



## Oh Baby!! LOOK HOW WE HAVE GROWN OVER THE LAST 50 YEARS!!

### The establishment of The National Hemophilia Foundation.

In June of 1948, Robert Lee Henry, a father whose son Lee was diagnosed with hemophilia in 1941, established The Hemophilia Foundation, Inc. In 1956, the name was changed to The National Hemophilia Foundation. Mr. Henry and his wife Betty Jane, whose lives revolved around Lee's hemophilia, believed that they could link hemophilia families together to provide mutual support, locate highly-regarded physicians who knew how to treat the disease and encourage researchers to find a cure.

The top priority of the Foundation in the 1940s and 1950s was to raise funds and awareness about this bleeding disorder. Fundraisers ranged from cocktail dances to social galas at New York City hotel ballrooms. The Henry's interviewed for an article in *McCall's Magazine*, a leading popular magazine of the day, which put the hemophilia foundation on the minds of physicians, researchers and families affected by bleeding disorders across the United States. The publicity generated from the *McCall* article, "His Parents Refused to Let This Boy Die," published in May 1951, encouraged parents around the country to form local chapters. The first local chapter, "The Metropolitan," was formed in New York City.....Los Angeles, Rochester, Chicago and The Delaware Valley Chapter, based in Philadelphia, followed.

### The medical community and families affected by bleeding disorders unite.

In the mid 1950s, medical information about hemophilia was growing; medical experts documented that there were at least two distinct

types of hemophilia. Bob Henry recognized the need to reach out to the medical community and did so at the 1954 Annual Meeting of the American Society for Clinical Investigation.

Mr. Henry poignantly addressed the pain of hemophilia and the need for advanced treatment prompted the physicians at the meeting to form a medical advisory council, later named the Medical and Scientific Advisory Council (MASAC). They elected Dr. Kenneth Brinkhous, an expert in hemophilia, to serve as its chair. Today, MASAC, comprised of scientists, physicians and other treatment professionals, establishes the quality of care guidelines for the treatment of hemophilia and other bleeding disorders by issuing bi-yearly recommendations. Their recommendations are used internationally.

### Scientific advances fuel growth and political advocacy.

In 1965, Dr. Judith Graham Pool, a researcher, developed the process for producing cryoprecipitate-extracting the clotting factor from fresh, frozen human plasma. This breakthrough not only represented a sterile and affordable source of factor, but led to advances in orthopedic surgery, rehabilitation and service delivery.

In order to reach the goal of comprehensive care, using a multidisciplinary approach, NHF needed to advocate for state and federal funding. The combination of scientific advancement and the comprehensive care delivery, as piloted by Dr. Shelby Dietrich of Orthopaedic Hospital, Los Angeles, became a political focal point for NHF. Likewise, home therapy programs were slowly starting and reimbursement became a major concern. Mary

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# The Winning Spirit

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# Delaware Valley Chapter News & Notes

## National Hemophilia Foundation DELAWARE VALLEY CHAPTER

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## RESOURCES FOR PENNSYLVANIA PATIENTS WITH BLEEDING DISORDERS

**Medicare (including Medigap and Medicare Advantage Plans)** For free counseling and personalized help, contact the APPRISE Program at (800) 783-7067 or visit them on the web at <http://www.aging.state.pa.us/aging/cwp/view.asp?a=3&q=173806>. You may also visit the Centers for Medicare & Medicaid Services website at <http://www.medicare.gov/> or call (800) MEDICARE.

**Social Security** If you think you may be eligible for social security benefits, visit the Social Security Administration website at <http://www.ssa.gov/>, contact your local Social Security Office, or call (800) 772-1213.

**Medicaid** For more information on Pennsylvania Medicaid, visit <http://www.dpw.state.pa.us/ServicesPrograms/MedicalAssistance/> or call (800) 842-2020.

**State Children's Health Insurance Program (CHIP)** The Children's Health Insurance Program (CHIP) offers free or low-cost health insurance coverage to uninsured children and youth up to age 19 who meet the specified financial requirements. Depending on the size of the family and household income, some families with enrolled children may have monthly premiums of \$38 to \$150 per child and co-payment of \$5 to \$50 for certain services. For more information on CHIP, visit <http://chipcoverspakids.com/> or call (800) 986-5437.

**Children w/ Special Health Care Needs Program** The Bureau of Family Health provides financial assistance for medical care and an array of support services for children and youth up to age 21 with special health care needs. To receive assistance, individuals must meet certain medical and financial requirements. Children and youth up to age 18 who are diagnosed with hemophilia are eligible for services. The Bureau is in the Department of Health. For more information, visit <http://www.dsf.health.state.pa.us/health/cwp/view.asp?a=179&q=244303> or call (800) 986-4550.

**Hemophilia or Chronic Disorders Assistance Program** The Hemophilia Program works in conjunction with the state hemophilia treatment centers (HTCs) to assist adults age 19 or older with hemophilia or von Willebrand disease with paying for medical care, clotting factor products and an array of support services. To be eligible, individuals must meet the specified eligibility requirements which include showing proof of diagnosis, citizenship, residency and health care coverage. The program is administered by the Bureau of Family Health under its special health needs initiative. For more information, visit <http://www.dsf.health.state.pa.us/health/cwp/view.asp?a=179&Q=232550&PM=1> or call (800) 986-4550.

**High-Risk Insurance Pool Program** Pennsylvania does not offer a high-risk insurance pool program for the medically uninsurable. However, the state has an open enrollment period in which any person who applies for health insurance through Blue Cross Blue Shield will be accepted regardless of any health conditions they may have. Choice of health plans may be limited and there could be a waiting period for some pre-existing conditions. For more information, visit <http://www.ins.state.pa.us/ins/site/default.asp> or call (877) 881-6388.

**Other programs** AdultBasic provides Medicaid benefits to uninsured people ages 19 to 64 who meet eligibility requirements. The program is administered by the Pennsylvania Insurance Department. For more information, visit <http://www.ins.state.pa.us/ins/site/default.asp> or call (800) 462-2742.

**General Health Insurance Questions** For general health insurance information, visit the Pennsylvania Insurance Department website at <http://www.ins.state.pa.us/ins/site/default.asp> or call (877) 881-6388. You may also get state specific insurance information at <http://www.healthinsuranceinfo.net/>.

# Chapter Happenings

## What's Over and Out!!!!

**The NHF Annual Meeting, November 1-3** in Orlando! Once again, the DVC was a shining star at the NHF Annual Meeting. We received a \$25,000 award (three years in a row!) from the PACT Foundation for our state advocacy initiative, HB 1105! Tim and Sheila Fehr, dedicated DVC volunteers, received a "Volunteer of the Year" award for all they do for our Chapter. Well deserved, Tim & Sheila!! Way to go!!



*L to R: Howard Balsam, NHF Interim CEO, Sheila & Tim Fehr, Ray Stanhope, NHF Board Chair.*

**The Lucky Hearts Casino**, our fall gala, was held on Friday, **October 26th** at the City Avenue Hilton! It was a fantastic success, raising \$90,000+ for the DVC and providing a great time for everyone who attended! A great big "thank you" to the event co-chairs, Jim and Lynn Lindquist, for making this such a special night for us!!

The **DVC Annual Holiday Party** was held at Jefferson Alumni Hall in Philadelphia on Saturday, **December 8th!!** It was a magical afternoon with arts & crafts, gifts for all, surprises galore and of course, an appearance from Santa Claus himself!! We want to thank Kim Bayer and her many "elves" who worked so hard to make this just about the best holiday party we have ever had. More than 500 people attended!!



## What's Coming Up!!

On Saturday, **March 29, 2008**, join other families and supporters at **Bowling for Fun!!** To be held at Thunderbird Lanes in Philadelphia! Have a great time, while raising money to support the DVC's Patient Assistance Program. For more information or to register, call the DVC office (215-885-6500)!! You don't have to be a pro to support this event!! Get ready, get set, get bowling for fun!!

On **April 5, 2008**, the **Annual Fashion Show and Luncheon** will be held at the Drexelbrook in Drexel Hill, PA! Our honored guest will be Lisa Thomas-Laury from Action News, Philadelphia!! This is an event you won't want to miss. Call the DVC office (215-885-6500) for more information or to get an invitation!!

On **April 25-27, 2008** the DVC will host its second **Women's Retreat** on the Hill, a weekend event for women in families with vonWillebrand disease (VWD). Rest, relaxation and information are the focus of this weekend retreat, designed just for women. For more information, call the DVC office (215-885-6500)!!

You are invited to participate in the **CEO Program**, a totally new way to look at future **Careers, Education and Opportunities** for young people 15-20 years of age with a bleeding disorder. During the day, you'll choose a job, a salary, a house and have a bank account, as well as a few unexpected surprises and challenges-just like in the real world! Created by the Indiana Hemophilia and Thrombosis Center, this is a fun way to develop your skills and talents while interacting with your peers!! Mark your

calendars for Saturday, **May 3, 2008** for the CEO Program!! Join other young adults for this workshop and get a chance to win a \$500 Best Buy Gift Certificate!! For more information, call the DVC office (215-885-6500)!! Space is limited to 30 people!!

Tuesday, **May 6, 2008...Annual Family Dinner!!** City Avenue Hilton!!

Saturday, **May 10, 2008...I Can Run for Alex!!** This is a new event, sponsored by the Hatfield Athletic Club and chaired by Christine and Tom Rowe (Alex's parents, of course)!! Join friends and supporters for a day of food, fun, running and walking to support the Delaware Valley Chapter!! To learn more about this wonderful day and to register, go to: [www.freewebs.com/icanrunforalex/index.htm](http://www.freewebs.com/icanrunforalex/index.htm) Dust off those running shoes and plan to be with us!!

C a l e n d a r	<b>March</b>
	5-7 NHFs Washington Days!
	29 Bowling for Fun!!
	<b>April</b>
	5 Fashion Show & Luncheon!
	25-27 VWD Retreat Weekend!
	<b>May</b>
	3 CEO Program for Teens!
	6 Family Dinner!
	10 Rowe Run!
	<b>July</b>
	11-16 Double H Camp #1!
<b>August</b>	
4-9 Double H Camp #2!	
<b>September</b>	
22 DVC Golf Classic!	
26-28 DVC Family Camp!	
<b>October</b>	
24 Fall Gala!	
<b>November</b>	
13-15 NHF Meeting/Denver!	
<b>December</b>	
6 Family Holiday Party!	

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*Oh Baby!!*

## LOOK HOW WE HAVE GROWN OVER THE LAST 50 YEARS!!

Gooley, the director of the Rochester Treatment Center and Peter Levine, MD, a New England medical director, convinced third party payers, such as Blue Cross, to insure their patients for care received outside of the hospital.

With new medical leadership, parents now leaned how to approach legislators and take part in advocacy measures. Hiring a legislative consultant and preparing “how to” packets describing advocacy strategies fostered The Hemophilia Act. This Act, passed in July 1975 in the United States Congress, authorized funding to Hemophilia Treatment Centers offering the comprehensive care model.

### The “Golden Era” of the 1980s evolves into the “Aids Era.”

During the Reagan years, government cut-backs threatened national programs. However, ongoing support from The Maternal and Child Health Bureau (MCHB), effective lobbying from NHF and the perseverance of the first generation of adult men with hemophilia, who had moved into community leadership positions, preserved the HTC network.

In July 1982, NHF's Executive Director, Alan Brownstein, received a call from the Centers for Disease Control and Prevention (CDC) that there were three reported cases of immune

dysfunction in people with hemophilia. The following years, known as the “AIDS Era,” was a time of confusion, denial and loss for NHF and the hemophilia community. During the course of the epidemic, the HIV virus infected approximately 50% of people with hemophilia in the United States.

During the late 1980s, a risk reduction model program involving the CDC, MCHB, the HTCs and NHF began and NHF officially established the Hemophilia AIDS/HIV Network for the Dissemination of Information (HANDI). This information service, originally focused on providing information on HIV/AIDS, has evolved and grown. Currently, HANDI provides resources on bleeding disorders, conducts library searches and provides referrals. NHF's HANDI has the largest library of bleeding disorder information in the world.

To serve its community suffering from HIV/AIDS, NHF's focus took a new direction toward developing research protocols and creating peer education and outreach programs. Consumers began forming support groups at both the local and national level, which paved the way for the first national NHF-sponsored Women's Outreach Network of NHF (WONN) and the Men's Advocacy network of NHF (MANN).

### Hope for a brighter tomorrow.

In the early 1990s, progress in genetic research raised hope for potential gene insertion therapy in hemophilia, an upbeat and positive message much needed for a community enduring the devastating effects of HIV/AIDS. Recombinant factor replacement therapies were introduced, giving the community effective treatments not derived from plasma.

Investigating the infection of people with bleeding disorders with HIV through the blood supply and improving HTC care for HIV still remained in the forefront. At the 1992 NHF Annual Meeting, the Special Assistance Council (SAC) was formed to pursue compensation for those in the hemophilia community affected by HIV. Since the 1990s and into this century, new medicine regimens are effective in managing the HIV virus in our community.

Today, NHF represents gender and ethnic diversity and its voice is embodied by both consumer and medical leadership. As a 501 (c) (3) charitable organization, governed by a board of directors, NHF is dedicated to finding a cure for all bleeding disorders and improving the quality of life for those affected through research, education and advocacy. Oh Baby!! Look how we have grown over the last 50 years!!

*The previous text was taken from HemAware, a publication of the National Hemophilia Foundation, October, 1998.*

## Walking to Raise Awareness about VWD!!

**A member of the DVC family is walking to raise awareness about bleeding disorders! Shirley Boozer, from Greeley, PA has walked 151 miles so far, and at 70 years old, she's not done yet!!! Thank you, Shirley, for all you are doing to raise awareness of this bleeding disorder which affects both males and females!! You are an inspiration. If you have an idea to raise awareness or raise financial support...call the DVC office. One person CAN make a difference!!**

## SPOTLIGHT ON YOUTH LEADERS

At the 2007 Annual Family Dinner on Tuesday, May 8th, nine distinguished youth leaders received awards for outstanding essay submissions. We have shared four excellent essays with you in the last two editions of *The Winning Spirit* and offer excerpts from the remaining five in this issue.

“Does hemophilia make me a liability? I think not. If anything, hemophilia has made me a fiercely competitive, extremely independent and an ever-so-compassionate human being. I have a whole lot to give to society. That is why young children with hemophilia should never worry about their own, individual and important roles in society. My so called liability is now an asset.”

*Stephen Nicolosi, Clarks Summit, PA*

“My vision for my future is to become a physician, to help those within the bleeding disorders community. I hope that in my future as a von Willebrand patient, health professional and advocate, I will continue to make a real difference for those with all bleeding disorders. I have and will continue to reach out to my peers about the importance of taking an active leadership role, small or large. I know that I cannot sit back and watch things happen. I need to help make them happen.”

*Josephine Droney, Linwood, NJ*

“My hemophilia caused my parents to join the Delaware Valley Chapter. When my parents got involved, I spent a lot of time with other hemophilia families. This has made me a better person and I had a lot of fun! I try to be a role model for younger boys with hemophilia. My ultimate goal is to become a Hematologist and work with kids at Children’s Hospital. I hope to be able to donate a lot of money to hemophilia research to find a cure.”

*CJ Felthaus, Philadelphia, PA*

“I participate in volunteer work for the Delaware Valley Chapter. Being able to volunteer for such a great group is by far, the best feeling I could every have. Helping to make a difference for other people in our hemophilia community is important work. The future of the Chapter and all the functions and events that happen throughout the year is dependent on the help of many people. Please get involved as much as you can, so we can make sure the activities continue.”

*Alex Littig, Roslyn, PA*

“My family and I have been active participants in various events throughout our years with the Delaware Valley Chapter. These events cover many topics that are helpful to my family. They answer questions and concerns that I may have regarding hemophilia. I would like to encourage all the younger children with hemophilia to stay strong. Believe that one day a cure will be found. Most importantly, follow all of your dreams and don’t let hemophilia stop you from doing anything. Live your life to the fullest. Hemophilia is not the deciding factor, you are.”

*Justin Cook-Morris, Willingboro, NJ*

You can now donate to the Delaware Valley Chapter of the National Hemophilia Foundation by credit card via PayPal!

Just go to our web site at [www.hemophiliasupport.org](http://www.hemophiliasupport.org) and click on the **Donate** button.



With your support, we can reach our goal to enhance the quality of life for patients affected by hemophilia and related bleeding disorders. We serve the 1700 patients that reside in southeastern Pennsylvania and Delaware.

**Thank you for your support!**

Your tax deductible donation to us will make a real difference in the lives of people affected by rare bleeding disorders.

# Legislative Update

## PUBLIC HEARINGS ON HB 1105 THE HEMOPHILIA STANDARDS OF CARE ACT

Two Public Hearings were held on HB 1105, *The Hemophilia Standards of Care Act* in September: September 10th at the Hemophilia Center of Western Pennsylvania, Pittsburgh and on September 27th at the Hemophilia Center of Central Pennsylvania, Hershey. Patients, parents, experts and hemophilia program staff presented testimonies before members of the Pennsylvania House of Representatives Insurance Committee. Following are some key points made in those testimonies supporting HB 1105:

“HB 1105 establishes a standard of care so that patients with hemophilia and vonWillebrand disease living in Pennsylvania can receive the following: Necessary and appropriate medical care, including the services of a physician experienced in hemophilia care; the full range of FDA-approved, medically-necessary blood clotting factor therapies; the specialized coagulation testing required for an accurate diagnosis and appropriate treatment at a clinical coagulation laboratory associated with a state-recognized hemophilia program. It is critical that the standards of care established in HB 1105 be adopted, so that the 1,700 persons with hemophilia and vonWillebrand disease in Pennsylvania may enjoy the quality of life that can be achieved through appropriate and timely treatment of their disorder.”

*M. Elaine Eyster, MD, Medical Director, Hemophilia Center of Central Pennsylvania*

“I currently serve on the Medical and Scientific Advisory Council of the National Hemophilia Foundation (MASAC). MASAC is composed of the leading experts and medical treaters of bleeding disorders in the United States, including physicians, researchers and other healthcare providers. Taken together, MASAC’s recommendations represent the medical standard of care for the treatment of bleeding disorders in the United States and these recommendations are equally respected around the world. MASAC has endorsed HB 1105 and believes that this legislation, when passed, will provide assurance that patients with bleeding disorders will continue to have access to quality medical care in Pennsylvania. I see firsthand, the problems my patients have in accessing what they need for the treatment of their bleeding disorders, due to

the changing practices of commercial insurance companies in Pennsylvania. Insurance companies, rather than the patients or medical providers who know their disease, are making decisions: this is a barrier to good medical care and good treatment.”

*Margaret V. Ragni, MD, Medical Director, Hemophilia Center of Western Pennsylvania*

“Having been the Insurance Commissioner of Indiana for more than 7 years, I can tell you that the provisions in HB 1105 would save both money and lives. Patients with bleeding disorders in Pennsylvania are fortunate to have seven state-recognized centers of excellence in hemophilia care. I know from my experiences in Indiana that the cost savings realized through treatment at a comprehensive hemophilia center is significant for both insurance companies and patients. I am surprised that the insurance industry can’t see the benefits of this standard of care. In HB 1105, you have the opportunity to provide solutions to some of the most common and costly problems faced by Pennsylvania residents living with hemophilia and other bleeding disorders. And, in doing so, you have the additional benefit of saving money for insurance companies and patients alike while improving the quality of life and life expectancy of those affected by these costly disorders.”

*Sally McCarty, Insurance and Advocacy Director, Hemophilia of Indiana*

“As healthcare costs have risen across the board, governments and the private sector alike have aggressively pursued ways to cut costs. It is understandable that hemophilia treatments get looked at. These are complex biologic therapies produced for a relatively small population and therefore, when looked at on a per-patient basis, they are expensive. However, the clotting factors and related medical services that people with bleeding disorders have come to rely on are merely what they need to stay alive and stay healthy – nothing more and nothing less. To curtail access to these needed treatments and thereby fail to protect this fragile population would be cruel and inhuman. Simply stated, HB 1105, The Hemophilia Standards of Care Act, is designed to prevent that from happening to people with bleeding disorders in the

Commonwealth of Pennsylvania. The brilliance of this legislation is that it manages to distill from MASAC Recommendations, the handful of things that people with bleeding disorders absolutely need and then it assures that people who need these things will have access to them.”

*Glenn Mones, Vice President for Public Policy, National Hemophilia Foundation*

“We don’t believe that insurance companies are trying to do harm to patients with bleeding disorders in Pennsylvania. We don’t believe that they are trying to withhold our access to medicines and treatment. Insurance companies, in an effort to control costs, are applying the same cost-containment strategies to hemophilia that have been implemented for other chronic conditions...preferred drugs, preferred providers, contracted laboratories and limiting the amount of medicine a patient can have in the home. On paper it makes sense, but it doesn’t work for hemophilia. It increases costs for the payers. We have spent the last three years collecting case examples of problems for patients from the seven hemophilia programs in Pennsylvania. These examples are a clear reminder that when patients cannot access proper care, costs to insurance companies and medical complications actually increase.”

*Ann E. Rogers, Executive Director, Delaware Valley Chapter*

“Most health insurance plans with prescription benefits now include “drug formularies.” The insurer’s objective is to provide the patient with the lowest cost drug that is effective in treating a particular health condition. Under many plans, the formulary is developed to discourage or prohibit the insured from using the most expensive name-brand drugs, when a lower cost generic drug would work equally well for a particular medical condition. With hemophilia, however, there are no generic drugs. There cannot be preferred products” for the treatment of hemophilia and there can be no exclusion from coverage of any product because it costs more. Only the physician and patient know which clotting factor is effective for that patient. Thus, all FDA-approved clotting factors must be available for patients with bleeding disorders.”

*George M. Levy, Chair, DVC Advocacy Committee*

# Legislative Update

## NATIONAL AND WORLD ORGANIZATIONS ENDORSE HB 1105

Following are statements from national and world organizations supporting HB 1105, The Hemophilia Standards of Care Act.

"We are writing in strong support of passage of HB 1105, "The Hemophilia Standards of Care Act." People with bleeding disorders need access to high quality care in order to live long, productive lives. This bill will ensure that Pennsylvanians affected by these disorders have unimpeded access to such care." *Raymond Stanhope*, Chair of the Board/National Hemophilia Foundation, *Alan Kinniburgh, PhD*, CEO/National Hemophilia Foundation, *Craig Kessler, MD*, Chair MASAC/National Hemophilia Foundation

"The World Federation of Hemophilia is an international not-for-profit organization dedicated to introducing, improving and maintaining care for people with hemophilia and related bleeding disorders around the world. HB 1105 addresses what all people with hemophilia need to sustain a quality life. Guaranteeing access to treatment for all patients with a bleeding disorder is a sound investment in the future of not only the patients, but also their families and the overall public health for the citizens of Pennsylvania. The World Federation strongly supports HB 1105, "The Hemophilia Standards of Care Act." *Mark W. Skinner, President*, World Federation of Hemophilia, Montreal, Quebec

"The Hemophilia Federation of America (HFA) a federation of 28 member organizations, strongly endorses HB 1105, "The Hemophilia Standards of Care Act." This important legislation will reduce exposure to unnecessary risks for patients with bleeding disorders in Pennsylvania and help limit the long-term costs associated with complications when proper care cannot be accessed." *Carl Weixler, President*, Hemophilia Federation of America

"The Committee of Ten Thousand, a national organization of people with hemophilia who have contracted HIV/and/or hepatitis C from FDA-approved medications, supports HB 1105, "The Hemophilia Standards of Care Act." The provisions of HB 1105 are sweeping in assuring access to care for patients with bleeding disorders in Pennsylvania." *Corey S. Dubin, President*, COTT

"The Plasma Protein Therapeutics Association (PPTA) strongly supports the enactment of HB 1105, "The Hemophilia Standards of Care Act." This bill would ensure that Pennsylvanians affected by these disorders have unimpeded access to care. It is crucial as a matter of public policy that the participants in Pennsylvania health insurance plans are not denied timely access to the treatments they need to keep them alive and functioning." *Julie Birkofer, Vice President* PPTA, North America

### HB 1105 Sponsor Speaks to the Issues



"Our highest priority must be protecting and preserving the right of all Pennsylvanians, especially our most vulnerable populations, to access the health care resources they need," said Representative Larry Curry, sponsor of HB 1105.

"It is crucial that we pass The Hemophilia Standards of Care Act so that patients with bleeding disorders continue to have access to specialized care. By trying to restrict such access, insurance companies are demonstrating that their highest priority is profits, not patients." This legislation seeks to prevent insurance companies from limiting access to essential treatment options, including the seven state-recognized hemophilia programs in Pennsylvania. Patients worry that insurance companies may, in the future, no longer pay for treatments at these centers. Instead, they could require patients to see an approved provider (physician) or to use a single "preferred" blood clotting product for the treatment of hemophilia. Given that not all patients respond the same way to every blood clotting product, this is a recipe for disaster. Restricting access is a "penny wise, pound foolish" approach to health care. The Hemophilia Standards of Care Act would help ensure continued access to proper care for all people in Pennsylvania with bleeding disorders."

## NOT A GOODBYE.....

Jamie E. Siegel, MD, Medical Director of the Cardeza Foundation Hemophilia Center (CFHC) for the past six years, has accepted a position at Novo Nordisk, Princeton. The good news....she will still be working in hemophilia as the Director of Hematology, responsible for doing clinical research in hemophilia. Dr. Siegel has left her handprint on each of us and she will be missed. She did her hemophilia fellowship at Cardeza from 1987-1989 under Dr. Sandor Shapiro and Dr. Jose Martinez. "Although my career has provided many opportunities for me to have a positive impact on the lives of patients, it was my experience as 'camp doctor' for the Brandywine Hemophilia Summer Camp that made me want to focus my clinical practice on helping patients with bleeding disorders. It took a little 'arm twisting' to get me to camp that first year, but I came back for the next five summers! When I returned to Cardeza six years ago, it was gratifying to



see so many of my 'campers' doing well as adults. They were more independent and self sufficient than I ever imagined."

Dr. Siegel's career has taken her many places: Easton, Pennsylvania, Cooper Medical Center, MCP Hahnemann and Robert Wood Johnson Medical Center. "I am confident that CFHC will continue to provide the best care to its patients. The Center has a long history of excellent physicians and has the two, best hemophilia nurses in the world, Kay Miller and Sharon Littig! The newest addition to the center's staff, social worker Bobby Korathu, has a keen understanding of how to help patients advocate for what they really need. He fits right in!

As I leave, I remain within the community, not only through my new work, but also by staying active with a community that has meant so much to me, both professionally and personally." *P.S. We miss you already, Jamie!*

# Bleeding Disorder Legal Hotline



The Delaware Valley Chapter is pleased to announce the Bleeding Disorder Legal Hotline. This free, confidential phone line is manned by an attorney, Beth Sufian, in Houston, Texas. She has over 17 years of experience helping people with chronic conditions understand the laws intended to protect them regarding health insurance and school/work issues. This Hotline was initiated by the Lone Star Chapter of the National Hemophilia Foundation in 2006. Hotline callers have reported that the information was helpful and would have been difficult to find without the help of this service. The Hotline can provide information on the issues listed below:

1. Obtaining and maintaining private health insurance.
2. Obtaining coverage from insurers for medical treatment.
3. How a small business can obtain health insurance.
4. Legal rights regarding Medicaid & Medicare.
5. Applying for Social Security benefits.
6. Appealing a denial of application for Social Security benefits.
7. Protection in the workplace from discrimination.
8. Family Medical Leave/Reasonable Accommodations in the workplace.
9. Insurance issues related to transitioning young adults.
10. Legal rights of children with medical conditions in the school setting.

**The Bleeding Disorders Legal Hotline is open to people affected with a bleeding disorder and the medical professions that provide care for them. Quite simply, the Hotline is designed to bridge the gap between the laws and the people who need to know about them. Call 1-800-520-6154 and get informed.**

**The Hotline is recognized by the National Hemophilia Foundation as a valuable resource to the bleeding disorders community**



## 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 four 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!!

**Birdsboro Branch**  
Tina & Jeff McMullen  
610-582-1731

**Camp Hill Branch**  
Shannon & Jay Penica  
717-975-2897

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

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

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.

## Planned Giving

When you make a future or planned gift, you help so many people. Remembering The Delaware Valley Chapter in your estate plans or will, directly impacts the lives of people living with hemophilia and related bleeding disorders and their family members. You will also touch the lives of those who might someday be affected by a bleeding disorder. Arrangements can be made to leave a legacy in your will for The Delaware Valley Chapter. You can leave a specific amount or a percentage of your assets. Gifts may include, but are not limited to: stocks, bonds, guaranteed investment certificates, real estate, art and jewelry. Speak with your financial advisor about Planned Giving. Your gift can make a real difference!!

## SPECIAL CAMP NEWS

It seems early to be thinking about sending the kids off to camp in the Summer of 2008, 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 buzzzzzzzz!!

### THE GOOD NEWS!!

Once again summer of '08, 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. 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 the following two sessions:

SESSION #1: JULY 11 TO JULY 16, 2008  
SESSION #2: AUGUST 4 TO AUGUST 9, 2008

*FOR AN APPLICATION, CALL THE DVC OFFICE AT 215-885-6500 OR ASK YOUR TREATMENT CENTER TEAM. THE DEADLINE FOR APPLICATION IS APRIL 1, 2008 AND SPACES ARE VERY LIMITED!!*

### CAMP DRAGONFLY FOREST!!!

Even if your child attends one of the weeks 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: June 28 – July 3, 2008

**Now you can make donations to the DVC on line with your credit cards @ [www.hemophiliasupport.org](http://www.hemophiliasupport.org)**