Hemogram

WPCNHF

Western Pennsylvania
Chapter of the National
Hemophilia Foundation

Summer 2011
Inside this issue

The Miller Family Auction and Car Show

Charlie Miller and Family

Saturday, June 18, 2011 was another beautiful day in Newell, WV for many of reasons. The sun was shining on the Sixth Annual Miller Family Auction and Car Show. The Car Show began at 10 am with the registration of cars and the live auction began at 11 am. Nearly 20 cars and a crowd of approximately 50 people participated in the event held at Clark Field located in Newell, WV. It was a beautiful day and a beautiful setting for such a great event.

The Miller Family Auction and Car Show is a charitable non-profit event with 100% of the proceeds going to the Western Pennsylvania Chapter of the National Hemophilia Foundation (WPCNHF). Of the amount donated every year there will be a $1,000 scholarship awarded to a qualified individual. We are 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 Miller Family Auction is to create a source of funding to support the charitable organization whose programs and activities benefit the bleeding disorders community; funding that will assist families with bleeding disorders to meet their socio-economic funding that will support research to find a cure for hemophilia; and funding that will support students with bleeding disorders through a designated scholarship program for higher education.

Charlie Miller Presenting
the Annual Trophy

Each year the scholarship is given to a WPCNHF member or immediate family member of a person with hemophilia, von Willebrand Disease, or a related inherited bleeding disorder. The

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2011 Benefit Wine Tasting

The WPCNHF held its annual Benefit Wine Tasting at Rivertowne North Shore on Wednesday, May 18, 2011. Over 100 people joined in the festivities of the evening. We would like to thank our sponsors:

Baxter BioScience
Rivertowne North Shore
Accredo-HHS
Pfizer
Affinity Biotech
Bayer Healthcare
BioRx
CSL Behring
Glades Pike Winery
Greenhouse Winery
Kavic Winery
Starr Hill Winery
Wilhelm Winery
The Winery at Wilcox

In addition to the wine and beer tasting at the event, winemaker Kenn Starr and Rivertowne North Shore Manager, Rob Bolte, spoke about making wine and brewing beer. Kenn talked about selecting wines and how wines are produced in Pennsylvania. He mentioned some of the history of the wineries in west/central Pennsylvania and the fantastic grapes grown in the Lake Erie Region. Rob did an excellent job of explaining the different tastes of beer and the ingredients that go into making beer varieties. He explained how adding hops to the process makes the beer slightly more bitter tasting and that lighter beers tend to have a more “clear” look to them. Additional fundraisers at the event included Chinese auction baskets and a 50/50 contest. Thanks to all who volunteered at the event and to all of our attendees for a very enjoyable event!

Please join us!

2011 Western PA Hemophilia Walk

Saturday, September 17, 2011
Boathouse at North Park
in North Pittsburgh

9:00 am Registration
10:00 am Walk Begins

Register for the Walk by visiting the WPCNHF website (www.westpennhemophilia.org) and clicking the Walk Banner

Letter from the Executive Director, Jennifer Wahlen

Dear Chapter Members,

I wanted to take the time to introduce myself to the Western Pennsylvania Hemophilia community. My name is Jennifer Wahlen, your new executive director and a native Western Pennsylvanian. I am happy to be home and am delighted to join such a well respected organization. I am anxious to begin our work together and expand awareness of hemophilia across all 26 counties in Western Pennsylvania. There are many fantastic fundraisers and educational programs on the agenda in the coming months and I look forward to meeting you and your family at our next event.

A dear friend of mine was always an inspiration to me; he volunteered at a local camp with children of all ages, genders and races each summer and fell in love with the camp and the kids. He was the definition of a "giver." When I learned about WPCNHF and Camp Hot to Clot, it reminded me immediately of my friend who is no longer with us. For the past year I had begun searching for the opportunity to give back to the community, just as my friend did for so many years. I know this is the perfect opportunity and I am anxious to help ensure that the needs of the bleeding disorder community are fulfilled. I know that this group has become a family to so many of you.

Prior to joining WPCNHF, I worked in Washington, DC on Capitol Hill and in the private sector for a trade association. My work in our nation's Capitol has provided me with significant experience in fundraising and advocacy which will make WPCNHF more efficient, successful, and vocal. I bring to WPCNHF new ideas and a passion for fundraising. I know that together we can bring WPCNHF to new heights and I am excited to learn more about each of you!

I thank you for welcoming me to your community. I know this is a team that is respected, both in Pennsylvania and on a national level and I am honored to be a part of this organization. I hope you will take the time to get to know me, and my colleagues, Madonna McGuire Smith and Janet Barone (if you don't already know them). These women work tirelessly to advance the Chapter and I am thrilled to join the team. I know that we can achieve a great deal at WPCNHF with your support. Please feel free to contact us at the office at 724-741-6160. We are happy to help in any way.

I hope to meet you and your family soon and I hope you will consider putting together a walk team this year. Thank you for all that you do on behalf of WPCNHF.

Sincerely,

Jennifer L. Wahlen
Executive Director

Letter from the President, Scott Miller

Dear Friends,

It is with great excitement that I welcome the new Executive Director of the Western Pennsylvania Chapter of the National Hemophilia Foundation, Jennifer Wahlen. After an exhaustive search, the Board has chosen Jennifer to lead the organization as we grow our membership, boost programming, and enhance our public awareness and advocacy efforts. We feel that Jennifer's strong background and experience will help us increase our presence in all the counties we serve and, therefore, increase services to our members.

I would also like to thank Kerry Fatula for her years of service to the Chapter, as a volunteer, board member, and finally, and most importantly, as Executive Director. Under Kerry, we increased our budget by over 25% and saw an increase in programming and awareness. I would also like to thank Janet Barone and Madonna McGuire Smith for their tireless hours of work through this transition.

Our annual Wine Tasting was a great success with a wonderful turnout to support our community. As the summer gears up, the Chapter is beginning its busiest times of the year. On tap for this fall is our Annual Golf Tournament and our third year with the Hemophilia Walk. The staff is also working on our second tree auction event, Take a Bough, for November. These events will allow us to raise money to continue our high quality programming and advocacy efforts. There are many programs on tap for the fall and winter, so watch the mail for the notices and invitations.

As always, we thank you for your continued support and ask that if you would like to volunteer or know of someone who would like to help out, please feel free to call the office. Also, please continue to support our events through participating and promoting them to your friends, family, and colleagues.

Thank you and have a wonderful summer!

Sincerely,

Scott E. Miller, CPA, Esq
WPCNHF Board President

Calendar of Upcoming Events

August 6
Baxter Facts First - Managing Pain,
Men's Group Social Event, Pittsburgh, PA

August 14 – 20
Camp Hot-To-Clot, Zelienople, PA

September 6
WPCNHF Driving for Bleeding Disorders Golf Classic,
Treesdale Golf and Country Club, Gibsonia PA

September 10
First Steps Education Program, Children's Hospital,
Pittsburgh, PA

September 17
NHF Walk, North Park Boat House, Allison Park, PA (Ask us about sponsorships!)

September 17
WPCNHF Run for the Lives 5k, North Park Boat House,
Allison Park, PA (Ask us about sponsorships!)

September 22
Pfizer Education Dinner, Bravo, Cranberry Township, PA

October 14
First Steps Program for New Families

October 15
Erie Outreach Education Day, Erie, PA

October 18
Happy Hour, Rivertowne, North Shore, Pittsburgh, PA ($20 donation)

November 10 – 12
NHF Annual Meeting, Chicago, Illinois

November 17 – 20
Take a Bough Tree Auction, Pittsburgh, PA

December 4
Winter Family Program, Wildwood Highland, Allison Park, PA

Ask us about sponsorship opportunites and how you can help!

Medical IDs Could Save Your Life

This article was published on hemaware.org
(http://www.hemaware.org)
by Kadesha Thomas
May 2011

For Robyn Salk, Saturday night is a time to dress up—perhaps a sequined blouse paired with slick, knee-high boots wrapped around a pair of skinny jeans. The penchant for fashion didn't change when Salk, 38, from Boca Raton, Florida, decided to purchase a medical identification bracelet.

Salk was diagnosed with mild hemophilia B in 2003. She says no one had told her she should be wearing medical identification for emergencies until two years ago at a Florida Hemophilia Association symposium in Deerfield Beach. The bracelet she ordered had black and silver beads—perfect for any outfit, she thought.

But during an emergency room visit, her husband, Jonathan, tapped a nearby emergency medical technician (EMT) on the shoulder. Raising Salk's wrist, he asked, "Would you know this was a medical ID bracelet?" "Probably not," the EMT said, waving his colleague over. Both agreed they would have ignored the fancy bracelet as just a fashion accessory.

"That was an eye opener," Salk says. "I realized my husband was right. I need to not worry about being fashionable, but about being alive." Days later, her new bracelet—a silver chain with her medical information engraved on a heart-shaped tag—arrived in the mail.

Guidelines for Wearing Medical IDs

Saving lives during medical emergencies is exactly why the National Hemophilia Foundation (NHF) encourages everyone who has a bleeding disorder to wear some form of medical ID. In a car accident or other medical emergency, medical personnel need to know if an unconscious injured person has a bleeding disorder.

"It changes the response to treatment in a lot of ways," explains Jocelyn Bessette Gorlin, RN, CPNP, a nurse practitioner at Children's Hospitals and Clinics of Minnesota in Minneapolis. "Ideally, the person with the bleeding disorder might get the first response, and the hospital would know to give factor to stop the bleeding before doing a CT scan. This is especially important if the person needs surgery and particularly important with head injuries."

Despite the importance, Gorlin discovered troubling results during a survey of nearly 100 nurses she completed in 2009 on the use of medical IDs. She found that no official guidelines existed and that parents of children with bleeding disorders rarely used medical IDs for their infants. Many of the nurses and EMTs surveyed had already encountered situations in which a person who had been shot was taken in for surgery without factor or someone died after being infused with the wrong factor.

Gorlin and NHF's Nursing Working Group developed a set of clinical guidelines that the NHF Board adopted in November 2010 as MASAC document #201, "Recommendation on Use of Emergency Medical Identification Devices for Children." The guidelines recommend that medical IDs be worn on the person's body, displaying an easily visible and familiar medical symbol, such as the caduceus, which has two serpents intertwined around a winged staff, or the staff of Asclepius, which has one serpent wrapped around a staff. The Nursing Working Group recommends medical IDs display the person's diagnosis, factor deficiency and emergency contact.

The risk of choking is one of the main reasons parents often do not use medical IDs for their infants. The guidelines encourage parents to avoid medical IDs with beads, charms or other detachable parts that a child could easily swallow. Gorlin also says that not only can the more fashionable medical IDs be overlooked, but they also tend to break or come off during regular activity. For children younger than 1, the guidelines recommend placing the emergency ID on the child's ankle.

Consumers Demand More Flair in Products

In the early 1990s, consumers began demanding medical identification styles with more flair than the plain metal bracelet and information tag, says Ramesh Srinivasan, MedicAlert Foundation®'s senior vice president of marketing and business development. Jewelry companies entered the market, designing bracelets, anklets, sports bands and dog tags. "There's always a fine balance to strike between style and functionality," Srinivasan says. "But you don't want vanity to prevail."

Most of MedicAlert's bracelet and necklace styles feature a stainless steel, gold or silver chain and information plate with lettering in myriad colors. Other styles include colorful beaded bracelets, sports bands and watches. "We've come a long way, but what has remained consistent is the emblem and the quality of the information engraved," Srinivasan says. The metal plate on all of MedicAlert's products has the staff of Asclepius flanked by the words "Medic" and "Alert" on the front.

MedicAlert requires all customers to register as members, so that clinical staff can review their medical information before it's engraved on the metal plate. In an emergency, the first responder can call a live emergency response service, 24/7, for more specific information on the member. The member's family contacts are also notified of the incident.

Medical ID Jewelry Designs Gaining in Popularity

The metal plate with one of the two medical symbols is also a mainstay on the designs offered by American Medical ID.® The Texas-based company's offerings include mostly metal bracelets, necklace pendants, sports bands and dog tags. Some of the dog tags even double as USB drives. These portable devices can be connected to most computers to save and transfer important medical information.

Toni Bissell, president and founder of the medical jewelry company N-Style ID,™ says she often does what Salk's husband did—she takes new designs to her local emergency medical personnel to ask their opinion. A creative design, however, is still important. "If people don't like them, especially children, they will not wear them," Bissell says. "When children and teens have a medical condition, they may already feel like an outcast. They want to wear something that everyone else might want. That actually makes them feel proud. I've had parents say, 'I bought this for my child, and now the other one wants one.'"

The Right Medical ID Style for You

Joe Mileson shows off his sports band medical ID.

Joe Mileson, 15, a high school sophomore from Spokane, Washington, opted for a cotton sports band to identify his diagnosis, severe hemophilia A. His band is decorated with music notes, a nod to his love of singing. He once tried a necklace, but says it felt weird and he would take it off to go swimming. His next style, a watch, pinched his arm.

Mileson knows other teenagers with chronic conditions who have gone as far as having their diagnoses tattooed on their bodies. People with bleeding disorders who are considering a tattoo should discuss the issue with their hemophilia treatment center first. Beyond any health concerns, tattoos may not be that effective. "The tattoo would have to be very large to put the necessary information, and that information might change," says Gorlin. "And the tattoo might fade over time."

Mileson agrees tattooing is not necessary, especially with so many styles of medical IDs available. "There's a style for everyone," he says. He eventually settled on the sports band because it is versatile enough to be worn during choir practice and lifeguard training drills without coming off.

Medical IDs for Small Children

While some teens and adults choose the medical IDs based on style, parents with small children may be more concerned about making sure it survives their child's curiosity. Tiffany Intal's daughter Annika, 2, was diagnosed at birth with severe factor VII deficiency. "I saw the medical ID jewelry as a form of insurance," says Intal, a medical assistant in Daly City, California, and hemaware.org's Diary of a HemoMom blogger. "You buy insurance for your house, for your car and for all the other 'what ifs.' If I'm unconscious during an emergency, or if someone can't speak on her behalf, then she'll have the medical ID jewelry."

A necklace or bracelet was out of the question, because Annika probably would have tried to chew them off. So, at the NHF Annual Meeting in 2009, Intal purchased a blue beaded anklet for Annika. At first, it sent Annika into a fit when Intal tried to put it on. But in the past year, the little girl has become accustomed to wearing it, although she still fiddles with it and manages to kick it off during tantrums.

Intal says most clinicians notice the anklet, but the most common reaction from strangers, is, "That's so pretty." Intal uses such comments as an opportunity to educate and to clarify myths about bleeding disorders, such as the belief that little girls cannot have them. "People usually seem very receptive to the information."

Now, Intal's two older boys, almost ages 8 and 6, who do not have a bleeding disorder, want medical IDs, too.

Advocacy News

by Jennifer Wahlen and Ann Rogers, MS

The proposed reduction in state support for hemophilia programs in Pennsylvania was a whopping 43 percent. A cut at that level would have immediately reduced care and services to people with hemophilia as state funding supports staffing.

In 1973, Pennsylvania was the first state to enact a State Hemophilia Program. This model of care for Pennsylvanians with hemophilia, a rare bleeding disorder, became the model for a national network of Hemophilia Treatment Centers across the United States put in place by a federal act of Congress in 1975. This system of care has been providing comprehensive care for people with hemophilia and von Willebrand Disease ever since.

The hemophilia line item within the Pennsylvania Department of Health budget ensures that patients with bleeding disorders have access to a multidisciplinary team of skilled care providers, highly specialized laboratory tests and factor replacement therapies which are necessary to prevent repeated life and limb-threatening bleeding episodes. Comprehensive services include diagnosis, clinical management, orthopedic and dental care, patient education, counseling and home factor infusion training and supervision. This model of care has increased the independence of these patients and reduced the overall costs of medical care and the need for state-funded assistance programs.

According to the Centers for Disease Control and Prevention, patients who receive their care from one of these centers of excellence, have better medical outcomes than patients treated outside this comprehensive care model. Hemophilia Treatment Centers have reduced not only complications for patients, but have reduced the costs of their care across the United States. Patients rely on this expert care to sustain their lives. Today, there are 140 such centers in the United States and there are 7 programs in Pennsylvania providing comprehensive care to more than 2,000 Pennsylvanians with hemophilia.

On June 30, 2011, Governor Corbett signed the state budget. Because of your advocacy efforts- your visits to Harrisburg and your support of the hemophilia community- the cut to hemophilia was not 43 percent, but 29 percent and the individual line appropriation for hemophilia funding was restored. This is far from where the community hopes to be, but without your efforts, the cut would have been devastating to the bleeding disorder community. Thank you for all that you do to support our community.

Kristen Jaworski RN, BSN, CCRC of the HCWP addresses Pennsylvania General Assembly in Harrisburg

The following article was taken from The Pennsylvania Department of Health Bulletin Summer 1976, Volume 37, Number 2.

“Hemophilia is a disease that affects hundreds of Pennsylvania residents. Effective treatment has been developed to permit hemophiliacs to lead reasonably normal lives, but without State financial support, only the wealthy could afford proper treatment and care.

The State of Pennsylvania became involved in helping the plight of hemophiliacs and their families in 1972 when Governor Milton J. Shapp first learned of the difficulties a Camp Hill family was having in providing money for the treatment of their son, Kevin Marshall. The family had exhausted all private savings and donations and could no longer afford the $1,000 a month hemophilia treatments. The family’s effort to obtain state aid was turned down by the Department of Public Welfare unless the father quit his job.

Governor Shapp learned of the situation through news stories early in November of 1972 and arranged for free treatments for Kevin at Hershey Medical Center. Only a month later, a bill providing for $250,000 for hemophiliac treatment (ACT 59A) passed the legislature and was signed by Governor Shapp to provide free, state assistance for 800 hemophiliacs in the state.

Hemophilia, for readers unfamiliar with the term, is an inherited disease in which the blood lacks certain clotting factors. Victims are sometimes called “bleeders.” The condition lasts throughout one’s lifetime--it doesn’t go away, nor does it improve. Victims bruise easily; bleed from the kidneys, into joints and also bleed excessively when injured and after operations. They know when they are bleeding, experiencing swelling and pain in the area affected.

Until recently, no treatment was available for such persons, except to splint bleeding joints and rest. This meant time off the job or out of school—which alone marked them as “different.” Chronic bleeding into joints causes severe arthritic crippling, preventing normal usage of limbs. Operations and dental work were out of the question—bleeding complications could result in death.

Nine hemophilia centers were established to care for patients. The centers provide evaluation and reevaluation of registered patients and supply blood products needed by them for blood coagulation. Most of the centers will also train patients or their parents in the techniques for treating themselves, if sufficient medical indication exists for home treatment.

The centers are responsible for determining treatment for patients, be it on an outpatient basis, at home, in the emergency room or for a surgical procedure. Most hemophiliacs are outpatients at one of the nine centers. However, home treatment is gaining in popularity.

Persons enrolled in the home treatment program have considerably more independence than those who are outpatients. Because of their ability to administer self treatment, there are fewer visits to the clinics and/or emergency rooms for treatment, more immediate treatment, more self assurance—all resulting in the patient's ability to lead a more independent life in better health, with much less time off from work or school and fewer hospital and doctor bills.

Before the scientific breakthroughs of less than ten years ago, hemophiliacs died at the average age of 11. Then researchers developed a way of isolating the necessary clotting factors in blood to make concentrates of blood plasma clotting factors. Mild hemophiliacs can take the concentrates only when needed to stop bleeding. Moderate or severe hemophiliacs are usually put on regular regimens of the concentrates.

However, some individuals develop inhibitors or antibodies to the concentrates which makes the concentrates relatively ineffective. Other medications are then used in treating these people.

Aside from the possibilities of developing inhibitors, the major problem thus far associated with the blood product concentrates is the danger of hepatitis. Because large pools of blood donors are required for making the concentrates, it is possible, even with the most sensitive tests and procedures, that the hepatitis virus is present in the concentrates. Though donors are carefully screened, the risk remains high.

The cost to the state for operating the hemophilia program was approximately $1,480,000 in fiscal year 1974-75.

State funds are used after all other applicable financial sources have been exhausted: private insurance, Federal Title XIX benefits and limited family resources. About 30 percent of those enrolled are required to share part of the cost concentrates. Their share can range from $50 to $1,500 a year. About 600 of the approximately 800 hemophiliacs in the state are registered in the State Program.

Although hemophiliacs don't usually really bleed to death, slow physical and mental deterioration can take place. Medication helps the body, but psychological support is needed from family, friends and the medical professionals in close day-to-day contact with the hemophiliac.

The program now serves as a lifeline for more than 600 patients whose medication alone can run as high as $12,000 a year.

Editor's notes:
Statistics above were from 1972. In 2011, the program now serves over 2000, whose medication can run from $300,000 or higher per year.

Junior National Championship

To celebrate the 10th anniversary of the Gettin' In the Game Junior National Championship, CSL Behring is combining the four regional competitions into one national competition to be held in the Dallas/Fort Worth, Texas region. Chapters throughout the U.S. are invited to nominate two participants each- one for golf and one for baseball. During the program, educational sessions will be available for parents and caregivers, and nominees will have the opportunity to:

- Participate in a clinic where they will learn the fundamentals of baseball or golf and enhance their skills in either sport.
- Learn about the importance of physical fitness.
- Show off their baseball or golf abilities in a national competition with fellow participants from around the country.

Pro golfer Perry Parker and baseball players Jesse Schrader, Ivan Sada, and Peter Dyson, each of whom has a bleeding disorder, will host the program.

The event will take place September 23-25, 2011. Attendees will stay at the Dallas/Fort Worth Marriott Hotel and Golf Club at Champions Circle, located 25 minutes from the airport. One hotel room will be offered per participant and meals will be provided on site. CSL Behring will sponsor each Chapter selected nominee and one accompanying adult to participate in the program. The sponsorship includes coordination and cost of airfare, ground transportation in Dallas/Fort Worth, and hotel arrangements. Attendees will be responsible for transportation to and from their hometown airport.

Nominees must be 7-18 years of age and have a bleeding disorder to apply. When applying please submit the following information:

- Name
- Gender
- Age/Date of Birth
- Bleeding disorder (Hemophilia A, Hemophilia B, von Willebrand disease, other)
- Parent/Caregiver Name
- Address
- City/State/Zip
- Phone number
- Parent email address
- In 250 words or less please tell us why you would like to be nominated for the 2011 Gettin' In the Game.

Deadline to apply is August 3. Late entries will not be accepted. Nominees will be selected by August 5. Applications can be submitted by email to info@westpennhemophilia.org or by mail to WPCNHF, 20411 Route 19, Unit 14, Cranberry Township, PA 16066.

The Miller Family Auction and Car Show (continued)

Continued from page 1

disorder. The candidate must provide proof of enrollment to an accredited school or vocational/technical center.

Don Groves was a witty, bright, loving, and caring man. He was a person with determination and spunk. He was deeply concerned about his family and his community. He was a father, a husband, a friend and mentor to many. Don Groves died in 2002 of complications associated with hemophilia. This special scholarship has been created in his memory because he was a model for us all. He was a kind and compassionate soul and a relentless fighter. He lived and died with the challenges of hemophilia. He was truly a man of whom we all can be proud. We at the Western Pennsylvania Chapter, joined by the Miller and Groves family, are proud to offer this scholarship program to young people, adults, and family members of those with a bleeding disorder to assist in their efforts to obtain a higher education.

Congratulations to Charlie, Paula and Reece Miller for another successful Auction and Car Show!!

Spotlight On Research

Phase I Clinical Research

by Kim Goldby-Reffner, RN, BS

It was a great pleasure to meet and speak with all those who attended WPCNHF Education Day, on Saturday March 5, 2011. When asked by the local chapter to provide a quarterly article pertaining to the topic of "research" for the Newsletter, the staff at HCWP jumped at the opportunity to contribute! It is our hope to provide general research information, along with updates on past and present studies offered at our center. We also look forward to any of your suggestions for topics, recommendations or questions. For this very first "kick off" article, I would like to re-iterate some the contents of my talk, primarily focusing on phase I research; answer the questions surrounding "orphan diseases and drugs"; and lastly, I will discuss a couple of Phase I studies which have concluded at our site.

"Research" is defined simply as the pursuit of knowledge. When doctors, nurses and researchers say "clinical research", we mean a branch of medical science which investigates safety and effectiveness of a new drug or device. An example of a new drug in the USA (approved by the Food and Drug Administration in 2009) is RiaSTAP®. This drug is used to treat bleeding episodes in congenital fibrinogen deficiency (also called Factor 1 deficiency). Before this or any drug becomes available by prescription for patients in the general population, evidence must be provided that the drug has potential benefit(s) and approval must be given by the FDA (Food and Drug Administration) for general marketing. The FDA is in charge of overseeing and examining safety and effectiveness information in clinical research studies.

Before a drug ever receives FDA approval, it passes through a series of clinical research experiments in humans (or research studies) and must be shown to be safe in a specific disease. These research studies can be broken down into "phases". There is a pre-clinical phase (which involves laboratory and animal testing) followed by human testing, which includes the categories: phase I, II, III and after approval, phase IV.

The first time a research drug is tested in humans is in a Phase I study. Phase I studies enroll only a small number of people and evaluate the safety of the research drug (also called "investigational product"). Typically healthy volunteers are used during this phase; however people with rare diseases and/or have a disease with limited treatment options may be studied instead. Hemophilia is a rare disease (also called an "orphan disease"). Studies investigating new Factor FVIII or FIX products only enroll people with a diagnosis of hemophilia. Interestingly, although von Willebrand disease (VWD) is more common than hemophilia, treatment options are limited. Drugs which are either: (1) used to treat rare diseases or (2) are not expected to recover the costs of development and marketing fall into a category of "orphan drugs". Products used to treat VWD fall into the category of "orphan drugs". An example of an orphan drug is recombinant von Willebrand factor (rVWF), (Baxter Healthcare) which has just finished phase I testing.

Patients with hemophilia and VWD are essential for testing new factor products in Phase I studies. When considering whether to participate in a Phase I study, it is important to remember that much laboratory and animal testing has been preformed prior to the phase I study. It is also important to remember that the primary focus in Phase I studies is to evaluate the safety of the research drug. It is not usually until later phases that efficacy (how well the drug works) is evaluated.

Over the past few years, Hemophilia Treatment Centers (including HCWP) have participated in Phase I studies for Hemophilia A, Hemophilia B and VWD. Recent examples involving Phase I research include studies involving potentially long acting Factor VIII and IX and recombinant VWF. Although these studies have completed recruitment, many centers are participating in the next Phase II/III studies. Feel free to ask your Hemophilia Treatment Center's doctor or nurse about any research opportunities. It is through your participation in research that we hope to advance treatment and improve the quality of lives for patients with bleeding disorders. Individuals who give their time and resources to find better treatments for others are said to be "altruistic". We could not do this these research studies without such individuals.

Next Article: Phase II/III Clinical Research

Meet the HCWP Staff


Adam Kufen, RN, BS

Submitted by Carol Stauffer, LSW, ACSW of the HCWP

Adam Kufen is a study coordinator and the newest member of the HCWP Research Team. He received his Bachelor's degree in Biology from California University of Pennsylvania, and then worked in education as a Professional Tutor for five years for a community college. From there, he received his nursing diploma from Ohio Valley General Hospital's school of nursing and began working in the field of clinical research, particularly in vaccination and disease management trials. He is adamant about education and has aspirations to pursue a Master's Degree.

Adam also leads quite an active lifestyle. This time of year you will find him running, biking, hiking, camping, kayaking, water skiing, and so on. He truly takes advantage of the warmer weather and feels energized and renewed by it. As the weather turns cold, he is still on the move hiking, skiing, cross country skiing, ice skating, and the like. With much of his spare time spent in the outdoors, he has a deep respect for these fragile places, volunteering his time with organizations like Pennsylvania's Department of Conservation and Natural Resources.

Adam is certainly a positive addition to the office dynamics. Not only does he bring high energy combined with a positive attitude, he is also the only permanent male presence in the office. In most cases he offers a unique perspective on things, but he has yet to contribute to the talks on hair or shoes. On a more serious note, he is truly excited to be at the center and to grow in his role as a staff member.

Join the Men's Group


John Conely, Men's Group Coordinator

We would like to introduce you to John Conely, a member of our Chapter. John is 29-years-old, and lives in the North Hills area of Pittsburgh. He has Hemophilia A and an inhibitor. John currently organizes activities for the Men's Group and he'd like to invite the men in our Chapter to participate in future events.

Men's Group activities are for both men who have a bleeding disorder and for Fathers of children with bleeding disorders. Educational and social opportunities are offered for men of all ages! John plans the meetings and events and always asks the members for their input for future meeting topics and social activities. On August 6, 2011, the Men's Group will be attending a Pittsburgh Pirates Baseball game, following an educational meeting on Pain Management.

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
- Cost Reduction
- Funding for Hemophilia Center Programs and Services
- Expansion of Patient Services
- Direct Communication with Treatment Team
- Service from People You Know and Trust

The Hemophilia Center supports patient choice consistent with the Veterans Health Care Act of 1992

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

If you would like to be notified of future events, please send an e-mail to John at: johnconely@yahoo.com. Note: John is creating a new e-mail distribution list. So, even if you have received communications from him in the past, please send him an e-mail if you'd like to continue to receive information from him.

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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.

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United Way

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**

Join the Bayer Virtual Walk for Hemophilia!
Make every step count

Believe it or not, you can help our chapter raise up to $15,000 in sponsorship funds by doing *virtually* nothing! That's right - all you need to do is join the 2011 Bayer Virtual Walk for Hemophilia!

An interactive campaign to raise money and awareness for those living with bleeding disorders, the Virtual Walk is encouraging participating local chapters to rally for the opportunity to receive sponsorship funds for their communities.

Our chapter is taking up the challenge and we need your support!

All you have to do is join the Virtual Walk and spread the word to friends and family! The more people who participate and choose to join the virtual walk for our chapter, the greater our chance to receive the first place sponsorship funds of $15,000!

Joining the Virtual Walk for Hemophilia is as easy as 1-2-3!

Participants simply need to:

1. Create and customize their virtual characters
2. Choose a message
3. Select the local chapter they are walking for

Share this message and invite everyone you know to participate! Every virtual walker gets us one step closer to $15,000 in sponsorship funds!

Together we will help raise awareness for bleeding disorders across the country!

Join the Virtual Walk at WalkForHemophilia.com

Spotlight on the Member

Nick and Marie Vizzoca Family

Spotlight on the Vizzoca Family

The Walk Kickoff commenced Saturday, July 25 at Fun Fore All and with that, walk chairs Nick and Marie Vizzoca were off and running. Months ago, Marie joined the Walk Committee with the intention to "help out with the festivities." A short time later, WPCNHF development director Madonna McGuire Smith began a search for a Walk Chair, and before she knew it, Marie was recruited as the 2011 Walk Chair. Her husband Nick immediately joined her and they have been working diligently to acquire additional sponsors and supporters for the Walk ever since. Nick and Marie spoke at the Walk Kickoff of the importance of every chapter member's involvement in the walk.

Nick and Marie are the parents of a 12 year old boy with hemophilia. They are passionate about raising awareness of bleeding disorders and supporting research for a cure. One thing Nick has learned is to never be afraid to ask people in the community to help. Whether it is to participate in the walk, volunteer their time on walk day, or solicit friends and neighbors to walk alongside you- every bit of participation helps spread awareness for bleeding disorders. Nick and Marie have begun meeting with local businesses and Pittsburgh sports teams, in hopes that these organizations will support this great cause.

It is not too late to join the Vizzoca's in their quest to garner more attention for the bleeding disorder community. To learn more about the Walk Committee, to register for the Walk, or volunteer for the Walk, please contact info@westpennhemophilia.org.

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

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