arrive at 8:30am- Organize and pass out Unite t-shirt, bags, and swag.

Clean up & Break Down Crew- Arrive by 11:30pm- Help break down tables and chairs, clean up, and load up truck.

Please e-mail Kara Dornish at kara@wpcnhf.org or call 724-741-6160 to sign up for any of the above volunteer opportunities. We appreciate all help and would like to thank you in advance for your interest and support!!



FACTOR REPLACEMENT REFLECTS THE PROTECTION WITHIN

For people with hemophilia, Factor treatment temporarily replaces what's missing.¹ With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.^{2,3}

Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 60 years.

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.** Wolberg AS. Plasma and cellular contributions to fibrin network formation, structure and stability. *Haemophilia*. 2010;16(suppl 3):7-12. **3.** King MW. Introduction to blood coagulation. <http://themedicalbiochemistrypage.org/blood-coagulation.php>. Last modified January 2, 2017. Accessed January 2, 2017.

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Parents & Tiny Tots

We were pleased to have Dr. Frederico Xavier from the Hemophilia Center of Western PA (HCWP) as a speaker at the Parents & Tiny Tots session on March 11. Dr. Xavier had an open discussion with families raising an infant or preschooler with a bleeding disorder. He talked about bleeding disorders and answered a number of questions regarding different types of bleeds, emergency situations, and emergency room visits.

Parents who have had experience raising a young child with a bleeding disorder joined us and participated in a panel discussion, facilitated by Kathaleen Schnur, LSW, HCWP. Marie & Nick Vizzoca, Zolina Jevack, and Janet Barone answered questions from Kathaleen and the families.

Kathaleen Schnur also talked about emergency situations—who to contact and what to do. Each family received and packed a “Go Bag” (backpack) to keep and have on-hand for emergencies. The contents included instant ice packs, emergency card for medical and insurance information, a notepad and pen for recording important notes/instructions



at the hospital or doctor's office, an instruction booklet about caring for a person with a bleeding disorder (written for emergency room/doctor office staff), plus items to keep little ones occupied, such as coloring books, crayons, and snacks. Each family will also receive an emergency letter from the HCWP to keep in the bag. The families will just need to

drop their factor in the bag and head out the door!

We thank the following sponsors of the 2018 New Parent Network series of events: Bioverativ, CSL Behring, and Genentech.

Western PA Chapter of the NHF Launches the 2018 Red Tie Campaign

In March 2016, hundreds of Pennsylvanians and thousands of Americans nationwide participated in the first-ever Red Tie Challenge during the first-ever Bleeding Disorders Awareness Month. Last year, we added a fundraising component to the campaign, and together with chapters across the country, we raised \$20,000 to support National Hemophilia Foundation's (NHF) advocacy, education, and research initiatives.

Now, it's time to put on your red ties again and join us for the 2018 Red Tie Campaign! This year, we're building upon the success of the fundraising goal from last year's Red Tie Challenge to launch a new campaign that celebrates our advocacy and awareness-raising efforts and challenges our community to raise \$25,000 to fight bleeding disorders.



For years, as the largest nongovernment funder of research awards, fellowships and grants, NHF has been the leading fight against bleeding disorders. In partnership with NHF, we have advanced the standard of care and the quality of life for our community. We aim to raise an increased level of funds and do even more to build awareness to support our research, education and advocacy initiatives in Western Pennsylvania and across the country.

To participate in the 2018 Red Tie Campaign, you can:

Sign: Join the fight to protect access to quality healthcare for people with bleeding disorders and for all Americans by signing our open letter.

Give: Make a donation to support NHF's innovative research, critical advocacy, and education programs.

Share: Follow #RedTieCampaign on Twitter, Facebook and Instagram, and create your own red tie style with our customizable photo booth.

To learn more about the Red Tie Campaign, visit RedTieCampaign.org.

Winter Social

The Chapter hosted a winter social for families who participated in the 2017 New Parent Network series of events.



This event, which was held at Lightning Bug, in Mars, PA, provided kids with an opportunity to burn off energy in the play area and play arcade games. Some of the older children even enjoyed a game of laser tag! It was a great way to enjoy

a winter afternoon and reconnect with the families. We thank the 2017 New Parent Network sponsors: Bioverativ, CSL Behring, CVS Specialty, Novo Nordisk, Octapharma, Pfizer, and Shire



Getting to Know HCWP Staff: Judith Kadosh, RN BSN



Birthplace: Pittsburgh

First job: Babysitter, Domino's pizza;

first real job Pediatric ICU Nurse at Rainbow Babies and Children's Hospital in Cleveland

Accomplishment you're proudest of: Raising 2 compassionate, independent self-sufficient children

What three words describe you best? Compassionate, hardworking, perfectionist

Dream vacation: Alaskan cruise with my children followed by a trip to Australia

Things you can do without: negativity, selfishness and mean-spirited people

Person you'd most like to have dinner with: Golda Meir

Movie you could see anytime: Toy Story 1 and 3

TV show you try not to miss: This is Us

Three things that can always be found in your refrigerator: yogurt, cottage cheese and milk

Secret vice: anything chocolate

Who would play you in the movies? Who would want to?

Your pet peeve about Pittsburgh: poorly kept roads and lack of public transportation options

People may be surprised to know that: I volunteered on a Kibbutz in Israel between moving back to Pittsburgh from Cleveland where I was responsible to pick apples in the orchard, feed restaurant linens through a drying press (and sometimes fixing it when it broke down) and being a hotel maid.

Von Willy Who?

By The 2018 Unite for Bleeding Disorders Walk Chair, Tracy Sethman

We discovered that our son had Von Willebrand Disease because of routine blood work to check his liver function due to a medication he had been on. Our son was in grade school when he was diagnosed. Not long after seeing the hematologist he had a serious knee injury and was admitted to the hospital to have DDAVP treatment for 3 days. We were completely blindsided when the call came in explaining why he had so much bruising and complications when he had



surgery at 5 1/2 weeks old. Life seemed to be turning upside down.

This all occurred in the mid 90's and the information highway was only beginning to get going so resources were limited

to what the doctor, social worker, or nurse could pass along. Next up, how do we allow our son to be "normal", can he participate at school, can he still ride his bike? The school district decided that he should only use the elevator and was to stay inside during recess. It makes me tear up looking back now, how horrible for a young boy. Fortunately, we put a stop to this and educated ourselves and the school.

During the visits to the hematologist we had to be tested simply because as they put it... this disease didn't fall out of the sky and land on our son. As you can imagine it turned out that my genes were the generous ones that not only

affected him but my daughter and myself also. This explains the severe bleeding situations that I found myself in since I was a young child, surgery difficulties, facing death during an ectopic pregnancy that had burst. Talk about having angels at your side – I certainly do.

That was then and now life is pretty much a breeze due to the knowledge and medications. The three of us live with a nasal medication on hand for life's bumps and bruises. If we need extensive dental

care or even surgery then intravenous dosing of DDAVP is first choice for prevention. We attend the local chapter's events, meetings, and stay informed.

Fundraising is not difficult especially when you are sincere and use a story or two of how VWD affects your entire family. Don't think for a minute that your loved ones brush it off and aren't concerned. Giving your friends and family information on VWD and even hemophilia is vital. Folks aren't learning

about bleeding disorders in school and it's not even in everyday conversations. All of us have sadly had to explain to a nurse or even a doctor what VWD is. That alone has caused us to jump on a soapbox because the National Hemophilia Walk is to raise not only funds but awareness. Get informed, inform your friends and family, and fundraise. Together someday these bleeding disorders will be in ordinary conversations and ALL medical staff will know too.

2018 Iced Tees Winter Golf Outing and Chili Cook-Off

WPCNHF's Third Annual Iced Tees Winter Golf Outing and the Second Annual Chili Cook-Off were held at Diamond Run Golf Club in Sewickley on Saturday, March 3, 2018. Registration began at noon and as the Chili Cook-Off Contestants set up their delicious chili, the brave golfers began to gear up for the cold weather. Each golfer received a long sleeve shirt and goodie bag filled with a variety of golf and winter weather items.

The Chili Cook-Off kicked off the event. Four contestants competed for their chance to win a trophy and a \$200 grand prize. Everyone had a chance to taste and vote on their favorite. It was a close call between chili chefs Adam Boyle, Scott Miller, Anthony Schiavone, and Brianna Pace. Scott Miller came out ahead and maintained his reigning title as the WPCNHF Chili Cook-Off Champion. He generously donated his prize money back to the Chapter. Thanks Scott!



At 2pm the golfers teed off for the 9-hole scramble. It was a chilly 40 degree day but the sun was out and the golfers were prepared. A tee sign was displayed at each hole containing a fact about Hemophilia and von Willebrand Disease.

Congratulations to the winners of the

tournament! Longest Drive went to William Shufesky and Melissa Dillon. Closest to the Pin went to Anthony Pirrello and Melissa Dillon.

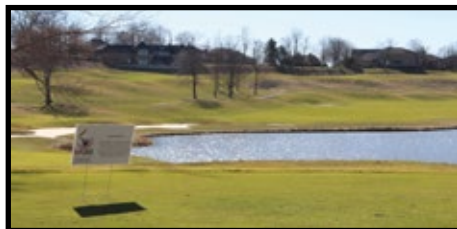
Third place went to Matt Pace and Dan Howard.



Second place went to Melissa Dillon, Cindy Yingling, and Gretchen Moran



First place went to William Shufesky, Scott Miller, and Anthony Pirello.



WPCNHF would like to thank everyone who participated in the event, sponsored the event, and donated items to help make the event a success! Thank you to our amazing volunteers Katy Logreco and Adam Boyle. We are excited to report that over \$14,000 was raised! 100% of this money will stay local to support the members of the Western PA Chapter of the National Hemophilia Foundation.



Retrospective Study Reflects Successful Transition to Extended Half-Life Therapies

Investigators at the Children's Hospital of Los Angeles (CHLA) recently published a retrospective review of patient clinical data, the findings of which reflect a series of largely successful transitions to extended half-life (EHL) therapies. The data was drawn from patients treated at CHLA's Hemostasis and Thrombosis Center (HTC).

"Clinical Use of Recombinant Factor VIII Fc and Recombinant Factor IX Fc in Patients with Hemophilia A and B," was published February 5, 2018 in the journal *Hemophilia*. The article's lead author was Guy Young, MD, Director of the HTC at CHLA. The results were also published as a poster abstract at 59th American Society of Hematology Annual Meeting and Exposition in December 2017.

The study focused on individuals who were previously treated prophylactically with a standard half-life (SHL) factor product, then switched to prophylaxis with an EHL

therapy. EHL therapies are designed to keep the infused clotting factor circulating in the body longer, stretching the time between infusions. The EHL products included in the study were a recombinant factor VIII Fc fusion protein (rFVIII-Fc) approved for several indications in adults and children with hemophilia A, and a recombinant factor IX Fc fusion protein (rFIX-Fc) approved for several indications in adults and children with hemophilia B.

While these therapies demonstrated to be both safe and effective in the clinical trials that paved the way for their approval by the U.S. Food and Drug Administration, Young and his colleagues sought corroborating evidence of their effectiveness in an actual clinical setting. They therefore conducted a retrospective review of "real world" clinical data on 36 patients, 17 with hemophilia A and 19 with hemophilia B. 35 of the 36 patients included in the study had a severe form of hemophilia, with one having moderate hemophilia B. Medical records from the HTC database showed that all 36 patients had been previously treated prophylactically with a SHL recombinant FVIII or FIX product and then transitioned to prophylaxis with an EHL therapy.

These patients subsequently experienced a reduction in both annual bleed rate (ABR) and annual joint bleed rate (AJBR). Data culled from the hemophilia A group reflected

a mean 232 days of treatment with rFVIII-Fc. The switch to an EHL product prompted a drop in ABR from 2.3 to 1.8 and decrease in AJBR from 1.3 to 0.71. Of the 17 patients in this group, eight (47%) experienced zero bleeds during treatment. Data from the hemophilia B group reflected a mean 228 days of treatment with rFIX-Fc. These patients experienced a fall in ABR from 2.5 to 2.1 and a drop in AJBR from 0.82 to 0.37. Of the 19 patients in this group, twelve (63.1%) experienced zero bleeds during treatment. The authors also reported no significant concerns associated with transitioning, including no reports of inhibitor formation.

The authors acknowledged study limitations that are often inherent in retrospective reviews. These include a scarcity of data related to product transition protocols and lack of pre-established parameters for measuring pharmacokinetics (PK). PKs are important as they indicate the concentration and duration of a drug's effect in the body and can be used to target factor levels that will help achieve a desired therapeutic response. Despite these study limitations, the authors emphasize the potential advantages of EHL therapies (reduced product consumption, increased adherence rates), provided enhanced PK screening and "future real world studies" for all EHL factor products are utilized.

Source: National Hemophilia Foundation



The Hemophilia Center of Western Pennsylvania

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



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bleedingdisorders.com

Jeison
Hemophilia A
Florida

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Now Approved

**A ONCE-WEEKLY SUBCUTANEOUS (GIVEN UNDER THE SKIN) INJECTION FOR
PEOPLE WITH HEMOPHILIA A WITH FACTOR VIII INHIBITORS**

We extend our appreciation to the individuals, families, and healthcare providers who participated in the clinical trials that led to the approval of HEMLIBRA®. We thank you and celebrate with the community who made it a reality.

Discover **HEMLIBRA.com**

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 with hemophilia A with factor VIII inhibitors.

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use.

HEMLIBRA may cause the following serious side effects when used with 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 signs and symptoms of TMA during or after treatment with HEMLIBRA.
- **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 the signs or symptoms of blood clots during or after treatment with HEMLIBRA.

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.



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.

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 OTHER POSSIBLE SIDE EFFECTS OF HEMLIBRA?

The most common side effects of HEMLIBRA include: redness, tenderness, warmth, or itching at the site of injection; headache; and joint pain. These are not all of the possible side effects of HEMLIBRA.

You may report side effects to the FDA at (800) FDA-1088 or www.fda.gov/medwatch. You may also report side effects to Genentech at (888) 835-2555.

Please see Brief Summary of Medication Guide on the following page for more important safety information, including **Serious Side Effects**.

Medication Guide Brief Summary
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. Discontinue prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent, and the dose and schedule you should use. HEMLIBRA may cause the following serious side effects when used with 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 with hemophilia A with 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.
- 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.
- 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 before the next scheduled dosing day and then continue with your normal weekly dosing schedule. Do not double your dose 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 7 days at 86°F (30°C) or below.
- 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

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
Issued: 11/2017



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ADYNNOVATE

[Antihemophilic Factor
(Recombinant), PEGylated]

ADYNNOVATE® is FDA approved
for patients of all ages with
Hemophilia A

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

moments **YOUR WAY**

*ADYNNOVATE allows you to infuse on the same 2 days every week.

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

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

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

+38% (n=25) of children (<12 years) experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds¹

Talk to your doctor and visit ADYNNOVATE.com

ADYNNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

Indications

ADYNNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNNOVATE when you have surgery. ADYNNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis). ADYNNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADYNNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

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

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.
- Have been told that you have inhibitors to factor VIII (because ADYNNOVATE may not work for you).

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 ADYNNOVATE 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.

You can have an allergic reaction to ADYNNOVATE.

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

The common side effects of ADYNNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

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

Please see the following page for ADYNNOVATE Important Facts.

For full Prescribing Information, visit www.ADYNNOVATE.com.

References: 1. ADYNNOVATE Prescribing Information. 2. Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2016 Nov 27. doi: 10.1111/hae.13119 [Epub ahead of print]. 3. Data on file.

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S31486 05/17





ADYNOVATE

[Antihemophilic Factor (Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

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

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

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

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

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

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

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

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

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

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

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

How should I use ADYNOVATE? (cont'd)

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

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

You should tell your healthcare provider if you:

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

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

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

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

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

What else should I know about ADYNOVATE and Hemophilia A?

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

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

The risk information provided here is not comprehensive.

To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.shirecontent.com/PI/PDFs/ADYNOVATE_USA_ENG.pdf or 855-4-ADYNOVATE.

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

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Meet Sue, your CoRe Manager



Hello! I'm Sue Cowell and I am a CoRe Manager for Bioverativ. It is my job to connect you with others in the community, introduce our educational programs, and to support you on your journey. I am here so we can take action together! I also previously served as Executive Director of Hemophilia of North Carolina.

Contact me!

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