Hemogram

WPCNHF

Western Pennsylvania Chapter of the National Hemophilia Foundation

Spring 2012
Inside this issue

Chapter News

This year, WPCNHF held our first annual Infusion day in conjunction with the Hemophilia Center of Western Pennsylvania (HCWP). Kristen Jaworski, RN, BSN, CCRC of HCWP committed to the event with her colleagues in order to further educate the bleeding disorders community. There were several stations setup throughout the event- an infusion station supported by Anne Graham, RN and Donna Flemm, a practice station supported by Sarah Simpson, RN, Kathy Betts, RN, and Cathy Kress, RN, a "pack your ER bag" station supported by Kristen Jaworski, and a Good

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Advocacy

The first few months of 2012 have been busy for the Chapter and advocacy has been a top priority. In March, Chapter staff members Janet Barone, Madonna McGuire Smith, Jennifer Pegher, Board president Scott Miller, Chapter members Sue, Travis, and Kyle Gaerttner, Cheri Marx, EJ Villegas, Cameron Cedeno, Mike, Maddie, Devin, and Erin Smith traveled to Washington, DC to advocate for the bleeding disorders community. This year the hemophilia community is facing a direct threat to the national network of hemophilia treatment centers. Specifically, the Center for Disease Control (CDC) has

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David Komar Obituary

It is with sadness that we announce that WPCNHF Chapter member David Komar passed away on February 8, 2012. The WPCNHF Board of Directors, staff and Chapter members would like to extend their deepest sympathies to David's wife Tracy, his daughters Jess and Jenn and the rest of the Komar family on their loss.

JOHNSTOWN - KOMAR David A. "Koogle," 45, Johnstown, died Wednesday, Feb. 8, 2012, at Memorial Medical Center. Born Nov. 21, 1966, In Johnstown, son of Jerome W. "Jerry" and Rose Marie (Zonin) "Kay" Komar. Preceded in death by his father. Survived by his mother, Kay Komar, johnstown; wife, Tracy L. (Lyttle) Komar; daughters, Jess and Jenn Komar; and sisters, Colleen Potts, and husband, David; Cindy O'Connor, and husband, Michael; and Caryn Knopp, all of Johnstown. Also survived by numerous nieces and nephews. David was an electrician and had a passion for cooking. His lifelong work was to be an outstanding chef. He was a former owner of Komar's Ferndale Deli, and cook at santoyo's Mexican Foods, Pizza Hut and Eat'n Park In Westmont. Donations can be made to the family to assist with burial expenses.

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

Letter from the Executive Director, Jennifer Wahlen Pegher

Dear Chapter Members and Friends,

I hope that our Spring newsletter finds you and your family well. It has been a busy few months for the Chapter as we continue to plan programs and fundraisers for the remainder of the year. I hope you take the time to look over the events that occurred earlier this year and plan to attend the events that will take place in the coming months. Our first annual Infusion Day took place in February in conjunction with the Hemophilia Center staff and it was a fantastic event. We hope to continue this event each year and we want to let you know that the event is for everyone! Mothers, fathers, grandparents, siblings, babysitters, and neighbors alike found value in this event. The nonthreatening and lighthearted atmosphere made everyone feel welcome, no matter the skill level. I would like to offer a heartfelt thanks to the staff of HCWP for their hard work on this great event. Their dedication to the bleeding disorders community does not go unnoticed.

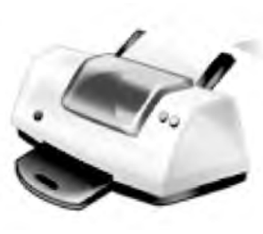
Included in this issue is a variety of scholarships available for individuals with bleeding disorders continuing their education. I hope you take the time to apply for a scholarship, or to refer a friend or family member to do so. Each presents a great opportunity for you to further your education.

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.

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 Friends,

I hope that our Spring Newsletter finds you ready for a wonderful summer after such a nice winter. I want to thank all of our volunteers that helped with our events over the winter. The chapter could not do the good work that it does without the assistance of our dedicated volunteers who help stuff envelopes, organize events, and help with the general needs in and out of the office. THANK YOU!

We have been busy on the advocacy side meeting with legislators in Washington D.C. and Harrisburg to promote legislation that would benefit our community. In Washington, we met with our Congressmen and Senators' offices to advocate for the funding of the Hemophilia Treatment Centers through the Centers for Disease Control. For many members of our community, the HTC provides high quality service on many levels through the physicians, physical therapist, social workers, insurance specialists, and other services it offers. The Center also gathers much needed data for the CDC to allow it to maintain a safe blood supply and improve research for bleeding disorders. I invite you to read the article in this newsletter related to the relationship between the Chapter and the HTC as I think it will be very helpful for you in understanding how we work together, yet separately, to provide a wide range of support services to the community.

In addition, we have a wonderful 2012 on tap, beginning with our Education Weekend in Seven Springs. The staff has been doing a wonderful job in planning what I expect to be wonderful educational events as well as some good socialization during our time together. I hope to see you all there.

As you read through this newsletter, please take note of the various events we have scheduled. The Golf Classic is always a fun time for all and raises much needed funds for the Chapter. The annual meeting will be a fun time for all and will help us all get excited about the 2012 Hemophilia Walk and Run for Their Lives, to be held in September. We continue to strive to have events throughout our territory and if you have ideas for educational or fundraising events in your area, please feel free to call the office. It is important to us for all of our members to feel welcome to our events and we are making efforts to spread our educational program throughout our 26 county service area.

I hope you all have a wonderful, safe, and happy summer and I look forward to seeing you all at the Annual Meeting / Walk Kickoff.

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

Calendar of Upcoming Events

Join us for the 4th Annual Western Pennsylvania Hemophilia Walk

In 2012 WPCNHF will be hosting our 4th Annual Hemophilia Walk. We had highly successful Hemophilia Walks during the last three years because our families have been so supportive! We hope for a bigger and better Walk in 2012.

Walk Information:

When:	Saturday, September 15, 2012
Where:	North Park, Northern Allegheny County, Harmar Grove (near the swimming pool)
What Time:	Registration begins at 9 a.m./Walk begins at 10 a.m.

Visit www.hemophilia.org/walk and select PA for more information and to register for the 2012 Western Pennsylvania Hemophilia Walk.

Monday, May 14, 2012
Driving for Bleeding Disorders
Treesdale Golf and Country Club, Gibsonia, PA

Saturday, June 9, 2012
Young Men's Group
Location TBD

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

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
Location TBD

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

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

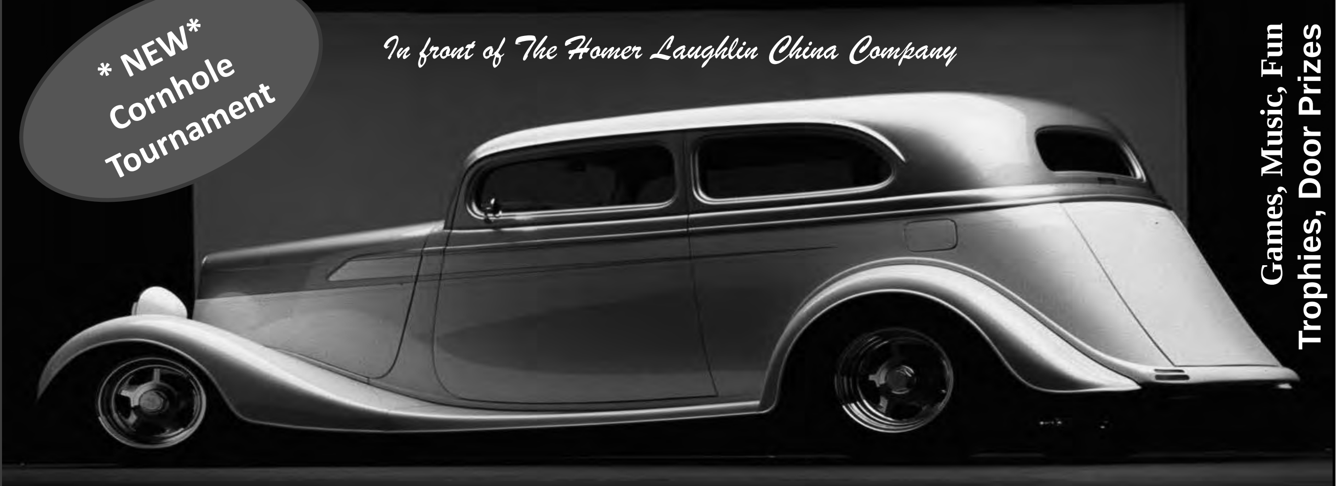
Saturday June 16th, 2012

7th Annual-Miller Family Auction-Car Show

Clark Field - St Rt 2 – Newell, WV

* NEW* Cornhole Tournament

In front of The Homer Laughlin China Company



Games, Music, Fun
Trophies, Door Prizes

Dash plaques to first 50 entries
Vehicle Registration starts @ 10:00am
Auction begins @ 11:00am – 3:00pm

$5 Dollar donation for registration

Benefits the Western PA Chapter of the National Hemophilia Foundation

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders
WPCNHF

Do you have items/funds to donate?

Contact: Charlie - Paula Miller @ 304-387-9724
Jim - Joyce Hill @ 740-282-1064
Denise Groves @ 330-532-4952

Ask us about sponsorship opportunites and how you can help!

They are two organizations that are dedicated to serving people with bleeding disorders in Western Pennsylvania: the Hemophilia Center of Western Pennsylvania (HCWP) and the Western Pennsylvania Chapter of the National Hemophilia Foundation (WPCNHF). Although both organizations provide services to the same population, they are two, separate organizations, which are often mistaken for being one in the same. It's not uncommon for the Hemophilia Treatment Center to receive a call from someone wanting to RSVP for one of the Chapter's events or for the Chapter to receive a call from someone looking for a nurse or doctor. In all cases, staff members from both organizations are happy to assist and direct callers to the proper organization. However, we'd like to take this opportunity to provide you with a description of both organizations and hopefully clear up any confusion!

Organization Name / Logo	The Hemophilia Center of Western Pennsylvania	WPCNHF Western Pennsylvania Chapter of the National Hemophilia Foundation
Contact Information	**Address:** 3636 Boulevard of the Allies Pittsburgh, PA 15213 **Phone:** 412-209-7280 **Website** http://www.hcwp.net **E-Mail:** hcwp@itxm.org	**Address** 20411 RT. 19, Unit 14 Cranberry Township, PA 16066 **Phone** 724-741-6160 **Website** http://www.westpennhemophilia.org **E-Mail** info@westpennhemophilia.org
Overview	The Hemophilia Center of Western Pennsylvania (HCWP) is a free-standing clinic in existence for over 35 years and under the Directorship of Margaret V. Ragni, MD. HCWP is the only hemophilia center providing comprehensive services to affected individuals and their families in 27 counties of Western Pennsylvania. At HCWP, there is a strong clinical research component, providing education, assessment, and enrollment on numerous protocols for safety and efficacy of new clotting factor concentrates, antiviral drugs for HIV and HCV, prospective epidemiologic studies of Hemophilia and von Willebrand disease complications.	The Western Pennsylvania Chapter of the National Hemophilia foundation (WPCNHF) is a non-profit 501c3 organization that has been in existence for over 50 years and is one of over 50 chapters across the country that is affiliated with the National Hemophilia Foundation. Jennifer W. Pegher is the Executive Director. WPCNHF is the only organization serving 26 counties in Western Pennsylvania that is dedicated to improving the quality of lives with those living with bleeding disorders, through education, advocacy, resource, and referral. Educational opportunities include a family education weekend, couples retreat, dinner meetings, and support group meetings. Advocacy events include Harrisburg Day. Major fundraisers include a Walk, Run, Take A Bough Holiday Tree Auction, and a Golf tournament.
Funding	The treatment center is supported by PA Department of Health, Health Resources and Services Administration, Centers for Disease Control and Prevention, and a Factor Program with separate funding for ongoing federal and pharmaceutical research projects.	The Chapter is supported by various Grants, Donations, and Fundraisers.
Staff & Board	Staff at HCWP includes Medical, Nursing, Psychosocial, Physical Therapy, Administrative and Clerical positions. HCWP is governed by a Board of Directors. Staff members from the HCWP are often invited to speak at WPCNHF educational programs and fundraising events.	Staff at WPCNHF includes 1 full-time Executive Director, 1 part-time Development Director, and 1 part-time Office Administrator. WPCNHF is governed by its own Board of Directors.

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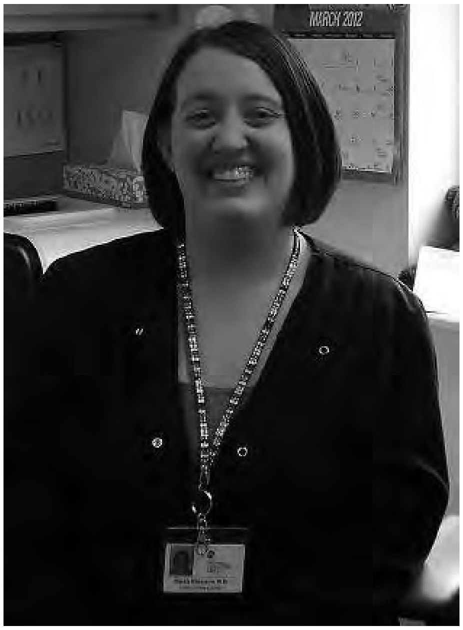
Meet the HCWP staff

JEFF WAHAL

Jeff began his role as the Center's CFO and Director ofthe Factor Program in February 2012. He has twenty years experience with various roles in the accounting and finance field, including fifteen in the medical community. In his most recent position, Jeff worked for ZOLL Medical's LifeVest unit and was responsible for the Company's financial reporting and planning. He has held the roles of Finance Manager and Controller at Precision Therapeutics and invivodata, respectively. Ieffhas a bachelor's degree in accounting from The Pennsylvanian State University and a master's degree in business administration from The University of Pittsburgh.

SARAH SIMPSON



Sarah is one ofthe new clinical nurses at HCWP. She started working at the Center in January, 2012 and brought with her extensive experience in emergency medicine. She received her nursing diploma from Ohio Valley General Hospital’s school ofnursing and began working in their lCU and then went on to ER nursing. Prior to this, she worked for five years as a medical assistant in a doctor’s office. Sarah loves education and plans to continue her schooling in the future.

Advocacy (continued from page 1)

Disease Control (CDC) has proposed in its budget for FY 2013 to support surveillance at only 50 hemophilia treatment centers in 2013, rather than the full network of 135 centers. While in Washington, we asked Congress to restore hemophilia treatment center funding and direct the CDC to maintain hemophilia program activities. Additionally, we discussed key health reform implementation issues that affect individuals with bleeding disorders and advocated for co-sponsors of HR 1919, the Bleeding Disorders SAFE Act, introduced by Representative Carolyn McCarthy of New York, which would create screening and education programs targeting adolescents with undiagnosed bleeding disorders. The meetings were productive, but we are far from accomplishing our goals. It is important that all bleeding disorders community members contact their representatives and senators and ask for their support of the bleeding disorders community. We cannot achieve our goals without your help. To learn more, please contact the office to see how you can join our efforts.

In early April, Chapter staff hosted Chapter members aboard a bus to Harrisburg for our annual Harrisburg Day to advocate for individuals in Pennsylvania living with vWD and hemophilia. Chapter staff members, Janet Barone, Madonna McGuire Smith, Jennifer Pegher, Hemophilia Center of Western Pennsylvania CFO Jeff Wahal, Chapter members, Heather Kosto, Martin Bobro, Celeste Bobro, Bianca Bobro, Allyson Laure, EJ Villegas, Amy Lowe, Alexandra Mahoney, Cameron Cedeno, Mike Smith, Maddie Smith, Devin Smith, and Erin Smith traveled to the state capital to advocate for the bleeding disorders community with state officials. In conjunction with the Delaware Valley Chapter of the NHF, Chapter members participated in over 160 scheduled meetings with House and Senate members. During our meetings we discussed several issues the bleeding disorders community faces. Most important was the discussion surrounding the Governor's budget for FY2013. We informed our legislators that we are concerned with the FY2013 budget as the hemophilia line item was cut an additional five percent. Chapter members asked members of the House and Senate to push for the reinstatement of funding for the hemophilia programs throughout the Commonwealth. Additionally, we let our legislators know that we continue to monitor the impact health reform will have on our community and informed our legislators that we would like to participate in conversations regarding such changes as health reform moves forward; particularly should decisions be left to the state. The state issues are incredibly important and our community should remain knowledgeable and vocal on the state level as well.

Thank you to all of our advocates who traveled to Washington, DC and Harrisburg. We could not advocate for the community effectively without you. If you were unable to join us this year, please consider joining us for our advocacy days in 2013. Both cities provide an excellent opportunity to educate your legislators on bleeding disorders, as well as the opportunity to educate yourself and your family on the legislative process. Remember, you are the best advocate as you have personal stories to share with your legislators. It is never too late to inform them of what is going on with you and your family. Additionally, please remember that personal contact in the district office is just as effective.

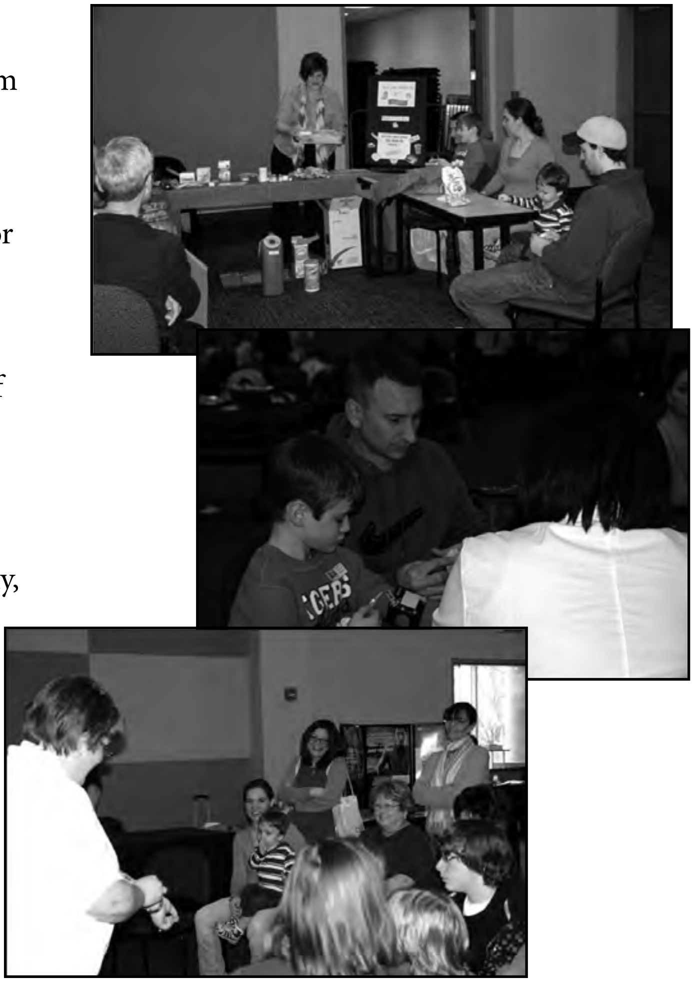
Any questions or concerns regarding legislation or advocacy efforts on the federal or state level can be answered by Chapter staff. Please contact the office of WPCNHF for more information or to offer comments.

Chapter News (continued from page 1)

Veins station supported by Kim Goldby-Reffner, RN, and Adam Kufen, RN. Prizes were distributed, games were played, songs were sung, and a good time was had by all. Some members of our community learned to infuse for their first time, while others stuck to the practice station. The level of participation or skill set did not matter as each attendee was educated in a way that has never been done before at a WPCNHF event.

WPCNHF would like to offer a special thank you to the staff of HCWP for their contributions to the event. Each member of the HCWP staff took several hours out of their personal time prior to the event to prepare for the fun-filled Infusion Day, in addition to the hours spent at the event itself. WPCNHF is incredibly grateful of their time and collaboration. Additionally, we would like to thank our sponsors for their support of our first annual Infusion Day. Sponsors were as follows:

Accredo HHS
Baxter BioScience
Bayer HealthCare
BioRx
CSL Behring
Hemophilia Center of Western Pennsylvania
Novo Nordisk
Pfizer



Spotlight on the member

The week of April 15 was National Volunteer Week and to celebrate the occasion, the Chapter would like to highlight an active and dedicated volunteer. Maria Steele-Voms Stein of South Fayette is a woman in our community living with von Willebrand Disease (vWD). Maria lives with her husband Silvio and daughter Amanda and she has been a star volunteer with WPCNHF for many years. Maria has donated much of her time and support to the Chapter and has encouraged others in the community to do the same.

Maria is a role model for individuals living with vWD. Maria realized she had vWD as she suffered from postpartum hemorrhaging and was forced to undergo a medically necessary hysterectomy in order to stop the bleeding. Maria was sent to be tested and discovered she had vWD. Yet, Maria has not let her diagnosis stop her. In her spare time Maria enjoys spending time with her family and friends, traveling, and attending WPCNHF and NHF events. Maria thoroughly enjoys volunteering for WPCNHF, particularly the Take A Bough planning committee. Maria served as the Walk team captain of the WPCNHF Winning Women Walk team in 2011 and hopes to promote Chapter women's activities going forward.

Maria's best advice to a new family diagnosed with a bleeding disorder is to ask questions. Maria states that each person is their own best advocate and that it is imperative to ask questions until you are satisfied with the answer. She also noted how important it is for families to get involved in the bleeding disorders community as you will be surprised what you can learn and gain. For Maria, she has gained a sense of belonging. WPCNHF is honored to have Maria as part of our community and proud to recognize her for being an extraordinary volunteer.

Please Join the Western Pennsylvania Chapter of the
National Hemophilia Foundation

FOR TWO GREAT EVENTS ROLLED INTO ONE!

Annual Meeting and 2012 Hemophilia Walk Kickoff

Thursday, July 19 at

5:00 p.m. with dinner beginning at 6:00 p.m.

At PNC Park's Lexus Club

Pittsburgh, PA

The evening includes:

- Dinner
- Annual Meeting
- Walk Testimonials
- Educational PNC Park tour of dugout, batting cages, warning track, press box, and clubhouse for children ages 5-15
- Family Carnival to Celebrate the Walk Kickoff
- Cash Bar & Chinese Auction

RSVP by July 3 via e-mail: rsvp@westpennhemophilia.org or phone: 724-741-6160 or 800-824-0016

Provide the following information:

1) Your first and last name
2) Your phone number and e-mail address
3) The total number in your party
4) The number of people in each of the following age groups:
    - # of children under the age of 5
    - # and ages of children ages 5-15
    - # of adults (over age 15)

Originally posted on Infuzr

How Hemophilia Has Shaped Who I Am: A 10-year-old's perspective

By Dillinger Gould

Hi! My name is Dillinger. I have severe hemophilia A. I have to get infused in the arm every other day. My earliest memory of having hemophilia was when I was three or four years old and I got my port put in at Children's Mercy in Kansas City. A port is something that doctors put in your chest or stomach that connects to your heart so that you can get poked in the port with meds that will help your blood to clot. Even though I lived in Wichita, Kansas, I had to go to an HTC a few hours away because neither Wichita nor anywhere else close by had a Hemophilia Treatment Center.

Around the time before I got my port put in, I did not know what hemophilia was or how I got it. When I was little, I barely cared or noticed it. I just thought it was a sickness I had to take care of for awhile. Why? I have no idea. I was really curious though. That's what got me thinking I want to become a doctor when I grow up. That's all I remember. Now I know hemophilia is a blood disorder in which my body does not clot, so I need my meds. My mom is the one who taught me everything I needed to know about hemophilia.

My mom (and camp) taught me how to mix my meds and infuse. Now I infuse, by myself, in my arm every other day. If I get a bleed I might have to infuse extra doses to heal, but I do not get bleeds very often because now that I'm older I have learned to settle down and do stuff that will not hurt me very much. Getting bleeds is sort of unexplainable because they feel different every time.

When I was a kid, I didn't care for hemophilia, but I didn't really pay attention to it. My feelings have changed a lot from when I was a kid to now. Now I feel embarrassed about having hemophilia, because sometimes I have to go to school on crutches or I get bloody noses and everyone stares at me. When I get hurt, I have to go straight to the nurse's office (unlike other kids) and I get hurt more easily and more often. It makes me feel different.

What I like about hemophilia is going to camp because I can do things I usually cannot do, like be real active and play sports without getting hurt because lots of people are watching and can take care of me if I get hurt. What I do not like about hemophilia is getting up early every other morning on weekdays to get an infusion before school. It's very boring and I wish I could sleep more.

I think doctors will hopefully find a cure sometime in maybe 5-20 years because it may be soon or it may be longer. I don't have the direct time, but I'm pretty sure it should be between those years.

Having hemophilia makes me feel different from other kids at school and in my neighborhood for many reasons. I cannot play rough (run, jump, play games like football...). I have to infuse myself every other day. I could get hurt easily. I could probably name them all day, but see, that doesn't matter to me. I have an awesome life and I don't ever want to ruin that. Hemophilia has played a large role in shaping who I am today and I wouldn't want who I am to be any different. But I would be honored if anyone helped find the cure.

Calling all men with a Bleeding disorder ages 16-27!

SAVE THE DATE: for a presentation titled, "Real Life with Bleeding Disorders"
Enjoy an afternoon of fun, games, and networking with fellow young men in Western PA.
This topic will touch on life with Hemophilia A but will be beneficial to all young men with bleeding disorders.

Saturday, June 9, 2012

Join WPCNHF and listen to young men from across the U.S. talk about everything from making the transition to college/trade school to differences between a job versus a career. Lunch will be served. Look for details in your mailbox soon….

Board of Directors

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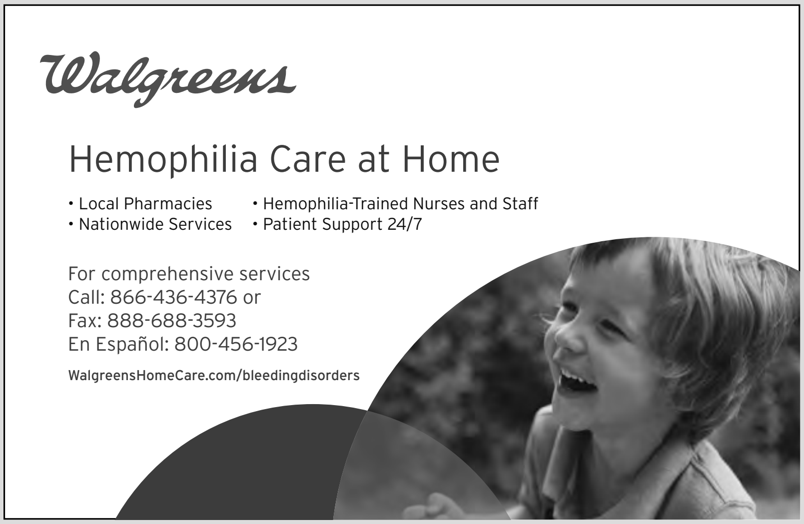
Office Administrator
Janet Barone

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.



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
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