

# NHF/DVC THE WINNING SPIRIT

Quarterly Newsletter, National Hemophilia Foundation, Delaware Valley Chapter, Winter 2012 – Volume 19 #1



National Hemophilia Foundation  
Delaware Valley Chapter

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**PSI**

If you need help paying insurance costs, go to our website for more information or call  
800-366-7741

[www.hemophiliasupport.org/fyi.htm](http://www.hemophiliasupport.org/fyi.htm)

The Chapter reserves the right to refuse admittance to any person at any event in its sole discretion.

## HEALTH INSURANCE EXCHANGES COMING IN 2014

### How Health Insurance May Be Changing for You

On July 11, 2011, the U.S. Department of Health and Human Services (HHS) published a Notice of Proposed Rulemaking (NPRM) outlining a framework that will enable states to build affordable insurance exchanges, state-based competitive marketplaces where individuals and small businesses will be able to purchase affordable private health insurance and have the same insurance choices as Members of Congress.

Exchanges will begin operating in 2014 and will make it easy for consumers and small businesses to compare health plans, get answers to questions, and enroll in or offer to their employees, a health insurance plan that meets their needs. Individuals will be able to find out if they are eligible for tax credits for private insurance or health programs like the Children's Health Insurance Program (CHIP); and small businesses may be eligible for the small business tax credit for coverage purchased for employees through the Exchange.

The Patient Protection and Affordable Care Act (also known as the Affordable Care Act, or the ACA) established and took the first steps in defining a set of core health services, called "essential health benefits."

### What Are Essential Health Benefits (EHB)?

The ACA included language mandating that all health insurance plans (providing health insurance through the state exchanges) must provide coverage for a basic set of ten core health services, or "essential health benefits," including:

- Ambulatory patient services;
- Emergency services;
- Hospitalization;
- Maternity and newborn care;
- Mental health and substance abuse disorder services, including behavioral health treatment;
- Prescription drugs;
- Rehabilitative and wellness services and devices;
- Laboratory services;
- Preventative and wellness services and chronic disease management; and,
- Pediatric services (including oral and vision care).

The Department of Health and Human Services (HHS) commissioned the Institute of Medicine (IOM) to research and make recommendations on the criteria and methods used to determine the essential health benefits package. The Delaware Valley Chapter provided comments to HHS on October 8, 2011 regarding what "essential health benefits" must be included to provide adequate insurance coverage for people with hemophilia and von Willebrand Disease who will purchase health insurance through their state's Insurance Exchange beginning in 2014.

*continued on page 5*

# FROM THE EXECUTIVE DIRECTOR

## THE DELAWARE VALLEY CHAPTER OFFICE HAS MOVED!

### National Hemophilia Foundation

#### DELAWARE VALLEY CHAPTER

14 E. Sixth Street, First Floor

Lansdale, PA 19446

Phone: (215) 393-3611

Fax: (215) 393-9419

Web: [www.hemophiliasupport.org](http://www.hemophiliasupport.org)

Ann Rogers, Executive Director

Kim Bayer, Administrative

Coordinator

Christine Rowe, Fund Development

Coordinator

Veronica Connelly, Administrative

Assistant

### New Address

14 E. Sixth Street, First Floor

Lansdale, PA 19446

Phone: (215) 393-3611

Fax: (215) 393-9419

After more than 20 years in Glenside, PA, the Delaware Valley Chapter has moved! "Our new location provides about 3,000 square feet of needed space. We outgrew our old home and were lucky to find just the right spot to move our operations. This new office has space to accommodate support groups, some of our administrative meetings and storage, all things we desperately needed. As we grew over the last two decades, our old space just couldn't accommodate our needs," said Ann Rogers, Executive Director.

Stop by for a visit. We would love to show you our new home!

### Board of Directors

Thomas D. Galvin, President

William L. Widerman, Vice President

Andrew B. Serrill, Treasurer

Cheryl A. Littig, Secretary

### Board Members

Leonard Azzarano

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Nanette Germain

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Graphic Artist: [www.chaley.com](http://www.chaley.com)

We gratefully acknowledge the pledge of support from the following manufacturers for 2012.

<b>Baxter Bioscience</b>	<b>CSL Behring</b>
Recombinate	Monoclate-P
Feiba NF	Mononine
Bebulin VH	Helixate FS
Advate	Humate-P
<b>Bayer Corporation</b>	Stimate
Kogenate FS	<b>Novo Nordisk</b>
Koate-DVI	NovoSeven® RT
	<b>Pfizer</b>
	BeneFix™
	Xyntha



At the DVC Walk/Run, held on Saturday, October 1, 2011, the Delaware Valley Chapter presented a check for \$25,000 to Denise Sabatino, PhD in support of genetic research at The Children's Hospital of Philadelphia. Events like this allow the DVC to continue to support important research advancing the promise of a cure for hemophilia.

*Dear Friends at the Delaware Valley Chapter:*

*Thank you so much for your generous donation in the amount of \$25,000 to support our research!*

*As you know, obtaining funding for research is particularly difficult right now, so your support at this time is critical to us. Your donation will facilitate our work while we wait for news of further funding from the National Institutes of Health.*

*We appreciate the ongoing financial support of the Delaware Valley Chapter. Donations such as this demonstrate not only your commitment to advancing the science of hemophilia and bleeding disorders, but help immensely to keep research moving forward. Again, my sincere thanks for your support and commitment!*

*Most sincerely,*

*Denise E. Sabatino, PhD*

*Denise E. Sabatino, PhD*

*The Children's Hospital of Philadelphia*

## Winning Spirit Newsletter GOING GREEN!!!

If you would like to receive your quarterly Winning Spirit via email (rather than through the mail), contact the Delaware Valley Chapter (215 393-3611) and let us know. Provide the following information in your email: name, current mailing address, home and cell phones and the email address you would like us to use. You will begin to receive your newsletter via your email. NOTE: IF YOU ARE A PATIENT REGISTERED AT AN AREA HTC, YOU WILL CONTINUE TO RECEIVE A HARD COPY VIA YOUR TREATMENT CENTER.

# CHAPTER HAPPENINGS

## Here's what's been happening!!

### DVC Golf Classic, September 20, 2011!

The sun shone brilliantly on our annual golf event at the scenic River Crest Country Club in Phoenixville. A great time was had by all! Special thanks to our chairperson Matt German and our event sponsor CSL Behring. We also gratefully acknowledge the many wonderful committee members and volunteers who pulled it all together and helped make it a huge success. Mark your calendars for September 18, 2012 for our next tee time!



### DVC Annual Family Camp Weekend, September 23-25, 2011!

With more than 400 people attending this year, we had a packed weekend of fun, great food and friendship! Despite a rainy start, a great time was had by all. If you missed it this year, mark your calendar for the weekend of September 21, 22 and 23, 2012. Details on the new location of our camp will follow in future issues of *The Winning Spirit!*



### DVC 5K Run and Family Walk, October 1, 2011!

Nearly a thousand runners and walkers joined us for our 2nd annual walk/run event, making it our most successful fundraiser of 2011! Due to the success of this event, the DVC was able to present a check for \$25,000 to the Children's Hospital of Philadelphia supporting genetic research efforts advancing the promise of a cure for hemophilia. Pfizer, was our generous event sponsor and provided their beautiful Collegeville campus for the day. Pfizer has already welcomed us back for the event on October 6, 2012! We are so appreciative of the many volunteers who helped in so many ways and we offer a big "thank you" to our chairperson, Heather Thompson, for all of her hard work. By the way, Heather received a Chapter

Volunteer Award at the NHF Annual Meeting in Chicago in November for her outstanding efforts for this event! Congrats, Heather!

We couldn't have done it without all our fundraising teams:

Cousins for a Cure – highest fundraiser with \$22,992 in donations!

Team Rocco V – hosted its own fundraising event that raised \$6,365 in one night!

Jack Rabbits – biggest team with 49 registered members!

Lucky Littigs

Race for Peyton & JR

Fans of Dan

Comstar Dukes

Carter's Crew

Remnants of Hurricane Half

Trotting for Tre

Team Dakota

Snyder Shamrocks

Team "T-Dawg" Tristan

Blood Brothers

Jogging for Jason

Miles for Matthew

Team Marco

Rockstar & Little Lynds

Stinger Bees

Gavin's Fight for a Cure

Pete's Team

Team Pfizer

Team Quest Diagnostics

Coram Cares

CSL Behring

The Boardwalkers

The DVC Board

### Annual Fall Gala, October 21, 2011!

Our live auction was the highlight of the evening at this wonderful event at the Hilton Hotel on City Avenue. Folks were not only jumping out of their seats to bid, but also jumping out of their seats to add goods to the auction! What a fabulous night of fun, food, gaming and dancing! Be sure to mark your calendar now to attend next year's Gala on October 19, 2012. Special thanks to Pfizer, our generous event sponsor, and all the loyal volunteers who made the evening simply spectacular.



# CHAPTER HAPPENINGS

## Annual Holiday Party, December 3, 2011!

All you could see were smiles & good cheer from ear to ear as Santa made a visit to Jefferson Alumni Hall for this annual holiday day of fun! Our DVC families had a truly magical day, with craft



activities and gifts for all of the children, and hilarious entertainment by Sam Sandler. What a fabulous way to ring in the holiday season! Many thanks to all our holiday helpers who truly live the spirit of giving! Next year's event will be on Saturday, December 1, 2012.

## Here's what's coming up!!

Call the DVC office (215-393-3611) for more information or to register for an event



### Bowling for Fun, February 25, 2012!

Join us at Thunderbird Lanes in Northeast Philadelphia for an afternoon of family fun to help us strike out bleeding disorders! For the low price of \$20 per person or a lane of 6 bowlers for \$100, you will enjoy three hours of bowling, shoe rental, a slice of pizza, beverage and bag of chips. We'll also have fabulous raffles and additional refreshments for purchase.

### Annual Fashion Show & Luncheon, April 14, 2012!

Check out the latest in spring styles at our dazzling Fashion Show, this year at a new location at the Cedarbrook Country Club in Blue Bell! Have a delightful day out with the girls while getting a sneak peek at the newest trends, featuring styles from Bow Ties, Old Navy and Banana Republic. You'll enjoy a scrumptious lunch, a fabulous show, and maybe even win one of our phenomenal raffle prizes!

### Women's VWD Retreat on the Hill, April 27, 28 and 29, 2012!

This is a weekend of education and relaxation for women in families affected by VWD. Education and programming are provided by local experts from the Hemophilia Treatment Centers. The retreat will be held at the beautiful ACE Conference Center in Lafayette Hill, PA. This event is made possible by a generous grant from CSL Behring.

### Broad Street ReRun, May 14, 2012!

Lace 'em up and hit the asphalt at our 4th annual run in Lansdale! This event is growing every year and helps raise awareness and funds for the DVC programs and services throughout the year. Not a runner? Join us for the 1/2 mile family walk or sign up to volunteer!

### Carlino's Golf Outing, June 4, 2012!

Fore! No, June 4! Join us for this spectacular day of golf, sponsored by Carlino's Foods of Ardmore, PA at the Edgemont Country Club in Edgemont, Pennsylvania! An afternoon of golf and great eats! Proceeds benefit the DVC's commitment to research and scholarships.

### Barbecue Cook-Off & Horseshoes for Hemophilia, June 9, 2012!

Kick off the summer BBQ season by attending this great family day! A fun-filled, all you-can-eat event at the American Legion in Hatfield Pennsylvania, our cook-off features finger-licking good food, horseshoe tournament, live music and a great day of fun for the whole family!

**Be sure to register with the Chapter office for the following educational programs (215-393-3611). (All programs include dinner)**

February 18th: *Aging in Hemophilia & Understanding Inhibitors*

At the DoubleTree Guest Suites in Plymouth Meeting, PA

February 24th: *VWD: Issues for Women*

At the DoubleTree Guest Suites in Plymouth Meeting, PA

## 2012

### Chapter Calendar

Call the DVC office (215-393-3611) for detailed information about the events listed here.

#### February

- 18 Aging in Hemophilia & Understanding Inhibitors! Plymouth Meeting
- 24 VWD: Issues for Women! Plymouth Meeting
- 25 Bowling for Fun!

#### March

- 8-9 NHFs Washington Days!

#### April

- 14 Annual Fashion Show & Luncheon!
- 27-29 VWD Retreat for Women!

#### May

- 8 Annual Family Dinner!
- 12 Broad Street ReRun!

#### June

- 4 Carlino's Golf!
- 9 Barbecue Cookoff & Horseshoes for Hemophilia!

#### August

- 2-7 Double H Camp!
- 26 Perk Up Half Marathon!

#### September

- 21-23 Family Camp!
- 18 DVC Golf Classic!!

#### October

- 6 DVC Annual Walk/Run!
- 19 Fall Gala!

#### November

- 8-10 NHF Annual Meeting: Orlando!

#### December

- 1 Holiday Party!

## HEALTH INSURANCE EXCHANGES COMING IN 2014

Ann Rogers, Executive Director of the Delaware Valley Chapter of the National Hemophilia Foundation provided the following comments to the Department of Health and Human Services on October 8, 2011.

*Hemophilia is a rare, chronic bleeding disorder affecting approximately 20,000 people in the US. Patients with chronic conditions, such as hemophilia, often require specialized care and services in order to live long and productive lives. People with hemophilia bleed internally, typically into their joints and muscles. Bleeding can be fatal depending upon where it occurs (in the brain, throat, chest, etc.) or when bleeding is untreated or improperly treated. Available treatments, called factor concentrates are life-sustaining and extremely effective, but come at a significant cost. The average annual cost of factor concentrate for an adult with severe hemophilia is approximately \$300,000; however that number increases significantly if surgery is needed or if a patient develops complications or a reaction to his clotting factor treatment. In these cases the costs may exceed a million dollars per year. (It goes without saying that insurers are familiar with this population!)*

### Concerns Regarding Essential Health Benefits

*The National Hemophilia Foundation, the leading organization representing thousands of people with hemophilia and other bleeding disorders, is committed to ensuring that individuals have access to the care and treatment they need. Because patients with chronic conditions, such as hemophilia and a related bleeding disorder called von Willebrand Disease, require specialized care and services throughout their lives, what is considered "essential" for most Americans may not address the needs of this population. It is imperative that any benefit package recognize the unique circumstances of people with high-cost chronic conditions such as hemophilia and von Willebrand Disease. The essential benefits package must ensure access to specialists and specialized treatments, and prescribed therapies.*

*For people with bleeding disorders, access to specialists (and sub-specialists) and appropriate sites of service are critical to the management of their disorder. For example, most specialists in hematology treat patients with more common blood-related cancers and have limited to no experience in treating patients with hemophilia and other non-malignant bleeding disorders.*

*Hemophilia Treatment Centers were established by a federal act of Congress more than 35 years ago and in 1976 were recognized under Title V of the Social Security Act (MCHS Block Grant). These centers bring together a multi-disciplinary team of providers including hematologists, nurses, physical therapists, social workers and pharmacists to provide highly specialized care to assess and provide treatment to those affected. Because these individuals have the need for life-long treatment vs. episodic care, it is important to take into consideration the site of care most effective for the patient. For example, preventative treatment most often takes place in the home setting, while treatment for acute bleeds may be addressed in the physician's office or the hospital either as an inpatient or outpatient.*

*Access to all FDA-approved factor concentrates (the medicine) is also crucial and there are only a few available choices. As factor concentrates are biologics, drug formularies imposed by insurers put patients at extreme risk. The limited products available are expensive biologics that do not have generic equivalents and are not necessarily interchangeable with one another. Hemophilia is unique to each individual and it is vital that the decision regarding which treatment is most suitable be left to the hemophilia physician in consultation with the patient AND NOT THE INSURER.*

*While HHS will need to develop a plan establishing essential health benefits with the general population in mind, as advocates for those with hemophilia and other rare bleeding disorders, we ask that HHS recognize that there will be outliers, like hemophilia care, that may need to be handled differently. Health plans will need greater guidance than the 10 categories of health services included in the law. Additional guidance should be given to plans to determine within the categories what services should be covered (for example, we believe that for patients with rare chronic diseases in need of life saving treatment, a separate process should be established for determining benefit coverage, cost-sharing and medical necessity).*

*Benefit packages must allow access to all categories so that patients can get the care most suitable for them. Individuals with hemophilia and other bleeding disorders, and other rare, chronic conditions, may require intensive care, and may rely heavily on specialists and prescription drugs. These are medical necessities and should not be limited or weighted in order to strike an arbitrary "balance." Moreover, utilization of specialized treatment facilities, such as the federally-recognized Hemophilia Treatment Centers (HTCs), does not neatly fit into a particular category of services. HTCs provide comprehensive, multi-disciplinary services in a single setting, and have been shown to improve quality of life and reduce morbidity and mortality of individuals living with this chronic disorder by 40% as well as costs of care, compared to patients with hemophilia who are treated outside this HTC system. Weighting certain services, even in order to provide "balance," could disrupt this highly efficient model of care. Allowing access to comprehensive care centers ensures that the most appropriate balance of care is provided to the patient by medical professionals.*

*The term "medical necessity" should not be defined by insurers, but should be determined by physicians in conjunction with the patient. People with rare and chronic disorders require specialized care, even when dealing with common ailments so as to prevent complications. Hemophilia patients, in particular, need access to therapies and medicines that may affect each individual differently. Only a properly trained medical professional who has an understanding of rare conditions like hemophilia or von Willebrand Disease should be able to determine what is medically necessary. A universal standard of "medical necessity" is not appropriate for people with rare and chronic conditions. We recommend that rare and orphan diseases, including hemophilia and other bleeding disorders, not be lumped together*

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# HEALTH UPDATES

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## HEALTH INSURANCE EXCHANGES COMING IN 2014

with common diseases and conditions when considering “medical necessity,” so as to better address the unique challenges those patients face.

Some guidance should be given on the concept of network adequacy, specifically as to the definition of “adequate.” Given that the meaning of the term can vary broadly from individual to individual, we would expect that it will also vary from state to state and a potential unintended consequence will be barriers to care. For example, if access to specialists is included as an essential health benefit, does that mean if one specialist from each specialty group is included, the network is adequate or does the plan have to offer sub-specialists? For example, many health plans will include a hematologist in their network, but may not include a Hemophilia Treatment Center, yet most hematologists outside of the hemophilia treatment center network have no experience treating a patient with hemophilia. The majority of people with hemophilia are currently seen at an HTC, whose multi-disciplinary team is dedicated to the care and treatment of this unique and VERY EXPENSIVE population. One way a plan within the exchange could limit their

“risk” would be to include a limited number of “specialists” but not include recognized centers of excellence or sub-specialists treating rare, chronic conditions. Hemophilia Treatment Centers must be included in plan networks for those plans to be adequate for people with bleeding disorders.

The Essential Health Benefits (EHB) package should provide assurance that the insurer must confer with the patient’s physician to discuss possible denials and the grounds for rendering such a decision. All must be in writing with clearly understood reasons for denial.

### Final Thoughts

We expect that people with hemophilia will look to the insurance exchanges across the United States as a way to purchase adequate, affordable health insurance. If the EHB does not provide some consideration of the unique needs of people with rare chronic diseases like hemophilia and von Willebrand Disease and if the insurance they are able to purchase does not pay for what they need, the coverage is useless.

For more information, go to [www.healthcare.gov](http://www.healthcare.gov).

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## MEDIC ALERT - MEMBERSHIP DUES RENEWAL



The Delaware Valley Chapter of the National Hemophilia Foundation is pleased to announce that we are able to pay the yearly Medic Alert membership renewal fee for patients with hemophilia or von Willebrand Disease who are treated at area HTCs.

### Here is what you need to do:

When you receive your membership renewal form from Medic Alert, simply mail or fax it to the Chapter office. The Chapter office will mail the form with a check directly to Medic Alert and a copy of the check and paperwork will be sent to you for your records. Please add a note telling us which treatment center you attend.

Need a Medic Alert bracelet? We can also pay for the purchase of the BASIC bracelet and pay the initial membership fee for

area patients with hemophilia or von Willebrand Disease who are treated at area HTCs. Fill out a Medic Alert bracelet order form COMPLETELY, send it to the DVC office and we will mail the form and a check directly to Medic Alert and also mail you a copy for your records. Please add a note telling us which treatment center you attend.

Consult your treatment center to make sure all pertinent information is on the form so an accurate bracelet is ordered. The Chapter cannot alter any information you have provided on the form and we can’t pay for another bracelet if you have entered incorrect information. We mail the form exactly as you have it filled out with a check to Medic Alert.

Any Questions, please call Kim Bayer 215-393-3611

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## HEALTH INSURANCE PLAN SUMMARY PLAN DESCRIPTION (SPD)

Recently, a local man with hemophilia was concerned when his employer would not provide him with a copy of his health insurance plan summary. The following was taken from the Department of Labor website:

“Under ERISA, plans are required to provide the Summary Plan Description every year.

“The plan administrator is legally obligated to provide to participants, free of charge, the Summary Plan Description (SPD). The summary plan description is an important document that tells participants what the plan provides and how it operates. It provides information on when an employee can begin to participate in the plan, how service and benefits are calculated, when benefits become vested, when and in what form benefits are paid, and how to file a claim for benefits. If a plan is changed, participants must be informed,

either through a revised summary plan description, or in a separate document, called a summary of material modifications, which also must be given to participants free of charge.”

If your employer refuses to provide this, you should contact the Employee Benefits Security Administration (EBSA) Regional Office to figure out how to get the employer to comply. Typically a call from EBSA will make that happen! For Pennsylvania, the EBSA Regional Office is in Philadelphia.

Philadelphia Regional Office  
170 S. Independence Mall West  
Ste. 870 West  
Philadelphia, PA 19106-3317  
Telephone: 215-861-5300  
Fax: 215-861-5347

## RESEARCH BREAKTHROUGH IN GENE THERAPY FOR HEMOPHILIA B

Researchers from the United Kingdom (UK) and the U.S. have made a breakthrough in hemophilia gene therapy. In a recently published study, the team reported successfully treating six patients with severe hemophilia B. The lead author of the study was Amit C. Nathwani, MB, ChB, PhD, Department of Hematology, University College London (UCL) Cancer Institute, London.

The UCL investigators used adeno-associated viruses (AAVs) as delivery vehicles, or vectors, to carry the genetic codes that trigger the production of the factor IX (FIX) protein. FIX is deficient in hemophilia B patients. Ideally, AAVs deliver the genetic material into living cells to sustain therapeutic effect without causing disease or triggering significant immune responses.

Nathwani and his team reported that a single injection of the gene therapy activated the production of small amounts of FIX--enough to allow four of the six subjects to cease treatment with FIX concentrates. The other two patients continued treatment with factor products but needed less frequent infusions. The patients have continued to produce their own FIX for up to 22 months.

Over the last decade, one of the major focuses for researchers has been on developing optimal AAVs. These viruses are often favored because patients have little or no immunity to them. Further, AAVs often target liver cells, which manufacture FIX. One potential drawback is long-term viability as liver cells do not live indefinitely and are slow to regenerate, which may affect the duration of the therapy.

The AAVs for this study were prepared by a team from the St. Jude Children's Research Hospital in Memphis, TN. The patients were recruited and treated with the therapy by investigators at UCL. Study co-author Katherine High, MD, and fellow researchers at the Children's Hospital of Philadelphia, are monitoring the study for any immune reactions.

High's laboratory has been conducting gene therapy clinical trials for hemophilia for more than a decade. "I think it's incredibly exciting, and I say that even though these people are my competitors," said High.

According to Edward G.D. Tuddenham, MB, BS, MD, director of the Hemophilia Center at the Royal Free Hospital in London, 20 additional patients will receive the therapy to help determine the optimal dose of the AAV. The aim is to deliver the highest possible dose while circumventing an unwanted immune response. "We are pretty close to the sweet spot," explained Tuddenham. "If all goes well, a genetic treatment for hemophilia B could be available for widespread use in a couple of years."

The study, "Adenovirus-Associated Virus Vector-Mediated Gene Transfer in Hemophilia B," was published online on December 10, 2011, by *The New England Journal of Medicine*.

Source: *The New York Times*, December 10, 2011. This article was prepared by the National Hemophilia Foundation.



Angela Forsyth, PT, DPT is a physical therapist in the Delaware Valley area with more than 15 years experience working with the bleeding disorders' community. For the past 11 years, she has served patients at the Penn Comprehensive Hemostasis and Thrombosis Program at the University of Pennsylvania in Philadelphia. During this time, in addition

to clinical work, she has given presentations at numerous local, national and international medical conferences and workshops focused on physical therapy and bleeding disorders. She is a physical therapy leader in Region III, has contributed to the field with journal and other publications, and has worked on many committees throughout her tenure at Penn. She is currently the Senior Vice Chair of the World Federation of Hemophilia's Musculoskeletal Committee, and will continue as Chair for the next 2 years.

Although Angie has resigned her position at Penn, she will continue to be actively involved with our community. The

Christiana Hospital's Hemophilia Treatment Center, under the direction of Dr. Michael Lankiewicz, is pleased to announce that Angie has joined their comprehensive care team. She will also continue her involvement with the NHF, the Delaware Valley Chapter and WFH and plans to focus on more publications this year.

Angie said, "It is sad to leave a position I have enjoyed for so long. I will really miss the patients and families that I have worked with over the years, but I hope to see them at Delaware Valley Chapter events and other conferences and functions. I am really looking forward to new challenges and working with the great team in Delaware."

If you would like to contact Angie, here's her email: [angelaforstyth@yahoo.com](mailto:angelaforstyth@yahoo.com)



Text **DVC** to 22828 from your cell phone to be added to our email list! Keep up to date on what's happening at the DVC and in the bleeding disorder community by signing up for the DVC monthly E-news!

## SPECIAL CAMP NEWS

It seems early to be thinking about sending the kids off to camp in the Summer of 2012, but we wanted to give you lots of time to get organized so that you can be sure your child will have a spot for one of the camp sessions. Here's the buzzzzzz!!

### THE GOOD NEWS!!

Once again, summer of 2012, DVC area kids with bleeding disorders will have an opportunity to attend The Double "H" Hole in the Woods Camp nestled in the mountains in Lake Luzerne, New York. This camp provides an outdoor Adirondack adventure for children with hemophilia each summer at no charge. Modeled after actor Paul Newman's Hole in the Wall Gang Camp in Connecticut, the Double "H" Ranch is a place where children with bleeding disorders can participate in a full range of activities and learn leadership skills, as well. The Delaware Valley Chapter will provide FREE transportation for one session (August 2-7, 2012) at Double H Ranch.

Continue to check the DVC website: [www.hemophiliasupport.org](http://www.hemophiliasupport.org) for updated information on camp for summer 2012

**THE DEADLINE FOR APPLICATIONS IS APRIL 1, 2012 AND SPACES ARE VERY LIMITED!!** Call the Chapter or consult your treatment center, if you have questions.



### CAMP DRAGONFLY FOREST!!!

Even if your child attends camp at Double "H" Hole in the Woods Ranch, they may be eligible to attend Camp Dragonfly Forest, right here in the Delaware Valley area!! This camp is free to all campers!! Call Dragonfly Forest directly with questions or to receive an application: 610-298-1820 (deadline is April 1st!!) and check out [www.dragonflyforest.org](http://www.dragonflyforest.org) for more details (including on-line registration)!!

Dragonfly Forest for DVC area kids with bleeding disorders: July 3-8, 2012.

## CHAPTER SQUAWK BOX

### *New with this Issue!!*

Many times throughout the year, readers write to the Chapter with questions. Here are a few recent ones and the answers!! Send us your questions!! We have the answers!

Question: Does the Chapter financially support research? We never hear much about that.

Answer: The Delaware Valley Chapter provides about \$75,000 annually in support of national and local coagulation research specific to hemophilia and vonWillebrand Disease.

Question: My sister's Chapter provides tickets to families for things like Water Parks and Major League Sporting Events. Why doesn't the Delaware Valley Chapter do that?

Answer: Treating our patient community to expensive entertainment venues is not part of our mission of service. We try to stay focused on activities where families can network and get some education and support, but that don't cost an "arm and a leg!" We provide lots of events and activities throughout the year that help in that way. Of course, if someone donated tickets like that to the Chapter, we would certainly love to host the event!!



The DVC provides about \$600,000 each year in support to families and local hemophilia programs. That includes things like scholarships, camp support, research support and lots of other things that help those we serve.

### Delaware Valley Chapter Support Network



In an effort to increase our service and help to families in areas outside of the central Philadelphia area, we have established five branches of the Delaware Valley Chapter. The purpose of the branches is to help network patients and families affected by hemophilia and von Willebrand Disease (VWD). If you are a patient or parent/s of a patient and would like to socialize with others who share your issues, please contact one of the following team leaders to get involved. These branches meet informally, in private homes, for social events and support. There is no charge for being involved....just networking with families just like you!! These branches are not open to any person who works or has a family member who works for any industry or company directly or indirectly involved in products or services for patients with bleeding disorders.

Delaware Branch  
Gail & Luke Vannicola  
302-378-1278

Lititz/Lancaster Branch  
Lorie & Brian Kerstetter  
717-626-9679

Mount Carmel Branch  
Jolene & Sam Scicchitano  
570-339-4137

Reading/Pottstown Branch  
Tina & Jeff McMullen  
610-582-1731