Hemogram

Western Pennsylvania Chapter of the National Hemophilia Foundation

Spring 2014

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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**

BOWLING MARATHON TO BENEFIT WPCNHF

The Western Pennsylvania Chapter of the National Hemophilia Foundation Strikes Out Bleeding Disorders

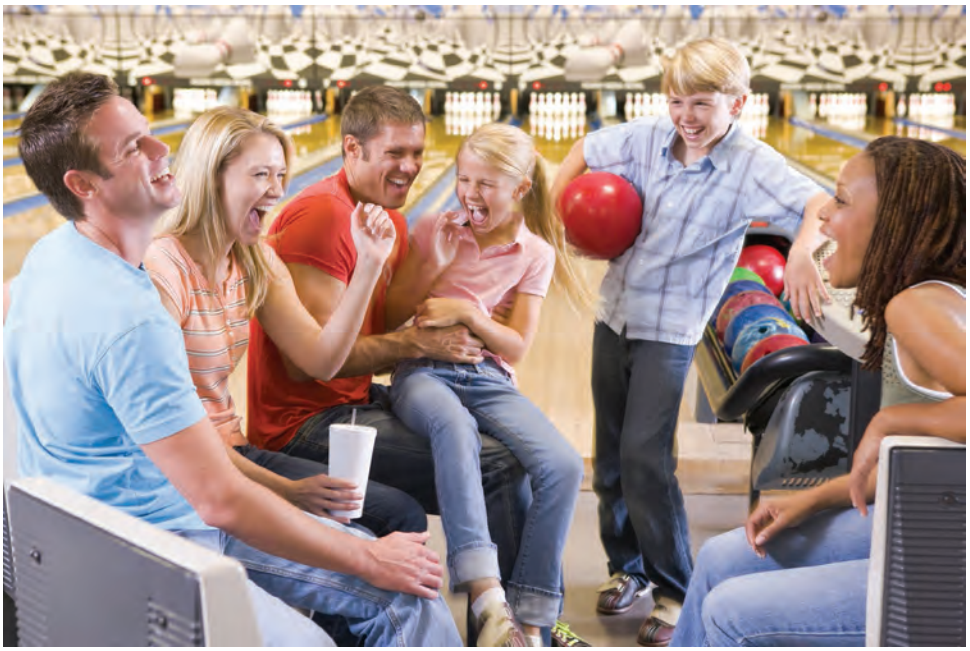
Starting on January 31, 2014 participants were given their own team fundraising page and asked to raise $1,000. After a cancellation due to weather, the 30 day fundraising campaign ended on Sunday, March 9, 2014 with WPCNHF's 2nd Annual Bowling for Bleeding Disorders bowling marathon.

Bowling for Bleeding Disorders was once again held at Paradise Island Bowl in Neville Township, Pennsylvania. This year, 14 teams bowled for three hours. The event was open to the general public and quickly sold out! The cost to bowl was $25 per participant which included shoe rental, bowling, pizza, wings, and unlimited soft drinks.

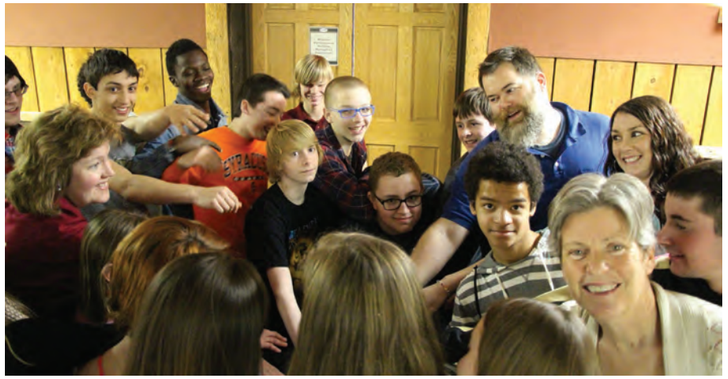
Trophies were given out during the event to the highest scoring and lowest scoring bowler and team and also to the highest fundraising team. The highest fundraising team award went to Gino's Gutter Gang who raised $700! Way to go!

Nearly 80 people attended the event. The sponsors of the event included Baxter, CSL Behring, the Hemophilia Center of Western Pennsylvania, Novo Nordisk, Grifols, Accredo, BioRx, and Pfizer. Over $16,000 was raised to benefit the Western Pennsylvania Chapter of the National Hemophilia Foundation.

WPCNHF would like to thank all who attended and participated in making the 2nd Annual Bowling for Bleeding Disorders a success.



FAMILY EDUCATION WEEKEND



There was a lot of energy at the Family Education Weekend this year! The event was held at Seven Springs Mountain Resort and there were approximately 160 family members in attendance, ranging from infants to people in their 80's!

The weekend education program began the evening of Friday, March 21, 2014, with vendor exhibits and dinner. Following dinner, the program kicked off with the opening session, Leading Edge: Gaming the System. This fun, engaging workshop was facilitated by Pat Torrey, an internationally recognized facilitator and trainer known for his powerfully engaging programs. Pat was able to show us how understanding different personality types and being resilient and creative can help us change our community and our health outcomes. The Leading Edge program was generously sponsored by Pfizer.

While the adults participated in the opening session, children ages 5-12 enjoyed some recreational time together and the teenagers began the first phase of their weekend program. Pat Torrey also designed an experiential training program to help our teens develop self-confidence, awareness and understanding of individual power, as well as develop personal responsibility for one's self. Throughout the program on Friday and Saturday, important life lessons were taught through fun games and unique experiences. Pat developed a parent segment for this program and on Saturday morning the parents first attended an interactive session with other parents of teenagers and then joined their teens in a dynamic parent/teen session.

The agenda for Saturday morning was categorized by Life Stages. There were educational programs for parents of infants, toddlers, and preschoolers; parents of school-age children; parents of teenagers; and adults with bleeding disorders— truly something for everyone! During the afternoon, there were general breakout sessions and new this year: two Ask the Doctor sessions. Saturday's program for the adults concluded with an opportunity to participate in two of three activities that have many health benefits and are generally safe for most people with bleeding disorders: Dance, Chair Yoga, and Strength Training with Resistance Bands.

The children's programs were full of fun and educational activities throughout the day. Young children learned how to "infuse" stuffed animals with toy medical kits and instruction from nurses from the Hemophilia Center of Western PA. Nurses from Children's Hospital of Pittsburgh presented an interactive hospital discovery program for young children and taught first aid to older children. The children also learned about the blood clotting process through creative games that were sponsored by CSL Behring. In addition, children participated in a Jr. Scientist program and a program called My Amazing Blood, which concluded with the children making yummy "blood sundaes!" The latter two programs were sponsored by Accredo. In addition, some of the children created cards for Project SHARE, a humanitarian program that donates factor to patients in developing countries. The children also enjoyed mini-golf, bowling, games, and crafts.

The Family Education Weekend concluded on Sunday morning with breakfast and the program Positive Assertiveness, sponsored by Biogen Idec. It was wonderful to see many families return from the 2012 Family Education Weekend and to have some families join us for the first time!

We have received many positive comments about the weekend and would like to thank members of the planning committee for their help with planning the agenda, identifying potential speakers, and for their willingness to speak and volunteer at the conference: Karen Slater, Diane Standish, LSW, Anne Graham, RN, and Kathaleen Manns-Schnur, MSW, LSW. We would also like to recognize and thank our volunteers who helped keep the children and teen programs running smoothly: Nikole Scappe, Melissa Kendrick, Jessica Graham, and Airin Roby. In addition, we like to thank nurses Anne Graham and Anna Dracar, from the Hemophilia Center of Western PA for being available throughout the weekend!

Of course, the Family Education Weekend would not be possible without generous support from our industry sponsors. We would like to thank the following for sponsoring educational programs:

- Baxter
- Bayer
- Biogen Idec
- CSL Behring
- Hemophilia Center of Western PA
- Novo Nordisk
- Pfizer

We would also like to thank the following companies for supporting the conference with Exhibit Displays and sharing their information with our members:

- Accredo
- Affinity
- Baxter
- Bayer
- Biogen Idec
- Biomed Pharmaceuticals
- BioPlus
- BioRX
- Coalition for Hemophilia B
- Cottrill's Pharmacy
- CSL Behring
- CVS/Caremark
- Factor Support Network
- Grifols
- Hemophilia Center of Western PA
- Novo Nordisk
- Octapharma
- Pfizer
- Walgreens

Letter From The President, Scott Miller

The first few months of the year have already been filled with some great programs and events. I am thankful for the work of all of our staff: Alison, Brittani, Janet, and Kara. They work tirelessly to improve this Chapter and to provide superior service to our members.

We just held our first of three fundraisers for the year – our 2nd Annual Bowling for Bleeding Disorders – which was very successful. Despite having to delay it a week due to a snowstorm, we still had over 70 bowlers and raised over $14,000 – more than a 100% increase over last year! Bowlers came from several hours away to support your chapter. It's so exciting to see this kind of growth – and lots of new faces – at events such as this, which are not only fundraisers, but awareness builders as well!

This year, you will see an increased effort to expand programing across our entire geographic territory. Since coming on the board, I have been passionate about serving our entire territory, which covers 26 counties, and the staff and Board are supportive of this vision. Therefore, as you see programs in your area, please take advantage of them and show your support for our efforts. You will continue to see an expansion in topics as well as geography. To that end, please feel free to contact Alison or Janet with any ideas you have for programs – what types of educational programs do you want to see us offer? We would love to hear from you with your thoughts and ideas of what we might do to fulfill our mission of making your lives better through education, advocacy, resource and referral.

As the sun begins to shine and summer approaches, I am looking forward to another wonderful year as the Chapter continues to serve our community. As always, feel free to contact the office with any questions or concerns you have. We are here to be a resource for you; therefore, you should never hesitate to call.

Sincerely,

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

Letter From The Executive Director, Alison Yazer

Dear Members and Friends,

I hope that our Spring newsletter finds you and your family well (and that the snow has FINALLY stopped for the season!). I keep waiting for us to hit our "quiet period," but with the continuous planning of fundraisers and events, it looks like we aren't getting one – which is a good thing for our members! We've already held several events and our first of three fundraisers for the year and we're still busy planning – upcoming events include our 3rd Annual Infusion Day in conjunction with the HCWP nurses and staff, our first joint Men's & Women's Group meetings, our Annual Meeting, the Walk and so much more!

This year, the NHF Annual Meeting is practically in our backyard – Washington DC – from September 18th-20th. Please keep your eyes out for a scholarship application for you and your family to attend this incredible event. We are hoping to send as many members as we can to this weekend-long educational and social event.

As always, please contact the staff of WPCNHF with any questions, concerns or suggestions. We can only meet your needs if we know what they are!
Thank you for all that you do on behalf of the bleeding disorders community.

Sincerely,

Alison Yazer
Executive Director

If you recently purchased insurance through the Marketplace and didn't sign up for automatic payments, be sure to pay your premiums to ensure continuous coverage!

Calendar of Upcoming Events

Tuesday, April 8
State Advocacy Day
Harrisburg, PA

Saturday, April 26
Infusion Day
Cranberry Township, PA

Thursday, May 1
Hemophilia A & Inhibitors
Homestead, PA

Saturday, May 10
Men's Group
Pittsburgh, PA

Saturday, May 10
Women's Group
Pittsburgh, PA

Thursday, May 15
Healthcare Reform
Robinson 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.

Wednesday, November 19 – Saturday, November 22
Take A Bough
Oxford Centre, Pittsburgh, PA

Combined Federal Campaign

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

WPCNHF CFC Number is: 81343

Ask us about sponsorship opportunites and how you can help!

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 (MulgG): maximum of 0.1 ng/IU ADVATE and hamster proteins: maximum of 1.5 ng/IU ADVATE. Patients treated with this product may develop hypersensitivity to these non-human mammalian proteins.

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

Neutralizing Antibodies

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

Monitoring Laboratory Tests

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

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

ADVERSE REACTIONS

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

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

Clinical Trial Experience

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

ADVATE has been evaluated in five completed studies in previously treated patients (PTPs) and one ongoing study in previously untreated patients (PUPs) with severe to moderately severe Hemophilia A (Factor VIII ≤ 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 ≥ 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 mulgG protein antibodies. Of these, 10 showed an upward trend in anti-mulgG 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)[a] with a Frequency ≥ 5% in 234 Treated Subjects[b]

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

[a] 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.

[b] 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.

[c] MedDRA version 8.1 was used.

Table 2
Post-Marketing Experience

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

[a] 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 antihaemophilic factor prepared using a plasma/albumin-free method: pharmacokinetics, efficacy, and safety in previously treated patients with haemophilia A. Haemophilia 2004 10:428-437.

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

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Navigating Patient Assistance Programs.

With the uncertainty of healthcare, many in the bleeding disorders community are concerned about the future cost and access to factor products. Co-payments and out-of-pocket expenses can result in a large chunk of a family's monthly budget. Many manufacturers of factor products have co-pay assistance programs that can provide a source of relief.

Manufacturer	Co-pay/Co-insurance Program Name and Contact Information	Notes
Bayer	Kogenate FS Co-pay/Co-insurance Assistance Pilot ProgramBayer Factor Solutions1-800-288-8374	• Must have Hemophilia A • Must have private health insurance • <400% FPL; eligible to receive up to $6,000 in financial assistance • >400% FPL; eligible to receive up to $500 in financial assistance • Must first contact Bayer's Factor Solutions to apply
Baxter	Hemophilia Co-pay/Co-insurance Assistance Pilot Program (facilitated by Patient Services, Inc)Patient Services, Inc.1-800-366-7741	• Must meet financial criteria for enrollment • FPL is set at 400% • Must have private health insurance • Funds can only be used toward patient's out of pocket expenses for Baxter hemophilia products • Apply online via PSI's website
CSL Behring	Corifact Co-Pay ProgramCaring Voice Coalition1-888-267-1440	• Must have Factor XIII deficiency • Must currently be using Corifact • Must have health insurance (public or private plans acceptable • Must meet income guidelines
Pfizer	Pfizer RSVP Co-Pay ProgramPfizer1-888-327-7787	• Must meet income eligibility requirements • Must not have public health insurance, may have private insurance
Novo Nordisk	SevenSECURENovo Nordisk SevenSECURE1-877-668-6777	• Must have hemophilia with inhibitors, Factor VII deficiency, or acquired hemophilia
Grifols	AlphaNine SD Savings Card ProgramGrifols1-85-355-2574	• Must have hemophilia with inhibitors, Factor VII deficiency, or acquired hemophilia

For those in the bleeding disorder community who are uninsured, underinsured, or experiencing lapses in insurance coverage, there are also assistance programs to help families facing financial strain to get access to factor products:

Manufacturer	Product Assistance ProgramName & Contact Information
Bayer	Bayer Factor Solutions - 1-800-288-8374 www.livingwithhemophilia.com www.kogenatefs.com
Baxter	CARE Program - 1-888-229-8379 https://nava.baxter.com/nava/redirectThereForYou.jsp
CSL Behring	Patient Assistance Program(Factor Assistance) - 1-800-676-4266 Assurance Program (For lapses in private health insurance) - 1-866-415-2164 www.allaboutbleeding-us.com
Pfizer	RSVP - 1-888-327-7787 Factor Savings Card - 1-888-240-9040 www.hemophiliavillage.com
Novo Nordisk	SevenASSIST - 1-877-668-6777 www.Changingpossibilities-us.com
Grifols	Grifols PatientCare Program - 1-888-325-8579 www.grifolspatientcare.com

Exercise and Menstrual Cramps

Article courtesy of HemAware
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Heating pad. Salt and vinegar potato chips. TV remote control. These creature comforts help many women get through that time of the month while they're curled up on the couch. But there is a better way to ride out the bloating, cramps and nausea that often accompany periods. The answer is just a walk, bike ride or yoga class away.

Cramps 101
Every month, the lining of the uterus, or endometrium, builds up to prepare for pregnancy. If the egg released by the ovaries is not fertilized, this thickened endometrium is shed. "At the time of the period, the arteries clamp down and there's a sloughing of the tissues that had built up during the second half of the cycle," says Michelle Warren, MD, professor of medicine and obstetrics & gynecology at Columbia University Department of Medicine in New York City. "Women with bleeding disorders may continue to ooze from those small arteries; therefore, their periods may be very heavy." Prolonged, heavy periods are called menorrhagia.

As the old lining starts to break down, hormone-like substances called prostaglandins are released. Prostaglandins cause smooth muscles in the uterus to contract, restricting the flow of blood and oxygen to the endometrium, which dies. These muscular contractions, or cramps, squeeze the dead endometrial tissue, the menstrual flow, through the cervix and out through the vagina.

Cramps usually begin a day before the first day of menstruation and peak the next day. They can be felt in several areas—the abdomen, lower back, hips and thighs. Cramps range from mild to severe, with pain that feels dull, sharp, continuous or intermittent. How strong the cramps are may be linked to the amount of prostaglandins and leukotrienes, chemical messengers that cause inflammation and trigger contractions, her body produces. It may also be a function of nerve stimulation. "There are innervations to the uterus that will cause cramping," says Warren.

For women with dysmenorrhea, or painful periods, it's important to rule out other conditions. Causes of secondary dysmenorrhea include ovarian cysts, pelvic inflammatory disease, endometriosis and uterine fibroids. (Read "A Difficult Combination," HemAware: hemaware.org/story/difficult-combination.)

Pain relief the natural way
The feel-good chemical in your brain, called an endorphin, is produced by the pituitary gland and hypothalamus when you exercise. Endorphin, or "endogenous morphine" (morphine produced in the body), is the natural version of morphine, the opiate pain reliever. "It increases the threshold at which you feel pain," Warren says. Endorphin also improves your mood and gives you a sense of well-being. That's why marathoners can become mileage junkies, logging in long runs and experiencing the so-called "runner's high."

So it makes sense that if you can do something physically to produce more endorphins, it's bound to take your mind off your body. You don't have to be an ultra-marathoner, though. Even 30-minute exercise segments can provide a positive effect.

Exercise options
Gentle stretching of the lower back or abdominal muscles might spell relief. "You're providing a different sensory input to that area, so it might help to alleviate some of the sensation of the cramping," says Deb Voss, PT, ATC, CSCS, of the Hemophilia Center of Western Pennsylvania in Pittsburgh. "Low back PT exercises include knee-to-chest exercises and lower-trunk rotation." Progressive muscle release—starting at your head or feet and tensing, then relaxing different muscle groups—might also help with cramps.

Certain yoga poses can help women dealing with painful cramps. A 2011 study in the Journal of Pediatric Adolescent Gynecology showed that pain intensity and duration were significantly lower in approximately 100 adolescent women with primary dysmenorrhea who performed the cat, cobra and fish poses. Plus, there's the added benefit of mindful meditation and focused breathing. "With yoga, you have the whole mind-body connection," Voss says. "Helping to relieve stress and strain, and letting go of some physical tension may help."

Aerobic exercise, in which your body uses oxygen for fuel, elevates your heart rate and breathing. It helps improve blood flow throughout your body and refocuses your thoughts. "Involving yourself in an exercise program can be very helpful," Warren says. "If exercise were a pill, I'd give it to everybody."

But with your body feeling like one big throbbing cramp, it's probably best to refrain from vigorous exercise during your period, say experts. "Women may not feel they're able to even develop the energy to do high-intensity activity," says Voss. Instead, some women may prefer light hiking, walking or swimming, she says.

So next time you're hit by a wave of menstrual cramps, stash the junk food and grab the leash. You and your four-legged friend will both benefit from a brisk walk.

FDA Approves New HIV Drug

Article courtesy of HemAware
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When the US Food and Drug
Administration (FDA) approved Tivicay® (dolutegravir), a new drug to treat HIV, in August 2013, it gave patients a new option for suppressing the virus. Tivicay is a 50-mg pill recommended for adults and children 12 years old and older in combination with at least two other HIV drugs. It is manufactured by Viiv Healthcare, a company established in 2009 by GlaxoSmithKline and Pfizer.

Tivicay advantages
Tivicay is in a class of HIV drugs called integrase strand transfer inhibitors (INSTIs). "They work by inhibiting integrase, a key enzyme that's used to integrate the HIV RNA into the HIV DNA," says Paul Sax, MD, director of the HIV program and the Division of Infectious Diseases at Brigham and Women's Hospital in Boston and professor of medicine at Harvard Medical School. By blocking HIV from inserting its genetic components into a person's cells, the virus cannot make more copies of itself, and chronic infection is prevented. The new drug must be taken daily and should never be stopped without consulting one's physician.

Tivicay is the third INSTI to get the go-ahead from the FDA, following elvitegravir in 2012, approved as part of a quad (four-drug combination) therapy, and raltegravir in 2007. It has a distinctive edge over other INSTIs in that it is well tolerated, can be taken with or without food, and, for some patients, is a once-daily pill. Unlike other INSTIs, it is less likely to cause drug resistance. It also doesn't require a boosting agent, such as cobicistat or ritonavir, which are used with other HIV medications.

Clinical trial results
During the multicenter international Phase 3 trials of Tivicay, 2,557 adults were tested. In two of the four clinical trials, the drug was given with two different nucleoside reverse transcriptase inhibitors (NRTIs), which block the action of reverse transcriptase, an enzyme HIV needs to reproduce. By combining drugs from different classes, HIV is prevented from mutating and then producing new strains that are resistant to the drugs. The goal of HIV therapy is to decrease a patient's viral load in the blood to undetectable levels.

The findings that are more relevant for people with hemophilia and HIV come from the SAILING trial of 719 adults, all of whom had failed their current therapy but had never taken an integrase inhibitor. They were divided into two groups. In addition to their background single or combination regimen, one group received 400 mg of raltegravir twice daily; the other received 50 mg of Tivicay once daily. After 24 weeks of treatment, 79% of the subjects in the Tivicay group were virologically suppressed, meaning they had fewer than 50 copies of HIV-1 RNA per cubic milliliter in their bloodstream. This was statistically significant compared with the raltegravir group, in which only 70% were virologically suppressed.

Possible side effects
Overall, patients experienced few side effects from Tivicay in clinical trials. The most common were insomnia and headache. Because dolutegravir can affect liver enzymes, patients with hepatitis B or C are encouraged to have blood tests for liver toxicity prior to and during treatment.

Tivicay is contraindicated for patients who take dofetilide, an anti-arrythmia drug, because it can increase concentrations in the blood, causing life-threatening events.
Safe for patients with hepatitis C

Patients with bleeding disorders who have HIV and hepatitis C most likely will be candidates for Tivicay. "The drug looks very promising for this group because it does not interact with medications that are currently used for treating hepatitis C," says Sax. "While increased rates of liver toxicity occur with all HIV medications in people with HCV, this drug does not appear to be particularly harmful to the liver." If you're interested in taking Tivicay, ask your hematologist or hepatologist if the drug is right for you.

Spotlight on the Member: Stacy McCarthy

"I was pregnant with my first child is when I found out I was a carrier. I was also diagnosed with VWD at this time, and with no known family history of this, I had no idea what VWD even was. My Ob-Gyn told me that my factor levels were so low that if I was having a boy that I should consider terminating my pregnancy! I went through amniocentesis and found out I was having a girl. Can you imagine if I didn't know anything about hemophilia and followed the doctor's suggestion?"

Knowing she was a carrier, and with a family history of hemophilia, Stacy McCarthy knew there was a chance her son would have it, so when he tested negative at birth, she was incredibly relieved. However, over the next 18 months, several incidents made her doubt the accuracy of Will's initial diagnosis – a circumcision that wouldn't stop bleeding, large hematomas from relatively minor bumps, etc. Every time, the pediatrician would have an explanation that made Stacy doubt her own instincts. After all, with Will having two older sisters, it wasn't as if he was her first child and she was just over-reacting to his injuries! At 18 months, while visiting family in Erie, Will was finally diagnosed with moderate Hemophilia B. Looking back, though, Stacy thinks it's probably a good thing she wasn't aware of Will's diagnosis before he learned to walk because she may have been tempted to bubble-wrap the entire house – or Will!

The first major bleeding incident Will had was when he was about 22 months old and he wanted a pickle. After opening the refrigerator, he helped himself to the large jar of pickles and promptly dropped it on his toe! Stacy, who was home visiting her family and had no factor with which to treat Will, called the Hemophilia Center of Western PA, who connected the family with a home health care company that was able to deliver factor and treat Will quickly, even though the McCarthy's weren't registered or signed up with them. It was then that Stacy realized how tightly-knit the bleeding disorder community truly is, and how willing people within the community were to help out – no matter what.

Stacy says that the biggest challenges they faced when Will was first diagnosed

was not knowing what they didn't know and not knowing what questions to ask in order to learn. Stacy found that the hematologist they saw where they lived when Will was first diagnosed wasn't particularly helpful, and it wasn't until they returned to Erie and Will was treated at the HCWP that they began to get the answers they were looking for. Additionally, the advances in treatment since Stacy's brother was growing up with hemophilia made things more confusing for her since what she knew was no

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Art of Transition

On Saturday, January 11, 2014, WPCNHF held the Art of Transition program in Johnstown, PA. This was the first time that the Chapter held a program in that community and five families from the area attended. This program was sponsored by Biogen Idec. The speaker, Christine Rowe, a mother of a child with a bleeding disorder, shared her personal stories with the group. The program covered topics including the stages of transition, the importance of the treatment process, transition in the school system, and how to encourage independence. We thank Biogen Idec for helping the Chapter bring this program to Johnstown.

If there's a program that you would like the Chapter to bring to a community near you, please call the Chapter at 724-740-6160 or send an e-mail to info@westpennhemophilia.org.

Hepatitis C Treatment Update

Anne Graham, RN

An estimated 4 million people in the U.S. are infected with Hepatitis C virus (HCV). The present standard therapy has a sustained virologic response (SVR) of 60% to 78%. (The SVR indicates an undetectable viral load or a clearing of the virus.) However, present medications used to treat HCV have a long duration of treatment (up to 48 weeks) and a high incidence of adverse events.

A new drug called sofosbuvir, recently approved by the FDA, when used in combination antiviral treatment, achieves a higher SVR (84 to 90 %) while shortening the duration of treatment and, for some types of HCV, eliminates the need for the medication causing the most adverse events. A concern with sofosbuvir is the cost- about $1000 per pill, and the cost for 12 weeks of treatment is $84,000. Some regimens require 24 weeks of treatment.

Another new medication with projected FDA approval in November, 2014, called declatasvir, when used with sofusbuvir, has also been shown to have a higher SVR with shorter duration of treatment in most patients. This includes patients with no response to prior therapy.

The staff at the Hemophilia Center will be discussing these treatment options with you at your next comprehensive clinic appointment. Please do not hesitate to call us for any questions or to schedule your appointment.

The Living Memorial

Article courtesy of LA Kelley Communications

Committee of Ten Thousand (COTT) has reached out to the bleeding disorder community for over 23 years, participating in collaborative efforts to benefit those with hemophilia. In recent years, COTT has focused its efforts to build a "living memorial" to those we have lost far too early to HIV/AIDS and hepatitis C, and for the families and friends who remember them today.

The Living Memorial project is not an attempt to rekindle the fires of controversy this tragedy symbolizes, but its mission is rather to celebrate the lives of the men, women, and children we miss every day—people who, through their sacrifice, have made factor VIII and factor IX safer for all of us.

Clotting factor VIII and IX concentrates were developed in the late 1960s and became available for home use in the early 1970s. For people with hemophilia, like me, who were born in the 1950s when only fresh frozen plasma was available to stop bleeding, factor concentrate was a miracle drug: first, to halt a bleeding episode, and ultimately, through prophylaxis, to prevent bleeds from occurring. Immediate infusion of factor minimized joint damage due to hemorrhaging, and led to increased mobility and less pain, so that people with hemophilia could lead a more normal life. Factor concentrates allowed many of us to treat at home instead of visiting emergency rooms every time we had a bleed. And factor opened a world of new possibilities to attend college, travel, and—most of all—become more independent.

Starting in the late 1970s through the mid-1980s, about half of our community became infected with—and many later succumbed to—HIV/AIDS and hepatitis C. Those who survived began a life-and-death struggle. By 1990, with the inception of COTT, a different kind of battle began: a battle for the truth, seeking to expose how factor manufacturers had allowed contaminated plasma to be used in manufacturing factor VIII and IX. The importance of this fight cannot be overstated. To this day, COTT labors to make sure an accurate history remains, always with the mindset that safety is paramount so that every generation can enjoy the benefits of factor without fear of blood-borne viruses.

The original founders of the COTT board were all infected with HIV, and most were also infected with hepatitis C. Most of them knew that inevitably they would succumb to AIDS or liver failure from hepatitis C. Nevertheless, they made great efforts to ensure that factor products became "cleaner" for future generations. Though their lives were shortened, their legacy was lengthened, as they became pioneers in blood safety. This legacy included working with government regulatory agencies such as FDA to establish more stringent regulations that protect the blood-product consumer today. As a community, we owe a debt of gratitude to all of these people, living or deceased, for their tremendous commitment and selfless efforts on our behalf to ensure safer factor products.

We must not forget the lessons of the past. COTT is working toward building the Living Memorial to honor those who died, and to give their families and friends a place to visit and reflect on our fallen heroes. The Living Memorial will have greater significance if the entire hemophilia community embraces the idea that all of us—past, present, and future—are in this struggle together, living with hemophilia and remaining vigilant that blood products are safe. Bridges of trust and respect must be built between the generations, because a fragmented community increases the chance of an inadequate response to any potential new crisis.

Although an official site has yet to be confirmed at the time of this writing, we do know that the Living Memorial will be located in San Francisco. Currently, COTT has raised over $10,000 (approximately 5% of what is needed to build the memorial) and we have received a donation in kind from the architectural firm RRM Design Group in San Luis Obispo, California. Under the direction of Eddie Herrera and his team at RRM, the initial renderings of the Living Memorial have been completed at no cost.

If you're interested in contributing to this valuable and significant project, please visit the COTT website at www.cott1.org to donate and to see the artists' renderings of the planned Living Memorial.

We look forward to the day when a cure is found for hemophilia, but until that time, let's honor the men and women who gave their lives so that we may have fulfilling lives today and in the future.

Jeffrey Moualim is CFO and fund development coordinator of COTT. He was cured of hemophilia through a liver transplant, but continues to help the community. He can be reached at jmoualim@aol.com.

Meet The HCWP Staff

Jacqueline Washington
Jacqueline Washington is a native of the Pittsburgh area and has been working in research for the past 20 years. Jacqueline joined the team in January. She is an experienced research coordinator and is associated with multiple investigational studies including AIDS clinical trials, behavioral studies with adolescents, diabetes research in children, health outcomes in the elderly population as well as a longitudinal study in liver transplant. Jacqueline is a graduate of the University of Phoenix with a Bachelor of Science in Health Administration. She is the mother of 3 and enjoys making jewelry and is a volunteer in children's ministry at her church.

Megan Hendricks
Megan is a native of Pittsburgh with a bachelor's degree in Art History from Penn State University and an RN Diploma from St. Francis Nursing School. After graduation from nursing school, she worked as a Midwife assistant and then went on to work as a research nurse at the University of Pittsburgh for 13 years. In January of this year, she joined the research staff at the Hemophilia Center of Western Pennsylvania as a senior regulatory coordinator who will work closely with Dr. Ragni on approvals for her research studies. She loves music and enjoys cooking and the beach.

Spotlight on the Member: Stacy McCarthy

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longer the most up-to-date treatment information.

Stacy's advice for parents of newly diagnosed children is first and foremost to make sure your child is seen at a treatment center – the mom's group with which Stacy was connected was invaluable to her as she navigated the early stages of adapting to having a child with a bleeding disorder. She also wants people to know that it's okay to feel like your entire life has changed – even turned upside down. You and your family will adapt and find your new normal in time.

Stacy also encourages people to ask ALL of your questions – even if you think they may be stupid questions. Perhaps most importantly, Stacy says it's important to advocate for not only your child, but for your rights as a parent to question test results, nurses and even doctors if you don't feel that they are correct. Trust your instincts - you have nothing to lose and everything to gain!
Stacy and Will enjoy golfing together and are actively trying to recruit the rest of the family to start playing, too. Will even placed second overall at CSL Behring's Gettin' in the Game℠ golf competition last summer! Will and his sisters love attending Camp Hot to Clot, and his older sister was even an LIT last summer. Will learned to self-infuse at camp when he was 8, and with his sister's not willing to be shown up, they learned to as well! So while they have all benefitted from being part of the bleeding disorders community, Stacy does say that it's difficult for Will's sisters sometimes, because when Will has a bleed, he obviously becomes the center of attention. The entire family enjoys participating in the Chapter's annual Walk, with each of the three kids trying to outdo each other in fundraising! They're hopeful that we will have better weather for the walk this year, but they'll be back – rain or shine!

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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.

Our Mission:

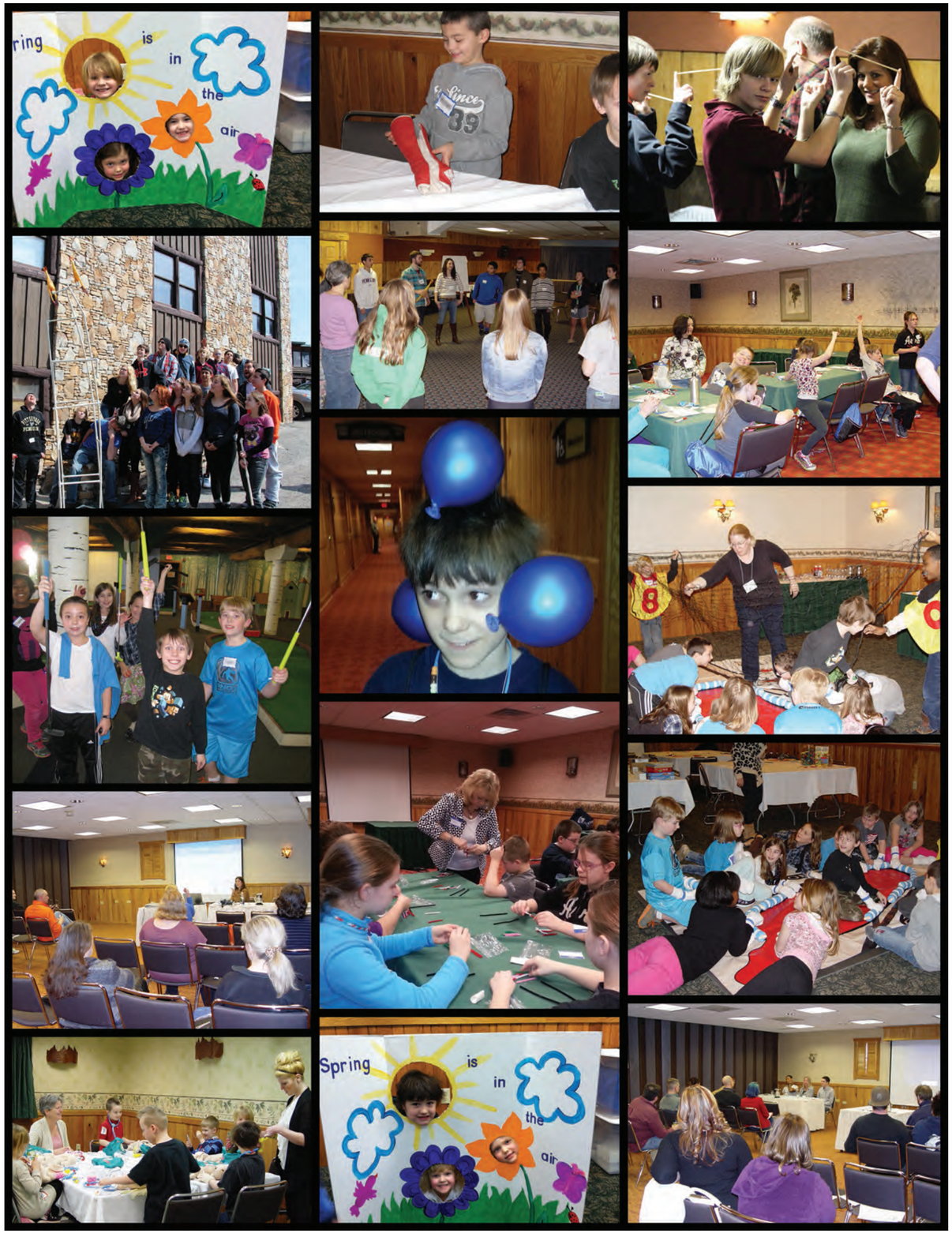
The Western Pennsylvania Chapter of the National Hemophilia Foundation is leading the way in Western Pennsylvania in improving the quality of care and enriching the lives of those with bleeding disorders through education, advocacy, resource, and referral.

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

Hemogram is published quarterly by the Western Pennsylvania Chapter of the National Hemophilia Foundation.



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