

Western Pennsylvania Chapter of the National Hemophilia Foundation

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DESIGNATE UNITED WAY GIFTS TO THE CHAPTER!

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

WPCNHF Contributor Agency Code Number is: 83

Hemogram

WPCNHF COMES TO ALTOONA

As part of the Chapter's commitment to provide more diversity and geographical outreach with our programs, we held our first program in Altoona (Blair County), PA! On Saturday, June 8, Baxter Healthcare sponsored a Facts First program entitled Emergencies Happen. Sarah Simpson RN, formerly an ER nurse and currently a clinical nurse at the Hemophilia Center of Western PA, was the speaker. We had a great turnout, made some new friends and welcomed some new families to the Chapter. We look forward to providing more programs in that area in the future. Following the program, the Chapter sponsored an Altoona Curve baseball game. The weather was perfect—it was a great night for a ballgame!

If you have suggestions for locations or topics for future events, please share them with the Chapter by calling us at (724) 741-6160 or emailing us at info@westpennhemophilia.org!

WOMEN'S RETREAT

By Maria Steele Voms Stein

The first WPCNHF Women's Retreat was held at Seven Springs on April 27-28. Nearly 40 women from our chapter gathered for a weekend filled with useful information. networking and fun. Whether the attendee was a woman with a bleeding disorder, a parent/grandparent of a child with a bleeding disorder, or a spouse/partner of a person with a bleeding disorder, there was something for everyone. There were informational sessions on von Willebrand Disease and Hemophilia. Additionally, there were general topic sessions on Advocacy, Health & Fitness, and Creative Writing. This was the first retreat specifically tailored to the needs of women in our community. We hope that more women will attend and enjoy future programs for women through the chapter.



Letter From The President, Scott Miller

Dear Chapter Members and Stakeholders,

What a wonderful Spring! The Women's Retreat was a resounding success, as were our first ever Altoona Educational event, our recent Men's Group gathering and Laurie Kelly's PULSE on the Road! I want to thank the staff, presenters, sponsors, and participants for their part in enabling us to provide such high quality programming as well as good camaraderie.

As summer kicks off, please remember

to mark your calendars for the Annual Meeting on July 28th in North Park. This year we are once again combining this event with our Hemophilia Walk Kickoff. The Walk has been one of our key fundraisers and I look forward to everyone's participation in the Walk on September 21 to help us meet our mission. In addition to our business meeting, representatives from NHF will be speaking about the hemophilia genotyping project, which is incredibly important to our community.

THANK YOU for your continued support of the Chapter and feel free to contact us if we can be of service or if you need assistance. I look forward to seeing you all at the Annual Meeting!

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

Letter From The Executive Director, Alison Yazer

Dear Chapter Members and Friends,

I hope that the arrival of our summer newsletter finds you and your family well. The Chapter continues to work toward increasing both the number and locations of our educational programs and I hope you plan to join us for some of these great upcoming events.

Our first ever Women's Retreat took place in April and proved to be a huge success! Members heard speakers on a variety of topics and a good time was had by all. We appreciate the women of our Chapter helping to plan and participate in this event. Included in this issue are a variety of articles and invitations that will help you and your family. Each item included in this newsletter, along with the myriad of education programs we plan for you, provides a great opportunity for you to learn more about your bleeding disorder.

I hope you are planning to join us for the Chapter's Annual Meeting and Walk Kickoff on Sunday, July 28th in North Park. Not only will there be a chance to meet and mingle with our Board, the Walk Kickoff, a great BBQ dinner (plus an ice cream sundae bar!), but there will also be time to visit with our industry partners and a presentation on Genotyping for Progress in Hemophilia: My

Life, Our Future: A nationwide campaign for progress in research in hemophilia. This campaign is incredibly important to our community, so I urge you to attend and learn more about this critical project.

As always, please contact the staff of WPCNHF with any suggestions, questions or concerns. Thank you for all that you do on behalf of the bleeding disorders community. On behalf of the staff of WPCNHF, I wish you a safe and happy summer!

Alison Yazer
Executive Director

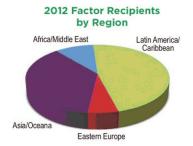
A Project SHARE Story

By Zoraida Rosado

Another Banner Year

Project SHARE had another banner year providing blood-clotting medicine to developing countries. In 2012 we donated 5.6 million IU of factor, valued at \$5.6 million, to 34 countries. Through these donations, we were able to provide relief to hundreds of people with bleeding disorders. We also donated NovoSeven, valued at \$427,000, to 6 countries. In a major contrast with past years, most of our donations in 2012 went to Latin America and the Caribbean.

SHARE visited Zimbabwe in December—our fourth trip there. Laurie Kelley also visited Zambia, making the first official visit by a hemophilia program there. She met with a newly formed hemophilia organization and submitted an assessment report to the World Federation of Hemophilia (WFH). SHARE provided



\$1,000 in funds to help the Haemophilia Foundation of Zambia (HFZ) create business cards and letterhead stationery.

Our deepest thanks go to all who have donated factor to Project SHARE, especially those who donated in memory of a loved one. Project SHARE is also grateful for the continued financial support of our corporate partners in 2012:

- ASD Healthcare
- Baxter Healthcare Corporation
- CSL Behring
- New England BioLabs
- Novo Nordisk Inc.
- Octapharma

Calendar of Upcoming Events

Sunday, July 28 WPCNHF Annual Meeting and Walk Kickoff North Park, Allison Park, PA

Sunday, August 4 – Saturday, August 10 Camp Hot-to-Clot Fombell, PA

Saturday, August 17 Men's Group Pittsburgh, PA

Saturday, September 21 Hemophilia Walk North Park, Allison Park, PA

Saturday, September 21 Run For Their Lives 5K North Park, Allison Park, PA

Thursday, October 3 – Saturday, October 5 NHF Annual Meeting Anaheim, CA

Saturday, October 19 Educational Program and Fall Fest TBD

Saturday, October 26 Educational Program and Social Event Erie, PA

Friday, November 22 – Sunday, November 24 Take A Bough Pittsburgh, PA

Tentative Dates: Saturday, December 7 or Sunday, December 15 Winterfest TBD



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

Cash For Trash Fundraiser



Recycle your inkjet and toner cartridges

Cartridges can be brought from home, work, or local businesses. Be sure to ask your employer to sponsor us by saving their empty toner cartridges. We receive funds for the Chapter for empty laser, fax, and copier cartridges. Inkjet cartridges can earn money too! Recycling cartridges not only helps to alleviate America's landfills, it makes "cents" too! All money earned from this program will go to WPCNHF. Please drop empty cartridges at:

WPCNHF 20411 Route 19, Unit 14 Cranberry Twp., PA 16066

Ask us about sponsorship opportunites and how you can help!



UNLOCKING SELF-POTENTIAL

PROPHYLAXIS WITH ADVATE REDUCED BLEEDS IN A CLINICAL STUDY^{1,a}

ADVATE is the only recombinant factor VIII (eight) that is FDA approved for prophylaxis in both adults & children (0-16 years)¹

Significant reduction in median annual bleed rate (ABR) with prophylaxis treatment compared with on-demand treatment^{1,a}



- 0 bleeds experienced by 42% of patients during 1 year on prophylaxis^{1,a}
- 98% reduction in median annual bleed rate (ABR) from 44 to 1 when switched from on-demand to prophylaxis^{1,4}
- 97% reduction in joint bleeds from 38.7 to 1 after switching from on-demand to prophylaxis^{1,8}
- No subject developed factor VIII inhibitors or withdrew due to an adverse event (AE)^{2,a}

In a clinical study, after switching from 6 months of on-demand treatment to 12 months of prophylaxis with ADVATE in 53 previously treated patients with severe or moderately severe hemophilia A.

Ask your healthcare provider if prophylaxis with ADVATE is right for you.

Detailed Important Risk Information for ADVATE

You should not use ADVATE if you are allergic to mice or hamsters or any ingredients in ADVATE.

You should tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines and dietary supplements, have any allergies, including allergies to mice or hamsters, are nursing, are pregnant, or have been told that you have inhibitors to factor VIII.

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

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

Side effects that have been reported with ADVATE include: cough, sore throat, unusual taste, abdominal pain, diarrhea, nausea/vomiting, headache, fever, dizziness, hot flashes, chills, sweating, joint swelling/aching, itching, hematoma, swelling of legs, runny nose/congestion, and rash

Call your healthcare provider right away about any side effects that bother you or if your bleeding does not stop after taking ADVATE.

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Indication for ADVATE

ADVATE [Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method] is a medicine used to replace clotting factor VIII that is missing in people with hemophilia A (also called "classic" hemophilia). ADVATE is used to prevent and control bleeding in adults and children (0-16 years) with hemophilia A. Your healthcare provider may give you ADVATE when you have surgery. ADVATE can reduce the number of bleeding episodes in adults and children (0-16 years) when used regularly (prophylaxis).

ADVATE is not used to treat von Willebrand Disease.

Please see Brief Summary of ADVATE Prescribing Information 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.

References:

 ADVATE Prescribing Information. Westlake Village, CA: Baxter Healthcare Corporation; July 2012.
 Valentino LA, Mamonov V, Hellmann A, et al. A randomized comparison of two prophylaxis regimens and a paired comparison of on-demand and prophylaxis treatments in hemophilia A management. J Thromb Haemost. 2012;10(3):359-367.



ADVATE

[Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method]

Brief Summary of Prescribing Information. Please see package insert for full prescribing information.

INDICATIONS AND USAGE

Control and Prevention of Bleeding Episodes

ADVATE [Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method] is an Antihemophilic Factor (Recombinant) indicated for control and prevention of bleeding episodes in adults and children (0-16 years) with Hemophilia A.

Perioperative Management

ADVATE is indicated in the perioperative management in adults and children (0-16 years) with Hemophilia A.

Routine Prophylaxis

ADVATE is indicated for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children (0-16 years) with Hemophilia A.

ADVATE is not indicated for the treatment of von Willebrand disease.

CONTRAINDICATIONS

Known anaphylaxis to mouse or hamster protein or other constituents of the product.

WARNINGS AND PRECAUTIONS

Anaphylaxis and Hypersensitivity Reactions

Allergic-type hypersensitivity reactions, including anaphylaxis, are possible and have been reported with ADVATE. Symptoms have manifested as dizziness, paresthesias, rash, flushing, face swelling, urticaria, dyspnea, and pruritus. [See Patient Counseling Information (17) in full prescribing information] ADVATE contains frace amounts of mouse immunoglobulin G (MulgG): maximum of 0.1 ng/IU ADVATE and hamster proteins: maximum of 1.5 ng/IU ADVATE. Patients treated with this product may develop hypersensitivity to these non-human mammalian proteins.

Discontinue ADVATE if hypersensitivity symptoms occur and administer appropriate emergency treatment.

Neutralizing Antibodies

Carefully monitor patients treated with AHF products for the development of Factor VIII inhibitors by appropriate clinical observations and laboratory tests. Inhibitors have been reported following administration of ADVATE predominantly in previously untreated patients (PUPs) and previously minimally treated patients (MTPs). If expected plasma Factor VIII activity levels are not attained, or if bleeding is not controlled with an expected dose, perform an assay that measures Factor VIII inhibitor concentration. [See Warnings and Precautions (5.3) in full prescribing information]

Monitoring Laboratory Tests

The clinical response to ADVATE may vary. If bleeding is not controlled with the recommended dose, determine the plasma level of Factor VIII and administer a sufficient dose of ADVATE to achieve a satisfactory clinical response. If the patient's plasma Factor VIII level fails to increase as expected or if bleeding is not controlled after the expected dose, suspect the presence of an inhibitor (neutralizing antibodies) and perform appropriate tests as follows:

- Monitor plasma Factor VIII activity levels by the one-stage clotting assay to confirm the adequate
 Factor VIII levels have been achieved and maintained when clinically indicated. [See Dosage and
 Administration (2) in full prescribing information]
- Perform the Bethesda assay to determine if Factor VIII inhibitor is present. If expected Factor VIII
 activity plasma levels are not attained, or if bleeding is not controlled with the expected dose of
 ADVATE, use Bethesda Units (BU) to titer inhibitors.
 - If the inhibitor titer is less than 10 BU per mL, the administration of additional Antihemophilic Factor concentrate may neutralize the inhibitor and may permit an appropriate hemostatic response.
 - If the inhibitor titer is above 10 BU per mL, adequate hemostasis may not be achieved. The
 inhibitor titer may rise following ADVATE infusion as a result of an anamnestic response to Factor
 VIII. The treatment or prevention of bleeding in such patients requires the use of alternative
 therapeutic approaches and agents.

ADVERSE REACTIONS

The serious adverse drug reactions (ADRs) seen with ADVATE are hypersensitivity reactions and the development of high-titer inhibitors necessitating alternative treatments to Factor VIII.

The most common ADRs observed in clinical trials (frequency ≥ 10% of subjects) were pyrexia, headache, cough, nasopharyngitis, vomiting, arthralgia, and limb injury.

Clinical Trial Experience

Because clinical trials are conducted under widely varying conditions, adverse reaction rates observed in the clinical trials of a drug cannot be directly compared to rates in clinical trials of another drug and may not reflect the rates observed in clinical practice.

ADVATE has been evaluated in five completed studies in previously treated patients (PTPs) and one ongoing study in previously untreated patients (PUPs) with severe to moderately severe Hemophilia A (Factor VIII $\leq 2\%$ of normal). A total of 234 subjects have been treated with ADVATE as of March 2006. Total exposure to ADVATE was 44,926 infusions. The median duration of participation per subject was 370.5 (range: 1 to 1,256) days and the median number of exposure days to ADVATE per subject was 128.0 (range: 1 to 598).

The summary of adverse reactions (ADRs) with a frequency ≥ 5% (defined as adverse events occurring within 24 hours of infusion or any event causally related occurring within study period) is shown in Table 1. No subject was withdrawn from a study due to an ADR. There were no deaths in any of the clinical studies.

IMMUNOGENICITY

The development of Factor VIII inhibitors with the use of ADVATE was evaluated in clinical studies with pediatric PTPs (< 6 years of age with > 50 Factor VIII exposures) and PTPs (≥ 10 years of age with > 150 Factor VIII exposures). Of 198 subjects who were treated for at least 10 exposure days or on study for a minimum of 120 days, 1 adult developed a low-titer inhibitor (2.0 [BU] in the Bethesda assay) after 26 exposure days. Eight weeks later, the inhibitor was no longer detectable, and *in vivo* recovery was normal at 1 and 3 hours after infusion of another marketed recombinant Factor VIII concentrate. This single event results in a Factor VIII inhibitor frequency in PTPs of 0.51% (95% Cl of 0.03 and 2.91% for the risk of any Factor VIII inhibitor development). No Factor VIII inhibitors were detected in the 53 treated pediatric PTPs.

In clinical studies that enrolled previously untreated subjects (defined as having had up to 3 exposures to a Factor VIII product at the time of enrollment), 5 (20%) of 25 subjects who received ADVATE developed inhibitors to Factor VIII.¹ Four patients developed high titer (> 5 BU) and one patient developed low-titer inhibitors. Inhibitors were detected at a median of 11 exposure days (range 7 to 13 exposure days) to investigational product.

Immunogenicity also was evaluated by measuring the development of antibodies to heterologous proteins. 182 treated subjects were assessed for anti-Chinese hamster ovary (CHO) cell protein antibodies. Of these patients, 3 showed an upward trend in antibody fiter over time and 4 showed repeated but transient elevations of antibodies. 192 treated subjects were assessed for mulgG protein antibodies. Of these, 10 showed an upward trend in anti-mulgG antibody fiter over time and 2 showed repeated but transient elevations of antibodies. Four subjects who demonstrated antibody elevations reported isolated events of urticaria, pruritus, rash, and slightly elevated eosinophil counts. All of these subjects had numerous repeat exposures to the study product without recurrence of the events and a causal relationship between the antibody findings and these clinical events has not been established.

Of the 181 subjects who were treated and assessed for the presence of anti-human von Willebrand Factor (VWF) antibodies, none displayed laboratory evidence indicative of a positive serologic response.

Post-Marketing Experience

The following adverse reactions have been identified during post-approval use of ADVATE. Because these reactions are reported voluntarily from a population of uncertain size, it is not always possible to reliably estimate their frequency or establish a causal relationship to drug exposure.

Among patients treated with ADVATE, cases of serious allergic/hypersensitivity reactions including anaphylaxis have been reported and Factor VIII inhibitor formation (observed predominantly in PUPs). Table 2 represents the most frequently reported post-marketing adverse reactions as MedDRA Preferred Terms.

Table 1 Summary of Adverse Reactions (ADRs) $^{\rm a}$ with a Frequency \geq 5% in 234 Treated Subjects $^{\rm b}$

MedDRA ^c System Organ Class	MedDRA Preferred Term	Number of ADRs	Number of Subjects	Percent of Subjects
General disorders and administration site conditions	Pyrexia	78	50	21
Nervous system disorders	Headache	104	49	21
Respiratory, thoracic and mediastinal disorders	Cough	75	44	19
Infections and infestations	Nasopharyngitis	61	40	17
Gastrointestinal disorders	Vomiting	35	27	12
Musculoskeletal and connective tissue disorders	Arthralgia	44	27	12
Injury, poisoning and procedural complications	Limb injury	55	24	10
Infections and infestations	Upper respiratory tract infection	24	20	9
Respiratory, thoracic and mediastinal disorders	Pharyngolaryngeal pain	23	20	9
Respiratory, thoracic and mediastinal disorders	Nasal congestion	24	19	8
Gastrointestinal disorders	Diarrhea	24	18	8
Gastrointestinal disorders	Nausea	21	17	8
General disorders and administration site conditions	Pain	19	17	8
Skin and subcutaneous tissue disorders	Rash	16	13	6
Infections and infestations	Ear infection	16	12	5
Injury, poisoning and procedural complications	Procedural pain	16	12	5
Respiratory, thoracic and mediastinal disorders	Rhinomhea	15	12	5

ADRs are defined as all Adverse Events that occurred (a) within 24 hours after being intused with investigational product or (b) all Adverse Events assessed related or possibly related to investigational product or (c) Adverse Events for which the investigator's or sponsor's opinion of causality was missing or indeterminate.

Table 2
Post-Marketing Experience

Organ System [MedDRA Primary SOC]	Preferred Term	
Immune system disorders	Anaphylactic reaction ^a Hypersensitivity ^a	
Blood and lymphatic system disorders	Factor VIII inhibition	
General disorders and administration site conditions	Injection site reaction Chills Fatique/Malaise	
defieral disorders and administration site conditions	Chest discomfort/pain Less-than-expected therapeutic effect	

^{*}These reactions have been manifested by dizziness, paresthesias, rash, flushing, face swelling, urticaria, and/or pruritus

References: 1. Shapiro A, Gruppo R, Pabinger Let al. Integrated analysis of safety and efficacy of a plasma- and albumin-free recombinant factor VIII (rAHF-PFM) from six clinical studies in patients with hemophilia A. Expert Opin Biol Ther 2009 9:273-283. 2. Tarantino MD, Collins PW, Hay PW et al. Clinical evaluation of an advanced category antihaemophilic factor prepared using a plasma/albumin-free method: pharmacokinetics, efficacy, and safety in previously treated patients with haemophilia A. Haemophilia 2004 10:428-437.

To enroll in the confidential, industry-wide Patient Notification System, call 1-888-873-2838

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Patented under U.S. Patent Numbers: 5,733,873;5,854,021;5,919,766;5,955,448;6,313,102;6,586,573;6,649,386;7,087,723; and 7,247,707. Made according to the method of U.S. Patent Numbers: 5,470,954;6,100,061;6,475,725;6,555,391;6,936,441;7,094,574;7,253,262; and 7,381,796.

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The ADVATE clinical program included 234 treated subjects from 5 completed studies in PTPs and 1 ongoing study in PUPs as of 27 March 2006.

MedDRA version 8.1 was used.

Inhibitor Insights

By Jo Schaffel

Using Apps When You Have an Inhibitor If you live with inhibitors, you know how complicated life can be. You or your child may be on several different medications and have a demanding treatment regimen. You may have several appointments a week at your hemophilia treatment center (HTC). On top of that, you have all the other responsibilities of parenthood.

The mobile apps profiled in this issue of PEN are designed to help organize your life and make it easier to track doctor appointments, treatments, bleeds, and medications. How well do they work if someone in your family has an inhibitor?

Benefits of Mobile Apps

For years, many parents, caregivers, and patients have tracked factor usage and bleeds on computer spreadsheets or with pencil in a paper logbook. These methods work well for many people, but they have limitations. Mobile apps are a more convenient method for keeping track of bleed data. These software applications are designed to run on smartphones, tablet computers, and other mobile devices.

The benefits? Tech-savvy teens and young adults (who often seem to be attached to their cell phones) might prefer to use apps to track their info rather than fill out an entry in a logbook or use a computer. Plus, data on bleeds stored electronically is easier to transmit to a doctor quickly in an emergency.

Some health insurance companies require detailed information about infusions: time, date, brand, lot number, bleed type, and dosage. A mobile app can help you keep track of all this info and make it easier to share with caregivers. And if you're away from home, it's easier to enter or scan product data and bleed info into a mobile app than use a logbook or spreadsheet. Some apps also allow you to set reminders for appointments or treatments as well as record factor usage. Newer apps allow a user to track not only factor usage, but every aspect of living with a bleeding disorder.

Several apps allow users to set up multiple

patient profiles—a benefit for parents and caregivers. And this way, older kids can take part in their own care and enter their bleed and treatment info on their own.

Will an App Work for You?

Novo Nordisk's HemaGo app was designed to be especially helpful for patients with inhibitors, according to the company's press release. It was developed to improve communication between hemophilia patients and their caregivers. Because treatment for inhibitors can be so complicated, the app makes it easier to keep track of all the details.

The HemaGo app allows users to record information on all medications that patients are using, including overthe-counter meds. This gives doctors a better overall picture of the patient, which can help prevent possible negative interactions. HemaGo can also record how much factor is used and the reason for each infusion.

Another useful feature of HemaGo is that it lets you record other data about a bleeding episode besides just the basics. What was the level of pain? How did the bleed affect work, school, or daily life? Where was the bleed, and how long did it last? This info is valuable for evaluating treatment regimens.

The data that you enter into the HemaGo app syncs with Novo Nordisk's website, called Changing Possibilities in Hemophilia,1 and can be shared with doctors or healthcare teams. You can use the app to create customized reports through Changing Possibilities, and then print out or email the reports to your healthcare team. HemaGo also allows you to set up reminders on your phone for appointments or treatments, or log prophylactic treatments.

MicroHealth offers another way to track bleed data electronically: a cloud-based program. It's not exactly an app, because people without smartphones can use it. You set up a customized profile online, and then specify who receives the information you send—this gives you control of your personal health data. The program sends you text messages asking questions such as whether you've infused or had a bleed. The answers you text back go into your profile and can be reported to

your healthcare team.

Liz, whose three year-old son has severe hemophilia A with inhibitors, is an enthusiastic user of MicroHealth. "Between ITI and later, prophy, we were doing three infusions a day," Liz explains. "I reached out to the MicroHealth team to help me set it up that way. They actually enhanced MicroHealth to fit my schedule perfectly." Liz set up her profile online, and now just texts MicroHealth if she needs to record anything. "They remind me to log when the next dose is due. That's an awesome feature." She no longer uses paper and pencil for logging. And she is teaching her son how to use the program.

If you do decide to use an app or online program to keep records, be cautious. As with any digital or electronic informationsharing tool, you need to be careful about your personal information. Check the company's privacy policy to see which information it collects and how secure your data will be.2

Mobile apps can help families with inhibitors organize and keep track of every aspect of a treatment plan, especially if several caretakers are involved or if you are on a complicated treatment regimen. Whether you are at school, work, or your HTC, your treatment data is at your fingertips. Having an inhibitor adds to the stress of having hemophilia and complicates daily living, but you may be able to reduce stress by using an appropriate app.

- 1. The company's website states that Novo Nordisk does not have access to patient-specific information. The company's access is restricted to generic information ("de-identified") in which the data has been stripped so that the individual source cannot be identified, in accordance with Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy and Security Rules. For info: www.novonordisk-us.com/documents/article_page/document/disclaimer.asp.
- 2. For more on privacy, see "Private Parts: Is Your Personal Health Information Exposed?" PEN, Feb. 2012.

Steps for Living

By Rebecca Baker

Exciting news for our bleeding disorders community! The National Hemophilia Foundation has given the Chapter new tools for providing education to you as your children age.

Since 2005, the Chapter has been offering First Step training programs for families with children ranging in age from birth to eight years old. Now the Chapter is equipped with the tools to implement Next Step training programs for families with children ages 9-15.

The Steps for Living training programs are an extension of NHF's Steps for Living

website, which provides educational resources for the bleeding disorders community and the general public. The information on the Steps for Living website is organized into four modules: First Step for ages newborn-8, Next Step for ages 9-15, Step Up for ages 16-25, and Step Out for ages 26 and over.

Janet Barone, Member Services Manager, Western PA Chapter of National Hemophilia Foundation, Jennifer Warner, M.A. Mental Health Professional I, Hemophilia Center of Western PA, and Rebecca Baker, Volunteer, traveled to Denver, Colorado in May 2013 to attend a train-the-trainer session to bring this new program here to Pittsburgh. The Next Step programs will help you navigate tough issues on anti-bullying, puberty and

menstruation, sibling support, planning for college, independence, and medical management just to name a few.

Stay tuned for our first program coming soon. The first topic we are going to address is puberty and menstruation for girls ages 9-15. We will have a light-hearted talk on some embarrassing issues to provide support, discuss ways to deal with heavy periods, and cover options for using your computer or smart phone to keep track of your periods. Janet, Jennifer and Rebecca are looking forward to sharing their knowledge with these girls and their mothers/female caregivers in a relaxed environment.

NHF Announces 2013 Excellence Fellowship Recipients

The National Hemophilia Foundation (NHF) is pleased to announce the recipients of its 2013 Nursing, Social Work and Physical Therapy Excellence Fellowships.

Nursing Fellowship

The Nursing Fellowship was awarded to Kimberly Jacobson, RN, CNP- Pediatric, Hematology/Oncology Clinic, Children's Hospitals and Clinics of Minnesota. Jacobson was awarded \$13,211 for her project, "Telehealth Videoconferencing for Children with Hemophilia and Their Families: A Clinical Project." She will partner with young patients with severe hemophilia and their families to better understand their technical capacity (computer, access to Internet, camera), to learn how to effectively use videoconferencing to manage bleeds, and to query fellow healthcare provider staff for their feedback on the technique. The project will aid in planning for future telehealth research in larger patient groups.

Social Work Fellowship

The Social Work Fellowship was awarded to Debra Honig, MSW, LCSW, and Clinical Social Worker Lucy Ramirez, MSW, LCSW, Rush Hemophilia & Thrombophilia Center-Rush University Medical Center in Chicago. Honig and Ramirez will use their \$10,000 award on their project, "Understanding the Role of Religiosity and Spirituality in Adolescent Patients with Inherited Bleeding Disorders." For the project, 40 teenagers/young adults (ages 12-21) with hemophilia will be recruited and asked to complete three questionnaires. The questions are designed to help discern the role of religion and spirituality in this age group and in their parents. Based on their findings, Honig and Ramirez anticipate possible changes in clinical practice to better incorporate factors such as spirituality.

Physical Therapy Fellowship

The Physical Therapy Fellowship was awarded to Lorraine M. Flaherty, PT, Hemophilia Care Program, Puget Sound Blood Center in Seattle, WA. Flaherty will use the one-year \$10,000 fellowship for her project, "Identifying Fall Risk in Patients with Hemophilia." Flaherty will create a screening tool for use during an annual comprehensive care visit. The tool will help PTs evaluate and target higher

risk patients, to implement fall prevention measures and enhance patients' quality of life

All grant and fellowship applications are subjected to a rigorous peer review process. Applications are critiqued on scientific merit and relevance to NHF research priorities. They are reviewed and scored in terms of significance, approach, innovation, investigator and environment.



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What Is XYNTHA?

Xyntha Antihemophilic Factor (Recombinant), Plasma/Albumin-Free is indicated for the control and prevention of bleeding episodes in patients with hemophilia A (congenital factor VIII deficiency or classic hemophilia) and for surgical prophylaxis in patients with hemophilia A.

XYNTHA does not contain von Willebrand factor and. therefore, is not indicated in 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, trouble breathing, chest tightness, turning blue (look at lips and gums), fast heartbeat, swelling of the face, faintness, rash, 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.

- The most common adverse reaction in the safety and efficacy study is headache (24% of subjects) and in the surgery study is fever (43% of subjects). Other common side effects of XYNTHA include nausea, vomiting, diarrhea, or weakness.
- 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.

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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Antihemophilic Factor (Recombinant), Plasma/Albumin-Free



Antihemophilic Factor (Recombinant), Plasma/Albumin-Free

Ronly

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 Wyeth Pharmaceuticals toll-free at 1-800-934-5556

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.

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:

- · 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

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

XYNTHA contains trace amounts of hamster proteins. You should not use XYNTHA if you are allergic to hamster protein.

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 or reasonably likely side effects of XYNTHA?

Common side effects of XYNTHA are

- headache
- fever
- nausea
- vomitina diarrhea
- weakness

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

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

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

This brief summary is based on the Xyntha[®] [Antihemophilic Factor (Recombinant), Plasma/Albumin-Free] Prescribing Information LAB-0516-3.0, revised 06/12, and LAB-0500-7.0, revised 06/12.





YOU'RE INVITED!

Please join the Western Pennsylvania Chapter of the National Hemophilia Foundation for two great events rolled into one!

The 2013 Annual Meeting and Hemophilia Walk Kickoff



and Flanders (Shelter 30) Walter Road, Allison Park, PA 15101

Date: July 28, 2013 • Time: 2:30 p.m. Location & Address: North Park, Flagstaff Hill (Shelter 29) Rain or shine the day includes:

- Sponsor Exhibits
- · Genotyping for Progress in Hemophilia: My Life, *Our Future:* A nationwide campaign for progress in research in hemophilia, this program is sponsored by ATHN, NHF, Puget Sound Blood Center and BiogenIdec Hemophilia.
- WPCNHF's Annual Meeting
- An Animal Show by Wild World of Animals
- BBO Dinner
- Outdoor Activities

Help us celebrate the 5th Annual Western Pennsylvania Hemophilia Walk by attending our Kickoff Event! All team captains, walkers and anyone interested in participating in the event are invited to join us as we rally together to make the Western Pennsylvania Hemophilia Walk a smashing success.

The Western Pennsylvania Hemophilia Walk will take place on September 21, 2013 at North Park in Northern Allegheny County.

There is no charge to attend the Annual Meeting/Kickoff Event but space is limited! Please RSVP by July 19 to 724.741.6160 or rsvp@westpennhemophilia.org.

Provide the following information:

- 1) Your first and last name
- 2) Your phone number and e-mail address
- 3) The total number in your party
- 4) Number and ages of children

Please visit our Walk website at www.hemophilia.org/walk





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

Pulse On The Road!

WPCNHF was pleased to welcome Pulse On The Road to our community! On Saturday, June 15, we heard from three great speakers on the Affordable Care Act and healthcare plans. Ruthlyn Noel, Senior Manager, Reimbursement & State Advocacy Northeast, Baxter Healthcare Corporation, presented: The Affordable Care Act: What you Need to Know; Laurie Kelly, President of LA Kelly Communications presented: The Importance of Choosing a Healthcare Plan; and Michelle Rice, Director, Public Policy for the National Hemophilia Foundation, presented: NHF's Insurance Selector Tool.

There was plenty of opportunity for questions both during and after the program. We learned that when comparing healthcare plans and trying to determine the out of pocket costs, it's important to know and understand which benefits you and your family typically use and how often you use them. Participants received a Personal Health Insurance Toolkit and Workbook and learned how to truly compare different types of healthcare plans to help determine what the actual out-of-pocket costs would be for them over a year. If you were unable to attend this program and would like a copy of the handouts, please contact the Chapter.

Industry News

Last month, Biogenic Idec announced that the US Food and Drug Administration (FDA) had accepted its Biologics License Application (BLA) for the marketing approval of ELOCTATE™ a recombinant factor VIII (FVIII) Fc fusion protein for the treatment of hemophilia A.

According to a Biogen press release posted on May 13th, 2013, ELOCTATE is the first hemophilia A product candidate in a new class of long-lasting clotting factor therapies.

"ELOCTATE has the potential to improve adherence by reducing the number of intravenous injections needed to prevent bleeds, which is an important need for people with hemophilia A," said Glenn Pierce, MD, PhD, senior vice president of Global Medical Affairs and chief medical officer of Biogen Idec's hemophilia therapeutic area. "For those people currently on preventative—or prophylactic—treatment, ELOCTATE provides the potential to reduce the number of intravenous injections by 50 to 100 per year."

The ELOCTATE BLA was based on results from "A-LONG," the largest registrational phase 3 clinical study in hemophilia A to date. In the A-LONG study, patients who injected ELOCTATE weekly or twice weekly had fewer bleeds. This is in contrast to the current prophylactic regimen for patients with severe hemophilia A, who typically infuse three times per week or every other day to maintain a sufficient level of FVIII in their bloodstream to prevent bleeds.

Meet The HCWP Staff



Matt Hindman is the accounting manager at the Hemophilia Center of Western PA. He is responsible for overseeing a timely and accurate monthly accounting close, maintaining effective accounting policies, managing the annual financial statement audit, and coordinating budget activities with the Executive Director. He started with the center in December 2012.

Matt joined the Hemophilia Center from PNC Bank where he worked for two and a half years in corporate finance. Prior to that, he worked in public accounting as an auditor supervisor for three years with Louis Plung and Co. in downtown Pittsburgh and as a staff accountant for two years with Henry Rossi and Co. in Monroeville.

Matt is a Certified Public Accountant (C.P.A.) in Pennsylvania and is a member of the PICPA. He earned his M.B.A. focused in accounting from Indiana University of PA (IUP) in 2005 and his B.S. in Communications Media, also from IUP, in 2002.



Spotlight on The Member: The Kosto-Bobro Family

Heather Kosto-Bobro and Marty Bobro will never forget the day they were told that their daughter, Bianca, was "one in a million!" Of course, as parents, they may have already thought that of their daughter, but now it was official—the words came from their hematologist, along with a diagnosis: Factor X deficiency. Bianca was 8 years old at the time. She had a history of easy bruising and bloody noses, but nothing that had caused any reason for alarm. Then she had a couple of surgeries done for some stomach-related issues she was having. A few days later she became pale and lost her vision.

Heather and Marty immediately took their daughter to the ER. She was admitted to the hospital, seen by a nutritionist, and was first treated for Vitamin K deficiency. Bianca had internal bleeding that resulted from the medical procedures she had a few days earlier and initial attempts to stop the bleeding were unsuccessful. Her levels continued to plummet and her parents were being prepared for the worst. Fortunately, a series of tests were being performed for bleeding disorders and the reason for the bleeding was identified. Factor X deficiency is very rare and there are currently no factor concentrate products to treat it. Bianca was treated with fresh-frozen plasma and fully recovered from that incident. Factor X affects men and women equally and occurs in approximately one person in every 500,000-1,000,000 people. Women with Factor X deficiency may experience heavy menstrual bleeding and certain



The Kosto-Bobro family with Senator Bob Casey during Washington Days 2013

complications during pregnancy and childbirth.

Although the Kosto-Bobro family was unaware of any family history of bleeding disorders, they have since learned that Bianca's maternal greatgrandfather had hemophilia. Bianca is now 11 years old and is doing well, overall. She does have frequent nosebleeds which sometimes lead to a missed school bus or a missed gym class, but her parents feel fortunate that she doesn't have any major day-to-day limitations (although, like many others with bleeding disorders, she needs to avoid certain high-impact sports). As she gets older, her condition may become more serious and she may need to take additional measures to manage her bleeding disorder.

Heather found out about WPCNHF a few months after Bianca's diagnosis. She said she immediately felt welcome and had concern for, and a connection to, all of members she met. She feels strongly that she needs to advocate for others because the Foundation is an amazing resource that has given so much to her family. She wants to give back in any way that she can. Heather, Marty, Bianca, and Celeste (their 13 year old daughter) have participated in Harrisburg Day the last two years. The family really

loves this particular advocacy event for both the educational value and for the opportunity to help make a difference at a basic level. This year, the family also participated in Washington Days for the first time and enjoyed learning more about the advocacy process on a national level

Bianca and her sister Celeste enjoy attending Camp Hot-to-Clot and have made a number of friends there. They also love to go camping as family, whenever they can. The family also enjoys reading, ice skating, and visiting museums. They keep an eye on the local calendars and participate in many community events in the region. They enjoy learning more about different cultures and trying new activities. The family also seeks out opportunities to volunteer at different organizations whenever they can. This past year, the family enjoyed volunteering at Take A Bough, the Chapter's holiday tree auction. This particular event gave them an opportunity create awareness for the general public about the Chapter and bleeding disorders.

When Heather was asked if she had any advice for families that are dealing with a new diagnosis, she said that at the risk of sounding cliché, she wants people to know that it does get better. She admits that a new diagnosis can be overwhelming and scary at first, especially when you don't know what the next step is. She advises people to not be afraid to reach out and ask for help. It will get better! You will soon develop your own routine and get things stabilized. You will find yourself saying, "I got this now."



HIT THE GROUND RUNNING!

Saturday, September 21, 2013

Location: North Park in Allison Park, PA
Registration Check-In Time: 7:30 am
Race Start Time: 8:30 am
Race Distance: 5K

An expected 100+ Western Pennsylvanians will hit the ground running to raise money for WPCNHF in the 4th Annual Run For Their Lives 5K!

Register online today at Active.com

—Come for the RUN and stay for the FUN!—



National Presenting Sponsor

Registration Check-In Time: 9:00 am

Walk Start Time: 10:00 am

Walk Distance: 5K

Baxter

Join us to support the **Western Pennsylvania Hemophilia Walk!** We will walk to raise critical **FUNDS** and **AWARENESS** for the bleeding disorders community. The event will include: a rock wall, a video game trailer, a gaga pit, a face paint artist, Sheetz Bros. Coffee Truck, WISH 99.7 FM and their "Sweet Treat Patrol," and much more! Register your team today!

For more information, please visit, www.hemophilia.org/walk or contact: Brittani Reed, WPCNHF's Fundraising and Events Manager, at 724-741-6160 or brittani@westpennhemophilia.org.

Board of Directors

PresidentScott Miller, CPA, Esq.

Vice President
Nathan Rost

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DirectorsJoan Reynolds

Jen Smith

Beth Villegas

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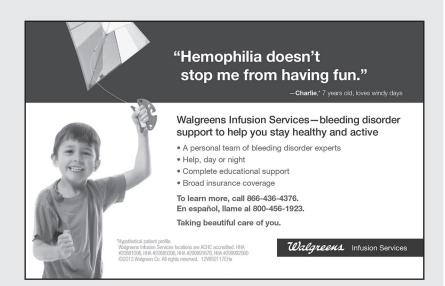
Executive Director
Alison Yazer

Member Services Manager Janet Barone

Bookkeeper & Office Assistant Bud Krapp

Fundraising & Events Manager Brittani Reed

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.



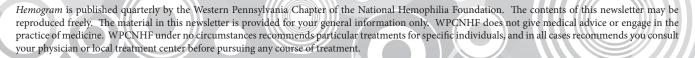
Our Mission:

The Western Pennsylvania Chapter of the National Hemophilia Foundation is leading the way in Western Pennsylvania in improving the quality of care and enriching the lives of those with bleeding disorders through education, advocacy, resource, and referral.

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@westpennhemophilia.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
- Legal pads for note taking
- Sticky Notes
- Forever U.S. Postage stamps
- ◆ 10 x 13 Ready-seal envelopes for newsletter mailings
- Paper towels
- Apartment-sized refrigerator









Join WPCNHF in our 5th Annual Western Pennsylvania Hemophilia Walk. The event will be held rain or shine in North Park on Saturday, September 21, 2013. Everyone is encouraged to attend the Walk! Feel free to bring your dogs, babies in strollers, children, neighbors and grandparents – bring everyone you know! Create your own Walk Team online at http://www.hemophilia.org/walk/. Walk questions can be directed to Brittani Reed at walk@westpennhemophilia.org. We hope to see you there!

Summer Fundraising Ideas

Baxter

- -Used-book sale: Everyone has books that have been sitting on shelves, in the attic or in the basement collecting dust. Ask your friends, family and neighbors to donate books they no longer want and set up a weekend book sale in your front yard during the summer.
- -Lawn Service: While you are mowing your lawn, mow someone else's for a donation.
- -Picnics/BBQ's: Are great places to raise some money. Ask your family & friends to make a donation!
- -Company Vacation/Comp Days: Ask your boss or HR director if they can swap one of your vacation/comp days for a day's pay.
- -Lemonade Stand: Open a lemonade stand for the final weeks of summer.
- -Summer Sports: Hold a 50/50 raffle at the kid's soccer, baseball and swim tournaments.
- -Car Wash: Ask teenagers and little ones to be the washers! Try saying donations accepted instead of charging a set fee.
- -Pet Sit: Offer to pet sit while your family, friends, or neighbors are on vacation this summer.
- -Face Painting: Set up a table at a local summer fair or festival. Kids love it!
- -Pledges for each mile you walk: Ask people to pledge an amount for each mile of the walk. For example, walk three miles at \$50 per mile and you will receive \$150.

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Walk Team T-Shirt Sponsor

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Biotherapies for Life™



Having issues with co-pays or gaps in coverage for your hemophilia A treatment?

We may be able to help.

Bayer offers a range of programs that can help you **navigate insurance questions about your hemophilia A** treatment. If you're having issues with co-pays or gaps in coverage, we may be able to offer assistance. Speak with one of our case specialists to find out more.

Call 1-800-288-8374 and press 1 to speak to a trained insurance specialist!

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Western Pennsylvania Chapter of the National Hemophilia Foundation

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