



**Western Pennsylvania
Chapter of the National
Hemophilia Foundation**

Summer 2012 Inside this issue

Chapter News.....	1
Letter from the President	2
Calendar of Events	3
Industry News.....	7
Spotlight on the Member	8
A note from HCWP	9
National News.....	11
Chapter Board and Staff.....	15

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

Family Fun at Education Weekend in Seven Springs, PA

Over 160 family members gathered the weekend of April 27, at Seven Springs Mountain Resort, for a weekend packed with education, camaraderie, and good times! Not only was it nice to welcome back so many returning families, but it was also great to have some new Chapter members join us, as well as some long-time Chapter members who attended the event for the very first time.

Whether an attendee was an adult with a bleeding disorder or a parent of a child with a bleeding disorder, there was something for everyone. In addition to general topics, such as Dental Care for people with bleeding disorders, there were also targeted breakout sessions included topics such as

Pre-employment Inquires, Pain Management, Calming Techniques for Adults & Children, Hepatitis C Updates, Challenges and Resources for older patients, and, of course, informational sessions and question/answer sessions on von Willebrand Disease and Hemophilia. Besides the educational track for the adults, educational programs and fun activities were held for children in

Continued on page 6



Being a Good Consumer: Knowing the Rules

By Dawn Rotellini, Director of
Chapter Development & Training,
NHF

Over the past few months I have received several calls regarding NHF's position and guidelines regarding Industry relationships with patients.

We understand our industry partners are important to both Chapters and patients. While we do not have guidelines to offer Chapters, NHF follows the law and we recommend that Chapters follow the same path.

The relationship that Industry (pharmaceutical companies and homecare companies) has with patients has evolved over the past several years. This is due to changes in laws, regulations and oversight that

Continued on page 7

Letter from the Executive Director, Jennifer Wahlen Pegher

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 future educational programs and fundraisers and I hope you plan to join us this summer for some of these great events.

Family Education Weekend took place in April and proved to be a great success and our annual golf classic took place in May and though we had fewer golfers in 2011, it seemed to be a great day. Thanks to our planning committees for all the hard work, both on Family Education Weekend and the Driving for Bleeding Disorders golf classic.

Last month, we welcomed our summer intern, Brittani Reed. Brittani joins us from Slippery Rock University in Slippery Rock, PA and she is proving to be a valuable asset to the Chapter as she helps us build a Twitter page, and liven up our Facebook page. When you see Brittani this summer please give her a warm welcome.

Included in this issue are a variety of articles and invitations that will help you and your family. I hope you take the time to apply for the NHF annual

meeting travel grant or the Junior National Championship event, consider attending one of our great educational groups or dinners coming up, or read more about healthcare reform. Each item included in this newsletter provides a great opportunity for you to learn more about your bleeding disorder. Additionally, I hope you take the time to read the article penned by the National Hemophilia Foundation's (NHF) Director of Chapter Development and Training, Dawn Rotellini. Over the years, Chapter members have asked staff, both at NHF and WPCNHF about appropriate versus inappropriate conduct between consumers and industry. This article provides great detail as to what is and is not appropriate behavior. Please consider these points when interacting with industry and remember the importance of being a good consumer.

As always, please contact the staff of WPCNHF with any 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.

Sincerely,
Jennifer Wahlen Pegher
Executive Director

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

Letter from the President, Scott Miller

Dear Chapter Members and Stakeholders,

What a wonderful Spring! Family Education Weekend was a great success! I want to thank the staff, volunteers, presenters, sponsors, and participants for their part in allowing us to provide such high quality programming as well as good camaraderie. Additionally, moving our golf tournament to May was met with great interest by the golfers and we look forward to next year's continuation of this wonderful event. Events like this help us raise the much needed resources to deliver our high level programs and services.

As summer kicks in, please remember to mark your calendars for the Annual Meeting on July 19 at PNC Park. This year we are 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 15 to help us meet our mission. We are excited about the new venue for the Annual Meeting at PNC Park as it will provide a great location for our business meeting and an opportunity to interact with others in the community.

The Chapter has also planned plasma safety educational sessions on August 21 and 22 at two different locations. This new program is a good addition to the variety of programs we deliver throughout the year. We have begun delivering much of our communication through email to reduce mailing costs; however it is our goal not to create "spam" email, but to deliver high quality content and communication tailored to your individual interests and needs. Please

watch your email for announcements related to our programs and events that might be of interest to you.

In response to your desire to continue to help the Chapter, we have begun including pledge cards with our newsletter. If you are interested in volunteering in any way (or for more information on how you might be able to help), please contact the Chapter office.

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

Sincerely,
Scott E. Miller, CPA, Esq.
WPCNHF Board President

Calendar of Upcoming Events

Thursday, July 19, 2012
Annual Meeting/Walk Kickoff
PNC Park Lexus Club
Pittsburgh, PA

August 5-11, 2012
Camp Hot-to-Clot
Camp Kon-O-Kwee
Fombell, PA

August 7, 2012
WPCNHF Women's Group Kickoff
TBD

August 21 and 22, 2012
Plasma Safety Dinner (2 locations)
TBD

Saturday, September 15, 2012
Hemophilia Walk
Harmar Grove at North Park
Allison Park, PA

Saturday, September 15, 2012
3rd Annual Run for Their Lives
Harmar Grove at North Park
Allison Park, PA

Saturday, September 29, 2012
Men's Group at Pirates Game
PNC Park
Pittsburgh, PA

Saturday, October 13, 2012
Oktoberfest
Erie, PA

November 8-10, 2012
NHF Annual Meeting
Orlando, FL

November 16-19, 2012
Take A Bough Holiday Tree Auction
TBD

SAVE THE DATE FOR THE 2ND ANNUAL RIDE FOR THEIR LIVES DICE RUN

***HOSTED BY THE UNGER FAMILY,
WPCNHF CHAPTER MEMBERS***

All proceeds benefit WPCNHF

When: Saturday, September 9, 2012
Where: Fairway 12 Restaurant and Lounge in
Conneaut Lake PA

Registration begins at 9:30 a.m.
The last motorcycle/vehicle will go out at 12:00 p.m.

The Ride will be approximately a 100 mile round trip including 4-5 stops along the way for a dice roll. The Ride will end back at Fairway 12 at 5:00 pm for prizes, Chinese auction, dinner buffet, drinks and fun!

Please contact Alicia Unger at ak_unger@yahoo.com for more details.



Ask us about sponsorship opportunities and how you can help!

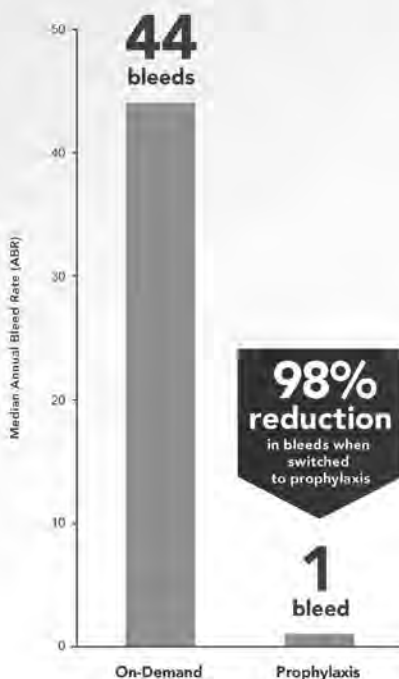


ADVATE IS THE ONLY RECOMBINANT FACTOR VIII (EIGHT) THAT IS FDA APPROVED FOR PROPHYLAXIS IN BOTH ADULTS & CHILDREN (0-16 YEARS)^{1,2}



PROPHYLAXIS WITH ADVATE

THE POWER TO REDUCE YOUR ANNUAL BLEED RATE (ABR)



ADVATE
[Antihemophilic Factor (Recombinant),
Plasma/Albumin-Free Method]
There's more to life.
advate.com | 888.4.ADVATE

Significant reduction in ABR¹

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:

- **Median ABR of 1** while on either prophylaxis regimen¹
 - prophylaxis every second day (20-40 IU/kg)
 - prophylaxis every third day (20-80 IU/kg, targeted to maintain FVIII trough levels ≥1%)
- **42% of patients experienced zero bleeds** during 1 year on prophylaxis¹
- **No subject developed factor VIII inhibitors** or withdrew due to an adverse event (AE)⁴

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 people with hemophilia A. Your healthcare provider may give you ADVATE when you have surgery.

ADVATE is not used to treat von Willebrand Disease.

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.

Please see Brief Summary of ADVATE Prescribing Information on the adjacent 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; December 2011. 2. Helixate FS prescribing information. Kankakee, IL: CSL Behring LLC; August 2009. 3. Kogenate FS prescribing information. Tarrytown, NY: Bayer Healthcare LLC; March 2011. 4. Valentino LA, Mammon 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.

Baxter and Advate are registered trademarks of Baxter International Inc.
©Copyright (May 2012), Baxter Healthcare Corporation. All rights reserved. HYL7583

TALK TO YOUR HEALTHCARE PROVIDER TO SEE IF PROPHYLAXIS WITH ADVATE CAN HELP REDUCE YOUR ANNUAL BLEED RATE (ABR)

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, Monitoring Laboratory Tests]

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 (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)* 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 any Adverse Event that occurred within 24 hours after being infused with investigational product OR all Adverse Events assessed related or possibly related to investigational product OR 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 ¹ Hypersensitivity ²
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

¹ 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 (AHF-PFM) from six clinical studies in patients with hemophilia A. Expert Opin Biol Ther 2009 9:273-283. 2. Tarantino MD, Collins PW, Hay FW 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 hemophilia A. Hemophilia 2004 10:428-437.

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

Baxter, Advate, Baxject and Recombinate are trademarks of Baxter International Inc. Baxter, Advate and Baxject are registered in the U.S. Patent and Trademark Office.

Patented under U.S. Patent Numbers: 5,733,873; 5,854,021; 5,919,766; 5,955,446; 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.

Baxter Healthcare Corporation, Westlake Village, CA 91362 USA

U.S. License No. 140 Printed in USA Issued December 2011

Baxter

Family Fun at Education Weekend in Seven Springs, PA

Continued from page 1

four different age groups. Full daycare service was also provided for children ages 4 and under, so that all parents would have the opportunity to learn and network with other families.

We received overwhelmingly positive feedback from the families that attended. (Note to participants: We reviewed all of your comments, and want you to know that, yes, there will be chicken nuggets next time!) Here's what some of the families had to say about the weekend:

- Very informative and enjoyable weekend.
- Loved it, the family had a blast and it was very fun and full of knowledgeable topics!
- It was a good weekend, I learned a lot and I'd like to attend again.
- Thank you for a fantastic event!
- Thank you for having this Family Weekend. This was a wonderful learning experience and I had a lot of fun meeting all the other families. I can see great things come of this!
- Your hard work is appreciated!
- This was my first Family Weekend. It was great!
- Thank you for all the time and planning that went into this weekend.
- Very well planned programs. It's good to see those you haven't had contact with for a while and it's good to discuss how everyone is handling their problems and learning new things.
- We had a wonderful time! Thank you so much.

We would like to offer a special thank you to our Planning Committee members, Karen Slater, and Kristen Jaworski.



Welcome to WPCNHF's Summer Intern, Brittani Reed

Brittani Reed has joined the Western Pennsylvania Chapter of the National Hemophilia Foundation this summer to complete a 300 hour internship for college credit. Brittani is a senior at Slippery Rock University dual majoring in Communication and Professional Studies with an emphasis in Non-profit Leadership. She will be graduating in December. During her internship at WPCNHF, Brittani seeks to learn valuable skills that she will use throughout her career in the non-profit sector. She hopes to obtain a job after she graduates where she can assist with fundraising and special event planning. Brittani would ultimately like to start her own nonprofit organization in the future.

Being a Good Consumer: Knowing the Rules

Continued from page 1

government agencies have seen as corrective action. What were they correcting? In the old days, you might say, things were just fine... many companies took care of needs that a patient or family might have because they were on their service (for homecare companies) or because they used that particular factor product (for manufacturers). What was wrong with that practice? The government began to view this as inducement to get business by the companies.

Whether or not you feel that the laws are justified, the fact is they are in place now and they help to regulate the actions of companies and how they interact with patients. The Office of the Inspector General of the United States Department of Health and Human Services (OIG) regulates the behavior of manufacturers and homecare companies through Advisory Opinions. While traditionally, manufacturers of factor products have been held under more stringent guidelines than homecare companies, that has also changed over time.

Focusing on manufacturers, they cannot give any items or support of monetary nature directly to patients or potential patients. Manufacturers are also regulated on how they do business with doctors, nurses, social workers, etc. They are regulated by federal and state laws. These laws are changing constantly – recently pharmaceutical companies have stopped providing pens and sticky pads and other giveaways with their logos on them at our Chapter meetings due to these changing laws. Currently, any item that is not “medically based” can be construed as inappropriate. (Have you noticed the lack of pens and sticky notes??)

In terms of homecare companies, in September 2002, the OIG issued an Advisory Opinion #02-14 regarding the provision of certain free goods to individuals with hemophilia. This Advisory Opinion was drafted in response to a request by a home infusion provider seeking guidance on the legality of providing free “safety related” goods to hemophilia patients. In addition, a Special Advisory Bulletin was offered by OIG to homecare companies on “offering gifts and other inducements to beneficiaries”.

So what does this mean to you the patient or to the companies? Here are some simple questions and answers found on the OIG’s website that may help:

1. Why were the Advisory Bulletin and the Advisory Opinion issued? To give healthcare providers and suppliers a better general understanding of the provisions of the federal Anti-Beneficiary Inducement Regulation. Safety items mentioned include, among other things, helmets, kneepads, medic alert bracelets, and pagers.
2. What items can a home infusion company provide to hemophilia patients for free? The monetary value will dictate, not the description of the item, what is and is not legal to be given to a patient. Items of “nominal” value do not violate the federal Anti-Beneficiary Inducement Regulation and the Anti-Kickback Statute. The limits of “nominal” value are set at **\$10 per individual item and no more than \$50 worth of items per individual per year**. The Advisory Opinion does specifically prohibit the provision of pagers to patients because they exceed this set financial limit.
3. My homecare company has been paying for me to go to regional or national education meetings such as HFA or NHF Annual Meetings. Does this violate the policies? **YES! As long as the support or gift value of more than \$10 per item or \$50 per year per person, it is not legal under OIG’s guidance.** The regulation prohibits gifts or payments in order “to induce patients” to select a particular supplier or provider of healthcare items or services.
4. What are the consequences if I or my homecare company break this law? Fines of up to \$10,000 per violation for the homecare company or supplier. If it is determined that the Anti-Kickback Statute was violated, fines, exclusion from Medicare and Medicaid and, criminal sanctions including jail sentences could be invoked upon a party giving or receiving prohibited remuneration.

Again, NHF understands the relationship Chapters have with industry partners are a vital part of success in doing business. There are ways that homecare and manufacturer companies can provide things like travel funds for patients to attend meetings; the company can donate as a charitable contribution to a Chapter to send patients/families to an Annual Meeting, but the company cannot dictate to Chapter which patient/family gets chosen.

Ultimately it is up to all of us to follow the rules and regulations that are in place, not just the companies. After all, we want to continue the positive relationships we have with these companies and not jeopardize the future of their support.

Spotlight on the member: Kim Ebsworth

Kim Ebsworth, of Moon Township is a woman in our community living with Type I von Willebrand Disease (vWD). Kim is married to Eb and has 5 children, ages 22, 21, 13, 8, 6. Kim and her family have been members of WPCNHF for many years and have encouraged other Chapter members to support WPCNHF's efforts. Her favorite WPCNHF event is the Family Education Weekend. In her spare time, Kim enjoys reading, dance, comedy, and bonfires.

Kim is the founder of the WHES-L Foundation, an organization whose mission is to provide assistance where needed in the

bleeding disorders community. Kim was diagnosed with vWD at the age of 35. She would bleed for 6 months after giving birth to each child. Kim also hemorrhaged severely when she had a miscarriage. For her, a bloody nose always ruined a fun time.

If she had to offer an advice to individuals living with bleeding disorders she would recommend that they take the bad experiences and turn them into something positive. She said it is important that individuals living with bleeding disorders reach out to our community without hesitation as "we are here for each other."

She would also like to encourage her fellow Chapter members to join the WHES-L Foundation next spring for the second annual Night At the Races - Derby Style. There, you will enjoy food and tons of fun while raising money for Camp Hot-To-Clot.

Kim has worked tirelessly on behalf of the community to educate both diagnosed and undiagnosed patients and the Chapter is grateful for her efforts. She would like to dedicate this acknowledgement of her hard work to the memory of her best friend, Jen Kmetz, who passed away unexpectedly on June 15.

Gettin' In the Game Junior National Championship 2012

To celebrate the 11th anniversary of the Gettin' In the Game Junior National Championship, CSL Behring is combining the four regional competitions into one national competition to be held in the Dallas/Fort Worth, Texas region. Chapters throughout the U.S. are invited to nominate two participants each- one for golf and one for baseball. During the program, educational sessions will be available for parents and caregivers, and nominees will have the opportunity to:

- Participate in a clinic where they will learn the fundamentals of baseball or golf and enhance their skills in either sport.
- Learn about the importance of physical fitness.
- Show off their baseball or golf abilities in a national competition with fellow participants from around the country.

Pro golfer Perry Parker and baseball players Jesse Schrader, Ivan Sada, and Peter Dyson, each of whom has a bleeding disorder, will host the program.

The event will take place September 21-23, 2012. Attendees will stay at the Dallas/Fort Worth Marriott Hotel and Golf Club at Champions Circle, located 25 minutes from the airport. One hotel room will be offered per participant and meals will be provided on site. CSL Behring will sponsor each Chapter selected nominee and one accompanying adult to participate in the program. The sponsorship includes coordination and cost of airfare, ground transportation in Dallas/Fort Worth, and hotel arrangements. Attendees will be responsible for transportation to and from their hometown airport.

Nominees must be 7-18 years of age and have a bleeding disorder to apply. When applying please submit the following information:

- Name
- Gender
- Age/Date of Birth
- Bleeding disorder (Hemophilia A, Hemophilia B, von Willebrand disease, other)
- Parent/Caregiver Name
- Address
- City/State/Zip
- Phone number
- Parent email address
- In 250 words or less please tell us why you would like to be nominated for the 2011 Gettin' In the Game.

Deadline to apply is Friday, August 3.
Late entries will not be accepted. Nominees will be selected by Monday, August 6. Applications can be submitted by email to info@westpennhemophilia.org or by mail to WPCNHF, 20411 Route 19, Unit 14, Cranberry Township, PA 16066.

A message from Margaret Ragni, M.D., M.P.H. at the Hemophilia Center of Western Pennsylvania:

Effective July 9, 2012, the NEW on-call number for hemophilia/von Willebrand disease/bleeding/ or clotting disorders is 1-888-990-HCWP. Patients should use this number for urgent problems that occur evenings or weekends, when the Center is closed.

Please note: The current phone number listed on any Medical ID bracelet or necklace does not need to be changed at this time. If medical personnel call that number, they will be transferred to the new number.

A Great Day for Golf!

The 8th Annual Driving for Bleeding Disorders Golf Classic was held Monday, May 14 at Treesdale Golf and Country Club in Gibsonia, PA.

Nearly 75 golfers participated in the event on what started out to be rainy but turned into a wonderful golf day. Various contests were available on the course; including but not limited to, a putting contest, Beat the Pro contest, men's and women's longest drives, and a 50/50 on the green contest. All participants had a great time trying their hand at one or all contests. Aaron "The Maneater" Mansfield, currently ranked 4th in the World for Long Drive competitors, was our "Pro" to beat. He added some friendly challenges to the course and raised additional money for the Chapter. Congratulations to Rick Walton, Chuck Kolias, Dave Kirkham, and B.J. Prassinios for finishing first in the tournament. WPCNHF would like to thank the golf planning committee for their efforts. Committee members were as follows: Erik Drotos, Rita Dull, Sam Rotellini, Nathan Rost, Rick Walton and EJ Villegas. Please look for more information in future newsletters about the 2013 Driving for Bleeding Disorders Golf Classic.





WHO:

An expected 100+ Western Pennsylvanians will hit the ground running to raise money for the Western Pennsylvania Chapter of National Hemophilia Foundation.

WHAT:

Western Pennsylvania's 3rd Annual Run For Their Lives 5K. Information about the race, including how to register, is available at <http://www.active.com/running/allison-park-pa/run-for-their-lives-5k-2012>.

WHEN/WHERE:

Saturday, September 15, 2012
Harmar Grove, in North Park (near the swimming pool) in Northern Allegheny Co.
Registration begins at 7:30 a.m. Race begins at 8:30 a.m.

WHY:

Hundreds of Western Pennsylvanians live with bleeding and clotting disorders. Hemophilia in particular can cause internal bleeding into the joints, resulting in pain and swelling and, if left untreated, can lead to permanent damage. More than ever before, improvements in care and therapy are allowing people with serious bleeding and clotting disorders to live better, fuller lives. But there's more work yet to be done.

All of the funds raised through the Run For Their Lives 5K race will remain in Western Pennsylvania. Those funds will be used to support educational programs and patient assistance offered to all families living with bleeding disorders in Western Pennsylvania.

WHAT CAN YOU DO:

1. Participate in Run For Their Lives 5K as a runner
2. Ask your family and friends to run in the race.
3. Come cheer on the runners and stay for the Walk.

CONTACT:

Madonna McGuire Smith
Western PA Chapter of NHF
(724) 741-6160
madonna@westpennhemophilia.org



WESTERN PENNSYLVANIANS LACE-UP THEIR WALKING SHOES TO BRING ATTENTION TO SERIOUS BLEEDING AND CLOTTING DISORDERS

WHO:

An expected 500 Western Pennsylvanians, including friends, family and supporters of those affected by hemophilia and other serious bleeding and clotting disorders will be Walking.

WHAT:

Western Pennsylvania's 4th Annual Hemophilia Walk. Information about the Walk, including how to register and donate, is available at www.hemophilia.org/walk.

WHEN/WHERE:

Saturday, September 15, 2012
Harmar Grove, in North Park (near the swimming pool) in Northern Allegheny Co.
Registration begins at 9:00 a.m. Walk begins at 10:00 a.m.

WHY:

Hundreds of Western Pennsylvanians live with bleeding and clotting disorders. Hemophilia in particular can cause internal bleeding into the joints, resulting in pain and swelling and, if left untreated, can lead to permanent damage. More than ever before, improvements in care and therapy are allowing people with serious bleeding and clotting disorders to live better, fuller lives. But there's more work yet to be done.

The Hemophilia Walk will raise funds to find better treatments and cures for bleeding and clotting disorders, and to prevent the complications of these disorders through awareness, education, advocacy and research. The Western Pennsylvania Walk is one of a series of Hemophilia Walks that will take place around the country.

2012 WALK GOALS:

- *Raise \$60,000
- *Have 40 registered fundraising teams
- *Each team raises \$1,000
- *Raise \$20,000 in local sponsorships

WHAT CAN YOU DO:

1. Register as a Walker or register a team (www.hemophilia.org/walk).
2. Ask your family and friends to support you.
3. Walk with us on Walk Day.
4. Help spread the word about the Walk to others.
5. Join us for the Walk Kickoff on July 21.

CONTACT:

Madonna McGuire Smith
Western PA Chapter of NHF
(724) 741-6160
walk@westpennhemophilia.org

WE NEED YOUR HELP!

An excerpt from The Commonwealth Fund Blog

State Health Insurance Exchange
Legislation: A Progress Report
By Sara R. Collins and Tracy Garber

The Affordable Care Act requires each state to establish by 2014 a new health insurance marketplace or “exchange” where individuals and small businesses can purchase affordable health insurance plans. The exchanges are the centerpiece of the reform law: they will be the main portals where people without employer-sponsored health insurance will go, either in person or online, to both find a health plan and learn about and apply for any federal subsidies for which they are eligible. The Congressional Budget Office estimates that by 2020, 22 million people will enroll in health plans offered through their state exchange.

In order to establish an exchange, states must give themselves the legal authority to do so. State legislatures can accomplish this by crafting and passing legislation for their governors to sign. In the absence of state legislation, governors in some states may pursue other mechanisms to give them the authority to establish and operate an exchange, such as an executive order. In states that do not opt to run their own exchanges, the federal government will operate a “federally facilitated exchange” in their state. But according to new guidance released by the Department of Health and Human Services last week, within the federally facilitated exchange, states may also choose a “state partnership exchange” in which they would operate exchange functions related to plan management and/

or consumer assistance.¹

HHS’s new guidance also gives states until November 16, 2012 to submit an “Exchange Blueprint” that will lay out how they intend to operate their exchanges, or whether they are electing to participate in a state partnership exchange.² HHS will grant approval to states to run their own exchanges by January 2013. HHS may grant conditional approval of an exchange if a state is at an advanced stage in the development of their exchanges but cannot demonstrate complete readiness by January 2013. In addition, states that do not have exchanges ready for operation in 2014 may apply to operate the exchange in 2015 or in subsequent years.

Legislation introduced in one or both houses, but did not pass. Legislators in three states introduced legislation in 2011 to establish exchanges that ultimately failed or died because of adjournment (light purple) (Oklahoma, Pennsylvania, and Texas). While governors and legislatures in some states with 2011 failed bills have continued pursuing other legislative or gubernatorial options in the 2012 session, there has been no similar activity in these three states. The Texas legislature meets every other year and was not in session this year. Legislation introduced in the 2012 session in nine states, Alaska, Arizona, Georgia, Idaho, Iowa, Minnesota, Nebraska, New Mexico, and Virginia, has died due to adjournment.

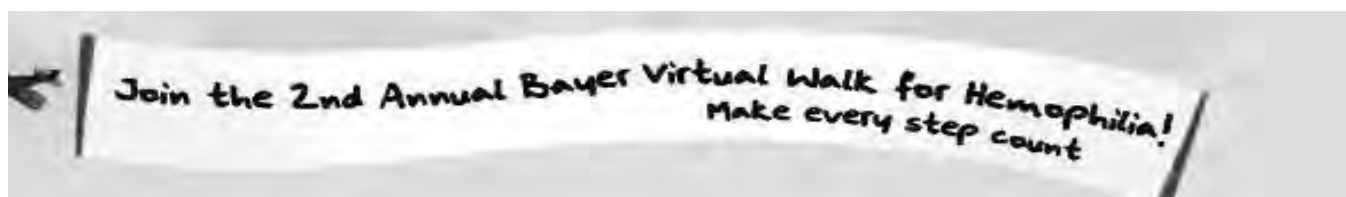
Looking Forward

This year is critical for states that have not

passed legislation, given that they must submit their Blueprint applications to HHS by November 16. While two states with exchange bills that are pending or passed (Ohio and Michigan) have legislatures that meet all year round, time is even shorter for many states. Legislatures in 27 states have already adjourned for the year and more will adjourn in May, including Missouri, where an exchange bill is pending, and Alabama, where an exchange bill passed one house. Two states with exchange bills pending or passed (New Hampshire and North Carolina) end their legislative sessions in July. It is possible other states may follow the example of Kentucky’s governor, who has indicated that he would issue an executive order to establish an exchange if the Supreme Court upholds the Affordable Care Act.

Planning for the exchanges continues apace in most states across the country, many of which do not have signed legislation in place. HHS has so far awarded 34 states and the District of Columbia multimillion dollar grants to establish their exchanges (Exhibit 2). HHS awarded Rhode Island and the state of Washington Level II establishment grants for more advanced exchange planning.

The Commonwealth Fund continues to update this blog post and the accompanying maps as implementation of the state insurance exchanges moves forward across the country. Visit <http://www.commonwealthfund.org/> for updates.



We want to announce the 2nd Annual Bayer Virtual Walk for Hemophilia! This year, the top 5 participating local NHF chapters with the most virtual walkers will receive sponsorship funds, as follows:

1st place - \$15,000, 2nd place - \$10,000, 3rd place - \$5,000, 4th place - \$2,500, 5th place - \$1,000.

WPCNHF has the opportunity to receive these sponsorship funds and we need your help. Joining the Virtual Walk for Hemophilia is as easy as 1-2-3! Participants simply need to:

1. Visit www.WalkForHemophilia.com
2. Create a virtual character and choose a message.
3. Select WPCNHF!

Bayer will also award up to \$30,000 to the National Office of the NHF in New York City, and up to \$7,000 to the Save One Life Foundation. To join the Virtual Walk, visit WalkForHemophilia.com.

NHF Annual Meeting Educational Grants

Educational Grants Available for NHF's 64th Annual Meeting – “Mapping Our Future”

The Western Pennsylvania Chapter of the National Hemophilia Foundation is pleased to offer Educational Grants for the National Hemophilia Foundation's 64th Annual Meeting, “Mapping Our Future,” in Orlando, Florida, November 8-10, 2012. Florida is one of the most popular destinations, as many attendees extend their visits to vacation in Orlando, taking in all the city has to offer.

During this yearly three-day gathering, you can be sure we will keep you busy, with educational sessions to attend, networking opportunities with others experiencing similar issues, and social events that help you unwind. The Activity Program for Kids & Teens will take a field trip to SeaWorld Orlando to enjoy thrilling rides, educational exhibits, animal shows and a chance to see everybody's favorite killer whale, Shamu. Universal Studios Orlando will open its gate for our Final Night Event. What could be more fun than a theme park at night?

A sneak preview of sessions includes:

- “It's a Guy Thing, Too: Men with von Willebrand Disease”
- “I Don't Need a Support Group—I have Facebook!’ Risks and Rewards of Life Online”
- “The Glass is Half Full: Reframing Emotional Challenges for Women”
- “Head, Shoulders, Knees and Toes! Exploring the Pros and Cons of Protection Devices, such as MedicAlert, Pads and Helmets.”

Eligibility

WPCNHF wishes to support individuals and/or families with bleeding disorders to attend the National Hemophilia Foundation Annual Meeting. Grant recipients will be determined through an equitable selection process conducted by a volunteer review team. Applicants who attended within the last four (4) years will not be considered.

What the Educational Grants Cover

Grants will cover the following:

- Airfare or Mileage/transportation to & from the airport in Chicago
- Hotel
- Annual Meeting Registration Fees

How to Apply for Educational Participant Grants

Fill out attached application and return to the WPCNHF office, postmarked no later than August 20, 2012.

Application Deadline

Letters must be postmarked by Monday, August 20, 2012.

Where to Send the Application

Western Pennsylvania Chapter of the National Hemophilia Foundation
20411 Rt. 19, Unit 14
Cranberry Township, PA 16066
ATTN: NHF Annual Meeting Educational Grants



“Mapping Your Future”

Orlando, FL

November 8-10, 2012

Application for Educational Grant to attend NHF Annual Meeting

Please fill out the following application and return it to the Chapter office, postmarked no later than August 20, 2012

Name: _____ Age _____

Address: _____

Phone: Home _____ Cell _____ work _____

How are you related to the person affected with a bleeding disorder:

Self _____ I am the parent _____ Spouse _____ Other(explain) _____

Name and age of affected person if not self: _____

Type and severity of bleeding disorder: _____

Please read and sign the following:

1. I have read the Application Guideline and understand the way grants are awarded and that if I win I will be responsible for any cost NOT LISTED on the grant guideline as being covered.
2. I agree to volunteer at one chapter event in the next year if I am awarded this grant.
3. I agree to write a short newsletter article describing my experience for the chapter newsletter if I am awarded this grant.
4. I understand that if I do not attend the meeting or fail to give a valid excuse I may be asked to reimburse the Chapter for all expenses incurred on my behalf.

Print your name _____

Signature _____ Date _____

Please answer the questions on the other side. Your application will be disqualified if you do not answer the questions.

Please answer these questions in the space provided or you may attach a separate page.

Have you ever been to an NHF Annual Meeting? If yes, how long ago did you attend? (applicants who attended within the last four years will not be considered)

Explain what type of bleeding disorder you or your family is affected by, how it has impacted your life/lives, and what you hope to gain by attending the NHF Annual Meeting.

SAVE THE DATE AND SEND YOUR CAMPER TO CAMP HOT-TO-CLOT THIS AUGUST!



Registration for Camp Hot-to-Clot is now available to Chapter members and other affected individuals living in Western Pennsylvania.

Who: Camp Hot-to-Clot is for boys and girls ages 7-17 with hemophilia and Von Willebrand Disease (vWD). Siblings and children of those with bleeding disorders are also welcome. There is a Leader in Training Program throughout the week at Camp for boys and girls ages 15-18 who show leadership qualities.

When: Camp Hot-to-Clot will take place from August 5 through August 11, 2012.

Where: Camp Hot-to-Clot takes place in Fombell, PA at Camp Kon-O-Kwee/Spencer, a YMCA camp.

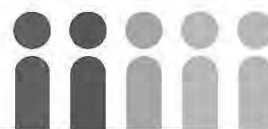
Why: Children will enjoy supervised activities such as hiking, fishing, swimming, and arts and crafts throughout the week. Not only will your child form lifelong bonds with their fellow cabin mates, but they will learn skills that will last them a lifetime. Don't delay- register today!

How: Register your child today by visiting <http://www.ecampfiresoftware.com/>

If you need a paper application, please call 412-209-7284.

Learn. Explore. Connect With Our Hemophilia Community on **Facebook.**

Our Hemophilia Community



Find us on **Facebook.com/OurHemophiliaCommunity**

Board of Directors

President

Scott E. Miller, CPA, Esq.

Vice President

Mike Covert

Treasurer

Sam Rotellini

Secretary

Jana Lambert

Directors

Joan Reynolds

Beth Villegas

Judy Carmassi

William Martin, DDS, FAES

Nathan Rost

Directors Emeriti

Jim Loll

Missy Unkovic

Staff

Executive Director

Jennifer W. Pegher

Office Administrator

Janet Barone

Development Director

Madonna McGuire Smith

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.

Walgreens

Hemophilia Care at Home

- Local Pharmacies
- Hemophilia-Trained Nurses and Staff
- Nationwide Services
- Patient Support 24/7

For comprehensive services

Call: 866-436-4376 or

Fax: 888-688-3593

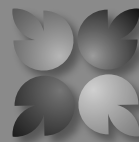
En Español: 800-456-1923

WalgreensHomeCare.com/bleedingdisorders

We're proud to be working with



Western Pennsylvania Chapter of the
National Hemophilia Foundation



Multi Print Media

connect.impact.succeed.

For all of your marketing needs.

www.multiprintmedia.com

412-875-9004



Sign up today

— FOR A —

**FREE TRIAL
PROGRAM**
FROM BAYER HEALTHCARE

***Enroll today for up to
SIX FREE DOSES OF FACTOR****

For more information,
visit **BayerFreeTrial.com**
or call **1-866-329-3449**

(Monday through Friday, 8:30 AM - 5:30 PM, ET).

©2012 Bayer HealthCare Pharmaceuticals Inc. All rights reserved.
BAYER and the Bayer Cross are registered trademarks of Bayer. 02/12 KN10000212

* SUBJECT TO APPROVAL.
TERMS AND CONDITIONS APPLY.

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.



Western Pennsylvania Chapter of the National Hemophilia Foundation

20411 Route 19, Unit 14
Cranberry Township, PA 16066

Phone: 724-741-6160

Toll Free: 800-824-0016

Fax: 724-741-6167

info@westpennhemophilia.org

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