Hemogram

Western Pennsylvania Chapter of the National Hemophilia Foundation

Fall 2015

Inside this issue

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

HEMOPHILIA 5K RUN AND WALK

Local families & friends hit the ground running to support a very important cause, our *2015 Run for Their Lives 5k* and our *Hemophilia Walk* on Saturday, September 12. The annual event, held at the North Park Harmar Grove Shelter, continues to be a resounding success with the help of so many individuals and business sponsors.

This year's highlights included an obstacle course in our Kid Zone 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, Face Paint Pittsburgh, Balloon Artist Billy Heh, Jolly Holly Balloon Art and special appearances from the Pittsburgh Pirate's Sauerkraut Saul, Pittsburgh Penguin's Iceburgh, Pittsburgh Steeler's Steely McBeam, and Tall Cathy from KISS 96.1.

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 Kelly Baker and Team Jaxson for donating and securing a large number of the baskets that were raffled off at the walk. We do appreciate your time & efforts! Congratulations to our top fundraising team Luke's Lineup who raised an amazing $6,465.00, our top fundraising individual Matt Pace who fundraised a total of $2,325.00, and our top youth fundraising individual Cameron Cedeno who fundraised a total of $965.00. Thank you for your passion and dedication!

This year's event had fabulous T-shirts designed by many of our walk teams. Thank you to SG Screenprinting 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 race. Congratulations to Gavinator's Army as the official T-shirt winner, raising over $190. Their T-shirt will be on display at the Hemophilia Treatment Center for the next year.

(Continued on next page)

A special shout out to our WPCNHF Board Treasurer, Nick Vizzoca for chairing this year's event and the continued support from our board members to ensure we are able to continue our mission - improving the quality of care and enriching the lives of those with bleeding disorders.

Lastly and most importantly, thank you to each and every one of you who literally 'took steps' to join our cause. 100% of the money raised from the Walk and Run stays local and will increase awareness of bleeding disorders, provide education to help people with bleeding disorders, and support advocacy initiatives at both state and national levels to help ensure access to medical care and equitable insurance reimbursement for all.

Mark your calendar now to kick off the holidays with our next big event, our 6th Annual Take A Bough Holiday Auction. This 4 day festival will showcase decorated trees, wreaths, and tabletop centerpieces that are all available for bid from November 20-23 at the Shops at Station Square.

Congratulations to our winners of the 5K Race, each of whom received an award, courtesy of Dick's Sporting Goods.

Mens' 5K:
First Place: Gary Puleio – Meadville, PA
Second Place: James McWilliams – Pittsburgh, PA
Third Place: Chris Gladish – New Kensington, PA

Womens' 5K:
First Place: Lisa Pacolay – Allison Park, PA
Second Place: Marie Young – Pittsburgh, PA
Third Place: Katie Berger – Pittsburgh, PA

Youth 5K:
First Place: Matthew Puleio – Meadville, PA
Second Place: Erica Puleio – Meadville, PA
Third Place: Anna Youk – Pittsburgh, PA

Special thanks to our Run for Their Lives 5K sponsors

Pacesetter Sponsor
Baxalta

Platinum Sponsors
CSL Behring, Bayer

Gold Sponsors
Hemophilia Center of Western Pennsylvania
Novo Nordisk
Octapharma

In-Kind Sponsor
Dick's Sporting Goods

Special Thanks To Our Hemophilia Walk Sponsors!

National Sponsors

Presenting Sponsor
Baxalta

Pacesetter Plus Sponsor
Novo Nordisk

Official Sponsors
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Biogen
Grifols
Pfizer Hemophilia

National Partners

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Accredo
Walgreens Infusion Services

National Team Member
Intuit

Principal Partner
Walgreens Infusion Services

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BioTek reMEDys

Pittsburgh Sponsors
Cottrill's Pharmacy
The Hemophilia Center of Western Pennsylvania

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SG Screenprinting
Sheetz Bros. Coffee Truck
The Pittsburgh Penguins
The Pittsburgh Pirates
The Pittsburgh Steelers
Trader Joes
WISH 99.7 FM

Letter From The President, Scott Miller

Dear Members, Friends and Supporters,

This has certainly been a great summer with an awesome week at camp, a lot of events and the Annual Hemophilia Walk and Run for Their Lives 5k. The chapter staff continues to do a fantastic job with our events. Please keep an eye on the event calendar and our updated website at wpcnhf.org, you will see so many excellent programs planned. We are seeing the fruits of the strategic plan that was adopted last year as we continue to improve our service and relevance for our members. I hope that as the Chapter expands its geographic outreach efforts, that you take advantage of these diverse educational opportunities. I know members in outlying areas are so pleased to see the Chapter offering events locally.

I want to thank all of those who participated in the Walk and the Run for Their Lives. The money raised from these signature events will ensure that we can continue our efforts in meeting our mission and providing you with educational programing and other resources to improve the lives of our members. You will also see information in this newsletter about Take-A-Bough. While this has become a signature event, in an effort to continue to refresh our events and increase awareness of bleeding disorders throughout Western Pennsylvania, this year, we will be hosting "The Final Bough." For this event, we are returning to Station Square, which is exciting for us. Please try to attend the event and tell your friends! This event is not only a fundraiser for our chapter, but provides awareness to Pittsburgh and the surrounding community about bleeding disorders and the Chapter's services. Keep your eyes open for information about our 1st Annual Winter Golf Classic which will be held next February!

I want to sincerely thank the board and the staff for their hard work and the community for being so welcoming to me and my family over my last 18+ years on the Board. Since I feel that good board governance requires rotation of leadership in order to allow for new ideas and allow the organization to thrive and grow to its true potential, this will be my final letter as your President. I will, however, continue to be involved in our various events throughout the region and look forward to seeing you at both The Final Bough and the Winter Golf Classic!

As always, thank you all for your efforts and please remember that the Chapter is here to serve you – our members. If there is a program you'd like to see, or if you have ideas for an event, please don't hesitate to get in touch with the Chapter.

Sincerely,

Scott E. Miller, CPA, J.D., DBA
WPCNHF Board President

Letter From The Executive Director, Alison Yazer

Greetings!

Time certainly has been flying by – not only the summer, but for me, another year at the Chapter. I am truly honored to continue serving the bleeding disorders community in our area as I begin my 4th year with the Chapter.

The Hemophilia Walk & 5k Run for Their Lives took place September 12, and despite the weather being less than perfect, we still had a great day! We had over 35 teams and raised over $50,000. Thanks to those 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, 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

HCWP Corner

We hope all of you are as excited as we are to welcome cooler weather, and that all of you had a wonderful and safe summer.

We have some exciting news and positive changes here at the Center. The first is that we are moving away from the alphabet assignment system so that all of the nursing staff can be familiar with all of the patients rather than just a subset. Every available nurse should be able to pick up where the last communication ended to better serve your needs. Another exciting change is that the nurses will rotate so that one nurse will be identified as the triage nurse to take all calls during clinic hours, which allows the other nurses who are caring for the patients to be undisturbed. The nurses will stay in the exam room with the physicians to facilitate and improve communication for the patient's plan of care. We are committed to our patients' care and satisfaction, and we feel that this is a constructive step.

We have updated our Patient Satisfaction Survey to obtain more specific feedback about our services. This survey will be given to all patients for all appointment types. We are also offering a self-addressed stamped envelope for those who would rather take the survey and complete it at home. We spend time reviewing the feedback and implementing your suggestions when possible, and we are grateful for your insight.

Some of our Center staff attended and participated at the NHF Annual Meeting this year in Dallas. Genetic Counselor, Michelle, gave four presentations, Social Worker, Kathaleen, gave 2 presentations, Medical Director, Dr. Ragni, gave one presentation, and our Clinical Research Coordinator, Jackie, assisted in the Teen Track program. Additionally, we had three award winners from the Pittsburgh area: Researcher of the Year; Dr. Margaret V. Ragni, Genetic Counselor of the Year; Michelle Alabek, and Ryan White Youth Award Recipient; Nikole Scappe. Congratulations to all three deserving winners!

See NHF Winners on Page 14

Calendar of Upcoming Events

Saturday, October 3
Dental Program – Amish Only
Dubois, PA

Wednesday, October 7
Hemophilia Overview – Amish Only
Meadville, PA

Tuesday, October 13
My Factor, My Body
Pittsburgh, PA

Wednesday, October 14
My Factor, My Body
Beaver, PA

Saturday, October 24
Self-Advocacy
Plus Exhibit Displays
Ligonier, PA

Friday, November 20 – Sunday, November 23
Take A Bough™
Pittsburgh, PA

Saturday, December 5
Winterfest
Wheeling, WV

Saturday, February 20
Iced Tees – Winter Golf Classic
Sewickley, PA

6TH ANNUAL TAKE A BOUGH
HOLIDAY TREE AUCTION TO BENEFIT WPCNHF

Visit the auction at
The Shops at Station Square on:
Friday, November 20-9am-9pm
Saturday, November 21-9am-2pm
Sunday, November 22-By Appt.

Bid on the auction items online at:
http://501Auctions.com/TAB

CFC® Combined Federal Campaign

Combined Federal Campaign

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

WPCNHF CFC Number is: 81343

Share Your E-mail Address with the Chapter

Are you receiving e-mail notifications regularly from the Chapter? If not, please consider sending us your e-mail address. We use e-mail to communicate time-sensitive information that would not be possible or cost-effective to send in a traditional mailing, such as opportunities to participate in paid phone or online surveys conducted by research and communication companies or opportunities to participate in online surveys conducted by the Chapter to help determine preferred locations and topics for our programs.

Please know that we do not share your e-mail address with other organizations. If you would like to be added to our e-mail list, please send an e-mail to **info@wpcnhf.org** and let us know.

Send us your e-mail address and you will receive:

- Program and special event invitations and updates
- Program registration reminders
- Notifications of scholarships and contests
- Survey opportunities, including:
  - Online surveys for Chapter program and event planning
  - NHF surveys for research or program planning
  - Notification of third-party paid surveys

WPCNHF Scholarship Winners

Congratulations to **Alexandria (Alex) McCarthy** and **Giovanna (Gianna) Rotellini**, winners of the 2015-2016 WPCNHF Scholarship! Alex is a freshman at Point Park University in Pittsburgh, studying forensics. Gianna is a freshman at the University of South Carolina, Darla Moore School of Business. We wish both girls all the best as they pursue their degrees!

Ask us about sponsorship opportunities and how you can help!

Study Focuses on Cardiovascular Disease in Hemophilia Patients

As life expectancy in people with hemophilia (PWH) continues to rise closer to the national average, hemophilia healthcare providers have grown increasingly interested in the conditions most commonly linked to aging. One of the more pervasive of these is cardiovascular disease (CVD), and associated conditions such as ischemic heart disease (hardening of arteries) and atrial fibrillation (irregular heartbeat rate/rhythm). A multidisciplinary team of investigators conducted a scan and review of medical literature associated with CVD in PWH published between 1980-2013. Their findings, "Consensus Review of the Treatment of Cardiovascular Disease in People with Hemophilia A and B," were published in the March/April issue of the journal *Cardiology in Review*.

The lead author of the review was Victor Ferraris, MD, PhD, Tyler Gill Professor of Surgery, Division of Cardiovascular and Thoracic Surgery at the University of Kentucky in Lexington. Ferraris and his coauthors acknowledged that data relevant to CVD in PWH is limited. That's because of the low numbers of hemophilia patients who have been documented with complications related to heart disease. The result is a lack of evidence-based guidelines from which to base treatment decisions.

"Accordingly, current recommendations for the medical and surgical management of common cardiovascular conditions in PWH derive from anecdotal experience and expert opinion. Most recommendations reflect guidelines and common practices for people without hemophilia," said Ferraris. "Ultimately, the rigorous, systematic investigation of management strategies for many cardiovascular conditions is unobtainable, given the relative rarity of hemophilia and even smaller numbers of PWH with any given cardiovascular condition."

However, Ferraris and colleagues did arrive at some conclusions. An examination of the literature suggested that low levels of factor VIII or IX did not necessarily offer hemophilia A or B patients extra protection against CVD conditions, including ischemic heart disease. In fact, the authors anticipate that older PWH will experience CVD rates comparable to the general population. Investigators added that recommendations relevant to the medical/surgical management of CVD in the aging PWH will be largely comparable to what is recommended for unaffected patients, as long as factor levels remain high enough to ensure adequate control of bleeds. They also acknowledged that the presence of an inhibitor to infused factor VIII or IX will complicate treatment and management in PWH/CVD considerably. The authors concluded that close collaboration between cardiology specialists and the comprehensive care team is crucial for quality clinical management.

"As the population of PWH ages, cardiovascular health care providers will encounter increasing numbers of PWH presenting with typical age related cardiovascular conditions, in addition to other acquired or congenital conditions spanning all ages," reported the authors. "To optimize resource utilization and clinical outcome and to minimize bleeding risk and complications, close consultation with a hematologist, ideally in association with a hemophilia treatment center, is essential."

Source: Heplive.com, June 29, 2015

Annual Meeting & Walk Kickoff

Over 120 members registered to attend WPCNHF's Annual Meeting and Walk Kickoff, held on July 23, 2015, at Dave & Buster's, in Homestead, PA. The evening began with exhibits from 14 home healthcare and factor manufacturer companies.

After the Chapter's annual meeting and Walk Kickoff presentation, the attendees enjoyed a buffet dinner. The program concluded with brief presentations by representatives from seven factor manufacturers: Baxalta, Bayer HealthCare, Biogen, CSL Behring, Grifols, Novo Nordisk, and Octapharma. The topics of the presentations varied from company to company and included research & development (including factor VII, factor VIII, Factor IX, von Willebrand Disease, inhibitors, gene therapy, clinical trials, manufacturing facilities & safety, plasma therapies, recombinant therapies, and humanitarian programs.

When the event was over, many families went to the arcade area to enjoy games and the company of fellow Chapter members.

We thank the following sponsors for helping to make this evening a success!

Accredo, Baxalta, Bayer Healthcare, Biogen, BioPlus, BioRX, Cottrill's Pharmacy, CSL Behring, CVS/Caremark, Factor Support Network, Grifols, Hemophilia Center of Western PA, Novo Nordisk, Octapharma, and Walgreens.

As I See It Don't Fear Heights— or Hemophilia

By Elizaveta Temidis

It is not the mountain we conquer, but ourselves. —Sir Edmund Hillary

My son John and I are avid hikers, and we love a good dose of adventure. John is 15, a sophomore at Wallkill High School, New York, and has severe hemophilia A. He keeps busy on the school's Nordic ski team, playing piano and French horn, and reading.

But last summer, John literally rose to new heights: he summited Mt. Whitney, the highest mountain in the contiguous US. Mt. Whitney is 14,509 feet above sea level, in the Sierra Nevada Range in California. A one-day permit means completing the 11-mile ascent and return hike—with an elevation gain and loss of 6,145 feet—in 24 hours.

Driving to the West Coast from New York in the family car was an adventure in itself! We departed July 30, a beautiful summer morning, with Ramen noodles, factor, and audiobooks.

The American West is beautiful and fascinating. Dust devils wander aimlessly on the Utah and Nevada plains. In Nebraska, a gigantic gate on Rt. 80 welcomes everybody to the Wild West! Carbon County in Wyoming proudly holds a Cow Plop annual event. Mustangs still roam free in Utah. Warnings about rattlesnakes are mundanely posted on garbage cans at rest stops. American pronghorn antelopes are the

second fastest land animals after cheetahs. Our car can outrun a Nevada sandstorm.

After a four-day drive through 11 states, we arrived in California on August 3 and pitched our tent at a campground 8,000

(Continued on page 11)

Meet Christine, your CoRe Manager

Hello! I'm Christine Rowe, and I have a son with severe von Willebrand disease. I'm also a CoRe Manager for Biogen. It is my job to connect you with others in the community, share insights taken from my personal experience, introduce our educational programs, and to support you on your journey. I am here so we can take action together!

Contact me!

Christine.Rowe@biogen.com | 267.249.8372

Biogen

Get to know us: **BiogenHemophilia.com/CoRes**

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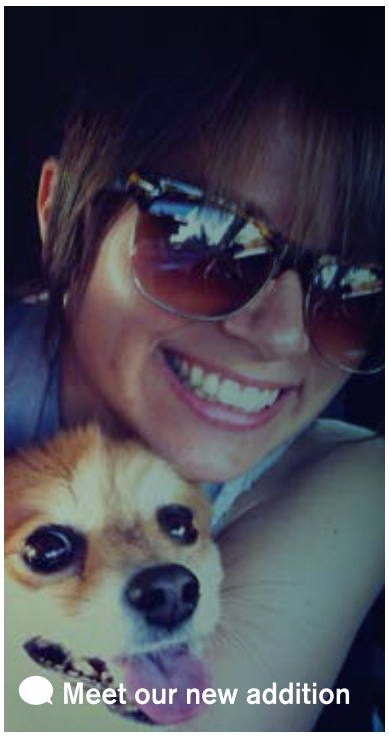
/BiogenHemCoRes

The Journey, Celebrated

Life is made of small moments that inspire, motivate, and make us feel that our work is worthwhile. As a company, as a team, and simply as individuals, we strive to discover, enable, and celebrate more of them.

Today, possibility is in the air.



Biogen

Get to know us: **BiogenHemophilia.com/CoRes**

/BiogenHemophiliaCoRes /BiogenHemCoRes

Our enduring commitment, brighter than ever.

Baxalta

For more than 60 years, we've consistently pursued advancements in the treatment of bleeding conditions.

Now, as Baxter's BioScience becomes Baxalta Incorporated, this proven heritage — along with the advancements we're making today to cultivate tomorrow's developments — fuels our global vision and promise: Our relentless desire to make a meaningful difference in the lives of real people — one person at a time. This promise to you can be seen in all we do, and helps to make us the company we are today.

Miriam
Caregiver, Miami, FL

Erie Summer Program

The Chapter finished off its summer programming in Erie, on August 29. The day began with exhibit displays from factor manufacturers and home healthcare companies. We would like to thank our Presenting Sponsor, Biogen, for delivering two great programs: Cracking the Code and The Power of Empowerment.

We would also like to thank the following for their support and exhibit displays:

- Affinity Biotech
- Baxalta
- Bayer Healthcare
- Biogen
- BioRX
- Cottrill's Pharmacy
- CSL Behring
- CVS/Caremark
- Emergent BioSolutions
- HCWP
- Pfizer
- Walgreens

As I See It Don't Fear Heights— or Hemophilia

(Continued from page 7)

feet above sea level, to get acclimated to the altitude and explore before the big hike. We protected ourselves against black bears that roam the campground at night, gawked at the amazing beauty of magnificent mountain ranges, and chopped enough firewood for evening campfires.

On August 7, we packed up and moved to Whitney Portal campground. We set up our tent, gathered our supplies, replenished our drinking water, and went to bed around 6:00 pm. We awoke four hours later, John infused his factor, and we set off on our grand new adventure at 11:45 pm.

Faraway flashlights moving on the side of the dark mountain assured us we were not alone. We stopped every hour for a snack and every 15 minutes for a gulp of water, watching for signs of altitude sickness. The last two hours before sunrise were the darkest and made us yearn for the sun like never before!

We greeted the sunrise at six miles, or halfway up the mountain, before going on to the infamous section of 99 switchbacks. The switchbacks were helpful and refreshing, and we named them after family members as we hiked. Freezing temperatures faded, and the views were astonishing! Reaching Trail Crest, we gasped at the amazing view of the Sequoia Kings Canyon Wilderness all the way to the Pacific Ocean. We were happy to see patches of fresh snow in mid-August, and even threw a few snowballs.

We reached the summit at 10:30 am—tired, but relieved, grateful, and at peace. The absolute quietness of this incredible place was interrupted only by unobtrusive shouts of joy from arriving hikers. We took a photo of us holding a hand-drawn birthday card for my mom, whose birthday is August 8; and of a toy squirrel monkey that we'd promised Alex, John's younger brother, to take to the top with us. Before heading back down, we celebrated with two little bottles of Coke, and spent the next hour in a relaxed, contemplative mood, taking our time, looking at the endless mountain ranges all around, while shivering in the cold, unrelenting wind.

The hike down to Whitney Portal seemed harder than our hike up. We were extremely tired and had one desire: to lie down in our tent and sleep. Yet the wondrous scenery of mountains and cliffs, which we hadn't seen during our ascent in the dark, made us stop in awe, taking photos and marveling at the beauty and ruggedness of this corner of the world.

The last two miles were the hardest. We needed to finish before dark. We sang every Russian and American song we knew, and recited every Russian poem we could remember. We got some curious looks, yet our method worked so well that we barely noticed the miles pass.

During the hike, John had no traumas or joint problems. He's been on prophylaxis since age one, and since he began training on the Nordic ski team two years ago, he's had fewer joint bleeds.

After a 22-mile round trip, a total of 19

hours and 15 minutes on the trail, and a 6,145-foot elevation gain and drop, we returned to our tent happy and exhausted. We texted our family that we were victorious, overjoyed, nauseous, and tired. Then we went to sleep.

We arrived home five days later, hungry and happy, full of news and impressions, eager to hug our family and grateful for everybody's support. It's possible that John, at age 14, might be the youngest person with severe hemophilia ever to climb Mt. Whitney! This climb proved to us that whatever challenges might stand in the way—hemophilia, fear of heights, or pain—our children with hemophilia need to pursue their dreams and live life to the fullest.

Elizaveta Temidis, 40, was born in St. Petersburg, Russia, and came to the US to study business in college at age 19. She is a high school mathematics and Russian language teacher with New Paltz High School and online Virtual High School. She helps run the Nyack Russian School and a Russian summer camp in the Catskill Mountains. She lives in Wallkill, New York, with her husband George and sons John, 15, who has severe hemophilia A, and Alex, 12.

Source: LA Kelley Communications, Inc. www.kelleycom.com

Spotlight on the Member: Meet the Aberegg Family

Mandy and Ryan Aberegg, from Shadyside, Ohio, are the proud parents of four-year-old Cooper! Cooper loves taking swim lessons, watching Paw Patrol, and riding amusement park rides! He's a happy, active boy who is attending his second year of pre-school. His parents are having a lot of fun with him, but can easily recall how worried and concerned they were when they first learned that their son had hemophilia and weren't sure how it would impact his life.

Shortly after Cooper's birth, the area where he had his vitamin k shot opened up and bled three times before it finally stopped. His parents thought it was odd, but really didn't know what to make of it, as they were new parents and were not familiar with bleeding disorders. The next day he was circumcised and blood kept oozing, as a result of the procedure. After several attempts to control the bleeding, the medical team used nitrate sticks to finally stop the bleed. Ryan and Mandy were concerned and asked the nurse to contact their pediatrician immediately and have blood work ordered. That evening, the pediatrician came to the hospital and told the Abereggs that there was something wrong with Cooper's blood, but he wasn't sure yet what it was. Mandy and Ryan were naturally upset and didn't know what to expect for their newborn son.

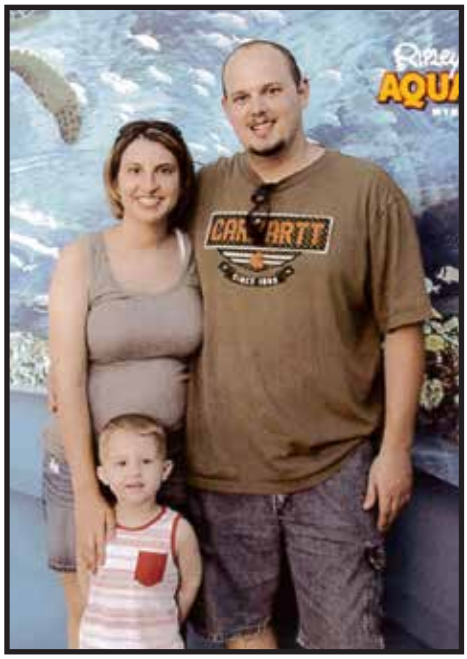
When Cooper was four days old, the family went to the Hemophilia Center of Western PA (HCWP), where they received the official diagnosis: Hemophilia B. Upon further testing, Cooper's levels have been diagnosed as severe.

Also, from genetic testing that was later done through the HCWP, the family has learned that Mandy is a carrier. They have no previously known family history of hemophilia.

The first bleed requiring treatment occurred when Cooper was about two months old. He was treated for a bleed in one of his eyes. Infusions were difficult, as finding a good vein was not easy and it would often take multiple needle sticks before a good vein could be accessed. For about the first year and a half of his life, he would receive infusions through veins in his head (due to a lack of good, accessible veins elsewhere). As parents, that was difficult for Mandy and Ryan to watch. When Cooper was approximately two-years-old, the medical team was able to access a vein in his arm and they have, for the most part, been using veins in his arms ever since.

Cooper continued to receive on-demand treatments until he was approximately 2 ½ years old. Around that time, he started to receive once-a-week prophylactic treatments, due to frequent bleeds. The family used to drive to Pittsburgh weekly for the infusions, but have since made arrangements with a local hospital, where he now receives his infusions. In addition, Cooper is now on a longer lasting factor product and only needs an infusion once every 12 days. Mandy and Ryan have attended the Chapter's Infusion Day (a program where HCWP nurses teach individuals and families about self infusion). They have learned the process and feel that they could administer the factor in an emergency; and when the time is right, they plan to transition to home infusions.

When Cooper was just a few months old, Mandy and Ryan took him to their first Chapter event—a Walk Kickoff. This was the first time they met other families with bleeding disorders. In addition, they became interested in the mission of the Chapter and decided to form a walk team: Cooper's Troopers! Their team has participated in the Walk fundraiser ever since and one year they even won the team t-shirt contest!



Mandy recommends taking one day at a time and says that getting to know other families with bleeding disorders has really helped them. They have attended Chapter events and talked with families with older kids. They saw kids running around and realized that they couldn't tell which kids had bleeding disorders and which did not. She now tells new families to not put their child in a bubble—to treat them as a child and let them live their lives. If there's an activity that you need to adapt, you'll figure out a way to do so. For example, the Aberegg's got creative with piping insulation and padded items such as shopping cart rails, furniture, and certain toys, so Cooper could still use them. They basically adapted, wherever they saw a need, so their son could play with toys and participate in activities that most kids his age would. And to help reduce bleeds on his bottom, when he was learning to walk, they doubled his diapers.

Mandy admits that at first the diagnosis was scary and overwhelming, but over time they learned more about it and life got easier. She feels strongly that parents need to be advocates for their children and suggests that parents speak up and not be afraid to say something, even to a doctor. As a parent, you know more about your child than anyone else.

What's next for the Aberegg family? They are expecting their second child, a girl, in February and Cooper is excited to be a big brother!

Meet the HCWP Staff

My name is Cynthia Ventrone. I was born and raised in Pittsburgh with strong family ties. I have one son, who is 27 years old. My medical background for 20 years was as a Nuclear Medicine Technologist. I worked in Pittsburgh out of college for 3 years in PRN positions, and then moved to Chillicothe, Ohio into a full time position. I was promoted to chief technologist and was in control on my own offsite facility and traveled to other facilities as needed. I was pulled back to Pittsburgh because my mother was in a motor vehicle accident and I had to care for her during multiple operations. I worked as an independent contractor for Life and Health Insurance Paramedical Examiner and Biomedical Health for 3 years, due to the job market. I came on board in February with The Hemophilia Center of Western Pennsylvania as the Medical Assistant/ Phlebotomist to Dr. Ragni, Dr. Malec and Dr. Seaman. I have learned a lot about the Hemophilia Community and have attended Outreach and Camp Hot-to-Clot. My personal time is spent attending to my gardens and home, attending outdoor outings, walking my Maltese dog Dinero, and caring for my family.

My name is Tom Peterson. I work in the factor program at HCWP. I've been in healthcare for over 20 years ranging from retail, mail order, and hospital pharmacies. Married to my wife, Renee for over 15 years, and we are proud parents of 12 year old twins, Alex & Emily who just started the 7th grade. We like vacationing at the beach and hope to live near one someday in the not so distant future.

My name is Linda Packard. I started with the Hemophilia Center as a temp in November 2011 and recently joined the HCWP staff as a part-time employee in July 2015 doing data entry with the American Thrombosis & Hemostasis Network (ATHN database.) I spent my entire adult career working in healthcare at Mercy Hospital (aka UPMC Mercy). I live in Oakland with my husband, Jack, and our dog, Lucy. I enjoy all types of activities including biking, exercising, running 5Ks, gardening, cooking/baking, and spending time with family and friends. It is a pleasure to work with such an awesome group of professionals at the Hemophilia Center and I look forward to continuing this journey with them.

I am Michael Andromalos-Dale. I come to ITxM and HCWP by way of Montefiore (Outpatient Transplant Service Center 3+ years), St Barnabas Nursing Home (1+ years), UPMC Passavant (Oncology floor 6 Pav 2+ years), and UPMC Shadyside (Respiratory floor 6 Main 4 + years). Before nursing I worked as an Exercise Physiologist working with Neurosurgeons, Chiropractors, MDs, sports teams, military groups, and weekend warriors both here and abroad (Saudi Arabia). I also have an Education Degree and have taught in high school, small college, and overseas in Saudi Arabia. I have a wonderful family with two children (a boy and a girl), plus four foster children. My wife is an exceptional wife, mom, & friend. My kids are grown, and I have three grandkids, whom I enjoy very much. I enjoy being here and believe the experiences dealing with families and staff are wonderful.

DESIGNED TO PREVENT AND CONTROL BLEEDS—
A FACTOR VIII THAT HELPS PREPARE YOU TO LIVE ACTIVELY

DON'T WING IT

xyntha® solofuse®
Antihemophilic Factor (Recombinant)

Bring it and be ready to infuse

XYNTHA SOLOFUSE brings together proven efficacy and all-in-one reconstitution—in a travel-anywhere kit.

Visit FreeTrialXyntha.com and see if you're eligible to get a one-time, 1-month supply up to 20,000 IU at no cost.*

What is XYNTHA?

XYNTHA® Antihemophilic Factor (Recombinant) is indicated in adults and children for the control and prevention of bleeding episodes in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia) and for the prevention of bleeding during surgery in patients with hemophilia A.

XYNTHA does not contain von Willebrand factor and, therefore, is not indicated for von Willebrand's disease.

Important Safety Information for XYNTHA

- Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction: wheezing, difficulty breathing, chest tightness, turning blue (look at lips and gums), fast heartbeat, swelling of the face, faintness, rash, low blood pressure, or hives. XYNTHA contains trace amounts of hamster protein. You may develop an allergic reaction to these proteins. Tell your healthcare provider if you have had an allergic reaction to hamster protein.
- Call your healthcare provider right away if bleeding is not controlled after using XYNTHA; this may be a sign of an inhibitor, an antibody that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests to monitor for inhibitors.
- Across all clinical studies, the most common side effects (10% or more) with XYNTHA in adult and pediatric previously treated patients (PTPs) were headache (26% of subjects), joint pain (25%), fever (21%), and cough (11%). Other side effects reported in 5% or more of patients were: diarrhea, vomiting, weakness, and nausea.
- XYNTHA is an injectable medicine administered by intravenous (IV) infusion. You may experience local irritation when infusing XYNTHA after reconstitution in XYNTHA® SOLOFUSE®.

Please see brief summary of full Prescribing Information for XYNTHA and XYNTHA SOLOFUSE on the next page.

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.

*You must be currently covered by a private (commercial) insurance plan. If you are not eligible for the trial prescription program, you may find help accessing Pfizer medicines by contacting Pfizer's RxPathways program. For questions about the XYNTHA Trial Prescription Program, please call 1-800-710-1379 or write us at XYNTHA Trial Prescription Program administrator, MedVantx, PO Box 5736, Sioux Falls, SD 57117-5736.

†This card will be accepted only at participating pharmacies. This card is not health insurance. No membership fees.

Save on XYNTHA†
Terms and conditions can be found at XYNTHA.com.

Pfizer RxPathways®

Need help accessing Pfizer medicines?
Pfizer's RxPathways program may be able to help.
Call **1-888-327-7787** or visit **www.PfizerRxPath.com**.

Pfizer RxPathways is a joint program of Pfizer Inc and the Pfizer Patient Assistance Foundation™.

xyntha®

Antihemophilic Factor (Recombinant)

xyntha® solofuse®

Antihemophilic Factor (Recombinant)

℞ only

Brief Summary

See package insert for full Prescribing Information, including patient labeling. For further product information and current patient labeling, please visit XYNTHA.com or call Pfizer Inc toll-free at 1-800-879-3477.

Please read this Patient Information carefully before using XYNTHA and each time you get a refill. There may be new information. This leaflet does not take the place of talking with your healthcare provider about your medical problems or your treatment.

What is XYNTHA?

XYNTHA is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia A. Hemophilia A is also called classic hemophilia. Your healthcare provider may give you XYNTHA when you have surgery.

XYNTHA is not used to treat von Willebrand's disease.

What should I tell my healthcare provider before using XYNTHA?

Tell your healthcare provider about all your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if XYNTHA may harm your unborn baby.
- are breastfeeding. It is not known if XYNTHA passes into your milk and if it can harm your baby.

Tell your healthcare provider and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

How should I infuse XYNTHA?

Step-by-step instructions for infusing with XYNTHA are provided at the end of the complete Patient Information leaflet. The steps listed below are general guidelines for using XYNTHA. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedures, please call your healthcare provider before using.

Call your healthcare provider right away if bleeding is not controlled after using XYNTHA. Your body can also make antibodies against XYNTHA (called "inhibitors") that may stop XYNTHA from working properly. Your healthcare provider may need to take blood tests from time to time to monitor for inhibitors.

Call your healthcare provider right away if you take more than the dose you should take.

Talk to your healthcare provider before traveling. Plan to bring enough XYNTHA for your treatment during this time.

What are the possible side effects of XYNTHA?

Call your healthcare provider or go to the emergency department right away if you have any of the following symptoms because these may be signs of a serious allergic reaction:

- **wheezing**
- **difficulty breathing**
- **chest tightness**
- **turning blue (look at lips and gums)**
- **fast heartbeat**
- **swelling of the face**
- **faintness**
- **rash**
- **hives**

Common side effects of XYNTHA are

- headache
- fever
- nausea
- vomiting
- diarrhea
- weakness

Talk to your healthcare provider about any side effect that bothers you or that does not go away. You may report side effects to FDA at 1-800-FDA-1088.

How should I store XYNTHA?

Do not freeze.

Protect from light.

XYNTHA Vials

Store XYNTHA in the refrigerator at 36° to 46°F (2° to 8°C). Store the diluent syringe at 36° to 77°F (2° to 25°C).

XYNTHA can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA at room temperature, carefully write down the date you put XYNTHA at room temperature, so you will know when to either put it back in the refrigerator, use it immediately, or throw it away. There is a space on the carton for you to write the date.

If stored at room temperature, XYNTHA can be returned one time to the refrigerator until the expiration date. Do not store at room temperature and return it to the refrigerator more than once. Throw away any unused XYNTHA after the expiration date.

Infuse XYNTHA within 3 hours of reconstitution. You can keep the reconstituted solution at room temperature before infusion, but if you have not used it in 3 hours, throw it away.

Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

XYNTHA SOLOFUSE

Store in the refrigerator at 36° to 46°F (2° to 8°C).

XYNTHA SOLOFUSE can last at room temperature (below 77°F) for up to 3 months. If you store XYNTHA SOLOFUSE at room temperature, carefully write down the date you put XYNTHA SOLOFUSE at room temperature, so you will know when to throw it away. There is a space on the carton for you to write the date.

Throw away any unused XYNTHA SOLOFUSE after the expiration date.

Infuse within 3 hours after reconstitution or after removal of the grey rubber tip cap from the prefilled dual-chamber syringe. You can keep the reconstituted solution at room temperature before infusion, but if it is not used in 3 hours, throw it away.

Do not use reconstituted XYNTHA if it is not clear to slightly opalescent and colorless.

Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

What else should I know about XYNTHA?

Medicines are sometimes prescribed for purposes other than those listed here. Talk to your healthcare provider if you have any concerns. You can ask your healthcare provider for information about XYNTHA that was written for healthcare professionals.

Do not share XYNTHA with other people, even if they have the same symptoms that you have.

This brief summary is based on the Xyntha® [Antihemophilic Factor (Recombinant)] Prescribing Information LAB-0516-5.0, revised 10/14, and LAB-0500-9.0, revised 10/14.

NHF Award Winners

Researcher of the Year
Margaret Ragni, MD
Hemophilia Center of Western PA

Researcher of the Year (named in honor of Dr. Murray Thelin) honors a distinguished scientist who has made major contributions to bleeding disorders-related research. (Dr. Murray Thelin [1927-1966], a biochemist who had hemophilia, played a major role in the development of a method for concentrating antihemophilic factor.)

Genetic Counselor of the Year
Michelle Alabek, MS, CGC
Hemophilia Center of Western PA

Genetic Counselor of the Year acknowledges an individual who has taken a leading role, carried out with excellence, in assisting, guiding and educating families and individuals on the genetic inheritance of a bleeding disorder. For nearly all of our families who learn they are carriers of a congenital coagulation disorder, the genetic counselor is one of the first resources to foster the family's understanding and to help them make informed decisions for the life ahead of them. The Genetic Counselor of the Year is both expert and empathetic. She is current with the latest research in anticipation of an enhanced role in the expanding arena of molecular therapies for coagulation disorders.

Meritorious Service Award
Ryan White Youth Award
Nikole Scappe

The Ryan White Youth Award is presented to a young person who has helped educate others both within the bleeding disorders community and among the general population by increasing awareness and understanding. Ryan White [1972-1990] had severe hemophilia and contracted AIDS in 1984 through infusion of contaminated clotting factor. He brought national attention to hemophilia and its complications, changed people's prejudicial attitudes, educated the public and generated national compassion.

Visit the Link Below to See Vidoes of All the NHF Award Winners:
http://www.hemophilia.org/Events-Educational-Programs/Annual-Meeting/Awards-of-Distinction-and-Excellence

Michael, 30 years old, *lives with hemophilia A.*

An injectable medicine used to control and prevent bleeding in people with hemophilia A

Novoeight®— designed to fit into your world

Purity

Two **20-nanometer filters** used in a 5-step purification process

Portability

Novoeight® offers the **highest storage temperature** for the **longest time**[a]– up to 86˚F for 12 months

Reliability

In one of the largest clinical trials of a recombinant factor VIII to date, **there were 0 inhibitors confirmed** in 213 previously treated patients[b]

[a]Compared with other recombinant factor VIII products.
[b]People with previous inhibitors and those new to treatment were not included in the trial. People with hemophilia A may develop inhibitors to factor VIII.

Please see Prescribing Information for complete storage instructions.

SATISFACTION GUARANTEED

Terms and conditions apply.

Visit **Novoeight.com** today to learn more.

Indications and Usage

Novoeight® (Antihemophilic Factor [Recombinant]) is an injectable medicine used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight® when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

Important Safety Information

You should not use Novoeight® if you are allergic to factor VIII or any of the other ingredients of Novoeight® or if you are allergic to hamster proteins.

Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction: rashes or hives, difficulty breathing or swallowing, tightness of the chest, swelling of the lips and tongue, light-headedness, dizziness or loss of consciousness, pale and cold skin, fast heartbeat, or red or swollen face or hands.

Before taking Novoeight®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII.

Your body can make antibodies called "inhibitors" against Novoeight®, which may stop Novoeight® from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Novoeight®.

Common side effects of Novoeight® include swelling or itching at the location of injection, changes in liver tests, and fever.

Please see brief summary of Prescribing Information on following page.

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.

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

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novoeight®
Antihemophilic Factor (Recombinant)

novoeight®

Antihemophilic Factor (Recombinant)

Patient Product Information
Novoeight® (Nō-vō-eyt)
Antihemophilic Factor (Recombinant)

Rx Only
This is a BRIEF SUMMARY of important information about Novoeight®.

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

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

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

Do not attempt to do an infusion 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 Novoeight® so that your treatment will work best for you.

What is Novoeight®?

Novoeight® is an injectable medicine used to replace clotting factor VIII that is missing in patients with hemophilia A. Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

Novoeight® is used to control and prevent bleeding in people with hemophilia A.

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

Novoeight® is not used to treat von Willebrand Disease.

Who should not use Novoeight®?

You should not use Novoeight® if you

- are allergic to factor VIII or any of the other ingredients of Novoeight
- if you are allergic to hamster proteins

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

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

You should tell your healthcare provider if you

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

How should I use Novoeight®?

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

Novoeight® is given as an injection into the vein.

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

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

You may need to have blood tests done after getting Novoeight® to be sure that your blood level of factor VIII is high enough to clot your blood. This is particularly important if you are having major surgery.

Your healthcare provider will calculate your dose of Novoeight® (in international units, IU) depending on your condition and body weight.

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

Development of factor VIII inhibitors

Your body can also make antibodies called "inhibitors" against Novoeight®, which may stop Novoeight® from working properly.

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

Use in children

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

If you forget to use Novoeight®

Do not inject a double dose to make up for a forgotten dose. Proceed with the next injections as scheduled and continue as advised by your healthcare provider.

If you stop using Novoeight®

If you stop using Novoeight® you are not protected against bleeding. Do not stop using Novoeight® without consulting your healthcare provider.

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

What if I take too much Novoeight®?

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

What are the possible side effects of Novoeight®?

Common Side Effects Include:

- swelling or itching at the location of injection
- changes in liver tests
- fever

Other Possible Side Effects:

You could have an allergic reaction to coagulation factor VIII products. **Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction:**

- rashes including hives
- difficulty breathing, shortness of breath or wheezing
- tightness of the chest or throat, difficulty swallowing
- swelling of the lips and tongue
- light-headedness, dizziness or loss of consciousness
- pale and cold skin, fast heart beat which may be signs of low blood pressure
- red or swollen face or hands

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

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

How should I store Novoeight®?

Prior to Reconstitution:

Store in original package in order to protect from light. Do not freeze Novoeight®.

Novoeight® vials can be stored in the refrigerator (36–46°F [2°C–8°C]) for up to 30 months or up to the expiration date, or at room temperature (up to 86°F [30°C]) for a single period not exceeding 12 months.

If you choose to store Novoeight® at room temperature:

- Note the date that the product is removed from refrigeration on the box.
- The total time of storage at room temperature should not exceed 12 months. Do not return the product to the refrigerator.
- Do not use after 12 months from this date or the expiration date listed on the vial, whichever is earlier.

Do not use this medicine after the expiration date which is on the outer carton and the vial.

The expiration date refers to the last day of that month.

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

The reconstituted Novoeight® should appear clear to slightly unclear without particles.

The reconstituted Novoeight® should be used immediately.

If you cannot use the Novoeight® immediately after it is mixed, it should be used within 4 hours when stored at ≤ 86°F (30°C). Store the reconstituted product in the vial.

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

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

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

For more information about Novoeight®, please call Novo Nordisk at 1-844-30-EIGHT.

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

Revised: 09/2014

For information about Novoeight® contact:
Novo Nordisk Inc.
800 Scudders Mill Road
Plainsboro, NJ 08536, USA

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

1214-00024657-1 12/14

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

WPCNHF Wish List

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

- White copy paper by the ream or by the case
- Colored copy paper by the ream for invitations and newsletter inserts
- Sticky Notes
- Forever U.S. Postage stamps
- 10 x 13 Ready-seal envelopes for newsletter mailings
- Paper towels

Our Mission:

WPCHNF 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.

RIXUBIS
[COAGULATION FACTOR IX (RECOMBINANT)]

For more information, contact your Baxalta representative today:

Erik Drotos
Phone: 412-518-7122
E-mail: Erik.drotos@baxalta.com

To learn more, visit www.RIXUBIS.com.

Baxalta

Western Pennsylvania Chapter of the National Hemophilia Foundation
20411 Route 19, Unit 14
Cranberry Township, PA 16066
Phone: 724-741-6160 Toll Free: 800-824-0016 Fax: 724-741-6167
info@westpennhemophilia.org

WPCNHF