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.

(Continued on next page)
**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.

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.

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**Outreach Programs**

Two dinner programs were held in Punxsutawney, in September: Linda Polhammer, 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.

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**Superhero Training Academy**

(a.k.a. Camp Hot-to-Clot 2018)

(Continued from previous page)

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. NHP staff and members of NHF’s National Youth 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 preparing for next year with your feedback.

*See more pictures on page 12*

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**PP-HEM-USA-0975-03**
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 Sk Run for ‘Their Lives and our 6th 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’s 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 HPF membership can do for you, so please check our website for information and invitations. Event information can 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 Yaer
Executive Director

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**Calendar of Upcoming Events**

<table>
<thead>
<tr>
<th>Event Description</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>WPCNHF’s 6th Semi-Annual Cornhole Tournament</td>
<td>Saturday, April 6, 2019</td>
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<tr>
<td>Winterfest</td>
<td>Saturday, December 6, 2019</td>
</tr>
<tr>
<td>Pittsburgh’s Bloody Bar Crawl Funding Event</td>
<td>Saturday, November 9, 2019</td>
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<tr>
<td>Women’s Night Out</td>
<td>Thursday, November 8, 2019</td>
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<tr>
<td>Seven Springs, PA</td>
<td>Saturday, October 13, 2019</td>
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<tr>
<td>Pittsburgh, PA</td>
<td>Saturday, October 13, 2019</td>
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<tr>
<td>Seven Springs, PA</td>
<td>Saturday, October 13, 2019</td>
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<tr>
<td>Women’s Night Out</td>
<td>Thursday, October 11, 2019</td>
</tr>
<tr>
<td>Seven Springs, PA</td>
<td>Sunday, October 13, 2019</td>
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<tr>
<td>Women’s Night Out</td>
<td>Saturday, November 17, 2019</td>
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<tr>
<td>Semi-Annual Cornhole Tournament</td>
<td>Saturday, November 24, 2019</td>
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<tr>
<td>New Parent Network</td>
<td>Thursday, November 28, 2019</td>
</tr>
<tr>
<td>Erie, PA</td>
<td>Saturday, December 21, 2019</td>
</tr>
</tbody>
</table>

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**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, responsive manner.

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**Column: YOU**

**Physical Therapy: A Customized Approach**

**Dr. Michael Zolotnisky**

As humans, we get tired of performing the same tasks over and over again, so we look for a new routine. One thing we often do is change our social media, 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 challenging 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, increased low back or neck pain, improper technique, or maybe just not enjoying the workout. I wanted to find workouts that would be fun, so I could see results. I got 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 help others.

Attaining my doctorate in physical therapy to assist people with bleeding disorders was a huge accomplishment in my life. I knew I could help physical therapy patients 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. I improved my mobility and strength. 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 you. I don’t think it’s realistic for everyone to do sports, but they don’t have to do something they couldn’t do something because their bleeding disorder prevented them. I had the same concerns at a young age, but I had hard work, I was able to overcome adversity and live 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 endurance training on the treadmill, manual therapy to improve mobility of his hips, knees, and ankles, laser therapy to reduce joint inflammation in his hip, and balance training to reduce his risk of falling and improve his overall gait. At 41 years of age, I am able to travel around the world 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 you choose are safe. Avoiding injury will improve your joint function and not be detrimental. When you’re being assessed by a physical therapist, make sure the assessment 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 used 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!”

Mike Zolotnisky, 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 neurologist at the MGH, he 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 exercise and therapeutic pain management, demonstrates kinesthetic tapping, 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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Publication: PEN 08 18 Column: YOU Ask us about sponsorship opportunities and how you can help!

**Board of Directors**

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- **Executive Director:** Alison Yaer
- **Secretary:** Janet Barone
- **Member Services Manager:** Kara Dornish
- **Marketing & Events Manager:** Sanjay Akut
- **Board Members:** Shannon Howard, Angelica Shepard
- **Emeritus Trustee:** Scott Miller, CPA, Esq., DBA

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**WPCNHF Wish List**

The chapter is always looking for donations 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

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**Staff**

- **Executive Director:** Alison Yaer
- **Director:** Kara Dornish
- **Member Services Manager:** Janet Barone
- **Marketing & Events Manager:** Sanjay Akut
- **Board Members:** Shannon Howard, Angelica Shepard
- **Emeritus Trustee:** Scott Miller, CPA, Esq., DBA

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**Missing a Newsletter?**

This newsletter is published quarterly by the Western Pennsylvania Chapter of the National Hemophilia Foundation. The content 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. We recommend that you consult your physician or treatment center before pursuing any course of treatment.
What is ADVATE?

ADVATE is a medicine used to replace clotting factor (factor VIII) in hemophilia A, a blood disorder. ADVATE is given directly into the bloodstream.

Do not use ADVATE if you:

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

Who should not use ADVATE?

You should not use ADVATE if you:

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

How should I use ADVATE?

ADVATE is given directly into the bloodstream. You may infused ADVATE at a hemophilia treatment center, at your healthcare provider’s office or your home. You should be trained on how to infuse your ADVATE by your healthcare provider or hemophilia treatment center.

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 call 1-800-FDA-1088.

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.
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

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.

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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.

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**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 Jewell 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.

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 Byker - $3,645
- Gino’s Gang - $2,405
- Team Jaxon - $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
- Cloting 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...
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.

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, Russel
Wermel of Conor’s Clan, Eileen Nikithser
of Conor’s Clan, Steve Stern of Rolling
for Ryker, Melinda Perry of Rolling for
Ryker, Charlotte Roshorough of Charlotte’s
Hemo Heroes, Maurice Prendergast of
Conor’s Clan, Barbara O’Connor of Luke’s
Incredible Lineup, Charlotte Herndon
Incredible Lineup, Cooper Averett 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 Camerons
Walking Sticks, Lynda Maxwell of Maxwell
House, Nikki Nicholas of Kramer’s
Gamers, Jen Wermel of Conor’s Clan,
Kelly Baker of Team Jaxson, Josh Baker of
Team Jaxson, Gabriel Pananak of Gabriel’s
Brusted 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 our 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.

Thank you to the winners of the
Awesome John Eyrolles Top Youth
Fundraiser Award, Charlotte Roshorough,
who raised an awesome $1,000! Charlotte’s
Hemo Heroes held many fundraisers
throughout 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 this year’s Walk Chair,
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, Russel
Wermel of Conor’s Clan, Eileen Nikithser
of Conor’s Clan, Steve Stern of Rolling
for Ryker, Melinda Perry of Rolling for
Ryker, Charlotte Roshorough of Charlotte’s
Hemo Heroes, Maurice Prendergast of
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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!

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

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

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

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 Husser, 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 wpccnhf.org
for more information.

*See more pictures on page 19*
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 2,000 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

Joshua Jarrett, MS  
Chief Development Officer
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.
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, obesity, weight, 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 conducted surveys 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 and measurements of weight, height, waist circumference and blood pressure and screenings of glucose and lipids. Patients and/or their caregivers also completed important for later term monitoring of factors such as body mass index (BMI), blood pressure, lipid profiles. While physical activity, smoking and nutrition data were collected, the HTC did not have access to validated questionnaires, further studies could be augmented using food logs 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 incorporate therapeutic lifestyle changes for a healthier 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. PFS 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 so it could not be used to determine if children were growing or gaining weight. Children were given a study packet to complete at home. Questionnaires were not validated questionnaires, future studies could be augmented using food logs 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).

“The HTC 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. PFS may perform targeted joint and muscle examinations and provide patient-specific recommendations to increase conditioning and sports participation.”

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Factor Replacement Reflects the Protection Within

For people with hemophilia, Factor treatment temporarily replaces what's missing.1,2 With a long track record of proven results, Factor treatment works with your body's natural blood clotting process to form a proper clot.3-6

Brought to you by Shire, dedicated to pursuing advancements in hemophilia for more than 70 years.7

Stay empowered by the possibilities.

References:

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 anyone in your household to complete the Member Information Form. Occasionally, the Chapter receives information that is not relevant to our database. Therefore, when we update our database, 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 can only share the information to 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.

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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.

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