

Western Pennsylvania Chapter of the National

Winter 2016 Inside this issue

Hemophilia Foundation

Welcome New Board Member

Matt Pace

See Cover Story

Join Us for the First Ever

Iced Tees Winter Golf Classic

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DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

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

WPCNHF Contributor Agency Code Number is: 83

<u>Hemogram</u>

HELLO AND HAPPY NEW YEAR!

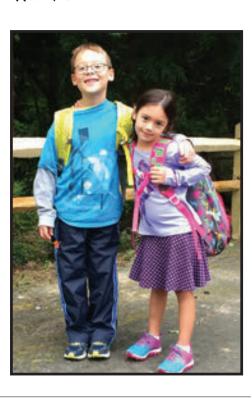
I wanted to take the opportunity to introduce myself as a new member of the Board of Directors for the Western PA Chapter of the National Hemophilia Foundation. I am a Marriage and Family Therapist and currently the Clinical Director and Assistant Professor at the Seton Hill University Marriage and Family Therapy Graduate Program in Greensburg, Pa. My family and I are relative new comers to Western PA by way of Buffalo, NY and South Florida, but have been part of the bleeding disorders community since our son Sebastian, now eight, was born with moderate hemophilia A.

Since our move to the area a little over one year ago, we have been so impressed with the incredible support from the Chapter led by Alison and her wonderful staff. From the AMAZING Camp Hot-to-Clot to the Hemophilia Walk/Run for Their Lives, my wife Brianna, Sebastian, his sister Bella, and I were very quickly made to feel like part of the WPCNHF family! I also recently hosted a men's group event that took us on an urban hike in downtown Pittsburgh and am excited to keep the momentum going with men's group events in the future.

I am honored to be a part of this very strong team of leaders dedicated to the bleeding disorders community in Western PA and hope to contribute in a meaningful way!

Warmly,

Matt Pace



TAKE A BOUGH

The 6th and Final Take A Bough was held at the Shops at Station Square, November 20th through the 23rd. It was an exciting year for the Chapter, as we raised nearly \$50,000! We are extremely grateful for the donations we received from our Chapter members, our partner organizations, and other donors who offered their support.

Planning and preparation for the 6th Annual Take A Bough began months prior to the event! We could not have done it without the hard work and dedication of our volunteer planning committee. Special thanks to the following committee members: Nora Latcovich, Dawn Rotellini,

Diane Standish, Maria Steele Voms Stein, Heather Kosto, Susan Eyrolles, Debbie Lowery,

(Continued on next page)









and Laureen Temple.

From November 13th through 18th, volunteers helped transform a former nightclub into a holiday extravaganza by setting up over 100 trees, wreaths and tabletop displays donated by individuals and businesses from all over Western Pennsylvania. Thank you to all the volunteers who helped including volunteers from Cigna Healthcare, Highmark Insurance, Bank of America, and Seneca Valley's JROTC students.

From November 20-23, the event was open to the public. Hundreds of people passed through the display throughout

the weekend. On Friday we even had a special visit from Elsa, Anna, Aladdin, and Jasmine! On Saturday we had two very talented dance groups visit Take A Bough! In the morning the students from Dance Mechanics performed a dance routine to Rockin around the Christmas Tree. In the afternoon the very talented students from Siri's School of Performing Arts put on a spectacular show with acrobatics and a kick line! A raffle for a \$500 "Done in a Day" gift card tree was offered for \$10/ ticket and helped us raise nearly \$1,000!

The event ended on November 23rd with a beautiful Donor Reception at the Hard Rock Café. Christmas music

was sung by the talented Nina Sainato while attendees enjoyed a custom pierogi station and a build your own s'more bar. Successful fundraisers like Take A Bough allow the Chapter to continue to carry out the mission of enriching the lives of those with bleeding disorders in Western Pennsylvania and respond to the needs of the community in a dynamic environment.

WPCNHF would like to thank all who sponsored the event, donated items, and all who volunteered their time to help make the event such a resounding success!





Letter From The President, Scott Miller

Dear Fellow Members and Friends of WPCNHF,

As many of you know, by the time you read this letter, I will have stepped down both as President and as a member of the Board of the Western Pennsylvania Chapter of Western Pennsylvania. It has been an honor and privilege to serve the membership of the Chapter and work with wonderful board colleagues for over 17 years. On January 1, 2016, I will be joining the board of the National Hemophilia Foundation (which requires my resignation from the local chapter to ensure transparency and integrity with the operations of both organizations). I make this move because I feel that the experience and lessons you have given me will help serve the broader organization and help individuals with bleeding disorders on an international level. I have truly enjoyed working with and for you, the members, of WPCNHF during this time and I will continue to be a part of the community.

I leave with mixed emotions as I have watched this organization grow from a small organization focused largely on Pittsburgh to a large, regional organization with a broader mission, established policies, and an ambitious strategic plan to move not only the organization forward, but increase services to and awareness of bleeding disorders throughout western Pennsylvania.

In 1997, DonPaul Lucas and I would meet with Pat Enright (the only employee of the organization at the time) for board meetings at a small, cramped office in Shadyside that was not conducive to the services needed by

our members. Since then, we have rented new space in Cranberry Township to better serve our 26 county region and increased our staff to three employees. Our budget has increased four-fold since my joining the board and nearly three-fold since becoming President in 2009. Hand-in-hand with this growth is an even larger growth in our scope of services, providing more services every year and expanding our outreach to meet the needs of more of our geographic region. In addition, our patient assistance, advocacy, and educational programs have increased both in number and attendance, as well as in our visibility in the community.

The organization is in good hands with a Board and Executive Director who are not only committed to the mission of the organization, but understand the needs of the community. Over the past five years, we have seen a lot of transition, which has made us a stronger, more effective, and more engaged organization. We achieved the goals of our first strategic plan in 2014 and embarked upon a new, more ambitious strategic plan that has our members' best interest at its heart.

The organization exists to ensure that we adhere to our values of Education, Awareness, Advocacy, Empowerment, and Support. The last two of these are very special to me. Over the last 17+ years, we have changed the focus of our organization to one that empowers our members to be advocates for their own health and welfare and to learn how to ask for a hand-up, when necessary, to improve their circumstance. We have increased awareness through new programs

such as the Hemophilia Walk, Bowling for Bleeding Disorders, and Take-A-Bough. We have increased the patient assistance pool and number of grants awarded exponentially with a focused effort to improve the lives of our members so that hopefully, some day, this fund will no longer be necessary. We have worked with the national organization to increase research support so that we can find advanced treatments and, one day, a cure for bleeding disorders.

All of this could not have been done without the great work of the women and men who volunteered countless hours to the organization, a dedicated staff, and the Board, working to keep the organization on mission and improve the quality of life for our members. It is my hope that I can continue to work toward these ends with the National Hemophilia Foundation and, through that work, support and bolster the work of the Chapter.

Thank you all for your kindness and generosity you have shown me and my family...for the life lessons you have given me over the years...and for being my friends during good and bad times. I will continue to make efforts to attend as many or more events as I did as a Board member and I look forward to seeing your continued engagement in and support of our Chapter's mission.

Sincerely,

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

Letter From The Executive Director, Alison Yazer

Dear Members & Friends,

2016? Already? Wow – time really is flying! 2015 was a great year for the Chapter...among other successes, we launched a new website and our new domain, wpcnhf.org (it's much more user-friendly than our old, longer one)! We held lots of great educational events and had lots of fun socializing, too!

We already have a variety of events planned for 2016, but I'd like to ask you to think about your interaction with the Chapter. Are we meeting your needs and expectations? Are there additional services you wish we would offer? Is there a specific educational topic you'd like to see covered, or a region in which you would like us to hold an event? Please participate in the needs assessment you'll be receiving soon. Help us help you!

I look forward to seeing every one of you at an upcoming event and wish each of you a happy, healthy 2016!

Sincerely,

Alison R. Yazer Executive Director

Calendar of Upcoming Events

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

Wednesday, February 24 – Friday, February 26 Washington Days Washington, D.C.

Sunday, March 6 Tiny Tots Part I Location TBD

Sunday, March 13 Tiny Tots Part II Location TBD

Saturday, April 16 Education Day Cranberry Township, PA

Friday, June 10 – Sunday, June 12 Family Camp Hopwood, PA

Thursday, July 21 – Saturday, July 23 NHF Annual Meeting Orlando, FL

Sunday, July 24 – Thursday, July 28 World Federation of Hemophilia – World Congress Orlando, FL

Thursday, August 4 WPCNHF Annual Meeting & Walk Kickoff Pittsburgh, PA

Sunday, August 7 – Saturday, August 13 Camp Hot-to-Clot Fombell, PA

Saturday, September 19 Hemophilia Walk North Park Boat House, Allison Park, PA

Saturday, September 19 Run For Their Lives 5K North Park Boat House, Allison Park, PA

Saturday, October 8 Oktoberfest Pittsburgh, PA

Sunday, October 30 Bowling Fundraiser Neville Island, PA

Saturday, November 12 Erie Fall Program Erie, PA



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

Ask us about sponsorship opportunities and how you can help!

Our enduring Baxalta commitment, brighter than ever. 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. Caregiver, Miami, FL Baxalta is a trademark of Baxalta In

HCWP Corner

Greetings HCWP Families,

We hope your holidays have been merry and bright! We are grateful for all of the beautiful cards and kind gestures we have received from so many of you over the past two months!

We at the HCWP have been working diligently in developing a more supportive program with focus on our young patients. The nursing staff has been working with Children's Hospital of Pittsburgh to improve venipuncture access techniques and comfort positions with our children and their families. Our social workers have been working with CHP's child life program to develop programming and increase skills to strengthen our work and

the experience of our young families. This is an exciting time as several novel treatment approaches are currently in clinical trials. These new therapeutics are being studied to see if they can be used to promote hemostasis in people with hemophilia. At the Hemophilia Center of Western PA we are excited to be participating in several of the research studies involving these therapies. If you are interested in learning more, please contact Judith Kadosh, our Research Nurse, at 412-209-7263 or the Office Manager, Mary Dulgeroff, at 412-209-7288 to make an appointment to discuss these opportunities with Dr. Ragni.

We are thankful to all of our patients and families who have been completing our Patient Satisfaction Surveys. Please continue to give us feedback. As a reminder, we also have our Consumer Advocacy Committee. Please call Kathaleen (412-209-7267) or Diane (412-209-7286) if you are interested.

As the New Year is upon us, please remember the importance of committing to your own health by maintaining your well visits at the HCWP. If your diagnosis is moderate to severe, you should be seen by your hematologist at least once per year. If you have a milder diagnosis you should be seen at least every other year. The importance of well visits is to review your current health and history as it applies to your hemophilia or other inherited coagulation disorders, counsel about ways to improve your health, and an exam tailored to your preventive care needs. HCWP is always available to answer any questions you may have and available to see you for any acute needs.

NHF and CDC Collaborate on Screening Patients for Inhibitors

November 24, 2015



The development of an inhibitor (an antibody to infused clotting factor) is one of the most devastating complications of hemophilia, since it prevents factor treatment from stopping bleeding. The Centers for Disease Control and Prevention (CDC) estimates up to 1 in 5 people with hemophilia will develop an antibody (inhibitor) to their infused factor product at some point in their lifetime. Inhibitors have a huge impact on the families they affect and are an important public health concern as well. As a result, both the CDC and the National Hemophilia Foundation (NHF) have undertaken a number of projects to better understand inhibitors with a goal of ultimately developing strategies to prevent their occurrence.

The CDC's Division of Blood Disorders has done significant surveillance and

research work in the last 10 years to better understand inhibitors and their impact on patient health. For example, the CDC's Hemophilia Inhibitor Research Study (HIRS) involved 17 US hemophilia treatment centers (HTCs) and was a public-private partnership with support from Pfizer and Baxter Healthcare (now Baxalta) through the CDC Foundation. The study had two key findings: all people with hemophilia are at risk of developing an inhibitor, even those with mild disease; and many individuals with an inhibitor may not have clinical signs, so inhibitor testing is critical for the diagnosis.

In response to these findings, the CDC has worked to reduce barriers to inhibitor screening. For instance, it has revised its hemophilia surveillance system, "Community Counts," to include inhibitor screening and is offering annual inhibitor screening for patients who are part of this surveillance system at no cost to HTCs or patients. Further, the CDC has improved the inhibitor test itself, making it more accurate and reproducible. For example, heat treatment of specimens precludes the need to "wash-out" or stop factor treatment before drawing the sample.

Based on these CDC efforts, NHF's Board of Directors and its Medical and Scientific Advisory Council (MASAC) recently took a major step by recommending that people with hemophilia be tested for inhibitors at least annually and more frequently if

clinically indicated. On October 6, 2015, NHF released MASAC Recommendation on Standardized Testing and Surveillance for Inhibitors in Patients with Hemophilia A and B (#236). NHF's MASAC relied heavily on research and surveillance supported by the CDC's Division of Blood Disorders over the past 10 years in making this recommendation.

NHF looks forward to continued collaboration with the CDC and the National Network of HTCs to ensure that annual inhibitor testing is implemented across the US. This is why NHF advocates for funding for the federal hemophilia programs at the CDC and at the Maternal and Child Health Bureau during its annual Washington Days advocacy event. These funds enable the CDC to work directly with HTCs to collect important information on inhibitors. They also allow the CDC to collaborate with NHF to develop consumer and provider education materials that emphasize the importance of regular screening as part of national prevention efforts. NHF will continue to advocate for continued CDC funding for research and surveillance to increase knowledge of the risk factors for inhibitors and to develop inhibitor prevention strategies.

Article courtesy of the National Hemophilia Foundation, 2015

WPCNHF NHF Annual Meeting Educational Grant

Educational Grants are Available for NHF's 68th Annual Meeting/WFH Meeting

The Western Pennsylvania Chapter of the National Hemophilia Foundation (WPCNHF) is pleased to offer Educational Grants for NHF's 68th Annual Meeting & The WHF Meeting in Orlando, FL, July 21st -25th, 2016. The Annual Meeting enables our community to come together and exchange information on a wide variety of topics, from the basics of diagnosis to the most recent and relevant developments in treatment and

technology. It is the premier opportunity for networking and support for individuals and families affected by bleeding disorders.

Grant guidelines and

applications were mailed to our members in late December. The deadline to apply is January 31. If you have any questions or would like a copy of the application and guidelines, please contact the office at info@wpcnhf.org or at 724-741-6160.





LEADERSHIP BEGINS WITH U

Introducing Leadership U, a **paid** summer **internship*** for full-time college students whose lives have been touched by hemophilia. Work alongside leaders at **Bayer**, while learning how to become a future **leader** in the hemophilia community.

*Includes lodging and transportation costs

ACCEPTING 2016 SUMMER INTERNSHIP APPLICATIONS AT BAYER LEADERSHIP U.COM

Applications are due no later than Friday, February 12, 2016 at 11:59 p.m. ET =

TT TT



Explore Bayer HealthCare's additional leadership opportunities, Step Up Reach Out and AFFIRM, at www.hemophilialead.net.

Now Approved!

For the Treatment of Adults and Children with Hemophilia A



Available **EARLY 2016**



Indications and Usage

NUWIQ is a Recombinant Antihemophilic Factor [blood coagulation factor VIII (Factor VIII)] indicated in adults and children with Hemophilia A for on-demand treatment and control of bleeding episodes, perioperative management of bleeding, and for routine prophylaxis to reduce the frequency of bleeding episodes. NUWIQ is not indicated for the treatment of von Willebrand Disease.

Important Safety Information

NUWIQ is contraindicated in patients who have manifested life-threatening hypersensitivity reactions, including anaphylaxis, to the product or its components. The most frequently occurring adverse reactions (>0.5%) in clinical trials were paresthesia, headache, injection site inflammation, injection site pain, non-neutralizing anti-Factor VIII antibody formation, back pain, vertigo, and dry mouth. Development of Factor VIII neutralizing antibodies (inhibitors) may occur.

Please see adjacent page for Brief Summary of Prescribing Information.



HIGHLIGHTS OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use NUWIQ safely and effectively. See full prescribing information for NUWIQ.

NUWIQ®, Antihemophilic Factor (Recombinant) Lyophilized Powder for Solution for Intravenous Injection Initial U.S. Approval: 2015

INDICATIONS AND USAGE

NUWIQ is a recombinant antihemophilic factor [blood coagulation factor VIII (Factor VIII)] indicated in adults and children with Hemophilia A for:

- · On-demand treatment and control of bleeding episodes
- · Perioperative management of bleeding
- · Routine prophylaxis to reduce the frequency of bleeding episodes

NUWIQ is not indicated for the treatment of von Willebrand Disease.

DOSAGE AND ADMINISTRATION

For intravenous use after reconstitution

- · Each vial of NUWIQ is labeled with the actual amount of Factor VIII potency in international units (IU).
- · Determine dose using the following formula for adolescents and adults:

Required IU = body weight (kg) x desired Factor VIII rise (%) (IU/dL) x 0.5 (IU/kg per IU/dL)

· Dosing for routine prophylaxis:

· Frequency and duration of therapy depends on severity of the FVIII deficiency, location and extent of bleeding, and patient's clinical condition.

DOSAGE FORMS AND STRENGTHS

NUWIQ is available as a white sterile, non-pyrogenic, lyophilized powder for reconstitution in single-use vials containing nominally 250, 500, 1000 or 2000 IU Factor VIII potency.

CONTRAINDICATIONS

NUWIQ is contraindicated in patients who have manifested life-threatening hypersensitivity reactions, including anaphylaxis, to the product or its components.

WARNINGS AND PRECAUTIONS

- · Hypersensitivity reactions, including anaphylaxis, are possible. Should symptoms occur, discontinue NUWIQ and administer appropriate treatment.
- Development of Factor VIII neutralizing antibodies (inhibitors) may occur. If expected plasma Factor VIII activity levels are not attained, or if bleeding is not controlled with an appropriate dose, perform an assay that measures Factor VIII inhibitor concentration.
- · Monitor all patients for Factor VIII activity and development of Factor VIII inhibitor antibodies.

ADVERSE REACTIONS

The most frequently occurring adverse

Subjects	Dose (IU/kg)	Frequency of infusions
Adolescents [12-17 yrs] and adults	30-40	Every other day
Children [2-11 yrs]	30-50	Every other day or three times per week

reactions (>0.5%) in clinical trials were paresthesia, headache, injection site inflammation, injection site pain, nonneutralizing anti-Factor VIII antibody formation, back pain, vertigo, and dry mouth.

USE IN SPECIFIC POPULATIONS

Pediatric Use: Lower recovery, shorter half life and faster clearance in children aged 2 - \leq 12 years. Higher doses and/or a more frequent dosing schedule for prophylactic treatment should be considered in pediatric patients aged 2 to 5 years.

PATIENT COUNSELING INFORMATION

Advise patients to read the FDA-approved patient labeling (Patient Information and Instructions for Use).

Because hypersensitivity reactions are possible with NUWIQ, inform patients of the early signs of hypersensitivity reactions, including hives, generalized urticaria, tightness of the chest, wheezing, hypotension, and anaphylaxis. Advise patients to stop the injection if any of these symptoms arise and contact their physician, and seek prompt emergency treatment.

Advise patients to contact their physician or treatment center for further treatment and/or assessment if they experience a lack of clinical response to Factor VIII replacement therapy, as this may be a manifestation of an inhibitor.

Advise patients to consult with their healthcare provider prior to traveling. While traveling, patients should be advised to bring an adequate supply of NUWIQ based on their current treatment regimen.

To report SUSPECTED ADVERSE REACTIONS, contact Octapharma USA Inc. at 1-866-766-4860 or FDA at 1-800-FDA-1088 or www.fda.gov/ medwatch.

Manufactured by: Octapharma AB

Elersvägen 40 SE-112 75. Sweden U.S. License No. 1646

Distributed by: Octapharma USA, Inc. 121 River Street, Suite 1201 Hoboken, NJ 07030

NUWIQ is a registered trademark of Octapharma. Issued September 2015.

Revised September 2015



Our JNC Experience

By Kimberly and Whes Ebsworth

Recently, my nine year old son, Whes, and I attended the Junior National Championship (JNC) sponsored by CSL Behring, in Arizona. Wow what an experience! We made many new friends and also enjoyed the company of old friends. The event was so well organized--from registration, to the travel arrangements, to returning home.

Whes was amazed at how difficult learning golf really is. He said "Mom, Perry Parker makes it look so easy."

After the first day of golfing, Whes sat at the desk in the room writing his plan for the next day. When his very own caddy arrived with a vest that read "Ebsworth," his smile went from ear to ear.

Whes attended a wonderful swimming lesson and also practiced holding his breath under the water. Our days were filled with so many activities, Whes barely stayed awake through the award ceremony!

I thank the Chapter for selecting Whes to participate. When I asked Whes what





the best part of the weekend was, he said "Getting to spend time alone with you, Mom."

My JNC Gettin' in the Game Arizona Trip

By Ethan Webb

I am Ethan Webb. I am nine years old and I have severe Hemophilia A. I would like to say thank you to the Western PA Chapter of NHF for choosing me to represent the Chapter for the JNC baseball tournament.

This trip had a lot of firsts for me. My first time flying on a big airplane. My first trip to Arizona. My first trip with my stepdad without my mom. It was also my first time-zone change and first time swimming outside in the month of October!

My mom and brother, Kyrie, dropped

us off at the Pittsburgh Airport. We waited in line for a while and I was nervous. I played on my tablet while waiting for the plane and while on the plane. When we got to the hotel, we had pizza. I loved it so much, I almost ate the whole thing!

Friday, we went to the gym after breakfast and then to the pool, where I ran into a friend! I never knew working out was

so much fun. The pool was amazing and had a supper slippy slide. Next, I played baseball and we did a lot of skill tests—catching, hitting, running. During the game, in the bottom of the ninth inning, with 2 outs and 2 strikes, I hit a grand slam making a 19-18 game, 19-22! My stepdad was cheering so loud and proud.



We had a lot of fun and we were given medals and also got autographs and signed baseballs. We also saw a roadrunner while we were there! The trip was a lot of fun and I hope to get to go again.



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

Indication

ADYNOVATE is used on-demand to control bleeding in patients 12 years of age and older with hemophilia A. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADYNOVATE if you:

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

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

You should tell your healthcare provider if you:

- · Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may

stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

You can have an allergic reaction to ADYNOVATE. Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

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

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

Please see following page for ADYNOVATE Important Facts.

For full Prescribing Information visit www.ADYNOVATE.com.

Reference: 1. ADYNOVATE Prescribing Information. Westlake Village, CA: Baxalta US Inc.

Baxalta, Advate, and Adynovate are trademarks of Baxalta Incorporated. USBS/MG159/15-0189





Important facts about

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated]

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

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

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

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

What is ADYNOVATE?

ADYNOVATE is an injectable medicine used to replace clotting factor (factor VIII or antihemophilic factor) that is missing in people with hemophilia A (also called "classic" hemophilia). Hemophilia A is an inherited bleeding disorder that prevents blood from clotting normally.

ADYNOVATE is used on-demand to control bleeding in patients 12 years of age and older with hemophilia A. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE

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

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

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

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

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

How should I use ADYNOVATE? (cont'd)

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

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

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

You should tell your healthcare provider if you:

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

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

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

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

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

What else should I know about ADYNOVATE and Hemophilia A?

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

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA approved product labeling can be found at www.ADYNOVATE.com or 855-4-ADYNOVATE.

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

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15E001-ADY-US



Researchers Learn More about FVIII Origins

In breakthrough research, Rice University (RU) scientists have uncovered more about the cellular origins of factor VIII (FVIII), a protein that plays a critical role in the blood clotting process. The study paper was co-authored by research biochemist Nancy A. Turner, BA, and hematologist Joel L. Moake, MD, at RU's Department of Bioengineering.

Earlier studies established that FVIII is produced in endothelial cells that line the walls of blood vessels in organs such as the heart, liver and intestines. RU investigators have delved further by looking for the specific source of FVIII generation and deployment from within different types of endothelial cells.

Turner and Moake's experiments focused on human umbilical vein endothelial cells (HUVECs)' which are found in large veins, and glomerular microvascular endothelial cells (GMVECs), which are located in the smallest capillaries of the kidneys. Although the presence of FVIII in these types of cells had not been previously confirmed, investigators had recognized them, particularly HUVECs, as a viable focus of research for several reasons.

"HUVECs are the generic human endothelial cells that (biological researchers) use the first time they do anything," Turner said. "They're cheap. They're easy to work with, and they've been the model for endothelial cells for, I don't know, at least 50 years."

With her expertise in biochemistry, Turner first conducted a series of lab tests to verify the presence of FVIII in HUVECs and GMVECs. Follow-up research confirmed that FVIII is not only synthesized in HUVECs and GMVECs, but is also stored in and secreted from Weibel-Palade bodies (WPBs) within these cells. WPBs are specialized organelles (part of a cell with a specific function) that also contain von Willebrand factor (VWF), another critical protein that binds to FVIII

during the clotting cascade. VWF works as a carrier for FVIII as it circulates in the bloodstream.

This discovery has future potential therapeutic significance for people with bleeding disorders. "Now that we recognize that factor VIII is normally synthesized in endothelial cells and stored in Weibel-Palade bodies, those become the precise, most effective physiological targets for gene delivery," concluded Moake.

The article, "Factor VIII Is Synthesized in Human Endothelial Cells, Packaged in Weibel-Palade Bodies and Secreted Bound to ULVWF Strings," was published online October 16, 2015, in the journal PLOS ONE.

Source: Rice University news release dated November 2, 2015



Biotherapies for Life™ CSL Behring

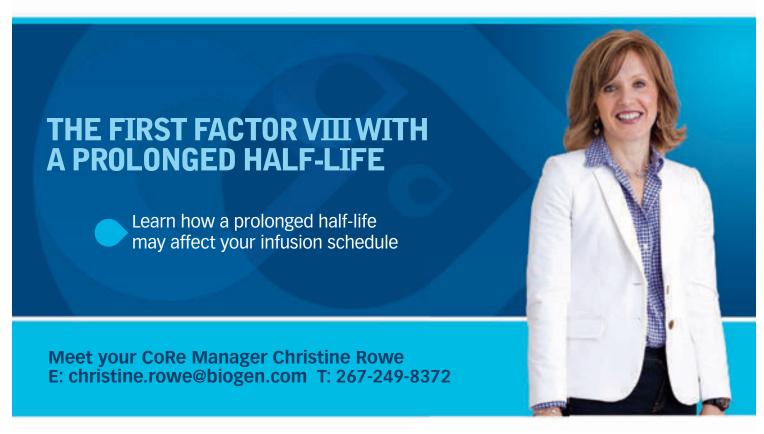
At CSL Behring, we are committed to providing treatments and supportive services that make a meaningful difference in the lives of people with bleeding disorders and those who care for them.

We set out on this journey with you more than a century ago, starting with the development of treatments for those with rare and serious diseases.

As we look to the future, we see the promise of new innovations and opportunities—just as we always have.

Over the years, we have never lost sight of what matters most: you and the countless others who inspire our efforts every day.





Indications

ELOCTATE [Antihemophilic Factor (Recombinant), Fc Fusion Protein] is a recombinant DNA derived, antihemophilic factor indicated in adults and children with Hemophilia A (congenital Factor VIII deficiency) for: control and prevention of bleeding episodes, perioperative management (surgical prophylaxis), and routine prophylaxis to prevent or reduce the frequency of bleeding episodes. ELOCTATE is not indicated for the treatment of von Willebrand disease.

Important Safety Information

Do not use ELOCTATE if you have had an allergic reaction to it in the past.

Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.

Allergic reactions may occur with ELOCTATE. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

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

Common side effects of ELOCTATE are joint pain and general discomfort. These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, and if bleeding is not controlled after using ELOCTATE.

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

Please see Brief Summary of full Prescribing Information on the next page.

This information is not intended to replace discussions with your healthcare provider.



FDA-Approved Patient Labeling

Patient Information

ELOCTATE™ /el' ok' tate/

[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

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

What is ELOCTATE?

ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ELOCTATE when you have surgery.

Who should not use ELOCTATE?

You should not use ELOCTATE if you had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ELOCTATE? Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby.
- Breastfeeding. It is not known if ELOCTATE passes into the milk and if it can harm your baby.

How should I use ELOCTATE?

You get ELOCTATE as an infusion into your vein. Your healthcare provider will instruct you on how to do infusions on your own, and may watch you give yourself the first dose of ELOCTATE.

Contact your healthcare provider right away if bleeding is not controlled after using ELOCTATE.

What are the possible side effects of ELOCTATE?

Common side effects of ELOCTATE are joint pain and general discomfort.

Allergic reactions may occur. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives.

Your body can also make antibodies called, "inhibitors," against ELOCTATE, which may stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

How should I store ELOCTATE?

- · Keep ELOCTATE in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated (2°C to 8°C or 36°F to 46°F) or at room temperature [not to exceed 30°C (86°F)], for up to six months.
- . When storing at room temperature:
 - Note on the carton the date on which the product is removed from refrigeration.
 - Use the product before the end of this 6 month period or discard it.
 - Do not return the product to the refrigerator.

Do not use ELOCTATE after the expiration date printed on the vial or, if you removed it from the refrigerator, after the date that was noted on the carton, whichever is earlier.

After reconstitution (mixing with the diluent):

- Do not use ELOCTATE if the reconstituted solution is not clear to slightly opalescent and colorless.
- Use reconstituted product as soon as possible
- You may store reconstituted solution at room temperature, not to exceed 30°C (86°F), for up to three hours. Protect the reconstituted product from direct sunlight. Discard any product not used within three hours.

What else should I know about ELOCTATE?

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

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ELOCTATE™ is a trademark of Biogen Idec.

Issued June 2014

Infusion of Humanitarian Aid to Help Sustain Hemophilia Treatment in Developing World

The World Federation of Hemophilia (WFH) and its Humanitarian Aid Program announce an international pledge of donated hemophilia therapies, which is unprecedented in size. The donation will provide 500 million international units (IUs) of critically needed hemophilia therapy over a fiveyear span.

This initial wave of donations, currently arriving at hemophilia treatment centers across the globe, represent the first phase of an overall 10-year commitment made by Biogen and Swedish Orphan Biovitrum AB (Sobi) to generate 1 billion IUs of hemophilia therapies for humanitarian use. The

countries currently receiving aid include Senegal, Kenya, Philippines, Dominican Republic, Uzbekistan, Jordan, Egypt, Morocco, Pakistan, El Salvador, Indonesia, Ghana, Myanmar, India, Sri Lanka and Nigeria.

The Humanitarian Aid Program was established in 1996 to provide treatment and care for individuals with hemophilia in the developing world, where the scarcity of adequate healthcare and sustained factor product supplies is felt most acutely. According to WFH, of the estimated 400,000 hemophilia patients worldwide, 300,000 live in places where there is little-to-no access to viable diagnosis, treatment and management. In such an environment, quality of life is severely diminished for people with bleeding disorders and life-threatening situations are more common.

"The majority of people with hemophilia in developing countries do not live past adulthood and if they do, they face a life of severe disability and chronic pain," said Assad E. Haffar, MD, WFH Humanitarian Aid Program Director. "The lack of access to clotting factor concentrates in these countries presents an urgent and important public health challenge."

"By expanding the WFH Humanitarian Aid Program through larger and more predictable donations, we may now be in a position to create a foundation for more sustainable and improved care in parts of the world where there is an urgent need," said WFH President Alain Weill.

To learn more about WFH's Humanitarian Aid Program go to: www.wfh.org.

Source: Joint press release from WFH, Biogen and Sobi dated October 12, 2015



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

Spotlight on the Member: Meet Angel Melendez

Thirty seven years ago, Angel Melendez, was born in Puerto Rico, where he lived with his parents, Angel and Aida and two brothers, David and Emanuel. As an infant and toddler, he experienced a lot of bruising and even a black eye, as he became more mobile and learned to crawl and walk. Angel is the oldest of three boys and there was no known family history of hemophilia. Naturally, his parents were concerned with his bruising and took him to a hospital Emergency Room for care. Through testing, he was diagnosed with Hemophilia A around the age of two.

For the next several years, his family would travel approximately 45 minutes to the hospital whenever he had a bleed. Once there, he would receive blood transfusions, which would take hours. At the time, there wasn't a hemophilia treatment center in Puerto Rico (today, there's one in San Juan). Influenced by the desire to have their son receive the specialized care he needed, the family made a decision to move to Philadelphia, PA, when Angel was five years old. In Philadelphia, he received care through a Hemophilia Treatment Center, which was located inside a hospital.

Angel was a typical, active boy. Although he wasn't permitted to play on an organized sports team, he enjoyed playing basketball, handball, and baseball with his friends. From a young age, he experienced bleeds and problems with his ankles; particularly, his right ankle. When he had a bleed, his mother would take him to a local hospital, now just five minutes from their home, where he would receive plasma.

By the time Angel was in the seventh or eighth grade, recombinant factor became available. When he was in the eighth grade, he experienced a bad bleed in his thigh and back, which caused him to miss three weeks of school. At this time, he started to receive factor treatments at home. A nurse would come to his home twice a week and he would go to the hematology/oncology department at St. Christopher's Hospital for Children once a week, until the bleed was resolved.

Angel was treated on demand (only when he had a bleed) throughout his childhood and into his adult years. In 2003, he moved to Pittsburgh with his wife, Tammy, and worked as a bank teller. In 2005, he was hospitalized due to a bleed in his lower back. At first, it felt has though he had had just strained a muscle after lifting something heavy at work, so he didn't think much of it. Later the following day, there was a sudden change in his condition and his wife rushed him to a hospital. It turned out that the pain he was experiencing was actually a bleed in his back. Tests revealed he had a hematoma the size of a football, which was pushing up on his organs. He had lost so much blood that he was gray

in color and there was concern from the medical staff that would not make it; they even asked if he had a will. He spent the next five days in ICU and was treated with factor every eight hours. When he was released from the hospital, a nurse came to his home and treated him over the following three weeks.

After the incident with his back, Angel met with Dr. Ragni and began receiving care from the Hemophilia Center of



Western PA. He knew he needed to make some changes and do everything he could to avoid another serious bleed. He began attending annual clinic appointments and also began prophylactic treatment. He has been on prophylaxis for nine years now. In addition, he found another job position at work that does not require standing or lifting heavy items.

In 2006, Angel and his wife attended their first Chapter event, the riverboat cruise. They have since been active members and have attended a number of educational programs and events. They have even formed a team for the annual Hemophilia Walk: Angel's Walk Team

Angel currently works as a quality assurance coach. When he isn't working, he enjoys playing video games, going fishing and bowling. He also enjoys playing poker, darts, and pool.

Angel is an advocate for prophylaxis and encourages others to talk with their medical team if they aren't currently being treated on a prophylactic basis. He believes that if he started prophylactic treatments when he was younger, he would have had fewer bleeds and fewer issues with his ankles. In addition, he believes that if kids infuse on a prophylaxis basis, they will live a more normal life and experience some of things that he wasn't able to experience as a child. Angel takes his infusion schedule seriously and "sticks" to it. He infuses in the mornings and to make sure he never misses a dose, he sets two alarms and a reminder e-mail. He has not missed a treatment in nine years!





Saturday, February 20, 2016 Diamond Run Golf Club 132 Laurel Oak Drive Sewickley, PA

The Western Pennsylvania Chapter of the National Hemophilia Foundation invites you to participate in the first ever loed Tees Winter Golf Classic! This unique event will take place at Diamond Run Golf Club in Sewickley, PA on February 20, 2016. The outing will include a 9-Hole Shotgun Scramble or a Driving Range contest depending on the weather and course conditions. We will be joined by special guests Mikey & Big Bob from the KISS 96.1 Morning Freak Show!

Every dollar raised stays local to benefit the members of The Western Pennsylvania Chapter of the National Hemophilia Foundation.

9:00 a.m. Registration
Coffee, Donuts, & Hot Oatmeal will be provided
10:00 a.m. Event Starts
9-Hole Scramble or Driving Range Contest
1:00 p.m. Lunch Buffet
Soup & Sandwich Buffet
1:30 p.m. Awards
Hosted by KISS 96.1 DJ, Tall Cathy

Your participation includes:

- 9-Holes of Golf or Driving Range Activities
- · Golf Cart
- · Gift Bag
- · One Drink Ticket
- Buffet Lunch

Participation Fees:

- Individual Participant Fee: \$125
- *Four-some Team Participant Fee: \$450
- *Lunch Only Participant Fee: \$50

register online at wponnf.org

Your IXINITY® Product Specialist, Grant Belsham

Every day I am inspired by people in the bleeding disorders community—their energy, positivity, and support for each other make me proud to be a part of their lives.

Let's talk about IXINITY and how you can get the most out of Emergent-sponsored programs, including the Generation IX Project and the B More™ Scholarship Program.





Contact Grant at 215.370.9818 or gbelsham@ebsi.com



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IXI 136-0915



Winterfest 2016

Winterfest was held on December 5 at Oglebay Resort & Conference Center. The day began with the program *Rebuilding the Body with Diet*, led by Carmen Honnef, a Registered, Certified Dietitian Nutritionist. Carmen is an active affiliate with Fox 11 news as a nutrition expert and independently works with elite athletes



in sports nutrition. The program was sponsored by Emergent BioSolutions.

After enjoying a buffet lunch, our members set out to enjoy the rest the beautiful, unseasonably warm day at the resort's zoo, museums, and other attractions. Those who stayed until dark were able to drive through the 6-mile Festival of Lights as they headed home!









Board of Directors

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Executive Director
Alison Yazer

Member Services Manager Janet Barone

Marketing & Events Manager Kara Dornish

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

WPCNHF Wish List

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

- White copy paper by the ream or by the case
- 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:

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

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



Save up to **\$12,000** in 2016!

Eligible patients can save up to \$12,000 annually on co-pay, deductible, and coinsurance costs with the Pfizer Factor Savings Card.



Beginning in 2016 (follow these steps):

- 1. Get your prescription for a Pfizer factor product from your doctor.
- 2. Visit PfizerFactorSavingsCard.com and fill out a brief registration form.+
- 3. Save and print your card right from your computer. The card is now activated.
- 4. Keep your card and use it for every purchase until the maximum benefit has been reached or the card has expired, whichever comes first.

This card will be accepted only at participating pharmacies. This card is not health insurance.

No membership fees. You will receive a total benefit of \$12,000 per calendar year, or the amount of your co-pay over one year, less a patient financial responsibility of \$10 per month, whichever is less.

If you have any questions about the use of the Pfizer Factor Savings Card, please call 1-888-240-9040 or send questions to: Pfizer Factor Savings Program, 6501 Weston Parkway, Suite 370, Cary, NC 27513. The Pfizer Factor Savings Card cannot be combined with other offers and is limited to one per person.

*Terms and conditions apply; visit PfizerFactorSavingsCard.com for complete terms and conditions. For commercially insured only. Medicare/Medicaid beneficiaries are not eligible.

1You can also request a card from your doctor, or by calling 1-855-PFZ-HEMO.

PP-HEM-USA-0280-0

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November 2015



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

