Hemogram

Western Pennsylvania Chapter of the National Hemophilia Foundation

Fall 2018

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

Superhero Training Academy (a.k.a. Camp Hot-to-Clot 2018)

Kapow! Blam! Zap! The superhero lingo was strong with our campers at Camp Hot-To-Clot 2018. A week full of character development including origin stories, heroes, nemesis, identities, and even vigilantes! Upon arrival at camp, it was discovered that a meteor was headed toward KOK and the campers had to go on a scavenger hunt to find astro-blasters in order to destroy the meteor; only former camper, Dastardly Dan stole those blasters (Oh no!). The campers spent the rest of the week engaging in superhero training activities to make sure they were ready to face Dastardly Dan. The staff strategically worked in bleeding disorder knowledge, importance of physical health, nutritional health, and strong mind sets as the campers navigated their way through the story of the week. The training culminated at the end of the week in an epic battle between Dastardly Dan and the campers using their astro-blasters to shoot down the meteor with great success!

The kids additionally engaged in typical camp activities such as gaga, zip lining, swimming in the NEW pool, trail of courage, fire building, and crafts.

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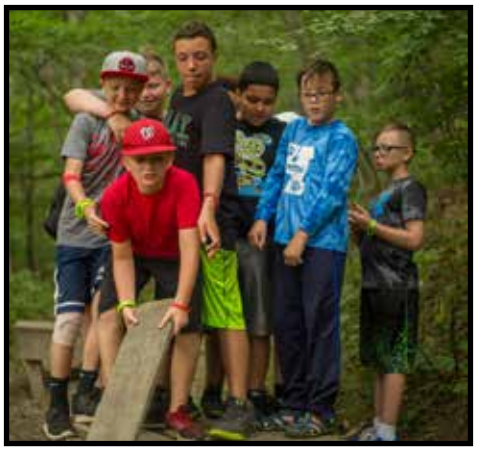

Superhero Training Academy
(a.k.a. Camp Hot-to-Clot 2018)

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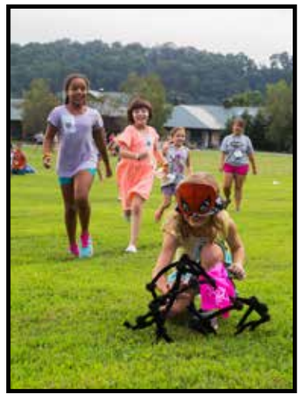
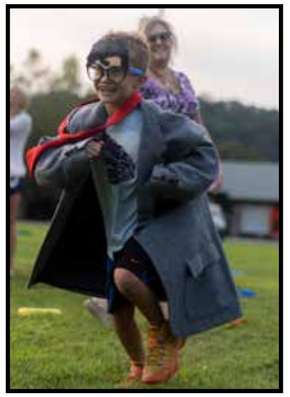
Throughout the week, the campers demonstrated the four core values of honesty, caring, respect, and responsibility. Four campers successfully earned the Big Stick award that requires the camper to not only successfully give their own medication, but also be knowledgeable about all aspects of their diagnosis, medication, dosage, preparation, and clean up. NHF staff and members of NHF's National **Y**outh Leadership Institute (NYLI) presented programming for our campers by age group about safe activities and how to make activities safe, and then did a separate program for the campers who are Leaders-in-Training (LITs).

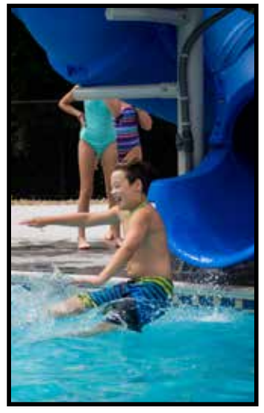
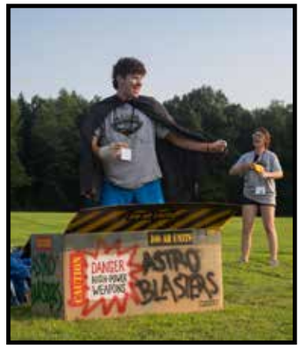
This year we had veteran campers return as counselors (a total of six), and we had nine LITs. We also had veteran campers volunteer throughout the week, as well as some patients. We are grateful for the many hours of volunteer time so many people committed to the success of camp.

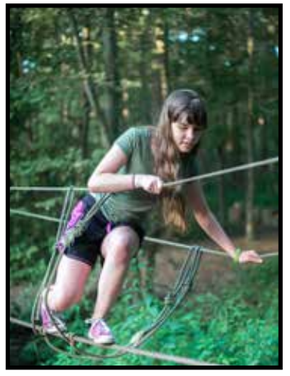
Please complete the camper surveys that were mailed out. Your camper's feedback is important to us. We are already planning for next year!

See more pictures on page 12







HCWP Corner

By Kathaleen Schnur

Greeting HCWP Patients and Families:

We are finally recovering from the excitement and energy of Camp Hot-to-Clot! Hoping your kiddos had as much fun as we did. The staff loves to spend time and connect with the kiddos outside the clinic as well as watching your children live-time develop confidence, demonstrate bravery, and support their peers throughout the week.

I am excitedly anticipating cooler temperatures, hot drinks, and all the flavors and colors that fall brings. I hope you and your families are doing well adjusting to the many changes that this time of the year brings. Now that the rush of summer holidays, travel, and just establishing a summer routine is coming to an end, it is time to readjust as the end of the year is approaching.

There are some things to consider for the affected child, specifically, communication with the school and/or child care facility. It is important to make them aware of your child's diagnosis and the emergency plan. Your local HTC can help facilitate by providing an in-service, documentation, and even a sports form to best support your child in their school environment.

Patients who are transitioning to college life/trade school have options to find support within their universities. Your HTC can help you review important details, consider different supports, and help you navigate the process. Your HTC can also remind you of the many scholarships available for persons with bleeding disorders.

Open enrollment for insurance is fast approaching as well. Anyone who needs assistance navigating the Marketplace or would like additional support, please contact your local HTC. Patients who are covered through the parents' policies need to remember that ends at age 26. If you do not have insurance coverage, please reach out to your HTC social worker. Additionally, if you are on Medicare or approaching Medicare, your local HTC can also help break down the sometimes confusing terminology and types of coverage.

Are you current with your appointment at your local HTC? If you can't remember, please reach out and call. We are sending cards as a gentle reminder for you to make your appointment. Don't put your health on hold.

Outreach Programs

Two dinner programs were held in Punxsutawney, in September. Linda Pollhammer, BSN, RN, Patient Affairs Liaison, with Pfizer, Inc., presented the topic Overcoming Challenges, on both nights. The presentation and conversations focused on coping with chronic illness; communicating with the health care team, family members, and others regarding hemophilia; and the importance of staying physically active with appropriate activities. We thank Pfizer, Inc., for providing these dinner programs.

Would you like the Chapter to bring a dinner program to a location near you? Is there a specific topic you would like to know more about? If so, please contact Janet Barone at the phone number, e-mail or mailing address on the back cover of this newsletter.

Letter From The Executive Director, Alison Yazer

Greetings!

Time certainly continues flying by – not only the summer, but for me, another year at the Chapter. I am thrilled to continue serving the bleeding disorders community in our area as I begin my 7th year with the Chapter.

The Hemophilia Walk, the 5k Run for Their Lives and our annual Cornhole Tournament took place September 15, and once again the weather was on our side and we had a great day! Thanks to everyone who worked hard to make this year's Walk such a success! I am glad so many of you joined us this year – this event couldn't succeed without you!

We have lots of exciting, new educational programs coming up, including sessions on gene therapy and what the Chapter's HFA membership can do for you, so please check your mail for information and invitations. Event information can also always be found on our website at www.wpcnhf.org. 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.

As always, please contact me at the office with any questions or concerns. Thank you for all that you do on behalf of WPCNHF.

Sincerely

Alison R Yazer
Executive Director

Calendar of Upcoming Events

Saturday, October 6
Oktoberfest
Pittsburgh, PA

Thursday, October 11-
Saturday, October 13
NHF's Bleeding Disorders Conference
Orlando, FL

Saturday, October 13
Pittsburgh's Bloody Bar Crawl
Fundraising Event in
Pittsburgh's South Side

Thursday, November 8
Women's Night Out
Monroeville, PA

Friday, November 16
New Parent Network
Erie, PA

Saturday, November 17
Fall Program
Erie, PA

Thursday, December 6
Winterfest
Mars, PA

Sunday, February 17, 2019
Bowling for Bleeding Disorders
Paradise Island Bowl
Pittsburgh, PA

March 22-24, 2019
Education Weekend
Seven Springs, PA

Saturaday, April 6, 2019
WPCNHF's 6th Semi-Annual
Cornhole Tournament
Cornerstone at Tonidale
Oakdale, PA

Ask us about sponsorship opportunities and how you can help!

Staff

Executive Director
Alison Yazer

Member Services Manager
Janet Barone

Marketing & Events Manager
Kara Dornish

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.

The Benefits of Physical Therapy: A Customized Approach

Dr. Michael Zolotnitsky

As humans, we get tired of performing the same tasks over and over again, so we switch our routine. One month we like Facebook, then Instagram, then Twitter, then Snapchat. Why do we always switch our social media, diets, pillows, destinations, or fashion trends? Our minds tell us that if we do the same thing repetitively, we'll get bored. The same goes for exercise.

We have to change our physical routines to avoid plateauing. Exercise needs to be consistently modified to help improve our bodies, to keep them from getting "bored." But how do we do that safely to avoid injury? People with bleeding disorders find it hard to exercise for various reasons. I had difficulty when I first began, because I was afraid of causing more damage to my joints. When you start a new routine, you may face challenges: soreness, increased joint pain from overload, increasing low back or neck pain from improper technique, or maybe just not enjoying the workout. I wanted to find workouts that would be fun, so I could see results, not get bored, and improve my overall well-being to reduce my joint bleeds. That's when I decided to pursue a career in physical therapy—to increase my knowledge and to help others.

Attaining my doctorate in physical therapy to assist people with bleeding disorders was a huge accomplishment in my life. I knew what it was like growing up with hemophilia. I endured persistent joint bleeds, had trouble walking, and felt different from my peers. When I learned that with proper exercise, I could greatly improve my joint health, I felt like I had my life back, and I swore never to lose that health. From age 13, I have been running, weight lifting, and playing sports. I haven't had a joint bleed in over 15 years; I attribute this to strength training and living a healthy lifestyle.

I wanted to educate the bleeding disorder community about what exercise can do for us all. I didn't want anyone to feel they couldn't do something because their bleeding disorder prevented them. I had the same concerns at a young age, but with hard work, I was able to overcome adversity and live like a "normal" person.

Exercise is my key to wellness, staying fit, and avoiding joint damage. I believe it's crucial for people with bleeding disorders. Maintaining optimal joint health will increase functional mobility, strength, and endurance; but most important, it will reduce the number of joint bleeds and improve overall quality of life.

And not just any physical therapy, but a personalized approach. No two people are the same, especially when it comes to bleeding disorders. When I sit down with a patient, I ask, "What do YOU want to get back to doing?" From there, we develop a personalized and customized treatment plan that relates to that patient's goals. For example, if someone wants to run, we watch him run on our antigravity treadmill, which uses three camera angles and allows dramatic reductions in impact and gravitational forces, helping the patient increase mobility without pain. This allows the patient to walk, run, squat, and jump in a pain-free environment.

If a goal is more sports-related—soccer, basketball, golf—it's imperative to assess the overall quality of movements: the golf swing, running, jumping, or shooting a basket. We find the root of the pain or dysfunction by assessing all of these movements, and by looking at the ankle, knee, hip, pelvis, and spine to make sure we aren't letting our patients put unnecessary strain on the body. A full-body approach is essential, so that every joint is covered.

Footwear is also important because increasing strain on the feet can affect overall walking, and can cause joint pain from the feet to the low back. As we age, our bodies change; so it's crucial to be reevaluated by a professional experienced in dealing with people with bleeding disorders. Flexibility is important, strength is important, but we need to make sure our bodies as a whole are symmetrical. We can use methods such as kinesio taping to place the joints in improved alignment, for joint support, and for reducing joint inflammation.

This customized approach yielded fantastic results when my first patient with hemophilia came to me for treatment. After developing inhibitors at an older age, being diagnosed with severe osteoarthritis of the hip, having brittle bones and severe weakness due to prior joint bleeds, he was facing total hip replacement. My evaluation showed that he had difficulty walking, balance deficits, poor core stability, and weakness in his knees, hips, ankles, core, and overall upper extremity strength. He used to walk a mile, but now it was hard for him to stand for five minutes with his cane. So his three months of treatment included endurance training on the antigravity treadmill; manual therapy to improve mobility of his hips, knees, and ankles; laser therapy to reduce joint inflammation in his hip; and balance retraining to reduce his risk of falling and improve his overall gait. At the end of treatment, he had stopped using a cane, and his hip surgery was canceled. This was unbelievable: a person with hemophilia could overcome his pain and even cancel his surgery!

I can't emphasize it enough: Physical activity is key. And it's not too late to begin a program. It's essential to make sure the movements are performed correctly, to improve your joint function and not be detrimental. When you're being assessed by a physical therapist, make sure the approach is customized and personalized, and that your program will constantly be updated based on your progress. I have lived by this approach for over a decade, and have lived life to the fullest. I overcame feeling weak and unable to do the things I wanted to do. It's my mission to help others overcome obstacles to return to their lifestyle. A bleeding disorder is just another bump in the road; don't let it control your future. My favorite phrase is "easy PT, hard life; hard PT, easy life!"

Michael Zolotnitsky, PT, DPT, who has hemophilia, is director of physical therapy at New Jersey Spine and Wellness in Old Bridge, New Jersey. Trained as an orthopedic and neurological physical therapist, Mike ensures his patients are offered a customized approach, including personalized aquatic therapy programs in indoor and outdoor pools. Mike is a national speaker for the hemophilia community, and lectures on safe exercises and alternatives to pain management, demonstrates kinesio taping, and runs aquatic therapy sessions. Mike has run three marathons in one year, and enjoys traveling and hanging out with his family, including his two nephews and his girlfriend. He is fluent in Russian.

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Column: YOU
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UNLOCKING YOUR SELF-POTENTIAL

ONLY ADVATE® HAS 15 YEARS OF EXPERIENCE IN THE REAL WORLD AS A RECOMBINANT FACTOR VIII[1]

- Proven in a pivotal clinical trial to reduce the number of bleeding episodes in children and adults when used prophylactically[2]*
- Third-generation full-length molecule, similar to the factor VIII that occurs naturally in the body[1,2]

*Multicenter, open-label, prospective, randomized, 2-arm controlled trial of 53 previously treated patients with severe to moderately severe hemophilia A. Two different ADVATE prophylaxis regimens (standard, 20-40 IU/kg every 48 hours, or pharmacokinetic-driven, 20-80 IU/kg every 72 hours) were compared with on-demand treatment. Patients underwent 6 months of on-demand treatment before 12 months of prophylaxis.[2]

The market leader in hemophilia A treatment
(Based on 2016 data published July 2017)[3]

Learn more at ADVATE.com

ADVATE Important Information

What is ADVATE?

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

ADVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

Who should not use ADVATE?

Do not use ADVATE if you:

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

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

What should I tell my HCP before using ADVATE?

Tell your HCP if you:

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

What important information do I need to know about ADVATE?

- You can have an allergic reaction to ADVATE. Call your HCP right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.
- Do not attempt to infuse yourself with ADVATE unless you have been taught by your HCP or hemophilia center.

What else should I know about ADVATE and Hemophilia A?

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

What are possible side effects of ADVATE?

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

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

For additional safety information, please see Important Facts about ADVATE on the following page and discuss with your HCP.

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

References: 1. Grillberger L, Kreil TR, Nasr S, Reiter M. Emerging trends in plasma-free manufacturing of recombinant protein therapeutics expressed in mammalian cells. *Biotechnol J.* 2009;4(2):186-201. **2.** ADVATE Prescribing Information. **3.** The Marketing Research Bureau, Inc. The plasma proteins market in the United States. 2016.

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ADVATE
[Antihemophilic Factor (Recombinant)]

ADVATE
[Antihemophilic Factor (Recombinant)]

Important facts about

ADVATE [Antihemophilic Factor (Recombinant)]

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

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

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

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

What is ADVATE?

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

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

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

ADVATE is not used to treat von Willebrand disease.

Who should not use ADVATE?

You should not use ADVATE if you:

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

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

How should I use ADVATE?

ADVATE is given directly into the bloodstream.

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

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

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

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

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

You should tell your healthcare provider if you:

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

What are the possible side effects of ADVATE?

You can have an allergic reaction to ADVATE.

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

Side effects that have been reported with ADVATE include:

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

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

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

What else should I know about ADVATE and Hemophilia A?

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

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADVATE. The FDA approved product labeling can be found at www.ADVATE.com or 1-888-4-ADVATE.

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

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New Parent Network Picnic

It was a beautiful day—perfect weather, wonderful families, good food, and fun times! Families from the New Parent Network program gathered on August 25th, for a summer social at Idlewild Park, in Ligonier. The day included a catered picnic, games to help families get to know each other, and park attractions.

The New Parent Network brings together families who have a child age 6 or under, with a bleeding disorder, for educational programs and social events. Throughout the year, the families are provided with opportunities to learn about raising a child with a bleeding disorder, support each other, and build their personal networks within the bleeding disorders community.

The next program will be held in November. The 2018 New Parent Network series of events is generously sponsored by: Bioverativ, CSL Behring, CVS Specialty, Genentech, and Shire. We also thank the Colburn Keenan Foundation for their support of the summer picnic.

2018 Unite for Bleeding Disorders Walk, Run For Their Lives 5K, and Cornhole Tournament

On the morning of Saturday, September 15th, families and friends gathered at the North Park Boat House to support a very important cause, the 10th Annual Western Pennsylvania Walk, renamed the Unite for Bleeding Disorders Walk, the 9th Annual Run for Their Lives 5K, and the WPCNHF's 5th Semi-Annual Cornhole Tournament. All three of these events continue to be a resounding success with over $80,000 raised to support the bleeding disorders community in Western Pennsylvania.

This year's highlights included appearances and a song and dance performance from Elsa, Belle, Tiana, and Super Girl from Angels From the Heart, a face painter, balloon artist, DJ, photo booth and a lot of special touches that made this day fun for the entire family. Thank you to: First Class Entertainment for the DJ and Photo Booth services, Cynthia Jewel from Face Paint Pittsburgh, Dragonfly Balloons, Kona Ice Pittsburgh, WISH 99.7 Street Treat Patrol, Star Wars characters from Garrison Carida 501st Legion, and the very talented princesses and super heroes from Angels from the Heart.

This day would not be possible without the support of our many team captains who rallied their runners and walkers and went over and beyond in all that they did.

Thank you to all 34 of our Walk Teams! A special shout out to the teams who really went above and beyond and raised $1,000 or more:

Conor's Clan - $9,823
Luke's Incredible Lineup - $6,835
Rolling for Ryker - $3,645
Gino's Gang - $2,405
Team Jaxson - $2,310
Kramer's Gamers - $2,125
Papa's Peeps - $1,813
Edinboro Fighting Scots - $1,780
Red 'N Plenty - $1,560
Maxwell House - $1,370
Cameron's Walking Sticks - $1,312
Clotting Cavaliers - $1,300
Charlotte's Hemo Heroes- $1,200

Congratulations to our top fundraising team, Conor's Clan, who raised the most money any team has ever raised for this event, an incredible $9,823! Thank you to the Team Captain of Conor's Clan and this year's Top Individual Fundraiser, Emily Nikithser, who individually raised an amazing $2,133. Emily joined the Hemophilia Walk in 2016 as the Team Captain of Conor's Clan. In her first year

(Continued on next page)

2018 Unite for Bleeding Disorders Walk, Run For Their Lives 5K, and Cornhole Tournament

(Continued from previous page)

as Team Captain, Conor's Clan raised over $8,150, in her second year they raised over $8,640! This year, Emily did an incredible job holding two very successful fundraisers 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 time at the Chapter. We are so incredibly thankful for Emily and her amazing team.

Thank you to this year's Walk Chair, Tracy Sethman. Tracy has been an active member of the Chapter for many years and always goes above and beyond to help the Chapter in any way she can. She worked tirelessly putting together the majority of the baskets raffled off at the Walk. She also dedicated many hours going over the planning of the Walk offering many tips and suggestions to make this year's walk successful. We are so thankful for all of Tracy's hard work and dedication to making the world a better place for those with bleeding disorders.

Congratulations to the winner of the Awesome John Eyrolles Top Youth Fundraiser Award, Charlotte Rosborough, who raised an awesome $1,000! Charlotte's Hemo Heroes held many fundraisers throughout to the year to help raise money for the Chapter including a Motorcycle/ Car Poker Run and Candy Apple Sale at a Back to School Festival. We are so thankful for Charlotte and her Hemo Heroes!

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:

Emily Nikithser of Conor's Clan, Scott Miller of the Edinboro Fighting Scots, Tracy Sethman of Red 'N Plenty, Gabbie Rose of the Clotting Cavaliers, Gwen Austin of the Clotting Cavaliers, Russell Werme of Conor's Clan, Eileen Nikithser of Conor's Clan, Steve Stern of Rolling for Ryker, Melinda Perry of Rolling for Ryker, Charlotte Rosborough of Charlotte's Hemo Heroes, Maurice Prendergast of Conor's Clan, Barbara O'Conner of Luke's Incredible Lineup, Christen Herndon of Papa's Peeps, Luke Miller of Luke's Incredible Lineup, Cooper Aberegg of Cooper's Troopers, Dawn Rotellini of Gino's Gang, Michelle Perry of Rolling for Ryker, Sam Miller of Luke's Incredible Lineup, Janet Barone of Cameron's Walking Sticks, Lynda Maxwell of Maxwell House, Nikki Micholas of Kramer's Gamers, Jen Werme of Conor's Clan, Kelly Baker of Team Jaxson, Josh Baker of Team Jaxson, Gabriel Paraniuk of Gabriels Brusied but not Broken, and Kara Dornish of Kara's Walkers

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 time out to vote for their favorite t-shirt the day of our Walk. Congratulations to Rolling for Ryker as the official Team T-shirt Winner, raising nearly $200!

Thank you to Pro Bike + Run for the great job they did managing the Run for Their Lives 5k and to everyone who participated in the run. We are excited to announce that over $10,000 was raised from the Run and will stay local to support the members of WPCNHF.

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

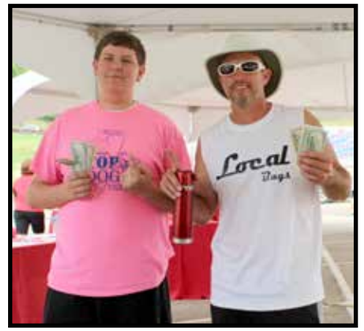
Top 3 Youth Finishers
1st Place: Kayli Yip
2nd Place: Kacey Yip
3rd Place: Dominik Gladish

Top 3 Female Finishers
1st Place: Tina Seech
2nd Place: Delaney McCarthy
3rd Place: Simone Knott

Top 3 Male Finishers
1st Place: Mike Sturtz
2nd Place: Mark Likoudis
3rd Place: Michael Frere

Thank you to Joe Castellano from Steel City Cornhole for running our 5th Semi-Annual Cornhole Tournament! The Cornhole Tournament brought in over $5,000 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 Trey and Adam - Trey Birchfield & Adam Hissner, second place went to Gators - Ricky Tyburski & Bernie George, and third place went to Double Js - Joe Castellano & Joey Castellano!

Last and most importantly, thank you to each and every one of you who came



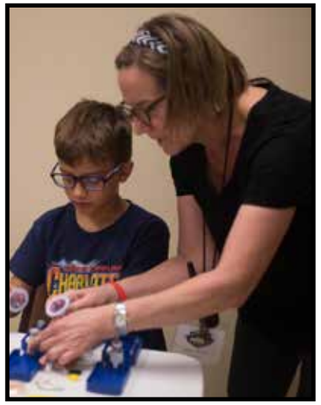
together with us to Unite for Bleeding Disorders. 100% of the money raised from the Walk, Run, and Cornhole Tournament stays local to promote patient advocacy and blood safety for everyone, support families in need by offering assistance with medical bills, travel, knee/elbow braces and other medical 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.

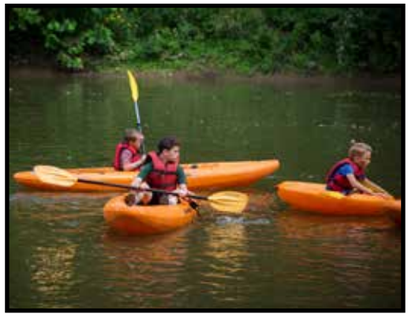
Mark your calendar now for our upcoming fundraisers! Pittsburgh's Bloody Bar Crawl will be taking place on Saturday, October 13th! Tickets are $30 and include an event t-shirt, a wristband for access to Bloody Mary drink specials, entry to 7 venues, access to raffles, prizes and contests at every stop, and a catered after-party at Foxtail! Get your ticket at give.classy.org/bloodybarcrawl.

Bowling for Bleeding Disorders will be taking place on Sunday, February 17th at Paradise Island Bowl. The cost is $25 and includes 3 hours of bowling, event t-shirt, shoe rental, pizza, wings, and unlimited soft drinks. Visit wpcnhf.org for more information.

See more pictures on page 19










Veterans Leadership Program
of Western Pennsylvania
(Founded by Vietnam Veterans)

August 24, 2018

Ms. Katherine Bush
Camp Hot-To-Clot
20411 Route 19
Unit 14
Cranberry Township, PA 16066-7512

Dear Ms. Bush and all our friends at Camp Hot-To-Clot,

Thank you for your very generous donation of sixty five (65) beautiful care packages made to Veterans Leadership Program of Western Pennsylvania, Inc. (VLP). We, along with the thousands of local Veterans and their children that we serve each year, are grateful for your contribution. This important gift will provide much needed support to Veterans, Service Members, and their families.

Your contribution helps us to serve over 2,900 Veterans each year – men and women who are homeless or about to be homeless, underemployed or unemployed. We work with them along their journey to self-sufficiency, financial sustainability, and a better quality of life.

Thank you for your confidence in the Veterans Leadership Program and your support of our mission. Your donation will make a real, meaningful, positive, and tangible difference to a vulnerable community over the entire continuum of military service: from pre-deployment, throughout deployment, and post deployment. VLP is honored to serve those who serve.

If you would like to learn more about our organization, we invite you to visit www.NeverForgetVets.org, engage with us on Facebook, Twitter, and LinkedIn, or call us at 412-481-8200.

Sincerely,

Ben Stahl, D.Sc.
Chief Executive Officer

We are speechless at your kindness and generosity. Thank you!

Toshua Jarrett, MS
Chief Development Officer

Veterans Leadership Program of Western Pennsylvania, Inc. is a 501(c)3 nonprofit organization, Federal Tax ID# 25-1434643. No goods or services were received in consideration of this gift.

2934 Smallman Street, Pittsburgh, PA 15201 · Phone (412) 481.8200 · Fax (412) 481.8202
www.NeverForgetVets.org

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**

HEMLIBRA™
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

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

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

HEMLIBRA™
emicizumab-kxwh
injection for subcutaneous use
150 mg/mL

Genentech
A Member of the Roche Group

San Diego HTC Looks at Cardiovascular Disease in Young People with Hemophilia

As individuals with hemophilia live longer and reach life expectancy rates comparable to the general population, their healthcare providers will continue to encounter clinical challenges inherent in treating and managing aging patients, including cardiovascular disease (CVD). There are several established risk factors associated with CVD such as hypertension, overweight, obesity and an abnormal lipid profile. With this knowledge in hand and with an eye towards prevention, investigators at the Rady Children's Hospital San Diego (RCHSD) Hemophilia and Thrombosis Treatment Center (HTC) decided to look at CVD risk factors in some of their younger hemophilia patients.

The lead author of the study was RCHSD medical director Courtney Thornburg, MD, MS. She and her research team approached patients during their comprehensive care visits, ultimately recruiting 43 males with hemophilia A or B between the ages of 5 and 20 (average age 12). Patient data and additional information was culled from a combination of electronic health records for clinical data, standardized measurements of weight, height, waist circumference and blood pressure and screenings of glucose and lipids. Patients and/or their caregivers also completed questionnaires relevant to medical history, lifestyle and family history (FH).

The results showed high rates of overweight and obesity among the participants. Investigators also observed other CVD risk factors, including (pre) hypertension in 28% and "borderline" high lipids in 19% of the subjects. Higher levels of physical activity correlated with normal weight levels, while higher weights were linked to greater factor consumption. Seven participants (16%) reported a FH of CVD. These and additional findings prompted the authors to hypothesize that cardiovascular risk factors could be identified and measured as part of a comprehensive clinic visit and that best practices to mitigate those risks could be integrated by the entire HTC team.

"HTCs may utilize internal resources, including dieticians, physical therapy (PT) and child life specialists to recommend therapeutic lifestyle changes for a healthy diet plus avoidance of tobacco and alcohol use. In addition, if children are identified with overweight or obesity at a comprehensive clinic visit they may be referred to the primary care physician for follow-up and/or to obesity and behavioral health programs as appropriate. PTs may perform targeted joint and muscle examinations and provide patient-specific recommendations to increase conditioning and sports participation."

The authors cited study limitations. The data was based on one HTC visit instead of over time, which is important for longer term monitoring of factors such as body mass index (BMI), blood pressure, lipid profiles. While physical activity, smoking and nutrition data were collected only by self-reporting without validated questionnaires, future studies could be augmented using food logs to measure caloric intake and accelerometers to measure physical activity. Lastly, future studies would also benefit from the inclusion of a healthy control group. The authors note that by addressing certain limitations, future studies could be more effective in CVD risk reduction, especially in concert with the primary care physician (PCP).

"Ultimately, resources will be required to monitor the impact of interventions on BMI, cholesterol, hypertension and physical activity. Further study is warranted to determine if HTCs can partner with PCPs and appropriate specialists to promote cardiovascular health and risk reduction. Interventions should include shared decision-making strategies to set realistic goals and methods of self-monitoring" concluded the authors.

This study "Risk Factors for Cardiovascular Disease in Children and Young Adults with Haemophilia," was published in the June 2018 issue of *Haemophilia*.

Getting to Know HCWP Staff

Featuring: Nancy Stinely, RN (AKA Nurse Nancy)

Birthplace: Pittsburgh, PA

First job: Federal Census Taker

Accomplishment you're proudest of: My blueberry muffins

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

Dream vacation: 30 days on Moorea Island

Things you can do without: Poor grammar, negative attitudes

Person you'd most like to have dinner with: Alexander Hamilton or Michael Collins

Movie you could see anytime: Monty Python and the Holy Grail &/or Blazing Saddles

TV show you try not to miss: Game of Thrones, Jeopardy

Three things that can always be found in your refrigerator: Butter, Milk, Ice Cream

Secret vice: I am a binge chocoholic. Any type, anywhere, anytime, anyplace, as long as it is chocolate!

Who would play you in the movies? Emma Thompson

Your pet peeve about Pittsburgh: Endless road construction and ridiculous parking.

People may be surprised to know that: I took Hula Dancing lessons when I was a child on the island of Guam.

Why it's Important for You to Return Your Member Information Form

In September, updated Member Information forms were mailed to all 600+ households on our mailing list and we are asking ALL of our members to complete the form, so we can update our database.

Over the years, the makeup of many of our members' households have changed; some family members have moved out on their own, and in other cases, families have grown. As you might imagine, sending a mailing to over 600 households can be quite a financial expense, as well as a labor intensive task. Therefore, when we have specific programs or social events that are targeted to a segment of our population (ex: women and/or girls with bleeding disorders, carriers, men and/or boys with bleeding disorders, parents, siblings, spouses/partners, type of bleeding disorder, etc.), we filter our mailing list and do our best to send the mail to only those to whom the information/invitation would be applicable. If we don't have up-to-date information for everyone in your household, you could be missing out on opportunities or the Chapter could be incurring unnecessary expenses by sending information that is not relevant to anyone in your household.

Is there no longer a person with a bleeding disorder or a carrier living in your household? If so, please encourage those who have moved out to register with the Chapter, so they can receive news and invitations to events. If you would still like to receive our newsletter and other pertinent information about bleeding disorders, that is fine! We understand that you may want to stay up-to-date on news related to bleeding disorders and hope that you will want to continue to support the bleeding disorders community.

In addition to knowing who is in your household, it's also important for us to know your preferred method(s) of communication. Over the years, we have added communication tools, including e-mail and social media, to help keep you informed. In the near future, we will also be implementing our new text messaging service. If you wish to receive e-mail and/or text messages from the Chapter, please be sure to provide an e-mail address and/or cell phone number when you complete the Member Information form. Occasionally, the Chapter receives time-sensitive information, and in those cases, we can only share the information through e-mail and social media (and in the future, text messages). For those of you who prefer to continue to receive information through the U.S. mail, we want you know that is remaining an option for our regular mailings. In fact, we will continue to mail a printed copy of our newsletter to all of our members.

If you need another copy of the Member Information form, please feel free to contact the Chapter or download a copy from our website.

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!

sue.cowell@bioverativ.com | 781.663.1719

Bioverativ

Connect with Us @BioverativCoRes

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Cranberry Township, PA 16066
Phone: 724-741-6160 Toll Free: 800-824-0016 Fax: 724-741-6167
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WPCNHF