



**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

SPOTLIGHT ON THE MEMBER: NIKOLE SCAPPE

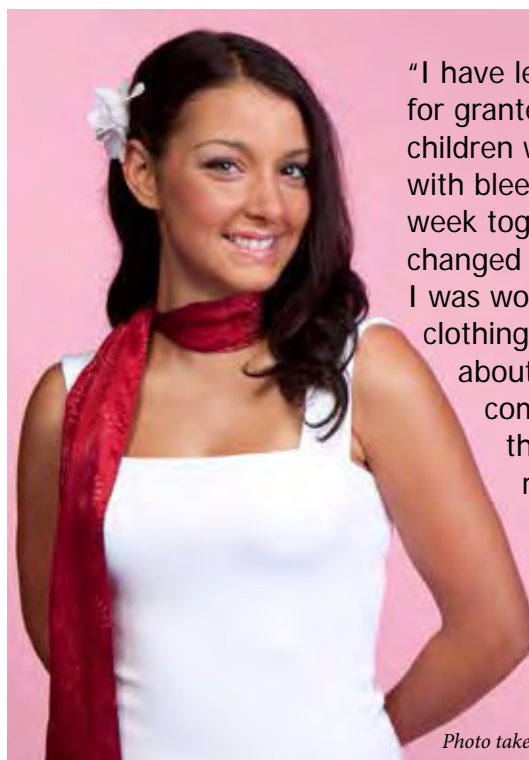
This month our spotlight is on twenty-two year old Nikole Scappe! Nikole is a young, energetic woman who, despite working and attending school, is actively involved in the bleeding disorders community. Nikole, currently lives in Coraopolis, PA and has been steadily involved in the community since she was diagnosed in 2003 with Type 1, severe von Willebrand Disease (VWD). Her mother, two sisters, and two brothers also have VWD. Nikole is in her last semester at the Community College of Allegheny College and will be transferring to La Roche College to major in marketing.

Nikole and her family have attended many educational programs with the Chapter over the years and at a young age, she had quickly become an expert. Just a few years after her diagnosis, she was sitting on a teen panel at a Chapter event, answering

questions for new families about raising children with bleeding disorders. When she was 16 years old, she had a tonsillectomy and woke up during the night with severe bleeding. She said that she and her mom, Kimberly Ebsworth, knew exactly what to do to stop the bleeding. She says that she might not have done so well if it had not been for the educational programs provided by the Chapter. Her mother is a nurse and they have both become experts and share their knowledge with others. Nikole infuses with factor to control her bleeds and says that taking factor allows her to live a normal life.

Throughout the years, Nikole has become involved in areas of the bleeding disorders community outside of the Chapter, and the experiences have had a great impact on her life. She has been a camper and counselor at both Camp Hot-to-Clot (for 10 years) and Camp HemoVon (for 5 years). Nikole says her life was changed when she was a teenager and spent her first week at Camp HemoVon. In her words, "I have learned not to take ANYTHING for granted. At

(Continued on page 12)



"I have learned not to take ANYTHING for granted. At Camp HemoVon, children with cancer and children with bleeding disorders spent the week together. That week completely changed my view on everything. While I was worried about the brand of my clothing, my new friends were worried about being alive the next year to come back to camp. It really put things into perspective and I realized I was meant to work in this community. There is nothing else in this world that gives me as much satisfaction as helping others."

~ Nikole Scappe

Photo taken by: Patrick McMullan

4th ANNUAL TAKE A BOUGH

HOLIDAY TREE AUCTION TO BENEFIT WPCNHF

Planning and preparation for the 4th 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: Anne Graham, Melissa Kendrick, Nora Latcovich, Dawn Rotellini, Diane Standish, Maria Steele Voms Stein, and Laureen Temple.

During the week of November 18-21, volunteers helped transform a former nightclub into a holiday extravaganza by setting up 94 trees, wreaths and tabletop displays donated by individuals and businesses from all over Western Pennsylvania. A huge thank you to Cigna Healthcare for sending 15 volunteers to help unload the U-Haul and set up the space!

From November 22-24, the event was open to the public. Hundreds of people passed through the display throughout the weekend. We even had a special visit from Santa, Mrs. Claus, Rudolph, and Princess the Elf on Saturday! A raffle for a \$500 "Done in a Day" gift card tree was offered for \$5/ticket and was won by Paul Dempsey.

The event ended with a beautiful Donor Reception on November 25, where Val Bias, Chief Executive Officer of the National Hemophilia Foundation, shared stories and inspired the attendees with his encouraging words. Christmas music was sung by the talented Nina Sainato. Brittani Reed recognized all of the sponsors and Alison Yazer shared all of the exciting changes at the Chapter during 2013. Successful fundraisers like Take A Bough allow the Chapter to continue to carry out the mission of improving the quality of care and enriching the lives of those with bleeding disorders in Western Pennsylvania.

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!

The 4th Annual Take A Bough was held at the Shops at Station Square, November 22-25. It was an exciting year for the Chapter, as we raised over \$55,000 after expenses! We are extremely grateful for the donations we received from our Chapter members, our partner organizations and other donors who offered their support.



Letter From The President, Scott Miller

Members and Stakeholders of the WPCNHF,

This has been a great year for the Chapter. Over the past two years, I have become more and more excited about the future of this organization. We continue to grow programs and events while maintaining funding to keep us sustainable in the near term. Our focus now is to look more long-term on funding and programming that will meet your needs.

There were so many different events this year – including 22 different educational opportunities and three very successful fundraisers. Take A Bough continues to

grow each year and has become not only a great fundraiser, but a wonderful awareness campaign, which was part of our original vision. We had over 100 members attend our WinterFest – all having fun and celebrating for the holidays.

Big things are happening at the Chapter and they are all because of and for you. The Board and Staff took note of a need to diversify the geographic locations of events and went to two new areas – Altoona and Washington – both of which offered us a warm welcome. We will continue to reach out to other, previously underserved areas in 2014 and beyond. If you'd

like to see the Chapter offer a specific program in your area, or have ideas for types of events or topics for educational programming, please let us know.

I want to thank you all for your continued support this past year and I wish you all a safe and happy new year. Please remember to watch our event calendar in the newsletter and on our website for future events.

Sincerely,

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

Letter From The Executive Director, Alison Yazer

Dear Members & Friends,

I can't believe that 2013 is already over – and what a year it was for the Chapter! We held 22 educational events covering a broad range of topics in a variety of locations throughout our territory; we held our first ever Women's Retreat which was a huge success; and we hosted three incredibly successful fundraising events which enable the Chapter to continue

providing services to our members free of charge.

While we already have some events planned for 2014, 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? We are only able to meet a

need we are aware of and that's where each of you come in. Please share your ideas with us. Help us help you!

I look forward to seeing you at an upcoming event and wish each of you a happy, healthy 2014!

Sincerely,

Alison Yazer
Executive Director

IHTC Launches Rare Coagulation Disorders Resource Room

The National Hemophilia Foundation (NHF) is pleased to announce the launch of the online Rare Coagulation Disorders Resource Room. The new website, www.rarecoagulationdisorders.org, is a dynamic resource for

individuals with rare coagulation disorders and their healthcare providers.

This website therefore provides current and searchable information on the basic science, clinical management, available laboratory and genetic testing, clinical trials and global research initiatives for these very rare, difficult-to-manage disorders. For instance, on the new site users will find information on factor XI deficiency and combined factor V/factor VIII deficiency.

The international Rare Bleeding Disorders Database (RBDD) Registry, the Indiana Hemophilia & Thrombosis Center (IHTC) and the Rare Coagulation Disorders Subcommittee of NHF, a group appointed by NHF's Medical and Scientific Advisory Council, all collaborated to develop this new resource room.

Calendar of Upcoming Events

Saturday, January 11
Art of Transition
Johnstown, PA

Wednesday, February 26 – Friday, February 28
NHF Washington Days
Washington, D.C.

Sunday, March 2
Bowling for Bleeding Disorders
Neville Island, PA

Friday, March 21 – Sunday, March 23
Family Education Weekend
Seven Springs, PA

Tuesday, April 8
State Advocacy Day
Harrisburg, PA

Saturday, April 26
Infusion Day
Cranberry Township, PA

Saturday, September 13
Hemophilia Walk
Allison Park, PA

Saturday, September 13
Run for Their Lives 5K
Allison Park, PA

Thursday, September 18 – Saturday, September 20
NHF Annual Meeting
Washington, D.C.

Friday, November 21 – Sunday, November 23
Take A Bough
Location 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

FDA Approves TRETEN[®] for the Treatment of Congenital Factor XIII A-Subunit Deficiency

On December 23, 2013, Novo Nordisk announced the US Food and Drug Administration (FDA) has approved TRETEN[®] (Coagulation Factor XIII A-Subunit [Recombinant]) for the routine prophylaxis of bleeding in people with congenital factor XIII (FXIII) A-subunit deficiency, a serious, rare bleeding disorder with limited treatment options. TRETEN[®] is the only recombinant treatment for congenital FXIII A-subunit deficiency. TRETEN[®] was proven safe and effective, offering patients once-monthly dosing with a short infusion time.

Patients with congenital FXIII A-subunit deficiency have a lifelong susceptibility towards bleeding, including spontaneous intracranial hemorrhage. Caused by a lack of the protein clotting factor XIII (FXIII), congenital FXIII deficiency is estimated to occur in one in three to five million births in the United States and affects all ethnicities and both genders equally.¹ As of 2011 estimates, only 1,054 patients are diagnosed worldwide, and approximately 115 live in the United States.² Of those with congenital FXIII deficiency, approximately 95 percent of these patients have a deficiency of the A-subunit.¹

Ask us about sponsorship opportunities and how you can help!

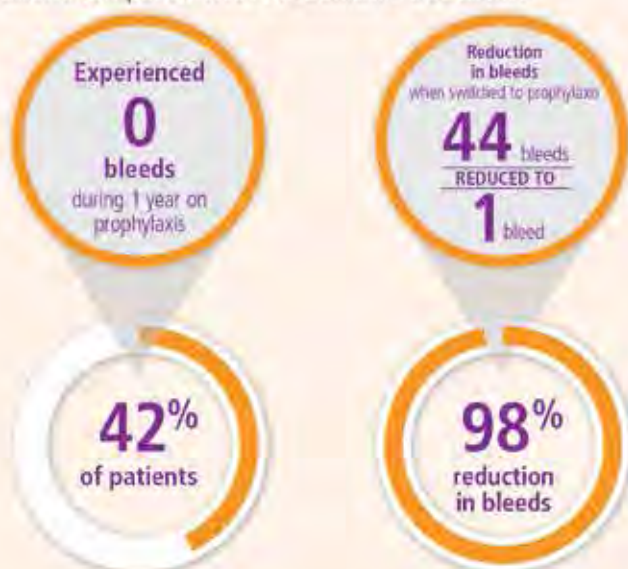
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UNLOCKING SELF-POTENTIAL

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,a}
- **57% reduction** in joint bleeds from 38.7 to 1 after switching from on-demand to prophylaxis^{1,a}
- **No subject developed factor VIII inhibitors** or withdrew due to an adverse event (AE)^{2,a}

^aIn 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:

1. ADVATE Prescribing Information. Westlake Village, CA: Baxter Healthcare Corporation; July 2012. 2. 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]

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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 trace amounts of mouse immunoglobulin G (IgG): 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 $\geq 10\%$ 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).¹

The summary of adverse reactions (ADRs) with a frequency $\geq 5\%$ (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% CI of 0.03 and 2.91% for the risk of any Factor VIII inhibitor development).^{1,2} 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 titer over time and 4 showed repeated but transient elevations of antibodies. 182 treated subjects were assessed for anti-mulG protein antibodies. Of these, 10 showed an upward trend in anti-mulG antibody titer 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 (WVF) 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)* with a Frequency $\geq 5\%$ in 234 Treated Subjects¹

MedDRA 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	Rhinorrhea	15	12	5

* ADRs are defined as all Adverse Events that occurred (a) within 24 hours after being infused 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.

¹ 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.

² MedDRA version 8.1 was used.

Table 2
Post-Marketing Experience

Organ System [MedDRA Primary SOC]	Preferred Term
Immune system disorders	Anaphylactic reaction* Hypersensitivity*
Blood and lymphatic system disorders	Factor VIII inhibition
General disorders and administration site conditions	Injection site reaction Chills Fatigue/Malaise 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 I et 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 antihemophilic 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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CHOP Invests in Spark and Gene Therapy's Future

The Children's Hospital of Philadelphia (CHOP), an institution on the forefront of gene therapy research for more than 20 years, has invested \$50 million in Spark Therapeutics, a biotech start-up company based in Philadelphia. The company will take control of two clinical gene therapy trials that originated at CHOP: a phase III study for inherited blindness caused by mutations of the RPE65 gene and a phase I/II study for hemophilia B. The move marks a significant step in advancing the use of gene therapy to treat diseases by correcting or replacing dysfunctional genes.

Katherine High, MD, has spearheaded much of CHOP's work in gene therapy for the last two decades. She is a Howard Hughes Medical Institute Investigator, the William H. Bennett Professor of Pediatrics at the University of Pennsylvania School of Medicine, and an attending physician at CHOP. High is also the director of CHOP's Center for Cellular and Molecular Therapeutics (CCMT), established in 2004 as a leading center for gene therapy translational research and manufacturing. Many of CCMT's leaders, including High, will take on management roles within

Spark or act as scientific advisors.

"Gene-based medicines are among the most complex therapeutics ever developed," said High. "We at CCMT have persevered through more than a decade of scientific and clinical development and are now closer than ever to realizing the ambitious vision of one-time, potentially curative therapies to address serious genetic conditions. The team at Spark has incredible goals for the treatment of diseases, including hemophilia B and inherited blindness, and we look forward to working with them to deliver groundbreaking new treatments to patients in need."

This partnership follows on the heels of a major breakthrough in gene therapy for hemophilia. In 2011, six hemophilia B patients at the University College London (UCL) Cancer Institute in London were successfully treated with gene therapy. The therapy incorporated the use of adeno-associated viruses (AAVs) as delivery vehicles, or vectors, to carry the genetic codes that trigger the production of the factor IX (FIX) protein, which is deficient in people with hemophilia B. Ideally, AAVs deliver the genetic material into living cells to sustain therapeutic effect without causing disease or triggering significant immune responses. The trial was expanded to eight patients, all of

whom generated increased levels of FIX.

The AAVs for the study were prepared by a team from the St. Jude Children's Research Hospital in Memphis, TN. The patients were recruited and treated with the therapy by investigators at UCL, while study co-author High and colleagues at CHOP have monitored patients for immune reactions.

According to a Spark news release, the company has entered into agreements with multiple academic institutions to assemble the technology, programs and capabilities needed to deliver its pioneering gene therapy products. Spark has exclusive rights to commercialize CHOP's proprietary manufacturing technology and will use clinical-grade gene therapy vectors produced by the CCMT's state of the art good manufacturing practices clinical facility.

Spark Therapeutics develops gene-based medicines for a range of diseases. It has produced AAV vectors for clinical studies for the past 20 years. Its goal is to be the nation's first commercial provider of gene therapy.

Source: The Philadelphia Inquirer and Spark Therapeutics news release, both dated October 22, 2013

Girls Only!

WPCNHF held its first ever Next Steps program on Sunday, October 13. The program, Girls Only!, was specifically for Girls ages 9-16, who have a bleeding disorder or are a carrier, and their mothers or other female caregivers. The program was held in Sewickley, PA, at the Clay Café.

Anne Graham, a nurse from the Hemophilia Center of Western PA, gave an overview on menstruation and bleeding disorders. Diane Standish, a social worker from the Hemophilia Center was also in attendance and contributed to the discussions.

After the presentation, everyone enjoyed painting pottery and spending time together!

Here's what some of the participants had to say:

"It was a fun & educational experience, all wrapped in one. I loved it!"

"I just wanted to thank you for having us at the Girls Only program. My daughter and I had a wonderful time! The program was very informative. After the program we enjoyed making pottery, what a great idea! The Girls Only! program was an excellent idea! Thank you so much for having us."



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500 IU



1000 IU



2000 IU



3000 IU

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.

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* You must be currently covered by a private (commercial) insurance plan. If you are not eligible for the XYNTHA Trial Prescription Program, you may find help accessing Pfizer medicines by contacting Pfizer's RSVP program at 1-888-327-RSVP (7787).

- 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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Printed in USA/September 2012





**Antihemophilic Factor (Recombinant),
Plasma/Albumin-Free**



**Antihemophilic Factor (Recombinant),
Plasma/Albumin-Free**

R_xonly

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 it can harm your baby.

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

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
- vomiting
- 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.

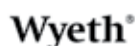
Dispose of all materials, whether reconstituted or not, in an appropriate medical waste container.

What else should I know about XYNTHA?

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

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

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



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Genetic Counseling at HCWP

By: Michelle Alabek, MS, CGC

In September 2012, the Hemophilia Center of Western Pennsylvania (HCWP) hired me as a genetic counselor to provide genetic counseling to patients and their family members. In my role at HCWP, I am able to specialize and focus on the genetics of bleeding and clotting disorders and to provide this service in-house, as part of our patients' comprehensive care. This helps to ensure that our patients and their families continue to have access to the best care possible.

Typically, I meet with patients when they come in for a comprehensive clinic visit. But, I am also available to speak with individuals outside of a comprehensive clinic visit or by phone. It has been a great experience working as part of the HCWP multidisciplinary team and getting to know the individuals and families in this community. I look forward to working with more patients and families in the future. In the meantime, I wanted to share some general information about genetic counseling and my role at HCWP.

Who are certified genetic counselors? (adapted from National Society of Genetic Counselors, 2013)

Certified genetic counselors are health care professionals with specialized training in medical genetics and genetic counseling. They provide information and support to families with a genetic diagnosis and to individuals who may have a chance for having an inherited condition.

What is genetic counseling? (adapted from National Society of Genetic Counselors, 2013)

Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process involves using personal and family medical history to assess the chance of a disease, promoting informed choices and adaptation to a genetic condition, and providing education about inheritance, genetic testing, resources, research and more.

Who may benefit from genetic counseling?

There are many different situations when genetic counseling for a bleeding disorder diagnosis may be useful. Some examples include when an individual:

- Has a personal diagnosis or family history of an inherited bleeding disorder
- Has a suspected diagnosis of a bleeding disorder, which may be confirmed by genetic testing
- Has questions about chances for other family members or offspring to have the same diagnosis
- Is interested in support for communicating with family members about a genetic diagnosis
- Is planning a pregnancy

Some roles of the HCWP genetic counselor include:

- Collect a detailed family history, focusing on bleeding disorders
- Provide education about bleeding disorder inheritance pattern to patients and family members
- Proactively identify individuals in the family who have a chance to have the same diagnosis
- Discuss with an individual his/her chance to have or to be a carrier of a specific bleeding disorder
- Assess whether genetic testing may be indicated for an individual or family members

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The Hemophilia Center of Western Pennsylvania

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

NHF Annual Meeting Grant Winner

Michael Zolotnitsky was the recipient of the NHF Annual Meeting Grant awarded by WPCNHF. Michael, a student in the Doctor of Physical Therapy Program at Chatham University, attended his first NHF Annual Meeting, in Anaheim, CA, in October. Here's what he has to say about his experience.

"My first time traveling to California was an unforgettable experience. Aside from the wonders of missing a four hour lecture on exercise physiology and a three hour research class, I met some extraordinary

people. It began with meeting the first ever hemophiliac to be treated with factor. It was amazing how open he was about his whole life with hemophilia, stating that an infusion gave him hepatitis-C and HIV. He is an inspiring individual who shared many life experiences with me, as well as what he is currently doing in the bleeding disorders community.

Never meeting another hemophiliac until this past July, it was astonishing to see how close people in blood brotherhood programs are. I met hemophiliacs younger than me, my age, and older than me from all over the world. I attended as many physical therapy presentations as I could. My goal is to be a future physical therapist and work with young adults with bleeding

disorders, so I found it helpful to listen to the speakers and take note of various treatment techniques and thoughts on how they treat their patients. I also made connections with the Physical Therapist Working Group program and was told to contact them after I graduate and possibly become involved in their organization.

Overall, my trip was informative, beneficial to my learning, and very interactive. I made new friends, possible future co-workers, and it gave me a larger perspective on hemophilia. I would love to attend another NHF Annual Meeting and am grateful for the pleasant experience."

NHF Annual Meeting

As you read in Michael's article, attending an NHF conference can truly be life changing. With the NHF Annual Meeting being held in our

backyard (Washington DC) in 2014, the Chapter would like to encourage as many members as possible to consider attending. It truly is an experience like no other – the networking and educational opportunities are incredible, and we'd like our members to take advantage! While we don't have details yet, the Chapter is

hoping to provide transportation and hotel accommodations to enable as many members as possible to attend the meeting. Please mark your calendars for September 18th-20th and keep your eyes open for details over the coming months!

LIMITLESS.

The possibilities when you're well cared for.



Participating Tricare Hemophilia Provider

At Biomed Pharmaceuticals, our commitment to the bleeding disorder community doesn't end with **skilled pharmacists, experienced infusion nurses, or dedicated customer service associates.** It continues through education, training, and involvement at the local and national level by Biomed's team of advocates who have extensive experience in the community. Improving the lives of patients and caregivers for a future of unlimited possibilities is our passion.

To learn more about Biomed bleeding disorder programs in Western Pennsylvania, contact **Marty Piper** at **484-431-0909** or **mpiper@biomed-rx.com**.



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SPOTLIGHT ON THE MEMBER: NIKOLE SCAPPE

(Continued from the Cover)

Camp HemoVon, children with cancer and children with bleeding disorders spent the week together. That week completely changed my view on everything. While I was worried about the brand of my clothing, my new friends were worried about being alive the next year to come back to camp. It really put things into perspective and I realized I was meant to work in this community. There is nothing else in this world that gives me as much satisfaction as helping others.” Nikole’s entire family recognizes the importance of summer camp for kids with bleeding disorders. In fact, her family has created the WHES Foundation, which holds an annual Knight at the Races event to raise money for Camp Hot-to-Clot.

Nikole has been involved in several programs with the National Hemophilia Foundation (NHF). From 2009-2012, Nikole served as a member of NHF’s Victory for Women. She was even featured in the Victory for Women calendar, which promoted awareness for women with bleeding disorders. Recently, she has been selected to be part of small Victory for Women task force, along with two other women from our Chapter, Victoria Baker and Maria Steele Voms Stein. This task force was formed to specifically help the Haemophilia Foundation of Nigeria. Nikole and the other women will be assisting the foundation with raising awareness of bleeding disorders in Nigeria.

In 2013, Nikole was also selected to be a member of NHF’s National Youth

Leadership Institute (NYLI). Members of NYLI learn how to become strong leaders in our communities and positively influence others. NYLI gives its members the ability to help not only their local chapters, but people all over the world. Recently, at the NHF Annual Meeting, the National Director of The World Federation of Hemophilia USA, Michael Rosenthal, made a statement that she found very powerful. He was discussing why we should help other countries when we ourselves need help. Mike’s answer was, “That’s what it’s all about folks.” Nikole could not agree with him more. Helping others is what NYLI and this community is all about. She’d like people to think about what an impact it would have on the world and the community, if we all took a little time out of our daily lives to help someone else.

Nikole has made many friends in the community throughout the years. Sadly, she has lost a couple of those friends, too. Recently, one of her friends and fellow campers, Rebecca Seelinger, age 18, lost her life in a tragic car accident. Four years ago, her best friend, John Eyrolles, who she had met years ago at camp, also lost his life in a tragic car accident. Nikole is responding by creating a program to help educate teenagers about driving safely. She wants to share her stories with youth to show them that whether they are a driver or a passenger, it’s so important to be safe. Sometimes circumstances out of one’s control can lead to an accident. However, she wants young people to think about the potential consequences of activities that can be avoided, such as reckless driving or texting while driving. Nikole is committed to continue to do whatever she can to help prevent tragedies like these from happening again.

Nikole considers her friends in the community to be her second family. She feels she’s been fortunate enough to meet and learn from some of the greatest leaders to ever come along in this community. She hopes to take a little from everyone she meets and use their knowledge to better the community and lives of others.

In addition to her involvement with bleeding disorder camps, NHF’s Victory for Women, and NYLI, Nikole has been active with the Chapter at a local level. She has volunteered for fundraising events including the Hemophilia Walk, Take A Bough, and Mixers with Shakers. She has also volunteered at the Family Education Weekend, and she has participated in the Chapter’s annual advocacy day in Harrisburg, to advocate for people with bleeding disorders.

Nikole advises others, especially new families, to remember that you are not alone! Be sure to attend ALL of the Chapter’s functions. She says that even if you can’t financially support your Chapter, consider donating your time and sharing your experiences.

When Nikole isn’t busy volunteering in the bleeding disorders community, she enjoys spending time with family and friends, dancing, playing disc golf, and generally being outdoors. Nikole is also a dance teacher and a bartender. She feels blessed to be able to help so many children, parents, and families over the years. There’s no doubt that Nikole will continue to help numerous people, as she is well on her way to becoming a strong leader in this community!

Hero Initiative

Novo Nordisk is pleased to announce the latest video in a series showcasing outcomes from the US Hemophilia Experiences, Results, and Opportunities (HERO) Summit for Solutions. The video, titled “The HERO Initiative: Improving Understanding of the Burden of Hemophilia on Families,”

explores how the disease can affect the entire family in different ways, such as emotionally, financially, and professionally. The video series provides insight into the key factors that may drive change, and each video is composed of interviews conducted with several key hemophilia stakeholders as they discuss potential takeaways from the data.

To watch the video, go to <https://www.youtube.com/watch?v=YJTD3HVMxU8>. For more information about the HERO initiative, visit <http://www.changingpossibilities-us.com/inhibitor/hero.aspx>.

Meet The HCWP Staff



Kathaleen Manns

Kathaleen Manns is a Pittsburgh native. She attended Point Park University where she obtained her Bachelor's in English Literature and Journalism Communications with a minor in dance. Kathaleen worked in the social services field primarily with persons having developmental, intellectual, and cognitive challenges from all age populations. She attended the University of Pittsburgh where she obtained her Master's in Social Work. After graduation, Kathaleen worked as a site coordinator for a program that helped empower local individuals to find employment, housing, insurance, and other resources that encouraged independence. When the agency exited the Pittsburgh community, Kathaleen returned to working as a therapist and behavioral specialist for children and their families. Outside of work, Kathaleen is an avid reader and writer, as well as active with dance classes, running, camping, and hiking.



Cheryl McShea

Cheryl (Cheri) McShea attended the University of Pittsburgh where she obtained her Bachelor's Degree in Physical Therapy. Over the next several years, she worked as a PT in acute care, inpatient rehabilitation, outpatient and home care. Cheri then had the opportunity to lead quality teams, develop specialty programs in wound care, pulmonary rehab, and cardiac rehab, participate in the design and implementation of interdisciplinary electronic medical records and to manage interdisciplinary rehab teams. She recently obtained her Doctorate degree in Physical Therapy from Chatham University, and is looking forward to being involved with the research projects at HCWP. Outside of work, Cheri enjoys traveling, exercise, and reading.



Judith Kadosh

Judith Kadosh joined the research team at HCWP in June. An experienced research nurse, Judith worked at the University of Pittsburgh for 10 years before joining HCWP. Her focus was on epidemiological research including longevity in families, cardiovascular disease, healthy aging and the National Children's Study. Judith also brings to HCWP a background in quality improvement both in research and managed care. A native of Pittsburgh, Judith is a graduate of the University of Pennsylvania School of Nursing. A mother of two, outside of work, Judith is also an active volunteer in her community.

Genetic Counseling at HCWP

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- Discuss genetic testing options, including risks, benefits and limitations
- Coordinate the genetic testing process, including communication of test results
- Help to facilitate communication between patient and family members regarding diagnosis and genetic testing results
- Discuss prenatal and pre-implantation testing options, when appropriate
- Communicate with other health care providers about genetics of bleeding disorders
- Assist with HCWP research studies that involve genetics or genetic testing

If you have any questions or are interested in more information about genetics or genetic counseling, please feel free to contact me at 412-209-7292.

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



"Hemophilia doesn't stop me from having fun."
—Charlie, 7 years old, loves windy days

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Walgreens Infusion Services

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

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