



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

Summer 2014
Inside this issue

**Join Us
for the
5th Annual
Run For Their
Lives 5K!**

See Page 2 for Details

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

HARRISBURG DAY

By Seth Martin

One word - community. I think nowadays there is nothing more important than the simple fact that without community we, as a culture, have nothing. I was proud as a hemophiliac to see our bleeding disorder community come together for Harrisburg Day 2014. I participated in the Harrisburg day event in the past and was happy to see many familiar faces moving our agenda forward. However, a more important fact is that many new faces were assisting in the effort.

I had the pleasure to speak with many elected officials that day. I felt that they were understanding of the issues facing patients within the bleeding disorder community. I made sure to explain that, as a patient with Hemophilia and age 31, I had personally seen the evolution of care from a time I dubbed the "dark ages" to today. Although there is still improvement needed, we have, without a doubt, made advances. The so called "dark ages" included a time of uncertainty dealing with HIV-AIDs and Hepatitis C scares, lack of access to care, and a far reaching misunderstanding of Hemophilia by the general public. I'm not going to continue on about the 80's and 90's,



but I know for a fact it's very important to keep things in a clear perspective. If we don't remember the failings and inadequacies of the past and the gains that our hard work have achieved, then we may have a tendency to fall back, and I can say without a doubt, we never want to go back.

(Continued on page 15)

EMPLOYMENT THEMED PROGRAM

To help address concerns of people with bleeding disorders regarding job searches, the Chapter offered an employment themed program for the first time. The goal of the program was to help individuals understand the employment law as it relates to the application and interview processes. The first session, To Disclose or Not to Disclose, was presented by Dr. Susan Lubinski who is an associate professor at Slippery Rock University, a lawyer, a Certified Public Accountant, and a Certified Fraud Examiner. She has taught employment law for 15 years and also has experience as a Human Resource Director.

Dr. Lubinski began by talking about two main laws governing workplace relationships: Title VII of the Civil Rights Act of 1964 and American Disabilities Act of 1990 (amended in 2008). She talked about the legal obligations of employers and elaborated on when employers can and cannot discriminate in the selection process. She talked about what to and not to include on resumes and also addressed resume fraud. She explained how applications should only contain questions that are relevant to the job and how misstatements or omission of material fact will result in disqualification. She talked about illegal and suspect questions that should not be asked on applications or in preliminary interviews or interviews. She gave examples and

(Continued on page 7)



HIT THE GROUND RUNNING!

Saturday, September 13, 2014

Location: North Park/Harmer Grove Shelter
Allison Park, PA

Registration: 7:30am

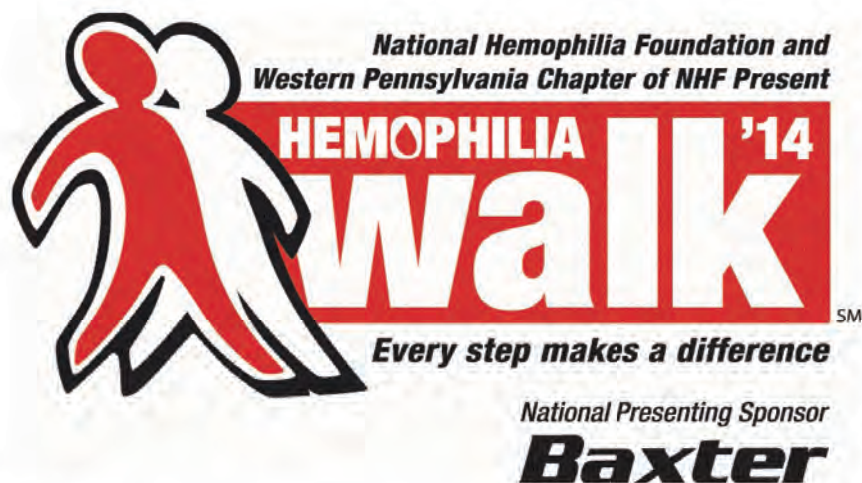
Race Start Time: 8:30am

Race Distance: 5K

An expected 100+ Western Pennsylvanians will hit the ground running to raise money for the Western Pennsylvania Chapter of the National Hemophilia Foundation in the 5th Annual Run For Their Lives 5K!

This year WPCNHF has partnered with Elite Runners! **Register today at**
www.eliterunnersracing.com

— COME FOR THE **RUN** AND STAY FOR THE **FUN!** —



Registration: 9:00am

Walk Start Time: 10:00am

Walk Distance: 5K

Join us for the 6th Annual Western Pennsylvania Hemophilia Walk! We will walk to raise critical **FUNDS** and **AWARENESS** for the bleeding disorders community. The event will include entertainment for the entire family. All proceeds **stay local** to benefit WPCNHF! Register your team today!

Letter From The President, Scott Miller

Dear Chapter Members and Stakeholders,

What a wonderful spring at the Chapter! Education Weekend was a resounding success, as were the simultaneous Men's and Women's Group Meetings! We also offered an insurance update, attended Harrisburg Day and Bowled for Bleeding Disorders at our 2nd annual bowling fundraiser! I want to thank the staff, presenters, sponsors and participants for their part in enabling us to provide such high quality programming as well as good camaraderie.

As summer kicks off, please remember to mark your calendars for the Annual Meeting on July 26th in Homestead. This year we are once again combining this event with our Hemophilia Walk Kickoff. The Walk has been one of our key fundraisers and I look forward to everyone's participation in the Walk on September 13 to help us meet our mission.

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, J.D., DBA
WPCNHF Board President

Letter From The Executive Director, Alison Yazer

Greetings!

I can't believe how quickly time has flown by and that it's finally summer after the winter that seemed to last forever! The Chapter hosted many great educational programs and fundraisers over the past few months and things are in full swing for the rest of the year. I hope that each of you had an opportunity to attend at least some of the events we held. We are trying to continually increase our programmatic

offerings, but we need to know from you what you're seeking...so let us know your ideas!

Things are changing constantly within the bleeding disorders community. We hope that you will continue to rely on the HCWP and the Chapter to keep you up to date on policies and legislation that can impact you and your family. If you have questions, please let us try to help answer them!

As always, please contact the office with any questions or concerns. We are here to serve you, but we can only do so with your input!

Sincerely,

Alison Yazer
Executive Director

Sensible Snacking

*Article courtesy of HemAware
copyright 2014*

How to incorporate healthy treats

Kids may crave salty chips, sugary sodas and caloric cookies at snack time. But the Academy of Nutrition and Dietetics (AND) urges families to incorporate healthier treats in kids' diets, such as fruits, vegetables, whole grains and nuts. All it takes is a little creativity and a well-stocked kitchen.

Here are some ideas to get you started:

- Dip carrot spears, celery sticks and jicama (a crunchy, potato-like veggie from Mexico) in low-fat dressing.
- Put Greek-style yogurt, skim milk and fresh berries in the blender for a tropical smoothie.
- Serve hummus, a dip made from chickpeas, with whole-wheat pita bread triangles.
- Make trail mix from nuts, dried fruit, low-fat cereal and chocolate bits.
- Toss hot popcorn with grated Parmesan cheese.

For more ideas on healthy eating, visit AND's website: eatright.org

If needed, please see original article for photos: <http://www.hemaware.org/story/sensible-snacking>

Calendar of Upcoming Events

Saturday, July 20
Joint Health
Washington, PA

Saturday, July 26
Annual Meeting & Walk Kickoff
Homestead, PA

Tuesday, August 5
Braving Change
Pittsburgh, PA

Saturday, August 16
First Step Program: Living Well with Hemophilia
Pittsburgh, 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

Biotherapies for Life® CSL Behring

TAKE CONTROL OF YOUR CONDITION AND YOUR LIFE...

Tap Into *my* Source

...A Broad Spectrum of Support Services From CSL Behring

<i>Financial</i> SUPPORT	<i>Education</i>	<i>COMMUNITY</i> CONNECTIONS
to help ensure access to treatment	about a wide variety of topics	so you can share experiences with others

Whatever your needs and preferences, let My Source™ be your source!
Visit www.MySourceCSL.com or call 1-800-676-4266.

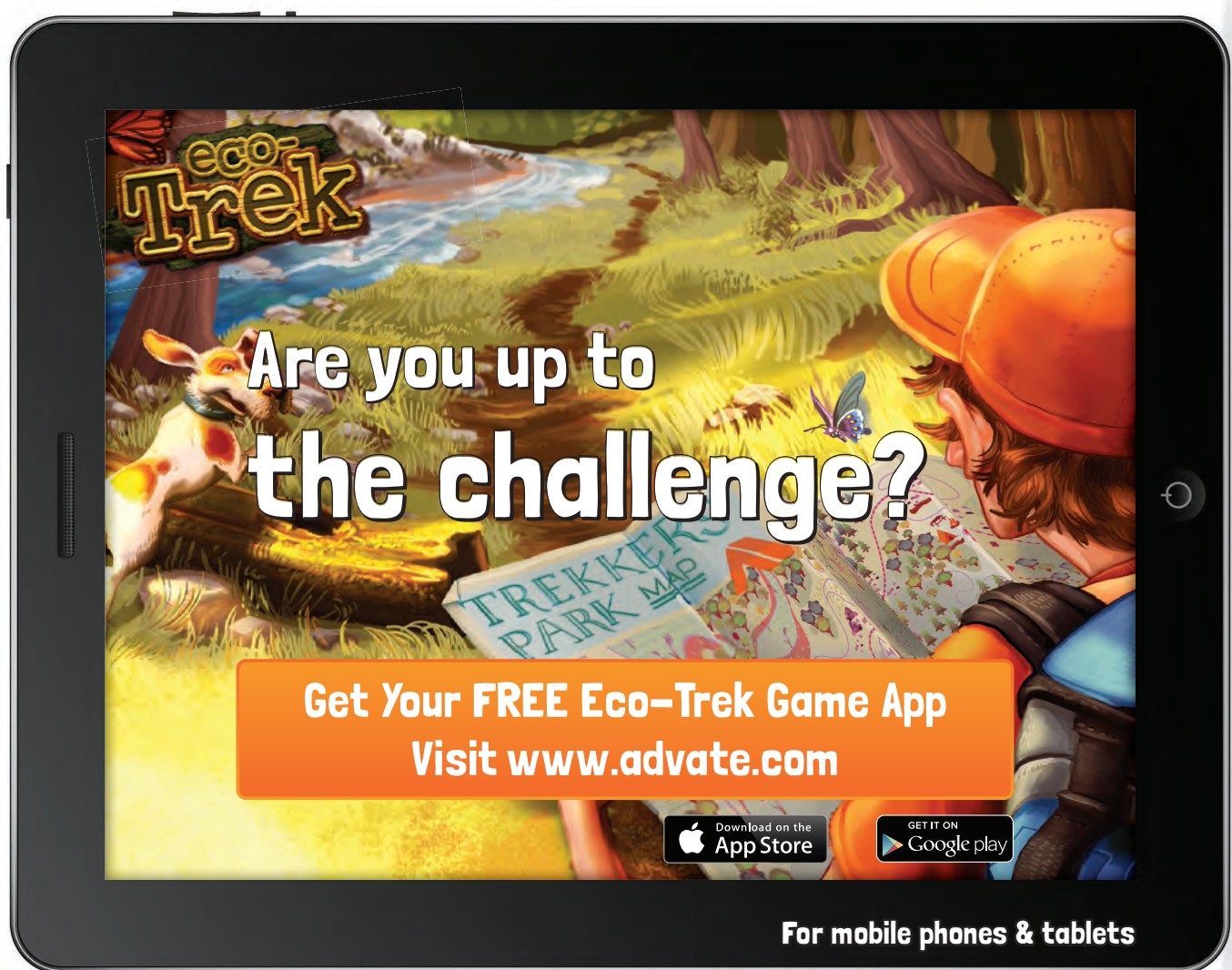
my
Source
Tap into it!

www.facebook.com/vonWillebrandandU




My Source™ is a trademark of CSL Behring LLC.
©2014 CSL Behring LLC 1020 First Avenue, PO Box 61501, King of Prussia, PA 19406-0901 USA
www.CSLBehring-us.com COA14-01-0006 2/2014

COAGULATION

Ask us about sponsorship opportunities and how you can help!



Eco-Trek is a one-player, multi-level game package that tests your outdoor survival skills

-  3 outdoor adventure games in 1
-  An online leaderboard for nationwide competition
-  Answer educational questions about ADVATE for bonus scoring

Bring your A-game to www.advate.com for your free download!



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

For more information, contact your Baxter representative today:

Erik Drotos

Phone: (412) 518-7122

Email: erik_drotos@baxter.com



Join the 4th Annual Bayer Virtual Walk for Hemophilia!

Help your local hemophilia chapter raise sponsorship funds by participating in the 4th annual Bayer Virtual Walk for Hemophilia.

Spread the word to your friends and family. Every virtual walker brings your chapter one step closer to making a difference in the community!

Virtually walk for a cause TODAY at www.walkforhemophilia.com.



Spread the
word and support
your community
TODAY!



Dr. Susan Lubinski



Kathaleen Manns-Schnur



Barry Haarde

EMPLOYMENT THEMED PROGRAM

(Continued from the Cover)

advised the group to handle those types of questions with a simple reply: "I would like to answer your question if you would first explain how that is job related."

Dr. Lubinski took time to address questions and concerns from the participants. For example, you may want to include experience such as volunteer work with the Chapter in your communications, but don't want to reveal that you or a family member has a bleeding disorder. If the subject of how you got involved with an organization comes up, you can just simply state that you have an interest in the cause. She also addressed how to handle a request for an accommodation that wasn't needed at the time someone was hired. A need for an accommodation, due to a medical condition, might occur at any time during one's employment; it's not always something that you can anticipate needing when you first start a job. A need may not occur until years later. Dr. Lubinski also addressed other concerns and issues that the participants had in regards to finding and maintaining employment.

Next, Kathaleen Manns-Schnur, MSW, LSW, of the Hemophilia Center of

Western PA facilitated a panel discussion with members who have bleeding disorders and are employed, entitled "So, tell me...what do you do for a living?" She asked the panel a number of questions about their experiences with finding and maintaining employment; other participants were encouraged to ask the panel questions as well. One person shared his experience on how he received an accommodation to perform his job and help prevent bleeds. We appreciate them sharing their experiences with their fellow members!

Get off your Aspirations! was the title of the last session. This interactive discussion was led by Barry Haarde. Barry has severe hemophilia and is a 32+ year survivor of HIV, has liver cirrhosis from hepatitis C, peripheral neuropathy, and a 14-year-old knee replacement. Despite all of this, he has completed three cross-country bicycle tours as fundraising efforts

for Save One Life! Barry traveled all the way from Texas to speak with our group. The goal of his program was to share best practices to help participants get off their aspirations. Barry guided the participants through a self-assessment on various aspects of their lives. Then the participants created a plan of action to sustain or improve these areas in the near future.

We thank all of our speakers for their contributions to this program. Here's what some of the participants had to say: "I enjoyed the program immensely. I learned a lot of information that I can share with my family." "I thought the program was beneficial. There was a lot of good information."

We'd like to thank Bayer HealthCare for sponsoring this program!





Now Available

A new treatment for hemophilia B

ALPROLIX provides protection* from bleeds starting with at least a week between prophylaxis infusions.

Dosing regimen can be adjusted based on individual response.

*Protection is the prevention of bleeding episodes using a prophylaxis regimen.



To learn more, contact CoRe Manager **Christine Rowe**

E: christine.rowe@biogenidec.com T: 267.249.8372

Indications and Important Safety Information

Indications

ALPROLIX, Coagulation Factor IX (Recombinant), Fc Fusion Protein, is a recombinant DNA derived, coagulation factor IX concentrate indicated in adults and children with hemophilia B for:

- Control and prevention of bleeding episodes
- Perioperative management
- Routine prophylaxis to prevent or reduce the frequency of bleeding episodes

ALPROLIX is not indicated for induction of immune tolerance in patients with hemophilia B.

Important Safety Information

Do not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX.

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

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

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

ALPROLIX may increase the risk of formation of abnormal blood clots in your body, especially if you have risk factors for developing clots.

Common side effects of ALPROLIX include headache and abnormal sensation of the mouth. These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider right away about any side effect that bothers you or does not go away, and if bleeding is not controlled using ALPROLIX.

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

Please see Brief Summary of full Prescribing Information on the next page. This information is not intended to replace discussions with your healthcare provider.

ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein], Lyophilized Powder for Solution For Intravenous Injection.

FDA Approved Patient Information

**ALPROLIX™ /all' prō liks/
[Coagulation Factor IX (Recombinant),
Fc Fusion Protein]**

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

What is ALPROLIX™?

ALPROLIX™ is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital Factor IX deficiency.

Your healthcare provider may give you ALPROLIX™ when you have surgery.

Who should not use ALPROLIX™?

You should not use ALPROLIX™ if you are allergic to ALPROLIX™ or any of the other ingredients in ALPROLIX™. Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using ALPROLIX™.

What should I tell my healthcare provider before using ALPROLIX™?

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

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if ALPROLIX™ may harm your unborn baby.
- are breastfeeding. It is not known if ALPROLIX™ passes into breast milk or if it can harm your baby.
- have been told that you have inhibitors to Factor IX (because ALPROLIX™ may not work for you).

How should I use ALPROLIX™?

ALPROLIX™ should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with hemophilia B learn to infuse their ALPROLIX™ by themselves or with the help of a family member.

See the **Instructions for Use** for directions on infusing ALPROLIX™. The steps in the **Instructions for Use** are general guidelines for using ALPROLIX™. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedure, please ask your healthcare provider. Do not use ALPROLIX™ as a continuous intravenous infusion.

Contact your healthcare provider immediately if bleeding is not controlled after using ALPROLIX™.

What are the possible side effects of ALPROLIX™?

Common side effects of ALPROLIX™ include headache and abnormal sensation in the mouth.

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

ALPROLIX™ may increase the risk of forming abnormal blood clots in your body, especially if you have risk factors for developing blood clots.

Your body can also make antibodies called, "inhibitors," against ALPROLIX™, which may stop ALPROLIX™ from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all the possible side effects of ALPROLIX™.

Talk to your healthcare provider about any side effect that bothers you or that does not go away.

How should I store ALPROLIX™?

Store ALPROLIX™ vials at 2°C to 8°C (36°F to 46°F). Do not freeze.

ALPROLIX™ vials may also be stored at room temperature up to 30°C (86°F) for a single 6 month period.

If you choose to store ALPROLIX™ at room temperature:

- Note on the carton the date on which the product was removed from refrigeration.
- Use the product before the end of this 6 month period or discard it.
- Do not return the product to the refrigerator.

Do not use product or diluent after the expiration date printed on the carton, vial or syringe.

After Reconstitution:

- Use the reconstituted product as soon as possible; however, you may store the reconstituted product at room temperature up to 30°C (86°F) for up to 3 hours. Protect the reconstituted product from direct sunlight. Discard any product not used within 3 hours after reconstitution.
- Do not use ALPROLIX™ if the reconstituted solution is cloudy, contains particles or is not colorless.

What else should I know about ALPROLIX™?

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

Manufactured by
Biogen Idec Inc.
14 Cambridge Center
Cambridge, MA 02142
U.S. License #1697

Spotlight on the Member: The Slater Family

If you've been to a Chapter event during the last decade, chances are good that you've met the Slater family! Karen and Jarred Slater live in Greensburg with their children Ian (age 11) and Raina (age 9) and have been active members of the Chapter since Ian was an infant.

Prior to Ian's birth, Karen didn't know that she was a carrier. When Ian was born he had severe jaundice and was treated accordingly. Everything else appeared to be fine. When he was two days old, he was circumcised and was sent home from the hospital. He was under the care of a pediatrician and continued to be monitored and treated for jaundice. Although he had many needle pricks in his heel to test his bilirubin levels (due to the jaundice) a bleeding problem wasn't suspected until blood continued to ooze from the site of his circumcision, days after the procedure. The pediatrician referred the family to Children's Hospital of Pittsburgh. When Ian was 11 days old, he was tested for a bleeding disorder and the results came back positive for

Hemophilia B. He was admitted to the hospital and received a series of factor infusions over a three day period.

The whole experience was overwhelming for the Slaters. But based on their experience, the hospital where Ian was born changed their protocol and the staff now asks all expectant mothers if they have a family history of bleeding disorders. Although Karen did not know that she was a carrier, she was aware of a bleeding disorder in a relative.

Now that there was an explanation for the bleeding, Karen began to learn as

much as she could about Hemophilia. When Ian was 11 months old, the family attended their first Family Education Weekend with the Chapter. This not only gave them an opportunity to learn more about hemophilia, but it also gave them the opportunity to meet other families that were going through the same thing that they were. The family has been active members of the Chapter ever since.

As their baby grew and developed, the family faced new challenges. Ian was very active and, like most toddlers with bleeding disorders, he had numerous bruises from crawling, learning to



The Hemophilia Center of Western Pennsylvania

The Hemophilia Center of Western Pennsylvania clotting factor program was established in 2000 as a complement to the Center's other comprehensive care services. The clotting factor program allows the Center the opportunity to offer clotting factor to its patients, thereby supplementing its comprehensive treatment care model and providing the best possible care for its patients.

Please contact the Center at (412) 209-7280 for more information about how this program can benefit you and the entire bleeding disorder community.

The Hemophilia Center of Western Pennsylvania supports patient choice consistent with the Veterans Health Care Act of 1992 and maintains a freedom of choice policy where patients are informed of their choices regarding factor replacement products.

Factor Program Services

- All factor product brands available
- Online factor ordering available
- 24 – 48 hour delivery
- Same day courier service for emergent needs
- On-call services, 24/7
- Home treatment supplies
- Lot tracking for recall notification
- Online home treatment records
- Insurance benefit information assistance

Patient Benefits

- Direct communication and service from the Center's treatment team
- Support of the Center's operations
- Expansion of patient services

walk, and falling. He had a number of bleeds that required trips to the ER for evaluation and treatment. Even though those were stressful times, the Slater's feel that their hospital experiences were good and that their son received fantastic treatment at their local hospital. Karen always contacted the Hemophilia Center of Western PA (HCWP) before heading to the ER; and the HCWP would call the hospital and give instructions to the ER staff. She said they never had an issue when following this procedure.

Although they received great care at their local ER, the Slaters found it stressful to have to make the trip every time their son had a bleed that required factor. When Ian was two years old, the decision was made to transition him from on-demand treatment to prophylaxis treatment. A home health care nurse, with pediatric experience, came to the house two times per week for several months to infuse Ian. Over time, the nurse trained Karen to infuse Ian and observed her until she was proficient and comfortable infusing him on her own. Karen has been infusing her son ever since. In addition, Jarred has

been infusing Ian for the past three years. He was able to use what he had learned at the first Chapter sponsored infusion day to begin infusing Ian at home. When Ian turned nine, he began to help with mixing the factor, pushing the factor, and logging his treatment records. Ian and his family members continue to learn more about home infusion through summer camp and the Chapter's annual Infusion Day.

Over the years, Karen has continued to take every opportunity to learn more about bleeding disorders. She has also given back to the community. For many years now, Karen has been a loyal member of the planning committee for the Chapter's Family Education Weekend. In addition to helping plan the event, she has volunteered at the event and has participated as a speaker and panelist. Karen and her family also help raise money for the Chapter by participating in the Walk and Run. In addition, Karen serves as a member of the Consumer Advocacy Committee for the Hemophilia Center of Western PA and participated in a meeting for the development of their 5-year strategic plan.

The Slater family is active and enjoys spending time together biking, hiking, swimming, attending sporting events, and watching movies. Ian leads an active lifestyle by participating in activities with the family and Raina has been dancing with the Laurel Youth Ballet for the past 4 years.

Karen recommends that families with bleeding disorders get involved with the Chapter. When she attended her first Chapter event, she gained a better understanding of what they would be facing with their son. It helped put her mind at ease. She and her husband learned more about hemophilia and saw others with the same diagnosis leading full lives. They saw the future and realized that the bleeding disorder was manageable and not beyond their ability. Although they were overwhelmed, they felt more equipped and relaxed after attending their first Family Education Weekend!



Skilled Pharmacists. Experienced Infusion Nurses. Dedicated Patient Experience Team.

Soleo Health provides a team approach to bleeding disorder therapy management.

To learn more, contact
Marty Piper at 484.431.0909.

SOLEO
HEALTH

Innovators in Specialty Infusion
Formerly Biomed Pharmaceuticals

www.soleohealth.com   

HCV Trial Recruits Bleeding Disorders Patients

Investigators of a new clinical trial for people with both chronic hepatitis C viral (HCV) infection and bleeding disorders are currently recruiting new patients. HCV trials often exclude patients with conditions such as hemophilia, which makes this new study noteworthy and relevant to the bleeding disorders community.

The Phase 2b, multicenter trial, “Efficacy and Safety of Ledipasvir/Sofosbuvir Fixed-Dose Combination and Sofosbuvir

+ Ribavirin for Subjects with Chronic Hepatitis C Virus and Inherited Bleeding Disorders,” is being sponsored by Gilead Sciences. In February 2014, Gilead filed a New Drug Application with the US Food and Drug Administration for ledipasvir (LDV)/sofosbuvir (SOF), a fixed-dose combination therapy for genotype 1 HCV. Both drugs are direct-acting antivirals. LDV is an NS5A inhibitor, a drug that disrupts nonstructural proteins HCV needs to replicate. SOF is a nucleotide analog polymerase inhibitor, which blocks polymerase, an enzyme that provides instructions for making copies of HCV RNA.

The purpose of the study is to determine the efficacy, safety and tolerability of

treatment with LDV/SOF fixed-dose combination for participants with genotypes 1 and 4 HCV infection, and SOF + ribavirin for participants with genotypes 2 and 3 HCV infection.

This trial is recruiting people exclusively with inherited bleeding disorders and chronic HCV infection (either mono-infected or HIV-1/HCV co-infected).

Learn more about the study, including eligibility information and recruitment sites, by going to clinicaltrials.gov.

Inhibitor Study Stresses Screening Importance

Results from a six-year study of patients with hemophilia A and B produced interesting findings. The Hemophilia Inhibitor Research Study (HIRS) enrolled 1,163 patients from 17 federally funded hemophilia treatment centers (HTCs). One of the goals was to predict which patients were at highest risk for development of inhibitors, antibodies to infused factor.

“A Study of Prospective Surveillance for Inhibitors Among Persons with Haemophilia in the United States,” was published in the March 2014 issue of *Haemophilia*. The lead investigator was Michael Soucie, PhD, Division of Blood Disorders, National Center on Birth Defects and Developmental

Disabilities, Centers for Disease Control and Prevention (CDC) in Atlanta.

A central laboratory performed periodic inhibitor tests using blood samples and genotyped the subjects. In all, 3048 inhibitor tests (some patients were screened more than once) were conducted. The main findings were:

- All people with hemophilia are at risk for developing inhibitors
- One-third of newly developed inhibitors were found in people with non-severe hemophilia
- One-half were older than 5 years old
- Six out of 10 people with hemophilia with an inhibitor had no symptoms
- 23 new FVIII inhibitors were identified

- 431 distinct mutations were genotyped, 151 of which had not previously been reported

HIRS investigators and CDC researchers determined that individuals with hemophilia of all ages were at risk for developing an inhibitor. Further, CDC now estimates that approximately 60% of people with an inhibitor have no symptoms. Without regular screening, a significant number of these patients may not be aware of it until they experience severe bleeding.

The CDC concluded that patients with hemophilia receiving care in federally funded HTCs will be tested yearly for an inhibitor by the CDC Division of Blood Disorders laboratory as part of Community Counts, its new blood monitoring program.

Source: CDC

Meet The HCWP Staff

Mary Dulgeroff

Mary Dulgeroff's family moved from Pittsburgh to Ann Arbor, Michigan where she grew up. She graduated from the University of Michigan with a double major in English and History.

Mary moved back to Pittsburgh and began working for UPMC where she worked for 28 years. She worked in Child Psychiatry at Western Psychiatric Institute and Clinic and then spent 12 years at Children's Hospital, working primarily in Neurology and

Cardiology research, before joining the Hemophilia Center of Western Pennsylvania (HCWP) in May 2014. At HCWP, she is working as an Administrative Assistant, helping Dr. Ragni, Mr. Wahal, and Ms. Karen Saban with their administrative tasks.

Mary is an avid reader and owns approximately 1,000 books. She also is interested in birds, owning several cockatiels, and is a member of the Cornell Lab of Ornithology at Cornell University and the National Aviary.

She enjoys amateur bird watching on the weekends and has had several articles published in the Journal of the National Cockatiel Society.

Nancy Stinely

Nancy Stinely is one of the new additions to the HCWP Clinical Staff who started in May of 2014.

A native Pittsburgher, Nancy earned her BSN at Duquesne University. For over 20 years she was a nurse at UPMC Shadyside Hospital where she gained experience caring for patients in multiple areas including: ICU, CCU, the Emergency Department, and the GI Lab.

A dedicated nurse, Nancy also has many outside interests. She is an avid fan of all Pittsburgh sports teams as well as a supporter of the city's performing arts. Travel is another passion that has taken her throughout the United States, Europe, and the Caribbean. Nancy also practices yoga and is always on the look-out for adventures in cooking and dining.

She looks forward to a mutually rewarding experience as she gets to

know the patients of the HCWP.

Walt Livingston Jr.

Walt Livingston Jr., lifetime resident of Lower Burrell, obtained his Registered Nurse licensure from Citizens School of Nursing in New Kensington, and his Masters from Waynesburg University. Walt has been in the medical field for 36 years, 17 of those as a paramedic and 19 years as a nurse with experience in fields of ER, ICU-CCU, and

Oncology. Walt also taught classes in the BSN program at Waynesburg University.

Outside of nursing, Walt has many hobbies, is an avid golfer, bowler and enjoys all Pittsburgh Sports. He enjoys spending time with his eight grandchildren and coaching his bowling youth groups at Wildlife Lanes

in Lower Burrell. Walt makes his home with his wife Denise and their yellow lab Bogie.

Board of Directors

President

Scott Miller, CPA, Esq.

Vice President

Nathan Rost

Treasurer

Sam Rotellini

Secretary

Mike Covert

Directors

Jen Smith

Nick Vizzoca

Directors Emeriti

Jim Loll

Missy Unkovic

Staff

Executive Director

Alison Yazer

Member Services Manager

Janet Barone

Bookkeeper & Office Assistant

Kara Dornish

Fundraising & Events Manager

Brittani Reed

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

Walgreens Infusion Services—bleeding disorder support to help you stay healthy and active

To learn more, call 866-436-4376.

En español, llame al 800-456-1923.

Taking beautiful care of you.

Walgreens Infusion Services locations are ACHC accredited. HHA #20881096, HHA #20885096, HHA #299991678, HHA #299992580 ©2013 Walgreen Co. All rights reserved. 12WIS0117EHb

Walgreens Infusion Services

Our Mission:

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

WPCNHF Wish List

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

- ♦ White copy paper by the ream or by the case
- ♦ Colored copy paper by the ream for invitations and newsletter inserts
- ♦ Legal pads for note taking
- ♦ Sticky Notes
- ♦ Forever U.S. Postage stamps
- ♦ 10 x 13 Ready-seal envelopes for newsletter mailings
- ♦ Paper towels
- ♦ Apartment-sized refrigerator

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.

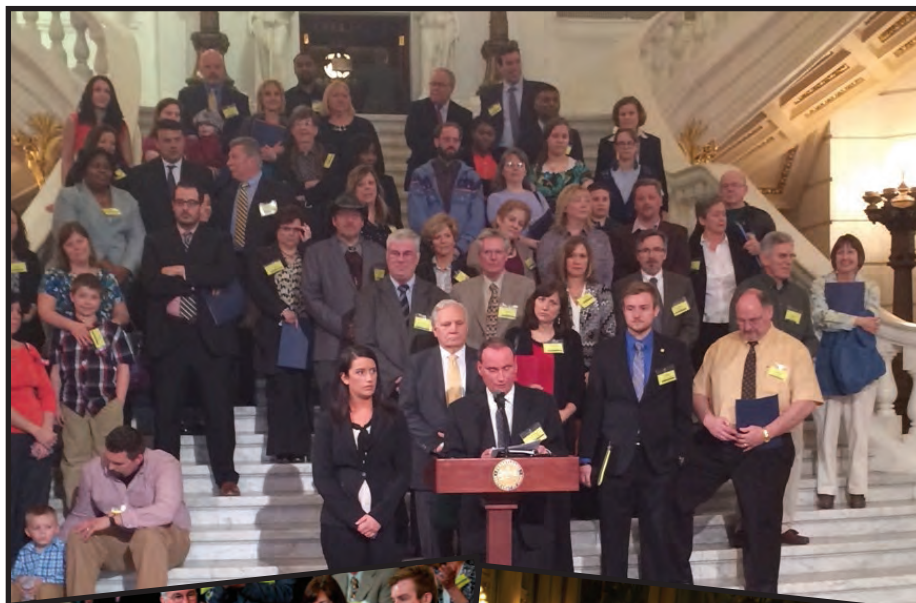
HARRISBURG DAY

(Continued from the Cover)

On a personal note, I come from a career background working in benefits verification and helping patients find the best possible costs in dealing with specialty drugs and their inherently higher than average costs. My experience includes helping the elderly to deal with high costs of tiered drugs and the Medicare part D “donut hole.” To quickly sum up the definition of “donut hole” is to say that it was a black hole where a patient hit a certain threshold of drug costs and was literally left to fall off a cliff into exorbitantly high medication costs. Luckily for our nation’s seniors, this was phased out giving the elderly the freedom to not have to choose between buying groceries or medication. In effect, the playing field was leveled and that is what we need for patients with conditions such as those in the bleeding disorder community.

Patients are already experiencing similar effects to that of the dreaded “donut hole,” but now this plays out in a younger demographic with specialty pharmacy tiers. Call it what you want from tiers to cost sharing, etc., but the simple fact is that by virtue of being afflicted with a rare disease, patients and patient’s families are slammed with extreme costs. This occurs due to the classification of a prescription by the patient’s insurance company. Placing bleeding disorder drugs in a high cost tier forces patients to realize thousands upon thousands of dollars upfront and greatly unexpected costs.

It’s clear that, unless the patient recently hit the lottery, it isn’t realistic to slam an individual or family with these kinds of costs. It quite simply comes down to punitive treatment toward those with some of the most debilitating diseases and that is no way to do business. Like it or not, patients are largely a captive audience when it comes to the insurance they have. Since the insurance companies are just counting revenue, we need legislative efforts to show that patients are more than dollars and cents. This is the message that was given to the state officials, quite simply their constituents are under fire and need help. In a time when salaries fall far behind the cost of living, the last thing a family or a patient needs is a bill



for thousands of dollars based on one month of their prescription needs.

Every time I have the honor to take part in these events, my morale is boosted by the simple realization that we all are so good at coming together to get the message out. I am hoping that our efforts weren’t in vain because I know that if our voices weren’t heard it won’t be for lack of effort on our group’s part. Each of us drove home the importance of what we were experiencing first hand in the arena of our care and dealing with countless insurance hurdles. We know what we go through as parents of a patient or those of us living with a bleeding disorder, but at Harrisburg Day 2014, we made sure to let our elected representatives know that we need help in these uphill battles. I know that with people like the Senators and Representatives I met that day we can work together to move forward with patient protections that are so dearly needed; not only for those with bleeding disorders, but for the millions of patients that have a need for specialty drugs.

On another important issue, we made sure to communicate to the elected officials that we had a certain level of funding from the state that was vital in helping the Hemophilia Treatment Centers. Many of the volunteers, including myself, thought there would not be any risk to this funding, but as it turns out this may not be the case. The funding level has remained at a constant level for quite a while and we weren’t asking for any additional money; however, it seems that our item may be cut in order to fund other items. I was really shocked to see that this would be under consideration since this funding is so vital to the treatment centers. We need to take time to reach out to our elected representatives and remind them that we need this funding.



RIXUBIS [COAGULATION FACTOR IX (RECOMBINANT)]

**For more information, contact your
Baxter representative today:**

Melanie Zembrzuski

Phone: (412) 400-9565

E-mail: melanie_zembrzuski@baxter.com

To learn more, visit www.RIXUBIS.com.

Baxter and Rixubis are trademarks of Baxter International Inc.
USBSMG45130004 © Baxter Healthcare Corporation. 2013

Baxter

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

