



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

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DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

If your company is participating in the United Way campaign, you may designate all or a portion of your gift to the Chapter.

WPCNHF Contributor
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is: 83

Hemogram

Take A Bough 2011

The 2nd Annual Take A Bough event was held at the Galleria at Pittsburgh Mills, November 18 - 21. It was an exciting year for the Chapter, as we raised over \$45,000 on this annual event. We are extremely grateful for the donations we received from our Chapter members, our partner organizations and the new donors who offered their support for the first time.

Planning and preparation for the 2nd Annual Take A Bough event began in February of 2011. We truly appreciate the hard work and dedication of our volunteer planning committee. Special thanks to the following committee members: Rita Dull, Melissa Kendrick, Nora Latcovich, Debbie Lowery, Scott Miller, Dawn Rotellini, Sam Rotellini, Diane Standish, Laureen Temple and Maria Steele-Voms Stein. In addition, a big thank you goes to Casey Mahaven, of Mahaven Events, for helping coordinate the entire event.



Decorated holiday trees at the 2nd Annual Take A Bough Event

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Chapter News

Nine First Step families gathered in Erie, on October 14, for a virtual tour of the emergency room (ER) at Children's Hospital of Pittsburgh and a discussion on ER visits. An in-person ER tour was prohibitive, due to certain rules and regulations at Children's Hospital, so Kristen Jaworski, R.N., B.S.N., CCRC, of the Hemophilia Center of Western PA (HCWP), brought the ER to us! She walked us through photographs of the hospital and different stations in the ER. The group discussed all stages of the process from what to do before you leave home to following up with your doctor the next day. Throughout the program, the families shared experiences and tips with each other and created a list of items to pack ahead time, in an ER bag, to help make the trips to the ER go more smoothly for all family members.



Kristen Jaworski, RN, BSN, CCRC of HCWP discusses ER preparedness with First Steps families

While the parents participated in the meeting, all of the children (many young children) were supervised and entertained with activities, by volunteers. We sincerely thank Laureen, Sarah, and Grant Temple, and Scott Miller for the gift of their time and energy, so the parents could participate in this program.

Letter from the Executive Director, Jennifer Wahlen Pegher

Dear Members,

Over the past several months you have seen some changes at the Chapter. From the Winter Family Program (previously the holiday party) to the request for a deposit for Family Education Weekend, these are just some of the changes we have made to ensure the Chapter is here for you and your family for years to come.

As our board President Scott Miller noted at our Annual Meeting in July, several pharmaceutical companies have changed their regulations in applying for grants, and as such, this has required the Chapter to combine education with many of our fun events. It may seem logical to forget about those companies and focus on the companies that will not discriminate based on the location of the event. I understand your concern; however, forgetting about those companies is not possible if we want the Chapter to continue to operate as usual. The events you and your family attend throughout

the year are funded by all companies. Without every vendor as a participant, it is extremely difficult to continue to host events in the same manner as years prior. In 2004, the Annual Meeting aboard the Gateway Clipper cost the Chapter \$12,000 for 361 individuals to attend. Today, the cost has doubled, yet the number of vendors has not. With that said, it is no longer feasible for the Chapter to continue to hold the Annual Meeting aboard the Gateway Clipper. I know this will disappoint many of you and many children as well; however, it is in the best interest of the Chapter to hold affordable events. This decision is difficult to make. This is also why there is now a refundable deposit requested in order for the staff to make a reservation for you and your family to attend Family Education Weekend. In the past, several families did not show for Family Education Weekend and other events, such as the boat cruise, despite their RSVP. As a result, it cost the Chapter several thousand dollars in no shows

alone. These unnecessary expenses are costs the Chapter cannot afford to cover going forward if we want to continue to service our members.

I know these changes are difficult to swallow and tough to embrace, but I ask that you consider the amount of money the Chapter spends each year to provide educational programs and activities for families in twenty-six counties. If we would like to keep the Chapter afloat, we must make these tough decisions and I hope that you will continue to support the Chapter by attending all events throughout the year. It is with you and your family in mind that each event is planned. Thank you for your support throughout the year!

Sincerely,

Jennifer Wahlen Pegher
Executive Director

Calendar of Upcoming Events

Saturday, February 25, 2012

Infusion Day
Cranberry Township, PA

March 7-9, 2012

Washington Days
Washington, DC

Friday, March 23, 2012

Men's Group: Power to Take Control and
Pittsburgh Power Arena Football
Pittsburgh, PA

Saturday, March 31, 2012

Couples Retreat: Foundation of
Intimacy and Healthy Relationships
Pittsburgh, PA

Tuesday, April 3, 2012

Harrisburg Day
Harrisburg, PA

April 27-29, 2012

Family Education Weekend
Champion, PA

Monday, May 14, 2012

Driving for Bleeding Disorders Golf
Classic
Gibsonia, PA

Ask us about sponsorship opportunities and how you can help!

Spotlight on the Member: Michelle Moser

Michelle Moser is a 19 year old young woman from Mars, PA. Michelle has von Willebrand's. When Michelle first heard of the Don Groves Scholarship, she thought it was out of her reach. However, she received the honor in July of 2011 and today she is a student at Butler County Community College where she just completed her fall semester. Michelle's GPA is 4.0 and she made the president's list in 2011. In her spare time, Michelle enjoys scrapbooking and she is currently employed at Joann Fabrics in Cranberry Twp, PA.

Michelle was diagnosed with vWD in 2006 as she had a bleeding episode. She attributes many of her successes in life to learning to cope with one of the biggest challenges of her life- vWD. When Michelle is having a bad day, she tries to remember her motto: "yesterday is history, tomorrow is a mystery, but today is a gift, that's why they call it the present."

She truly is an inspirational young woman. Her advice to those of you considering an application for the Don Groves Scholarship is simple: "Don't let anything stop you. When I applied I thought I wouldn't get the scholarship, but you should go for it, no matter what people tell you." Congratulations, Michelle!

The Don Groves Scholarship will accept applications once again this year. The generous donor, the Charlie Miller family, will pass along a flier in the coming months. The deadline for your application will be June 29, 2012.

Dear Friends of WPCNHF:

Please plan to participate in our Harrisburg Hemophilia Awareness Day (including VWD) on April 3, 2012. **THIS IS THE SINGLE MOST IMPORTANT DAY FOR BLEEDING DISORDERS IN PENNSYLVANIA THIS YEAR** and we need your help. It takes many people to make a difference and we know we can make a great impact this year. With healthcare reform on the horizon and the ongoing battle between UPMC and Highmark, now is the time to let your legislators hear your voice.

We hope you will join us for the entire day as we make visits to local members of the PA House of Representatives and ask for their support of legislation that supports individuals with bleeding disorders. We will also ask legislators to continue to support state funding to the hemophilia programs in Pennsylvania. A bus will transport you to and from the state capitol. Further information will follow via email. If you would like to learn more or to be added to our email list, please contact Chapter staff at 724-741-6160. We know it is difficult for many of you to take time off of work or away from school, but it is vital that you make time to join us this year. Thank you for your consideration.



**Please join us!
Harrisburg
April 3, 2012**

A Special Thanks to our Generous Sponsors and Donors from 2011. They are as follows:

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Sheryl Bennett	Lori Chute	Kitty Duchi	Luca Giorgi
Cindy & Bill Berenson	Ryan Chute	Steve Duchi	Glaceau/Vitamin Water
Linda Bernd	Citizens Bank	Erica & John Dudash	Glades Pike Winery
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The Brados	Greg Conley	Jessica Evans	Hemophilia Alliance
Jennifer Brauser	Alyssa Conner	Dawn Evans	Hemophilia Center of Western Pennsylvania
Bob & Marcie Brazer	Mark & Ann Connolly	Susan Eyrolles	Joe and Christen Herndon
Bonnie Bridge	Jim Constantin	Jenny Fair	Nathan Hileman
Barbara Britton			

Chapter Outreach

Put salt pork where? Can tea bags really help stop bleeding after a tooth extraction? Is acupuncture an effective option for reducing pain in people with bleeding disorders? Do these alternative methods work and are they safe? Kristen Jaworski, R.N., B.S.N addressed these topics and much more during her presentation, entitled Complementary and Alternative Medicine: Can it be used for Bleeding Disorders?

Kristen and the attendees discussed the facts and fiction of treatment claims for using complementary and alternative medicines to stop bleeding or reduce joint pain, during the Erie Outreach event held in October. This program was both interesting and enlightening! The Chapter has received very positive feedback on this program and hopes to offer it again in other areas of our region. In fact, one of the goals for the Chapter this year is to continue to expand our outreach program throughout Western Pennsylvania. When possible, we plan to offer specific educational sessions in multiple locations, to better accommodate and serve more of our members in outlying areas (as we did with the dinner program entitled Factor Forward: An In Depth Look at Breakthrough Therapies and How They Will Impact You and Your Factor, which was offered in both Pittsburgh and Erie, in the month of November). Of course, regardless of where an event is held, all of our members are always welcome to attend and we hope to see you throughout the year!

***Please join the Western Pennsylvania Chapter
of the National Hemophilia Foundation
for a Couples Program facilitated by Inalex
Communications speaker Jack Kakolewski***

***“Foundation of Intimacy & Healthy
Relationships in Coping with
Bleeding Disorders”***

Saturday, March 31, 2012

***Please join us for a follow-up couple's session from the
2011 program, “Ways to Maintain and Deepen your
Relationships”***

This program is for couples only!

In 2011, WPCNHF hosted a session for couples entitled, Ways to Maintain and Deepen your Relationships. Though this is a follow-up session, you do not have to have attended the session in 2011 in order to attend this session. This is a relationship coaching workshop specifically for couples with a bleeding disorder or those raising a child with a bleeding disorder. In a supportive community environment, participants learn practical tools and techniques, strategies, skills and goal clarity to connect more closely with the one they love. This session is for couples in a new relationship who want tools to start off successfully, as well as those in long-term, committed relationships who want a deeper connection. In addition to the main workshop you will have the opportunity to spend quality time together and network with other couples navigating the same situation.

***Space is limited so RSVP today.
Participants must be 21 years of age or older.***

When: Saturday, March 31 at 10:00 a.m. until approximately 2:00 p.m.

Where: The Renaissance Hotel, 107 6th Street, Pittsburgh, PA

Who: Couples in a committed relationship who are affected by a bleeding disorder

RSVPs must be received no later than March 5, 2012 to rsvp@west-pennhemophilia.org or 724-741-6160

Please include the following information:

- Names and ages of both attendees
- Phone number
- E-mail address

***Children are not permitted to attend this event.
There is no daycare provided for this program.***

Chad, Heather, and Connor Hillegas	Taylor Lichty	Michael Engdahl, Esq.	Jillian Pevo
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Mary Hiller	Kristin & Michael Light	Adam Miller	Pfizer
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Mark Hiltz	Margie Linville	Charlie Miller and Family	Gardens
The Hoffman Family	Emma Jean Lipniskis	Dave and Cindy Miller	Vikki Pickard
Kristin Hokoyama	Jeff, Antoinette and Sarah Lipniskis	Dr. Jim Miller	Joe Piscitello
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Kimmie Johnson	Vicki Mansfield	Brianna Murray	Brian Praetzel
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Marv Levin	Violet Metropoules	Karen Peterson	Douglas Sain
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Joseph Silipo
Beth Simoes
Brendon Simpson
Emily Skufca
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Karen Slater
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Karen Smith
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Matthew Stevens
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Kristy Stockmal
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Target at Mt. Nebo
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Sue Taylor
Vergil Taylor
Joanna Taylor Stone
Laureen Temple and Family
The Andy Warhol Museum
Cahouet Charitable Trust
The First National Bank
The Kruger Street Toy and Train Museum
The Original Fish Market
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Mindy Zeh
Lei Zhang
Ziccardi Patios & Sunrooms Inc.
Vicky Zyra

Please forgive any errors and omissions. If your name was omitted, we sincerely apologize for this oversight. Please contact the Chapter and we will ensure you are recognized. We appreciate every donation.

2011 NHF Annual Meeting



Alicia and Landon Unger enjoy the final night event at NHF's Annual Meeting

Submitted by: Alicia Unger, mother of 20 month old, Landon and 2011 NHF Annual Meeting Grant Recipient

My son and I were fortunate enough to receive a grant from WPCNHF to attend the 2011 National Hemophilia Conference. This was big excitement for me as I am always eager to gather more information and connect with other families within the bleeding disorders community.

I attended various seminars during the conference, each of which I happily walked away with a better understanding of information learned in the past or had been taught something completely new. I gained a lot of knowledge about new medications coming in the future and learned how I can be the best possible advocate for my little boy. I was also glad to attend a seminar that explained the differences between the four largest bleeding disorders. I didn't realize that each disorder can have such different complexities.

I was truly inspired by going to the legacy of Ryan White session. This story was a real heart breaker, but Mrs. White and her son are such inspiring people! It was wonderful to learn that Ryan had his head held so high through such difficult times and challenges he faced. I did cry the entire time, but it's great to see how far the Hemophilia society has come.

We thoroughly enjoyed our time in Chicago and very much appreciate the opportunity WPCNHF provided us in going! We look forward to attending again in the future! Thank you!

Highmark & UPMC Contract Update

Diane S. Standish, LSW

There is news on two fronts in our Western Pennsylvania insurance saga. First, the PA House of Representatives passed a bill (HB 2052) in December that would allow the state to extend the June 30, 2012 expiration date of the Highmark-UPMC contract, then force both parties into mediation and binding arbitration. The

bill will now go to the PA Senate, which is already working on a similar bill.

Second, as you may have already heard through the media, Highmark and UPMC have announced that Highmark subscribers will be able to continue to see UPMC doctors at current in-network (cheaper) rates until June 30, 2013. (The contract ends on June 30, 2012, but has a one-year phase-out time.) Previously, it was clear that Highmark could still use UPMC facilities at in-network

rates until the 2013 date, but there was uncertainty about whether Highmark subscribers could still see UPMC doctors at those rates. Now it is clear that both UPMC facilities and doctors will still be included (at in-network rates) in the Highmark network through June 30, 2013.

UPMC is still refusing to consider negotiating a long-term contract with Highmark beyond June 30, 2013. However, most observers see the recent announcement as a positive step that may

bode well for the future of these two health care giants.

As a reminder, the Hemophilia Center of Western PA will continue to provide services to all of our patients regardless of insurance coverage. Both the Center and Chapter staffs are keeping a close watch on the Highmark/UPMC situation and will keep you posted.

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Take A Bough 2011 (continued)

During the week of November 14 – 17, numerous volunteers helped transform an empty store into a holiday extravaganza by setting up 93 trees, wreaths and tabletop displays donated by individuals and businesses from all over Western Pennsylvania.

From November 18 – 20 the event was open to the public. Hundreds of people passed through the decorated holiday items throughout the three day event. We offered a jewelry make-n-take craft as well as a children's craft option where kids of all ages were able to decorate ornaments to take home. A raffle for a \$600 Tree of Gifts was offered for \$5/ticket and was won by the Shoemaker family.

A very big thank you goes out to all who sponsored the event, donated trees, wreaths and table top displays and all who volunteered their time to help make the event such a success.

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NHF CEO, Val Bias, addresses supporters of WPCNHF's Holiday Tree Auction

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Hampton Dental
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The event ended with a beautiful Donor Reception on November 21 where Val Bias, CEO of the National Hemophilia Foundation and Dr. Margaret Ragni of the Hemophilia Center of Western Pennsylvania inspired us with their encouraging words.

It was an exciting event and we hope to continue the tradition for years to come. Mark your calendars for November 16 - 18, 2012. Look for more information to come!

Planning for the trip to the ER

- Call your hemophilia treatment center or your physician. They can contact your local ER to let them know you are a hemophilia or von Willebrand (vWD) patient and you are on your way.

What is the phone number? _____

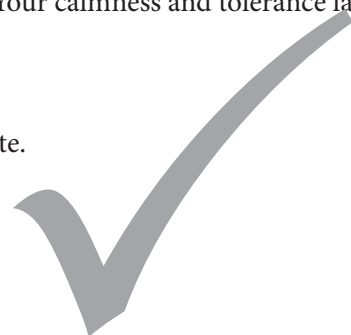
- Know your specific diagnosis and treatment plan. Have your exact diagnosis firmly in your mind, or better yet, written out.

What is your diagnosis? _____

- Clotting factor and infusion supplies (check with your local ER to make sure they will allow you to bring these items).
- An ice pack so you can begin icing and elevating the bleeding joint or muscle on the way to the ER and continue once you arrive.
- A letter or wallet card from your physician that outlines your treatment regimen, including dosage, so that necessary treatment can be administered without delay. Make sure the letter includes your physician's name and phone number in case the ER physician needs more information regarding your hemophilia diagnosis.
- Snacks, books, music and your favorite blanket or pillow?
Do you have an ER bag? _____
- Your knowledge of hemophilia/vWD facts. Don't expect ER personnel to be experts on bleeding disorders or the symptoms of bleeding disorders. Know enough about your diagnosis and its treatment to be able to explain it to personnel.
- Be specific with the triage nurse. Describe your bleed in specific and precise terms. Don't downplay the situation.
- Factor first. Remind the ER nurse that the first thing you need is factor, not a CAT scan or an x-ray.
- Don't throw out the factor. Vials of factor don't always match up exactly with the dosage calculated and the ER nurse's first instinct may be to toss out the leftover factor. Instead, remind the ER staff that leftover factor should be infused.
- Be prepared for questions about bruises. If questions sound threatening, stay calm and remind staff matter-of-factly that bruising is common among people diagnosed with hemophilia or vWD.
- Be patient but persistent. If you have not received treatment after a reasonable amount of time, contact your hemophilia treatment center or your primary care physician.
- Stay informed and in charge. Be careful about consenting to invasive procedures unless you fully understand them, are sure of their necessity, and pre-treat ahead of time. This includes unnecessary blood testing.
- Always treat ER personnel with the respect and dignity you want for yourself. Your calmness and tolerance lays the groundwork for a positive collaboration with the ER staff.

References:

The Emergency Room: Prepare to Succeed. Canadian Hemophilia Society website.



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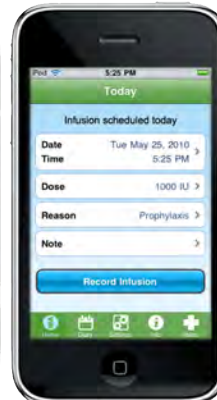
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Our Mission:

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



Western Pennsylvania Chapter of the National Hemophilia Foundation

20411 Route 19, Unit 14
Cranberry Township, PA 16066

Phone: 724-741-6160

Toll Free: 800-824-0016

Fax: 724-741-6167

info@westpennhemophilia.org

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