



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

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5 Creative Ways to Raise Money for Your 2012 Walk Team

1. Have a birthday party and ask your guests to bring donations instead of presents.
2. Host a garage sale and sell 2011 Walk Water and other WPCNHF logo items such as wristbands.
3. Host a Pampered Chef fundraiser, or any other home marketing company fundraiser such as Mary Kay or Schwann's.
4. Create black and gold items such as earrings, hair ribbons and bookmarks and sell them throughout the year.
5. Use a skill you have and "sell" your time such as hair cutting, lawn mowing, handy man, etc.

Hemogram

Hemophilia Walk Highly Successful



John's Army and Blood Brothers and Sisters teams join WPCNHF for the 2011 Hemophilia Walk.

The 2011 Western Pennsylvania Hemophilia Walk was again a highly successful event. We raised over \$45,000 on a beautiful day in North Park. The weather was fantastic! There were 30 registered teams representing families and businesses from all over Western Pennsylvania. We were honored to receive \$14,000 in Walk sponsorships (single donations of \$250 or more) from 36 businesses and families. In addition, we received 590 individual and family donations.

WPCNHF also hosted a 5K Race the same day. Run For Their Lives 5K started with registration at 7:30 a.m. and the race began at 8:30. The winners of the Run For Their Lives 5K were:

Men – Paul Stodley with a time of 17.55 min
Women – Christine Forrest with a time of 21.21 min

Congratulations to all who participated in the race! Thank you to all who contributed as sponsors of the Run For Their Lives 5K. Our donations and the number of participants increased in 2011. The Chapter looks forward to an even bigger race in 2012!

The Walk started with registration at 9:00 a.m. Stretching and warm-up began around 9:45 a.m., as the Run For Their Lives 5K awards were being presented. The Pittsburgh Pirates Parrot, Chick-Fil-A Cow and the PNC Linky mascots entertained the crowd between the Run and the Walk. The Walk officially began at 10:00 a.m. Many of the walkers completed the full 5K course. All walkers were rewarded with a Walk Medal at the finish line.

Following the Walk the festivities continued with some music from DJ

Letter from the Executive Director, Jennifer Wahlen

Greetings!

I can't believe how quickly time has flown by. 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.

The Men's and Moms' Groups were a success. We are glad that so many of you are joining us to educate yourselves and relieve some stress with other members of the community.

Camp Hot-to-Clot was fantastic this year! Campers enjoyed an Amazing Race theme, where they visited various countries and participated in many challenges throughout the week. Co-Directors Jackie Lucas and Dawn Rotellini, as well as planning committee members Kristen Jaworski, RN, BSN, CCRC, and Debbie Voss, PT, DPT, ATC, CSCS, of the HCWP worked tirelessly to plan a full week of activities for the kids and it was a memorable experience for all. Congratulations ladies on a successful Camp!

The golf classic was a success despite it being held on a rainy day. Thanks to Janet and Madonna and a highly effective Golf Committee, we had a record 99 registered golfers, 18 tee signs sold, and 23 donated auction items on which golfers could bid. It was a great day!

The Hemophilia Walk took place September 17 and we had over 30 teams and over \$45,000. I am glad so many of you joined us this year and I hope more of you plan ahead and join us on September 15, 2012. Remember, the funds raised permit the Chapter to host events throughout the year, particularly Erie Outreach, Education Weekend, and Annual Meeting, to name a few. Every dollar raised allows us to continue to host these events- all you have to do is ask your neighbor, boss, or family to give a small donation. Thanks to those of you who worked hard to make this year's Walk a success!

The 2nd Annual Run for Their Lives 5K was held in conjunction with the Walk and we had over 50 registered runners. It was a great run and all proceeds benefit WPCNHF and help defray the costs of our programs throughout the year.

Upcoming events include education dinners in both Pittsburgh, PA and Erie, PA, the second annual Take a Bough Holiday Tree Auction at the Galleria at Pittsburgh Mills, from November 18-20, and the Winter Family Program on December 3, at the Carnegie Science Center. I hope you and your family will join us.

Things are changing constantly within the

bleeding disorders community. Industry is changing rules and regulations for support of Chapter events, but there are also changes ahead in the insurance world. Rest assured, your doctors and nurses at the HCWP will continue to offer services to you and your family, regardless of your coverage. Chapter staff will continue to work with your legislators in Harrisburg to encourage consideration of H.B. 635 in the House Insurance Committee. As you know, H.B. 635 would create a standard of care for Pennsylvanians with hemophilia and other bleeding disorders, allowing them continued access to the hemophilia centers in Pennsylvania.

As always, please contact Madonna, Janet, or me at the office with any questions or concerns. Thank you for all that you do on behalf of WPCNHF.

Sincerely,

Jennifer L. Wahlen
Executive Director

Calendar of Upcoming Events

November 3

Mixers with Shakers
Doubletree Hotel, Pittsburgh, PA

November 3

Educational Dinner (Factor Forward: An In Depth Look At Breakthrough Therapies and How They Will Impact You and Your Factor)
Sheraton Erie Bayfront Hotel, Erie, PA

November 4

Educational Dinner (Factor Forward: An In Depth Look At Breakthrough Therapies and How They Will Impact You and Your Factor)
Rivertowne Pour House, Monroeville, PA

November 10 - 12

NHF Annual Meeting
Chicago, Illinois

November 18 - 20

2nd Annual Take a Bough Tree Auction, The Galleria at Pittsburgh Mills, Pittsburgh, PA

December 3

Winter Family Program
Carnegie Science Center, Pittsburgh, PA
NEW DATE AND LOCATION!!!

Ask us about sponsorship opportunities and how you can help!



WPCNHF
Cordially Invites You to Our

HOLIDAY JEWELRY-MAKING PARTY

November 15, 2012
6:00 p.m. to 8:00 p.m.

Galleria at Pittsburgh Mills
Take A Bough location
Near Dick's Sporting Goods

*All items made this evening will be sold during the Take A Bough event November 18-20.
This is an opportunity to help the Chapter raise additional funds during Take A Bough.*

Please R.S.V.P. by November 14 to
Madonna McGuire Smith at
madonna@westpennhemophilia.org or
call (724) 741-6160

Medical News: Western PA Insurance Update

By Diane Standish, LSW

Highmark. WPAHS. UPMC. If you follow the news, you have been hearing a lot about these three entities recently. What's going on? I'll attempt to explain it briefly here.

The two biggest health care systems in Western Pennsylvania are the University of Pittsburgh Medical Center (UPMC) and West Penn Allegheny Health System (WPAHS). Each of these nonprofit corporations owns multiple hospitals in our region, and many doctors' practices are affiliated with either one system or the other.

The major health insurance providers in Western Pennsylvania are Highmark Blue Cross/Blue Shield and UPMC Health Plan. The latter is, of course, owned by the UPMC system.

Highmark has had a contract for a long time with UPMC (the medical system) that allows Highmark subscribers (patients) to go to UPMC hospitals and doctors at in-network rates. That contract will expire in June 2012.

Recently, Highmark announced that it plans to buy WPAHS. UPMC then announced that once its contract with Highmark expires, UPMC will not renew it, and Highmark subscribers will no longer be able to go to UPMC hospitals and doctors at in-network rates. Then the sparks started to fly!

The Highmark-UPMC contract allows for a one-year "run-out" period when the contract ends, meaning Highmark subscribers would still be able to use UPMC medical providers at in-network rates till June 2013. However, it is not clear that this would include physician services.

At this time, neither Highmark nor UPMC is willing to "come to the table" to discuss the possibility of renewing

that contract. Both parties have launched media campaigns to try to sway the general public toward their position, and of course, to encourage us to choose their insurance plan. Millions of dollars are at stake, so both Highmark and UPMC Health Plan are aggressively marketing their insurance plans, as you have probably seen in the newspaper and on TV.

So how does this affect you? If the two parties do not negotiate a new contract, and you are a Highmark subscriber, as of June 2013 (or perhaps sooner, depending on resolution of contractual issues), you will have to pay out-of-network (higher) copays and deductibles if you choose to go to UPMC hospitals, facilities, and doctors. These cost increases could be significant. However, you will pay in-network (lower) rates if you choose WPAHS hospitals, facilities, and doctors. If you are a UPMC Health Plan subscriber, you will continue to pay in-network rates for UPMC services.

But what will the UPMC and WPAHS networks look like in 2012 and 2013? We have all watched the UPMC system grow exponentially in the past dozen years or so, as it has acquired more hospitals and physician groups. Now that the WPAHS system is more financially stable because of Highmark's purchase, we expect that it will become more competitive with UPMC by buying more hospitals and physician groups, too. Will WPAHS try

to persuade some UPMC facilities and doctors to leave that system and join WPAHS, and vice versa? This is what many people are anticipating. Amidst all of this confusion, there is one bit of good news for you! The Hemophilia Center is a freestanding, independent medical office that will continue to offer services to all of our patients, regardless of insurance coverage. The Center is accredited by both the Highmark and UPMC Health Plan networks (meaning we are an in-network provider for both plans). So we expect "business as usual" at the Center.

This situation is complex and worrisome to patients and health care providers. State legislators and the PA Insurance Commission are working to bring about quick resolution. Be assured that both the Chapter and Hemophilia Center are paying close attention to their progress and will keep you advised of any major news as we become aware of it. As always, feel free to call the Hemophilia Center staff (412-209-7280) if you have any questions about your insurance coverage. We are all hoping that our two major health care systems will end their current stalemate and work together, putting patients' needs first. Published on hemaware.org.



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Industry News: Junior National Championship Update



Devin Smith, Chapter Member, impresses instructors with his arm at the JNC baseball workshop.

To celebrate the 10th anniversary of the Gettin' In the Game Junior National Championship, CSL Behring combined four regional competitions into one national competition that was



Will McCarthy (far right, in front), Chapter Member, stands with fellow golfers on the course in Dallas, TX. Will received the award of Most Improved Golfer.

held in the Dallas/Fort Worth, Texas region. The Chapter received applications from individuals in the community and selected Will McCarthy to attend for golf and Devin Smith to attend for baseball. Will and Devin each attended

the event with one parent and both young men learned a lot. During the program, Will, Devin, and their respective parent attended educational sessions where they learned about the importance of physical fitness and participated in a clinic where they learned the fundamentals of golf or baseball and enhanced their skills. Pro golfers and baseball players with bleeding disorders hosted the program. Will received the award of Most Improved Golfer and he had an amazing time. Devin enjoyed playing baseball with the pros and is now officially obsessed with the MLB. We are proud of our young athletes and their participation in this great event!

Driving For Bleeding Disorders Golf Classic

Fore! The Driving For Bleeding Disorders Golf Classic was Tuesday, September 6 and was held at Treesdale Golf and Country Club in Gibsonsia, PA. Over 90 golfers turned out for the event, despite the rain. Various contests were available on the course; including but not limited to, putting contest, Beat the Pro contest, men's and women's longest drives, and a 50/50 inside the circle contest. All participants had a great time trying their hand at one or all contests. A good time was had by all. Congratulations to David Lichina, Jarrad Pencek, Carl Hummel and Ben Abebe for finishing first in the tournament. The 2012 golf classic will take place on Monday, May 14 at Treesdale, so be sure to brush up on your skills and join us next year!

National News: Immunizations and Hemophilia

Published on hemaware.org
By Melanie Padgett Powers

September 2011

Children and adults with bleeding disorders can and should receive the recommended immunizations for their age group. These vaccinations are often given by their primary care physician.

Most vaccinations can be given subcutaneously, or under the skin, instead of intramuscularly, or into the muscle, to reduce the risk of a muscle bleed. However, some healthcare providers may prefer to give intramuscular injections using a smaller needle in a larger muscle, like the thigh, according to "Caring for Your Child," published by the National Hemophilia Foundation.

Primary care physicians should contact your hemophilia treatment center (HTC) with any questions, particularly about intramuscular injections. HTCs can also instruct you on whether factor infusion is needed before an intramuscular injection.

Children and adults with bleeding disorders may develop bruises at the site of the immunization. Treating the area with ice can help reduce the bruising and ease discomfort.

In addition to the recommended vaccine schedule, the hepatitis A and hepatitis B vaccines are strongly recommended for everyone in the bleeding disorders community.

You can stay updated on the recommended vaccines by age group through the Centers for Disease Control and Prevention's yearly immunization schedules. Schedules are listed for children (birth through age 6), adolescents (ages 7 through 18) and adults. There is also a "catch-up" schedule to help people who've missed vaccines get back on track.

Preteens and Teens Need Vaccines, Too

As children reach middle school and high school, parents may not think about immunizations as regularly. But older kids need vaccinations, too, including a tetanus

booster and a meningitis vaccine.

The CDC recommends all preteens ages 11–12 be vaccinated against meningitis with the meningococcal conjugate vaccine. A booster dose should be given at age 16 because current data show that vaccine protection wanes in most adolescents within five years. If a teenager hasn't had the meningitis vaccine, the CDC recommends parents talk to the teen's doctor about getting the vaccine now, particularly if the teenager is preparing to move into a college dorm or military barracks. Bacterial meningitis, which can cause brain damage, hearing loss, learning disabilities and death, is more commonly diagnosed among preteens and young adults.

Other Vaccines to Consider

Parents may also want to consider the human papillomavirus (HPV) vaccine for their children. Some types of HPV can cause cervical cancer and genital warts. The CDC recommends the HPV vaccine be given at ages 11–12. All girls and women ages 11 to 26 should be vaccinated with the three-dose HPV series. The vaccine has also been approved for boys and men ages 9 through 26 for protection against genital warts.

Another important vaccine to consider for your family is the influenza vaccine. CDC recommends a flu vaccine every year for everyone 6 months and older, including immunocompromised people, such as those with HIV. Immunocompromised people should not use the FluMist® nasal spray because it contains a live form of the vaccine; it is only recommended for people through age 49. Flu season runs from October through May, often peaking in January or February.

Jennifer Domm, MD, a hematologist at Vanderbilt Children's Hospital in Nashville, Tennessee, encourages parents to talk over vaccination recommendations with their HTC and to stay updated on vaccination schedules. "Any child who gets any of these routine childhood diseases that can be prevented can experience severe symptoms," she says. "Overall, the benefits of vaccinations certainly outweigh the risks."

**United
Way**



DESIGNATE UNITED WAY GIFTS TO THE CHAPTER

**If your
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participating in
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campaign, you
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all or a portion
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the Chapter.**

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Beading with Moms

A great time was had at the Moms' Group meeting in July! A small group of women from our chapter gathered at the Chapter office for beading and camaraderie. Darla Clayton taught the group how to make beautiful beaded earrings and bracelets, to keep or give away as gifts.

The women at the Moms' Group enjoyed making the jewelry so much that they would like to have another beading session, with all women who would like to attend, to create earrings and bracelets that can be sold at this year's Take A Bough, Holiday Tree Auction.

The group also thought it would be really nice to have similar gatherings and educational meetings that included all women from our community who are affected by a bleeding disorder: carriers, spouses, women with a bleeding disorder, sisters, grandmothers, etc. So keep an eye out for educational meetings and special



Beautiful earrings and necklace created by Chapter Member, Darla Clayton.

gatherings for the new WPCNHF Women's Group!

If you'd like to suggest a topic for the WPCNHF Women's Group and/or would like to join us to create jewelry for the Chapter to sell at the Take A Bough fundraiser (all beading supplies are provided), please send a note to info@westpennhemophilia.org and put "Women's Group" in the subject line.

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First Annual Fire and Iron Dice Roll: Ride For Their Lives

It was a beautiful day in Conneaut Lake, Pennsylvania on Sunday, September 25, 2012. The sun was shining on the First Annual Fire and Iron Dice Roll: Ride For Their Lives. The morning started out overcast with a chill in the air, but just before 10 a.m. as the riders were getting on their motorcycles the sun began to shine, the clouds cleared and it warmed up. It truly turned out to be a beautiful day! Thank you so much to Alicia Unger for organizing the event!

Between 10 a.m. and 12 noon, 44 bikers and riders departed from the Conneaut Lake Fire Station #2 for five dice roll locations. The first stop was Fairway 12 Restaurant and Lounge. The second stop was Avonia Tavern. The third stop was Kwik Fill and the fourth and fifth stops were Hunters Inn and Dry Dock Bar and Grille. At each stop the riders were given two dice to roll and their scores were recorded. The prize money totaled \$250. Sharon Smock was the first prize winner at \$150 and all was donated back to WPCNHF. Barb Pfaff was the second place winner at \$100 and she donated back \$40. Jim Muma was the third place winner, receiving \$50.

Following the Ride all were invited back to the Conneaut Lake Volunteer Fire Department Station #2 to enjoy a nice hot meal served by Diane's Deli out of Waterford, PA. In addition, there were 24 baskets raffled off in a Chinese Auction and a 50/50 contest was held. Alicia was able to raise \$2,000 for the Chapter!

Thank you to all who helped as volunteers and sponsors of the Fire and Iron Dice Roll event. There were volunteers who helped Alicia in advance of the event as well as throughout the day of the

event. The sponsorship was overwhelming – thank you to the following sponsors:

CSL Behring
Fire and Iron Station #2
Station #3
Conneaut Lake Volunteer Fire Dept
Ziccardi Builders Inc.
K & M Graphics Inc.
Peirce Contracting

Watson Auto Service
Hickory Grove Orchard
Greenville Auto Parts
Economy Electric Supply
The Richard Pitts Insurance Agency
Ram Tool
Street Track and Trail

The Fire and Iron Dice Roll is a charitable non-profit event with 100% of the proceeds going to the Western Pennsylvania Chapter of the National Hemophilia Foundation (WPCNHF). WPCNHF is dedicated to improving the health and well being of individuals and families living with bleeding disorders and the priority placed on those living with or serving those with bleeding disorders. The mission of the Fire and Iron Dice Roll is to create a source of funding to support this charitable organization whose programs and activities benefit the bleeding disorders community; funding that will assist families with bleeding disorders to meet their socio-economic needs; and funding that will support research to find a cure for all bleeding disorders.

Congratulations to Alicia and Landon Unger and their family for such a successful event! Look for information in upcoming newsletters if you have a motorcycle and are interested in participating in the 2nd Annual Fire and Iron Dice Roll: Ride For Their Lives.

Spotlight on the Member: Alicia and Landon Unger



Chapter Members, Alicia and Landon Unger

January of 2010 was both an exciting and terrifying time for Alicia Unger of Conneaut Lake, Pennsylvania. Alicia gave birth to her son Landon on January 15. Alicia was assured by doctors prior to Landon's birth that she was not a carrier of hemophilia so she was preparing herself for a "normal" new mom experience.

Shortly after Landon's birth he was

circumcised as most little boys are, but his didn't go as smoothly as expected. He had bleeding difficulties for several days following the procedure. After much stress, discussions with doctors and an ambulance ride to Children's Hospital of Pittsburgh, Landon was diagnosed with severe hemophilia B.

Since his birth Alicia has experienced a variety of challenges that all families face while raising a child with a bleeding disorder, but she is facing those challenges alone. She is the only parent involved in Landon's life so every decision and every move rests on her shoulders. Even as she shoulders that burden, Alicia is one of the most positive and enthusiastic people involved in our Chapter. She is an active volunteer and organizes her own fundraisers (see article on the Fire and Iron Dice Roll) on behalf of the Chapter.

Alicia creates a fun and educational environment for Landon by taking him to the zoo, going for long walks, playing ball and swimming as often as she can. Alicia and Landon enjoy the Walk as their favorite WPCNHF activity, besides the Fire and Iron Dice Ride. They have benefitted from the educational programs offered by the Chapter but the most valuable information has been the interaction with other families who experience the same challenges in their daily lives. The affected families of our Chapter have touched her life beyond her expectations. It is because of this connection that she feels dedicated to the Chapter and its members that she tirelessly volunteers to help the Chapter. Alicia and Landon are looking forward to all of the experiences they will have over the coming years as members of the Chapter.



The Hemophilia Center of Western Pennsylvania

FACTOR PROGRAM

Services

- Factor Products
- Home Treatment Supplies
- On-Line Factor Ordering
- On-Line Home Treatment Log Submission
- 24 - 48 Hour Delivery
- Lot Tracking for Recall Notification
- Patient Education
- Insurance Benefit Information Assistance

Benefits

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412-372-8199

RIVERTOWNE NORTH SHORE
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412-322-5000

For more information and upcoming events visit our website - myrivertowne.com

Hemophilia Walk Highly Successful (continued)



Paul Stodley finishes the Run for Their Lives 5K first with a time of 17:55. Congratulations, Paul!

Dave from First Class Entertainment. Other activities included a giant inflatable slide, Irish dancing from the Bell School of Irish Dance, balloon art, face painting, a photo booth, an inflatable skee ball game and lots of food. Prizes were awarded to a variety of teams and individuals. By the day of the Walk, the top fundraising team secured more than \$5,000 (Congratulations BoardWalkers!) in donations and the top three individuals raised over \$2,000 each (Congratulations Scott Miller, Alicia Unger and Trent Clayton!).

Our 2011 Walk was successful because of the dedication of our Walk Chairpersons, planning committee, teams and team captains. We would like to extend a big thank you to



Chapter Members Mandy Abergg (left), her son Cooper (far right), and Mandy's cousin Erica Duvall (middle), smile after finishing the Walk. Cooper was the youngest walker this year. Congratulations, Abergg family!

Nick and Marie Vizzoca for taking on the duties of being our Walk Chairpersons this year. The Vizzoca's worked to secure monetary donations as well as auction items, including a football signed by Hines Ward and Mike Wallace. Thank you, Nick and Marie! In addition, our Walk planning committee, Darla Clayton, Alicia Unger and Marie Vizzoca worked tirelessly throughout 2011 planning for our big day. And, finally we would like to extend a huge thank you to the following team captains for their hard work and fundraising efforts:

Accredo HHS	Melissa Kendrick
Andrew's Allies	Laurie Lipniskis
BoardWalkers	Scott Miller
Cameron's Walking Sticks	Janet Barone
Cooper's Troopers	Mandy Aberegg
Cruzzin' 4 Bruzzin'	Kim Ebsworth
Cushing Clan	Jessamyn Cushing
Eligio's Factors	Patricia Collins
Factor Ian	Karen Slater
Garrett's Gang	Kris, Heather and Garrett Kramer
Gino's Gang	Dawn Rotellini
Heights Hikers	Madonna McGuire Smith
ITXM Central Blood Bank	Amy Heaster
Jeff's Journey	Elmira Rizzo
John's Army	Missy Conely
Landon's Letters	Alicia Unger
Luc's Troopers	Marie Vizzoca
Matt's Factor	Lenore Hiller
Royal Blood Brothers and Sisters	Stacy McCarthy
Super Ritchey Bros.	April Ritchey
Team Baxter	Erik Drotos
Team Eskelson	Denise Eskelson
Team Grifols	Nora Latcovich
Team HCWP	Diane Standish
Team JAVAC	Heidi Gross
Von Willewhat?	Cassie Miller
VWD Won't Stop Me!	Darla Clayton
Wahlen's Walkers	Jennifer Wahlen
Walgreens	Cindy Griceck
WPCNHF Winning Women	WPCNHF Staff

Congratulations to the winner of our t-shirt voting contest – John's Army raised the most money through coin voting – their t-shirt received \$45.87. John's Army t-shirt will be on display at the Hemophilia Center of Western Pennsylvania throughout the year until a new winner is crowned at the 2012 Walk. Congratulations, John Conely!

Planning has already begun for the 2012 Western PA Hemophilia Walk and Run For Their Lives 5K. Save the date of September 15, 2012, for an exciting day in North Park!

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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.

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 needleless reconstitution system

mixers with shakers

WPCNHF has been selected to participate at Mixer With Shakers, a fundraising opportunity for non-profits through the Pittsburgh Airport Area Chamber of Commerce.

event details

Thursday, November 3, 2011
 5:30pm-9:00pm
 Doubletree Hotel, Pittsburgh Airport

A Chapter member will be the bartender for the WPCNHF and everyone interested in attending and supporting the Chapter should send an e-mail to info@westpennhemophilia.org. Tickets are \$20 and support WPCNHF. Please join us!

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.



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