

## DVC Board Members.... Who are They?



The Delaware Valley Chapter Board of Directors is comprised of some pretty wonderful people who serve for one year terms without compensation. As a non-profit corporation, the DVC is proud of its rich tradition as a volunteer-driven organization, with strong Board leadership provided to the many committees that do the work for our local community. Here are the people who lead our daily mission. Their contributions are many and their dedication consistent and strong. We are lucky to have their talents and guidance. Eleven of the current seventeen members of the Board have a family connection to a bleeding disorder.

### **Keith Moore, President**

Keith has been on the DVC Board since 2000 and serves as President (since 2004). He is a past Vice President for the Chapter, as well. Keith is involved in all aspects of Board activity from setting policy and strategy, attending local, state, regional and national meetings and participating in fundraising events. Keith has been instrumental in enhancing philanthropic contributions to our organization, including corporate contributions from Philadelphia-based companies. He is Vice President of Business Development for Lockheed Martin Integrated Systems and Solutions, managing over \$5 billion per year in new business. He is responsible for the development of business and capture strategies to expand core businesses and win new opportunities in defense, intelligence, homeland security and international markets. Keith and his wife, Suzanne, reside in West Chester.

### **Jim Lindquist, Vice President**

Jim has been a member of the DVC Board of Directors since 2003 and currently serves as Vice President. Jim has worked on the upgrade of the DVC office computer systems and the development of the DVC annual budget. He has been the master of ceremonies at the Oktoberfest (now the Gala) for the past several years. Jim also served on the Board in the early 1990's when he ran the Sports Brunch and served as Board Vice President and an NHF Regional Director. Jim is an engineer and Principal at Kling, a national building design firm. He lives in Paoli with his wife Lynn and their two dogs.

### **Andrew Serrill, Treasurer**

Andy has been a member of the Board for eleven years. He currently serves as Treasurer for both the Delaware Valley

Chapter and Hemophilia Patient and Program Support, Inc. (HPPS) and also serves on the Board Finance Committee. Andy is a PECO Energy retiree and currently owns a personal income tax preparation business. He lives with his wife in Hatboro, Pennsylvania.

### **Cheryl Littig, Secretary**

Cheryl has been a member of the Board since 2002 and currently serves as Secretary. She is very active with Chapter fundraising events, the Holiday Party and Family Camp and serves on the Patient Service Committee. Cheryl works in insurance billing for a small company and resides in Roslyn, Pennsylvania with her husband and son.

### **Alicia Goodman-Blackshear**

Alicia has been a member of the Board for 13 years. She has chaired The Annual Family Dinner and is a member of the Patient Service Committee. Currently she serves on the Scholarship Committee. Alicia has contributed to and supported many Board committees, including the Ladies' Committee, Oktoberfest, and Family Camp. Alicia has worked in the medical community for over 15 years. She is currently employed as a medical insurance specialist. Alicia lives in Philadelphia with her husband, Gino, and their children.

### **Laura Carlino**

Laura joined the Board in 2000. She and her husband, Pat, own Carlino's Specialty Foods, Inc. in Ardmore, Pennsylvania. Laura is also actively involved in The Sandy Rollman Ovarian Cancer Foundation. Laura has helped the Delaware Valley Chapter raise hundreds of thousands of dollars through her leadership of "The DVC Golfing for a Cure" and "Moose Night." Laura lives in Haverford, Pennsylvania with her husband and four children.

### **Clifford B. Cohn, Esquire**

Cliff is a practicing attorney and founder of Cohn & Associates, a law firm that represents clients in diverse litigation matters. He has served on the Board of the Delaware Valley Chapter since 1995 and was President of the Board until 2004. In 2005, Cliff was elected to the Board of the National Hemophilia Foundation. He has more than 25 years of service to the business community, serving on many boards

# The Winning Spirit

**Winter 2007  
Volume 14  
Number 1**

in  
this  
issue

## **2 DELAWARE VALLEY CHAPTER NEWS & NOTES**

## **3 CHAPTER HAPPENINGS**

## **3 CHAPTER CALENDAR**

**4** *When Carriers Bleed Women who carry the hemophilia gene need clotting factor levels tested by Lori Herring*

**5 ON THE HEALTH FRONT**  
• *Is Tylenol Bad for Your Liver?*  
• *Bleeding Disorders and Analgesics*

**7 LEGISLATIVE UPDATE**  
*Who Will Pay Our Medical Bills?* by Glenn Mones

## **8 CAMP INFORMATION**

National Hemophilia  
Foundation

**DELAWARE VALLEY CHAPTER**

222 S. Easton Road, Suite 122

Glenside, PA 19038

Phone (215) 885-6500

fax (215) 885-6074

e-mail: hemophilia@navpoint.com

Ann Rogers

*Executive Director*

Sue Stinger

*Program Coordinator*

**Board of Directors**

Keith W. Moore, *President*

James R. Lindquist, *Vice President*

Andrew B. Serrill, *Treasurer*

Cheryl A. Littig, *Secretary*

**Board Members**

Alicia Blackshear

Laura Carlino

Clifford B. Cohn, Esquire

Kathy DiMichele

Patricia Felthaus

Noel A Fleming, Esquire

Adam Gusdorff, Esquire

Elaine Jones

Steven Lampe

George Levy

Kathleen Sell

Pauline Tache

Kathryn Warhol

*The Winning Spirit*

is published quarterly by the National Hemophilia Foundation, Delaware Valley Chapter. The contents of this newsletter may be reproduced freely, but please attribute the source. The material in this newsletter is provided for your general information only. The Delaware Valley Chapter does not give medical advice or engage in the practice of medicine. DVC under no circumstances recommends particular treatments for specific individuals, and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

Graphic Artist:  
www.chaley.com

## From the Executive Director



Families with newly-diagnosed children are getting together!!!  
**"First Step" Makes a Difference.....!!!**

In 1995, the National Hemophilia Foundation (NHF) and the Centers for Disease Control and Prevention (CDC) started a new parent and family program called "First Step." This program provides families with information and support once their child has been diagnosed with a bleeding disorder. The Delaware Valley Chapter has started a "First Step" Program locally and invites you to join other families to learn and find support!!



If you would like to register for upcoming "First Step" events, call the DVC office (215-885-6500). You will have the opportunity to meet other parents of young children or those newly diagnosed with a bleeding disorder in a social setting. Join other "first steppers" and find out how to *step to success!!*

You are invited to join us for

## "A Women's Retreat on the Hill"

May 18, 19 and 20, 2007!!!

*An educational retreat for women in families with von Willebrand Disease*

This weekend retreat will provide information to women about von Willebrand Disease (VWD) at the beautiful ACE Conference Center in Lafayette Hill, Pennsylvania. Located just beyond historic Chestnut Hill at the north end of Philadelphia, this fabulous facility provides a spectacular setting for a weekend retreat for women. The retreat lodge sits in the middle of 300 acres of luxurious woodland and is a perfect environment that encourages reflection and personal interaction.

On this weekend, you will find a relaxed atmosphere with plenty of opportunities to reduce stress, rediscover ways to have fun and increase your awareness of VWD and the support networks that are available to you. Fabulous accommodations, peace and quiet and wonderful meals...what could be better?

This program is open to 30 women, ages 18 and older that have VWD or have children or spouses with VWD. We will offer programs designed to further your understanding of VWD, how to live positively and develop a support network. We are sure that you will enjoy and value this gentle break in your busy schedule!!

*\* All of your hotel and meal expenses will be covered by a grant from CSL Behring \**

Space is limited to 30 women for this conference. To register for "A Women's Retreat on the Hill" please complete the enclosed registration form and return it to the Delaware Valley Chapter by March 1, 2007!!! Any questions, just give us a call: 215-885-6500!!

### \* Agenda \*

Friday, May 18th

5 pm to 7:30 pm Arrival & Dinner  
8 pm to 9:30 pm Opening Program

Saturday, May 19th

8:00 am to 8:45 am Breakfast  
9:00 am to noon Morning Session  
12 pm to 1 pm Lunch  
1:15 pm to 4 pm Afternoon Session  
7:00 pm Dinner & Evening Fun!

Sunday, May 20th

8:00 am to 9 am Breakfast  
9:15 am to 11 am Morning Session  
11:30 am Lunch & Departure

*We Gratefully Acknowledge...the pledge of support from the following manufacturers for 2007*

Baxter Bioscience  
Recombinate  
Hemofil M  
Proplex T  
Feiba VH  
Bebulin VH  
Albumin (Human)  
Advate

Bayer Corporation  
Kogenate FS  
Koate-DVI

CSL Behring  
Monoclate-P  
Mononine  
Helixate FS  
Humate-P  
Stimate  
Gammar-P I.V

Grifols  
AlphaNine SD  
Alphanate  
Profilnine SD

Wyeth  
BeneFIX™  
ReFacto

Novo Nordisk  
NovoSeven™

## April

14 Fashion Show!  
17 Harrisburg Day!

## May

8 Family Dinner!  
18, 19, 20 Women's  
VWD Retreat Weekend!

## June

4 Carlino's Golf!  
30-July 6 Dragonfly Forest  
Camp

## July

12-17 Woods Camp #1!

## August

5-10 Woods Camp #2!

### The **National Hemophilia Foundation's 58th Annual Meeting** was held in Philadelphia on **October 12, 13 and 14, 2006!!**

As the host Chapter, we were very proud to be acknowledged by the NHF in so many ways. Here are some of the highlights of this great meeting, which, by the way, had the second highest attendance on record for an NHF national meeting!!

*We hosted Ben Franklin's 300th Birthday Party at the Franklin Institute on Friday, October 13th with Wyeth as the Event Sponsor!! Our deepest gratitude to Renee Caserta and the Wyeth team for an evening we will never forget!! Renee thought of every detail and after a whole year of planning, we enjoyed every minute of this fabulous night!! A great big "thank you" to our dear friends at Wyeth for partnering with us as we welcomed families from around the country to one of Philadelphia's best attractions!!*

*The DVC was honored by the NHF for our state advocacy work in Pennsylvania on behalf of our community!! Ann Rogers received the "NHF's Advocate of the Year Award!"*

*Art Stinger, a local member and great DVC volunteer, received an NHF "Volunteer Award!" Way to go, Art!! And thanks for all you continue to do for us!*

Note: The NHF's 59th Annual Meeting will be held in Orlando, Florida on November 1-3, 2007!! Mark your calendars!!

**Casino Royale** was held on **Friday, November 3rd** at the Hilton Hotel on City Avenue in Philadelphia! Kathryn Warhol, Committee Chair and Board Member "went over the top" for this spectacular event!! Raising more than \$90,000 for the DVC, this fall gala was just a terrific evening of food, fun, dancing, gaming and support for our mission of service!! Thanks, Kathy for all your hard work and creative ideas!! See ya' next fall!!!

*Left: 2006 Casino Royale Chair, Kathryn Warhol (DVC Board) w/Andy Serrill, DVC Treasurer. Right: supporters & friends: L to R Keith & Cheryl Littig, Art & Sue Stinger.*

The **DVC Annual Holiday Party** was held at Jefferson Alumni Hall in Philadelphia on Saturday, **December 9, 2006** and Kim Bayer, Committee Chair and her dedicated volunteers (The A Team!!) planned a great day of fun and surprises for the 400 people who attended!! Santa was on hand to ring in the holiday spirit!! We left "full of good cheer" with goodies in hand!! Thanks, Kim for bringing us this DVC holiday tradition!! Can't wait till next year!

### **And Here's What's Coming Up!!**

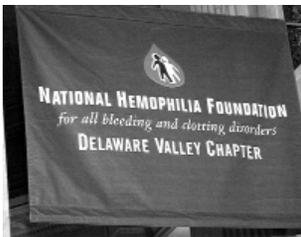
The Fashion Show April 14!!!  
Harrisburg Day April 17!!  
The Family Dinner May 8!!  
Women's Retreat May 18, 19, 20!!  
Camps for Kids (back page)!!



*Ben and Evan blow out the candles!*



*Above: Dan Levin & Cavan Redmond (Wyeth) with Ann Rogers & Keith Moore (DVC)! Below: Ann Rogers with Renee Caserta... a great big "Thank You to Wyeth!!!"*



*Night at the Franklin! A Birthday Bash!*



## When Carriers Bleed *by Lori Herring*

### Women who carry the hemophilia gene need clotting factor levels tested

*The following article was taken from the November/December 2006 issue of HemAware, a publication of the National Hemophilia Foundation.*

Despite common understanding, it's not just men with hemophilia or women with von Willebrand disease (VWD) who have bleeding problems. Sometimes women who are carriers of hemophilia bleed as well. These carriers have the gene for hemophilia, but don't necessarily display all the symptoms of the disease.

A study published this year in *Blood*, the journal of the American Society of Hematology, looked at bleeding issues that affect carriers, with a focus on spontaneous bleeding events, bleeding after trauma and bleeding after surgery. The Dutch researchers wanted to compare the risk of bleeding among carriers vs. noncarriers.

It was no surprise that carriers with very low factor levels tended to have bleeding problems. But it was a surprise that women whose factor levels were in a range considered to be mild (40% to 60%) could also experience bleeding that may require treatment. This was true of carriers of hemophilia A and B.

#### The Increased Risk

Fully one-quarter to one-third of carriers with clotting factor levels less than 60% experience an increased risk of bleeding with surgical procedures, including dental work, notes Peter Kouides, MD, research director at the Mary M. Gooley Hemophilia Center at the University of Rochester in New York.

The study found that the risk of prolonged bleeding (more than five minutes) from small wounds was two times higher for carriers than for noncarriers. Tooth extraction also can be an ordeal for carriers: the risk of bleeding for more than three hours after having a tooth pulled was twice as high for carriers as noncarriers.

Also, low clotting factor levels were associated with increased joint bleeding and menorrhagia (heavy menstrual bleeding). However, gum bleeding and large bruising did not appear to be problems for the carriers.

This study was the first in more than 50 years to look at carrier issues in a sizable group of women. More than 500 women were involved in the study, and a little more than half were hemophilia carriers. (Women who reported coagulation disorders other than hemophilia, such as VWD, were excluded from the study.)

#### The Near-Invisible Problem

One of the challenges for women who are carriers of hemophilia is that many may not know their factor levels. But the likelihood of that knowledge increases if they have visited a hemophilia treatment center (HTC) or have given birth to a child with hemophilia.

Generally, healthcare professionals at HTCs "try hard to obtain at least one baseline level" measurement of clotting factor levels in hemophilia carriers, Kouides

says. "But since their bleeding history is likely to be mild and only related to intermittent invasive procedures, we may not often see these patients except when they are bringing their child in." A

vivid example of this, Kouides says, occurred when a sister and brother came to the emergency room after falling through a glass door.

The girl, who suffered the worst of the fall, was a hemophilia carrier, and the boy had severe hemophilia. "The mother had to remind the emergency room staff, who were spending more attention on her son because he was a person with severe hemophilia, that her daughter can bleed too," Kouides says. "Since the girl took the brunt of the fall and had more scrapes, she should have been attended to first."

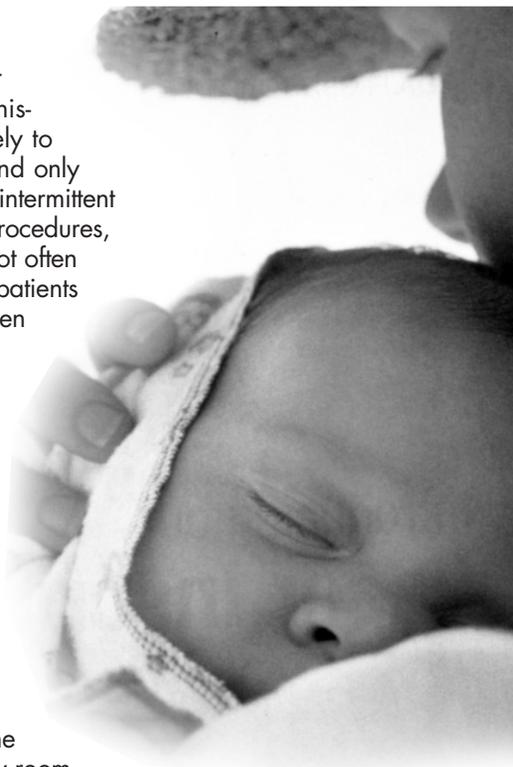
#### More Research Needed

Experts believe it's time to undertake a large study of carriers here in the United States. "It's important to study a more demographically, ethnically diverse population," Kouides says. "Along those lines, the CDC [Centers for Disease Control and Prevention] is planning a universal data collection specifically related to women, and they plan to collect similar data to this study."

This study underscores the need for women who are hemophilia carriers to have their clotting factor levels tested at least once. Those tests are best performed at an HTC where clinicians have the expertise to correctly interpret the results.

"This was a very well conducted epidemiological study by a reputable group," Kouides says. "The findings deserve our attention and should compel us to try hard to obtain factor levels on each of our carriers."

Kouides says immediate family members of carriers should also be evaluated, including a factor level check.



## Is Tylenol Bad for Your Liver?

The following article was taken from the November/December 2006 issue of *HemAware*, a publication of the National Hemophilia Foundation.

A recent study shows that healthy young adults who take acetaminophen for just a few days may experience an increase in liver enzymes.

Acetaminophen – commonly known as Tylenol – often is recommended for people with hemophilia for acute pain and chronic arthritis pain because it is one of the few painkillers that may not interfere with bleeding [coagulation].

The liver problem in this study was detected in patients who took two 500-mg caplets of acetaminophen four times a day, for two or three days. The study found that elevations of the liver enzyme alanine aminotransferase (ALT) occurred whether a person was taking acetaminophen alone or with hydrocodone or a morphine derivative. This suggests that neither hydrocodone nor morphine affected ALT levels, according to the study's lead author, Paul B. Watkins, MD, of General Clinical Research Center, University of North Carolina at Chapel Hill.

Elevated ALT levels are an indicator of liver toxicity. Of the patients taking acetaminophen, 31% to 44% had ALT levels more than three times the normal upper limit, Watkins' multi-center team reports. Patients taking placebos had no ALT elevations.

The study, published in the July 5, 2006 issue of the *Journal of the American Medical Association*, is the first to show that acetaminophen taken at normally recommended doses can raise ALT levels. It also found that the high ALT levels persisted for several days even after patients stopped taking acetaminophen and it was no longer detectable in their blood.



People with bleeding disorders who also have hepatitis C face a higher risk of liver toxicity from other medications they take because the liver is already compromised. Patients with HIV/AIDS also must be closely monitored for toxic liver effects from their medications.

Watkins says it was unclear whether the higher ALT levels should concern healthy adults. He says he believes levels return to normal after repeated use of acetaminophen [has stopped] and is conducting a new study to test his hypothesis.

If you are taking acetaminophen as part of a pain relief regime, consult your doctor about the possibility of liver complications.

## Bleeding Disorders and Analgesics

The following article was taken from the November/December 2006 issue of *HemAware*, a publication of the National Hemophilia Foundation.

The National Hemophilia Foundation's Medical and Scientific Advisory Committee (MASAC) Document #155, Guidelines for Emergency Department Management of Individuals with Hemophilia, addresses the use of pain medication as follows: "Aspirin and aspirin-containing products are contraindicated in

individuals with hemophilia. Acetaminophen and/or codeine may be used for analgesia. Non-steroidal anti-inflammatory drugs may be carefully administered to select patients, such as individuals with chronic arthritic pain who are not actively bleeding or being treated for a recent bleeding problem."

*continued from page 4*

### When Carriers Bleed *by Lori Herring*

## Women who carry the hemophilia gene need clotting factor levels tested

These screening tests are especially important for a family member who may be getting a surgical procedure.

Also, it is important that women with factor levels in the range of 40% to 60% understand that they also may experience bleeding problems. Traditionally, a female carrier for hemophilia is one with factor levels less than 50%; and mild hemophilia is defined as a clotting factor level less than 40%. But these strict definitions could change. According to the study, "These findings could have implications for the

current definition of clotting factor levels considered to be 'reliable' to perform medical interventions."

In other words, "It's reasonable to keep one's antennae up regarding this lest the patient suffer excessive bleeding at the time of an invasive procedure," Kouides says.

### To Learn More...

Plug I, Mauser-Bunschoten EP, et al.: Bleeding in carriers of hemophilia. *Blood*.2006; 108 (1):52-56.

## DVC Board Members....Who are They?

and committees including the audit committee of publicly traded companies such as Publicker Industries/Publicard, Lesley Fay, Sassco Fashions; private companies,

Glasstech, South Point Ethanol, a joint venture between Ashland Oil, the Ohio Farm Bureau and UGI, as well as private foundations, PNC Inc. and Neuman-Publicker Foundation. Cliff is an avid golfer and dedicated youth baseball coach and lives in Villanova, with his wife and teenage son. Cliff is Golf Committee Chair, past president of the DVC and current NHF national board member.

### **Kathy DiMichele**

Kathy has been a member of the Board for seven years. She co-chairs two annual fundraisers that have netted over \$500,000 to help the Chapter. She is an active member of the Ladies' Committee and Patient Service Committee. Kathy lives in Bryn Mawr, Pennsylvania with her husband and eight year old son.

### **Patricia Felthaus**

Pat joined the Board in 2001. She serves on the Patient Service Committee of the board and has been very active on many committees that plan both patient events and fundraisers. She is married and has three sons. She has been a federal employee for more than twenty years and is a native Philadelphian. Pat resides in northeast Philadelphia with her husband and youngest son.

### **Noel Fleming, Esquire**

Noel joined the Board in September 2006. He is an attorney in a law firm that specializes in advising nonprofit organizations in all matters related to their charitable operation. He is a native of Ireland. Prior to coming to America, Noel worked in a large bank based in Dublin. He lives in Chester County with his wife and two young children.

### **Adam Gusdorff, Esquire**

Adam has been on the Board since 2003. Adam is an attorney who has represented nonprofit and charitable organizations in court proceedings and has advised such organizations through the process of seeking and complying with federal tax exempt status. Prior to becoming an attorney, Adam worked as a sportswriter in suburban Philadelphia for eight years. He resides in Chester County with his wife and two young children.

### **Elaine Jones**

Elaine has served on the DVC Board for the past 11 years. As an RN, Elaine has volunteered at the "Double H Hole in the Woods Ranch Camp" for children affected by hemophilia and von Willebrand Disease. She is an active member of the Nominating Committee, Ladies' Committee and Patient Services Committee of the Board. Elaine resides in Hatboro with her husband and children.



### **Steven Lampe**

Steve joined the Board in 2002. He is a Portfolio Manager at Delaware Investments and heads the DVC Finance Committee and Nominating

Committee and serves on the Patient Service Committee. He previously worked at Price Waterhouse, consulting to nonprofit institutions such as the Annenberg Fund. Steve and his wife live in Blue Bell with their three children.

### **George Levy**

George has been a member of the Board for nearly ten years. He currently serves as the President of Hemophilia Patient and Program Support, Inc. (HPPS) a separately incorporated organization of the Delaware Valley Chapter. George chairs the DVC Advocacy Committee and is very involved in supporting efforts to achieve passage of state legislation in Pennsylvania that will protect patient access to care.

### **Kathleen Sell**

Kathy has been a member of the Board since 1986, serving as Secretary for several years. She currently serves on the Ladies Committee for the Annual Fashion Show and Luncheon and has served on committees for the DVC's Golf Outings and the fall fundraising event. Kathy also coordinates the arrangements for the DVC's Annual Family Dinner and currently serves on the Patient Service Committee. She lives in Philadelphia with her husband and works for Frankford Hospital. Kathy has two adult sons.

### **Pauline Tache**

Pauline has been a member of the Board since 1987. She has been active on numerous committees. She serves on the Ladies' Committee and the Patient Service Committee and is a past member of the Oktoberfest Committee. Pauline was the newsletter editor for three years. She is a registered nurse at Abington Memorial Hospital and resides in Hatfield with her husband.

### **Kathryn Warhol**

Kathy joined the Board in 2005. For the past sixteen years, she has worked as a certified nurse anesthetist while being involved in many philanthropic organizations. Kathy has been an active member of the Pennsylvania Hospital Auxiliary and served as Chairman of the Auxiliary from 2002-2004. During her tenure she chaired the Auxiliary's premier fundraising gala, renovated and restructured the Pennsylvania Hospital's thrift shop, and helped organize multiple fundraising events resulting in increased profits. In addition, she is a board member of the Philadelphia Youth Orchestra and has served as an active fundraiser for the English Speaking Union. Presently she chairs the DVC's Annual Fall Gala. Kathy resides in Haverford with her husband.

# Who Will Pay Our Medical Bills? *by Glenn Mones,* NHF's Vice President for Public Policy and Consulting Editor of HemAware

*The following article appeared in the November/December 2006 issue of HemAware*

In 2006, the challenge of accessing high-quality care increased for members of the bleeding disorders community. Although the National Hemophilia Foundation (NHF) and other community organizations and supporters are working diligently to fix these problems, they are not likely to be solved soon. Our entire community will need to expand its efforts to make progress on several fronts.

Decades ago, our biggest challenges were contaminated products, product shortages and not having enough properly trained medical professionals.

Luckily, today we enjoy a good supply of safe, effective products and a range of skilled treaters. But we increasingly face a different challenge: Who is going to pay our medical bills?

Medical costs in the United States have skyrocketed and public and private insurance companies are on the prowl for every possible way to save money. Some hemophilia patients can easily rack up more than \$100,000 in medical bills each year. It comes as no surprise that these high costs have popped up on the radar screen of insurers that are now trying to limit health coverage in several different ways.

## Less Insurance Coverage

Offering scaled-down plans that only cover basic care is one way employers and insurers can cut costs. These plans are inadequate for patients with chronic conditions or other critical needs.

The recent federal Health Insurance Marketplace Modernization Act, also known as the Enzi Bill, would have made this more likely. It gave companies the right to sell policies across state lines to small businesses, avoiding regulatory authority at the state level. The legislation was designed to offer insurance to more Americans, but it could make it harder for patients with chronic conditions to get adequate coverage.

NHF and other community groups opposed the new law and launched a grassroots campaign to defeat it. Legislators responded to our call and the bill never made it to the floor for a full vote. However, it is likely that variations of the bill will reappear during the next session of Congress.

## Less Drug Coverage

Another way insurers can cut costs is by limiting access to a full range of approved products (drugs). At the private insurer level, this is accomplished through a formulary, a list of covered drugs.

Employers and insurers are starting to use pharmacy benefit managers to lower drug costs. As a result, formularies are becoming more common and more restrictive. In some cases, patients may be required to get prior authorization from their insurance company and/or be required to pay a higher co-payment if their medication doesn't appear on a particular formulary. In other cases, payment for a prescribed drug may be completely denied.

Public payers, like state Medicaid programs, use a similar tactic called a "preferred drug list," or PDL. Last year, the PA Department of Public Welfare almost implemented the first Medicaid PDL (in the United States) that would have restricted patient access to a limited number of products.

The Delaware Valley and Western Pennsylvania Chapters with help from the NHF, combined forces to oppose the measure. In the campaign's critical final phase, NHF supported the efforts of its two Pennsylvania Chapters by working with an outside consultant to launch a highly successful media campaign that

## Hemophilia Awareness Day in Harrisburg!!

### WE NEED YOUR HELP!!

The Delaware Valley and Western Pennsylvania Chapters are moving forward with "Standards of Care" legislation to protect patient access to therapies, treatment centers and home supportive services in 2007. As part of our efforts, members of both Chapters will be participating together in a **Hemophilia and VWD Awareness Day in Harrisburg on April 17, 2007**. We will have buses bringing patients and families from the Philadelphia and Pittsburgh areas to the State Capitol. We will meet with legislators to tell them our personal stories and ask for their help in securing support for our legislation.

Personal stories about how bleeding disorders have affected our own families are the most powerful tool we have to get the attention of legislators. We need 200 people to join us in this effort. We appreciate that you would take a personal day from work or a vacation day to help make a difference for our Pennsylvania community of patients.

If you would be willing to give us a day to support this important effort, give the DVC office a call right away (215-885-6500)!! We'll add you to the list of our faithful legislative volunteers!! **We really need your help!!!!**

showed how this decision would harm families with bleeding disorders. The campaign ultimately succeeded and the PDL that was implemented did not restrict product access.

Although Pennsylvania was the first state to try the PDL tactic, it will not likely be the last. The Federal Deficit Reduction Act (DRA) gives states a variety of new options on how they run their Medicaid programs. Several states have received preliminary approval from the Centers for Medicare & Medicaid Services on their new Medicaid plans. Also, some states, including Florida, want to set annual caps on benefits. This could have disastrous consequences for patients whose medical costs are high because of an inhibitor, a surgery or other chronic conditions.

These are just a few examples of the way the reimbursement picture has changed this year and will likely continue to change in 2007. NHF is working closely with Chapters, community advocates and organizations to monitor the shifting landscape. We are trying to stop efforts to limit consumer access to high-quality care. We believe any measure with even the slightest potential to harm patients should be avoided.

Much more effort is needed to ensure that insurance companies understand our concerns. The more insurers understand us, the more likely they will pay for medications and treatments that are medically necessary to protect the lives and health of people in this community. NHF will continue reaching out to community members and ask for assistance with these crucial efforts at both the federal and state levels.

#### Post Note

*The Pennsylvania Chapters are moving forward with standards of care legislation in 2007 that will protect patient access to factor replacement therapies, treatment programs and home supportive services in Pennsylvania. PLEASE, PLEASE, PLEASE CALL THE CHAPTER OFFICE (215-885-6500) TO REGISTER TO PARTICIPATE IN OUR AWARENESS DAY IN HARRISBURG ON APRIL 17, 2007!!! WE NEED YOUR HELP!!*

# SPECIAL CAMP NEWS

Once again summer of '07, 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 bleeding disorders (boys and girls!!) 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 12 TO JULY 17, 2007  
SESSION #2: AUGUST 5 TO AUGUST 10, 2007

## NEWS

### ABOUT DRAGONFLY FOREST!!!

**Dragonfly Forest**  
your place to soar



Spending a week at camp for Philadelphia area children with hemophilia and Von Willebrand Disease (VWD) will be as close as Westtown, PA in 2007!! Dragonfly Forest will be settling into a more permanent home this summer on the 600 acre campus of the Westtown School, just outside of West Chester, Pennsylvania!! Even if your child attends one of the weeks at Double "H" Hole in the Woods Ranch, they are still eligible to attend Dragonfly Forest!! This camp is free to all campers!! Call the DVC with questions or

to receive an application (deadline is April 1st!!) and check out [www.dragonflyforest.org](http://www.dragonflyforest.org) for more details (including on-line registration)!! What a fabulous site for a summer camp!! You won't believe it!!

DRAGONFLY FOREST SESSION FOR DVC AREA KIDS JUNE 30 – JULY 6, 2007

**FOR AN APPLICATION, CALL THE DVC OFFICE AT 215-885-6500  
OR ASK YOUR TREATMENT CENTER TEAM. THE DEADLINE FOR  
APPLICATION IS APRIL 1, 2007 AND SPACES ARE VERY LIMITED!!**

## Delaware Valley Chapter **ESSAY CONTEST!!!!** Top Prize = **\$2,000 U.S. Savings Bond!!!!**

On Tuesday, May 8, 2007, we will hold our Annual Family Dinner at the Hilton Hotel on City Avenue, as in past years. This year's theme Our Future...Our Possibilities...An Evening with Youth Leaders, will profile local youth affected by bleeding disorders and their personal stories. As part of this special night, you will see an amazing performance by the famous Patrick Droney Band (headliners at the NHF Meeting in Philly, October, 2006!!) In addition, the DVC will award three prizes for the top three essays submitted by local teens with bleeding disorders. Here's how you can apply to be considered!!

### DVC Essay Awards

- First Place = \$2,000 U.S. Savings Bond!!
- Second Place = \$1,000 U.S. Savings Bond!!
- Third Place = \$500 U.S. Savings Bond!!

If you are a person with a bleeding disorder (boy or girl with VWD or hemophilia), between the ages of 13 and 19 and you are treated at a local hemophilia program in the Delaware Valley Chapter area, you may submit an essay to be considered. Here's the scoop!!

Your essay should be no longer than two pages (double-spaced). You must submit your name, date of birth, full mailing address, home and cell phone numbers and your e-mail address and you must state the name of your treatment center and your diagnosis.

#### Your essay should include:

- a. How your bleeding disorder has affected your life and your family in a positive way...
- b. How you view yourself as a future leader...
- c. What your goals and dreams are...
- d. How your treatment center has helped you...
- e. How you have worked to make a difference for yourself and others, or how you plan to make a difference for yourself and others through getting

involved with the Delaware Valley Chapter or other family, school or community groups and activities...

- f. Words of encouragement to help other young people with bleeding disorders get involved and make a difference in their community...

Feel free to include other pertinent information about your goals for the future.

Mail or e-mail your submission to:  
The Delaware Valley Chapter/NHF  
222 S. Easton Road, Suite 122  
Glenside, PA 19038  
215-885-6500

e-mail: [hemophilia@navpoint.com](mailto:hemophilia@navpoint.com)

All essays will be reviewed by a Chapter Committee and the top three will be selected. Awards will be given at the Annual Family Dinner on May 8, 2007. Award winners will be notified in writing during April 2007 and must read their essay at the Annual Family Dinner on May 8th!!

Get ready!! Get set!! Get writing!!