

NHF/DVC

The Winning Spirit

Quarterly Newsletter
National Hemophilia Foundation
Delaware Valley Chapter
Summer 2010 - Volume 17 #3

SENATOR GREENLEAF RECOGNIZED FOR SUPPORT OF HEMOPHILIA LEGISLATION

HARRISBURG, PA

On May 6th, members of the Delaware Valley Chapter of the National Hemophilia Foundation presented Senator Greenleaf with an award at his district office in Willow Grove for his support of *HB 620*, The Hemophilia Standards of Care Act. The Pennsylvania Senate also adopted a resolution sponsored by Greenleaf designating April as Hemophilia Awareness Month in Pennsylvania.

“I look forward to the final passage of *HB 620* to preserve access to the medication and services for hemophilia patients,” said Senator Greenleaf. “Also, I believe that we must work to raise awareness about hemophilia to ensure that the disorder is understood by the general public and the needs of patients are considered.”

Post Note: *HB 620*, *The Hemophilia Standards of Care Act* awaits consideration in the Senate Public Health and Welfare Committee. YOU CAN HELP BY E-MAILING OR CALLING Senator Pat Vance (Chair, Senate Public Health and Welfare Committee) and asking her to bring *HB 620*, *The Hemophilia Standards of Care Act* up for consideration in her committee RIGHT NOW!!!!!!!!!!!!!!!!!!!!!!

TELL HER THIS IS URGENT!

EMAIL: VANCE@PASEN.GOV

PHONE: 717-787-8524

We Have Enough Senate Support To Pass This Bill Right Now, But It Can't Be Voted On Until It Is Released From Committee! If It Isn't Released, It Will Die At The End Of This Legislative Session!

THIS IS URGENT!



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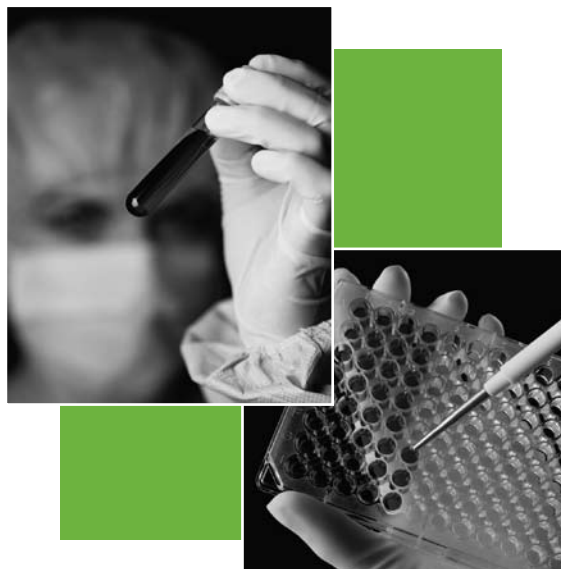
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Graphic Artist: www.chaley.com

We gratefully acknowledge the pledge of support from the following manufacturers for 2010.

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Hemofil M	Mononine
Feiba NF	Helixate FS
Bebulin VH	Humate-P
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Kogenate FS	NovoSeven® RT
Koate-DVI	Pfizer
	Benefix™
	Xyntha



In 2008, the National Hemophilia Foundation launched Phase I of its Campaign for Our Future (The Campaign). The Campaign is a fund-raising initiative to achieve NHF's vitally important ACT initiative - *Access to Care Today; Achieve a Cure Tomorrow*. The Delaware Valley Chapter, a proud early contributor of The Campaign, supports NHF's goals of ensuring the best care available for all those living with bleeding disorders through a collaboration of national and local efforts.

In Phase 1 of The Campaign, NHF received support from every major stakeholder group; every NHF national board member, every

NHF chapter, all major pharmaceutical firms, hemophilia-related organizations, Medical and Scientific Advisory Council (MASAC) members and individual leaders across the country.

Through their commitment and support, the ACT initiative is flourishing. Please read more about the ACT initiative via the NHF website: <http://www.hemophilia.org/campaignforourfuture>.

With more than 90% of NHF's goal reached, \$7.3 million to date, Phase II of The Campaign is now beginning, focused exclusively on raising money for research. RESEARCH IS OUR FUTURE! I would like to invite you to support Phase II of the Campaign, an effort to significantly expand and accelerate NHF's commitment to better treatments, and ultimately, a cure.

For more than 60 years, NHF has been a leader in the field of scientific research for bleeding disorders and remains the largest non-governmental organization committed to this type of science. One of NHF's premier research programs is its Judith Graham Pool Postdoctoral Research Fellowship in Bleeding Disorders (JGP). The Delaware Valley Chapter, along with Chapters around the country, is a long time contributor to the JGP Program. We, and others, are expanding our commitment to research through Phase II of the Campaign.

In the late 1960s, Dr. Pool's ground-breaking research revolutionized the current treatments for bleeding disorders. Inspired by her ingenuity, in 1972 NHF established a fellowship in her name to enable other talented scientists to devote themselves completely to advancing new treatments and finding a cure. For additional information about NHF's Research Program and the Judith Graham Pool Postdoctoral Research Fellowship in Bleeding Disorders visit the NHF website <http://www.hemophilia.org>.

I hope you will consider making a 100% tax-deductible contribution that will directly support the Judith Graham Pool Fellowship. Your gift in whatever size will be the catalyst for potential discoveries, paving the way for a better life for current and future generations of individuals living with hemophilia and all bleeding disorders. Thank you in advance for your gift of support.

Warm regards,

Ann

Ann E. Rogers, Executive Director

A donation envelope is included with this newsletter!

CHAPTER HAPPENINGS

Here's what's been happening!!

Spring Speaker Series, Central PA! Two special Saturdays of education for families in central Pennsylvania.

- **March 20:** *Living Well with Hemophilia: Understanding the Challenges*
Presented by: Jennifer Maahs, NP, Indiana Hemophilia and Thrombosis Center, Indianapolis, IN.
- **March 27:** *Hepatitis: Current HCV Treatments & Future Developments*
Presented by: Carolyn Francis, RN, CNP, MS, Lombardi Comprehensive Cancer Center, Georgetown, Washington, DC.
- **March 27:** *Prophylaxis: Is It Right for Me?* Presented by: Joanna Davis, MD, Hemophilia Treatment Center, Miami, FL and David Ungar, MD, Hemophilia Center of Central PA.

Annual Fashion Show and Luncheon, Saturday, April 10! A beautiful day of fashion and fun at the Drexelbrook in Drexel Hill, PA. This event raised more than \$70,000 supporting the mission of the DVC! Thanks to Jennifer Sawyer and Lynn Lindquist, Co-Chairs and their wonderful committee that made this year's event so spectacular! Next year's date: April 9, 2011!

CEO Program for Teens, Saturday, April 17! Held at the Radisson Valley Forge Hotel, this interactive leadership program helped teens look at future careers, education and opportunities in a totally new way. This national program geared to adolescents, was developed by the Indiana Hemophilia and Thrombosis Center and was sponsored by Baxter.

Harrisburg Awareness Day, Tuesday, April 20! Families and volunteers from across the state gathered in Harrisburg to promote the passage of *HB 620, The Hemophilia Standards of Care Act*. Our Senate visits provided an opportunity for people affected by bleeding disorders to restate the importance of *HB 620* and why this medical standard of care is urgently needed in Pennsylvania. More than 150 people participated!

VWD Women's Retreat on the Hill, April 23-25! This annual spring retreat provided an educational opportunity for women in families affected by VWD. A spectacular program of education and networking provided by local experts from the hemophilia treatment centers. This event was sponsored by a grant from CSL Behring. See you next spring!

Annual Family Dinner, Tuesday May 4! Truly a special, special night. We honored three outstanding local hemophilia program medical directors, Dr. Blatt (Christiana), Dr. Catherine Manno (CHOP) and Dr. Barbara Konkle (UPENN) and heard "Life Perspectives" from members of our community. Special legislative awards were presented to Representatives Lawrence Curry (D-154) and Richard Grucela (D-137) for their leadership which led to the passage of *HB 620* in the PA House of Representatives on August 9, 2009. A night to remember!

Broad Street Re-Run, Saturday, May 15! This second annual 5 mile run, ½ mile kids' run and a 1 mile family walk was held in Lansdale, PA on Saturday, May 15th! What a spectacular day with more than 850 runners and walkers, music, food, awards and fun! Super Mario and Luigi from Nintendo were there as well as Senator Bob Mensch (supporter of *HB 620*) and Dan Reavy from the Verizon Foundation and Mayor Andy Szeckley!



CHAPTER HAPPENINGS

2010 Chapter Calendar

Call the DVC office (215-885-6500) for detailed information about the events listed here.

July

10-15 Dragonfly Forest Camp!

August

5-10 Woods Camp for Kids Session #2!

September

10 Planning for Your Future

20 DVC Golf Classic!

23 Keller Williams Golf for DVC!

24-26 Family Camp!

October

2 DVC Walk/Run!

9-10 Couples' Retreat!

22 Fall Gala!

November

11-13 NHF Annual Meeting New Orleans!

December

4 Holiday Party!

Here's what's been happening!

BBQ Cookoff & Horseshoes for Hemophilia, Saturday, May 22! These two great events were both held at the Hatfield American Legion! Twenty grilling clubs competed and hundreds of supporters came out to enjoy the day to benefit the programs of the Chapter! Lots of fun for the whole family!

Carlino's Golfing for a Cure, Monday, June 7th! A wonderful day of golf, friends and fantastic food, sponsored by Carlino's Foods in Ardmore, PA. This event was held at Edgemont Country Club in Edgemont, PA. A big, big "thank you" to Pat and Laura Carlino and their employees and Kathy and John DiMichele for being so generous to the DVC and its commitment to supporting research!!!



Here's what's coming up!!

For detailed information on the following events or to REGISTER, call the DVC office (215-885-6500) or e-mail kimb@hemophiliasupport.org.

Planning for Your Future, Friday, September 10! Personal finances are always easier with a PLAN! This program provides an overview of personal financial planning, including saving for your future, maintaining adequate insurance coverage and planning for vocational or professional education. Scott Miller, CPA, Esquire, DBA teaches accounting full-time at the university level in addition to maintaining a legal practice where he concentrates in estate planning and administration, taxation and business & corporate law issues. Dr. Miller has been engaged with the hemophilia community his entire life, having served on the board of the Western Pennsylvania Chapter/NHF for more than 10 years. He currently serves as Chapter President.

DVC Golf Classic, Monday September 20! Sponsored by CSL Behring, this event will be held at Radnor Valley Country Club in Villanova. Dust off those golf shoes and join us for this important and fun day!

The Keller Williams Golf Classic, Thursday, September 23! We are honored that Keller Williams Real Estate of Blue Bell, PA has chosen The Delaware Valley Chapter as the recipient of funds raised at the Keller Williams Blue Bell Charity 4th Annual Golf Outing which will be held at the Center Square Golf Club in Norristown, PA 19403. Any willing golfer is invited to play!!

DVC Annual Family Camp Weekend, September 24-26! Make sure you register early, as space is limited. We can only accommodate 350 people. Family Camp will be held at Camp Green Lane, just outside of Lansdale, PA.

The DVC Hemophilia 5K Run and Family Walk, Saturday, October 2! Local teams are building now. Go to: hemophiliasupport.org to register your family/team for this wonderful day. This event will be held at the Pfizer Campus in Collegeville, PA! Get your team together and come out to support the Chapter! Big incentives if you can make a team. Ever been to Chicago?

Building Strong Relationships for Couples, October 9-10! This overnight retreat will be held at the beautiful Hershey Lodge. Limited to 25 couples.

Annual Fall Gala, Friday, October 22! This event will be held at the Hilton Hotel, City Avenue. This is always a spectacular night!

NHF Annual Meeting, New Orleans, November 11-13! This annual meeting brings medical providers, patients, families and scientists together for three days of education and training. For more detailed information visit the NHF website at: www.hemophilia.org.

Annual Holiday Party, Saturday, December 4! Mark your calendars for this fun day, held at Alumni Hall, Thomas Jefferson University Hospital in Philadelphia. Food and fun for all! Each child receives a gift.

VIEW POINT

On April 23 and 24, 2010, I attended the Hemophilia Federation of America Symposium in Kansas City, MO. Among the wide range of topics discussed was how The Healthcare Reform Act impacts our community and how states are dealing with the new law. Also discussed: the pressures on state budgets and restrictions to state-run programs, private and public insurance plans, genetic information access, navigating the ER and the UDC genotyping/CDC project. Overall, it was an informative and enjoyable experience and I was proud to represent the DVC at this important conference. Great fellowship among all attendees.

Hal Muschek

On Sunday, May 2nd, the Scicchitano family of Mt. Carmel, PA held a fundraiser (not their first) to benefit the Delaware Valley Chapter! They raised more than \$1,500 at the Coal Bowl Bowling Center & Arcade on Tioga Street in Coal Township, PA! We can't thank them enough for keeping our mission in their hearts and for working so hard to run such a fun event for such a great cause! Our heartfelt thanks to the Scicchitano's, Sam, Jolene, Jake, Seth and Ben!! You can't underestimate the power of just one family!



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 Disorder Legal Hotline is open to people affected with a bleeding disorder and the medical professionals who 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.

Hemophilia and Healthcare Reform: What You Need to Know

Healthcare reform will occur in stages *By David Linney*



While national healthcare reform passed in March, implementing it will occur in stages. The legislation is detailed and has many provisions. It is important for you to understand what the legislation does and does not do.

The legislation does not create a national health insurance program. Rather, it fills the gaps in our current system, helping to provide insurance options for roughly 32 million of the 46 million Americans who have no insurance.

Some of the legislation will go into effect within six months of the March 2010 enactment, but a large portion will not be implemented until 2014 or later.

Changes in 2010

Effective in June, 90 days after the legislation's enactment:

- Temporary national high-risk pools will offer insurance for individuals with pre-existing conditions who have been uninsured for at least six months. These risk pools will be operational until January 1, 2014, when options through the insurance exchanges become available.

Effective in September, six months after the legislation's enactment:

- Pre-existing condition exclusions for children will be eliminated in all health plans.

- Young adults up to age 26 may be covered as dependents under all health plans.
- Lifetime limits will be prohibited for all individual and group plans.
- Prior to 2014, annual limits on coverage will be restricted as determined by the US Department of Health and Human Services.
- Rescissions—or health policy cancellations usually due to higher use of benefits and pre-existing conditions—will be prohibited, except in cases of fraud.

Changes in 2011

Effective January 1, 2011, insurance companies will be required to pay rebates to enrollees if the company does not spend a minimum percentage of enrollees' premium dollars on healthcare, as opposed to administrative expenses. For large group plans the minimum is 85%; for individual and small group plans the minimum is 80%.

Changes Beginning in 2014

- Pre-existing condition exclusions for adults will be eliminated for all health plans.
- Waiting periods for new policy coverage to become effective will be limited to 90 days for all plans.

- Annual limits on new individual and group plans and existing group plans will be prohibited.
- Medicaid eligibility will be extended to all uninsured low-income individuals younger than age 65, including adults without dependent children, who have incomes up to 133% of the federal poverty level (FPL). Current poverty guidelines are \$14,404 for an individual and \$29,326 for a family of four.
- Most citizens and legal residents will be required to have health insurance or pay a tax penalty.
- Employers with 50 or more employees that do not offer insurance may face a tax penalty if any worker receives federal subsidies to purchase health insurance.
- Individuals and small employers will be eligible to purchase insurance through state-based American Health Benefit Exchanges. Individuals with incomes between 133% and 400% of the FPL (or \$14,404 to \$43,320 for individuals and \$29,326 to \$88,200 for a family of four) will be eligible for premium and cost-sharing credits, also known as subsidies.

Previous article taken from HemAware.org, an online publication of the National Hemophilia Foundation, 4/10.

Gene Therapy for Hemophilia B Enters into New Phase of Development *By Molly Polen*

A cooperative effort by researchers from the U.S. and the United Kingdom (UK) to develop a gene therapy for hemophilia B has resulted in a new phase of clinical development.

Netherlands-based Amsterdam Molecular Therapeutics (AMT), a company that specializes in gene therapy for different diseases and disorders, announced in March that the first patient has been dosed in a Phase I/II exploratory clinical trial with a gene therapy product for hemophilia B. The study includes the use of AMT's proprietary gene therapy technology. The principal investigator of the trial is Arthur W. Nienhuis, MD, a faculty member at St. Jude Children's Research Hospital in Memphis, TN.

The gene therapy in the trial uses adeno-associated viruses (AAV), small viruses that do not cause disease and produce mild immune responses, as vectors (delivery vehicles) to introduce a functioning factor IX (FIX) gene into the liver cells of subjects with hemophilia B. The goal of the therapy is to trigger long-term FIX protein production through a single administration of the therapy. This could reduce or eliminate bleeding episodes in hemophilia B patients. Earlier pre-clinical studies of FIX gene therapy were promising, demonstrating the potential for long-term FIX production.

The seminal work on this therapy was started more than a decade ago by St. Jude researchers Andrew Davidoff,

MD, and Amit Nathwani, MD, PhD, now with the University College London (UCL). The current trial involves the collaboration of St. Jude, UCL and a number of other institutions in the UK and the U.S.

The purpose of the current trial, which has been approved by both the UK Medicines and Healthcare products Regulatory Agency and the U.S. Food and Drug Administration, is to measure the safety and efficacy of different doses of the therapy. Upon a successful trial, AMT intends to follow up with additional clinical studies.

Source: *Medical News Today*, March 11, 2010

Local Mom Provides Comments to Health and Human Services Secretary

On April 7, 2010, local mom and Delaware Valley Chapter member, Christine Rowe of Lansdale, PA provided personal comments to a member of the Obama Cabinet, Secretary Kathleen Sebelius, in Philadelphia. Christine told the story of losing her job and health insurance benefits for her family. "When I lost my job last year, my family lost their health coverage as well. My husband is self-employed, so my family relied on coverage through my employer. Because my son has a bleeding disorder (pre-existing condition), my family was denied coverage by every insurer in the area. We were unable to pay the cost of his \$30,000 per month factor bill. With nowhere else to turn, we were forced to turn to Medicaid to help him get the medicine he needs to survive." Starting in September (2010), Christine and her son, along with millions of other families dealing with this issue will no longer have to worry about being denied coverage because of a pre-existing condition.



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.

CAMP HILL BRANCH

Shannon & Jay Penica
717-975-2897

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

Pennsylvania Bleeding Disorders Premium Assistance Program



Program Objective The Pennsylvania Bleeding Disorders Premium Assistance Program

The **Disorders Premium Assistance Program** was established in 2009 to provide assistance to residents of the Commonwealth with Hemophilia and von Willebrand Disease. This program offers financial assistance to subsidize private health insurance premiums and insurance case management services.

This Program May Help

- Patients in need of financial assistance to cover health insurance premium costs (even premiums deducted from payroll).
- Those who need assistance identifying individual health insurance options to make informed choices.
- Patients that have either lost or are at risk of losing Medicaid benefits due to age.
- Patients who are terminated from their employment and qualify for COBRA benefits.
- Patients who have hit the lifetime maximum on their policy.

Referral Process

This program will receive referrals from **The Delaware Valley Chapter of the National Hemophilia Foundation, the Western PA Chapter of the National Hemophilia Foundation and other community partners like Hemophilia**

Treatment Centers, State Agencies, Patient Organizations, Home Care Companies, etc. Patients can also **contact PSI directly**. If approved, patients will transition into private insurance or continue with their current private insurance policy and PSI will subsidize the premium cost. The amount of financial assistance offered by PSI to approved clients is determined on a sliding scale* based on a client's total household income, dependants, the cost of living for the state of residence, and pre-determined extenuating circumstances.

Program eligibility will be determined by the following guidelines:

- Diagnosis: Hemophilia/von Willebrand Disease
- Hemophilia Severity: Moderate or Severe
- Von Willebrand: Actively treating with a factor product
- Resident of Pennsylvania
- Household Income at or below 200% of the Federal Poverty Level (FPL%)
- This pilot program will assist as many patients as funding permits.
- Per the PSI Choice Policy, the patient will be responsible for the choice of product, provider, vendor, and prophylactic treatment.
- Approved patients:
 - Will be required to provide updated financial documentation for review

on an annual basis.

- May have a cost share of 5% to 7% of their health insurance premium.
- May be able to utilize up to \$11,000 of assistance annually.

How can PSI help me?

I already have a private insurance policy. PSI may be able to provide financial assistance with your insurance premium.

I don't have a private insurance policy. PSI can provide resources for private insurance policies offered in your state that might work for you. Once you select and enroll in a private plan, PSI may be able to provide financial assistance with your insurance premium.

I and/or my child are currently enrolled in Medicaid or I will soon age out of Medicaid eligibility. PSI can provide resources for private insurance policies offered in your state that might work for you. Once you select and enroll in a private plan, PSI may be able to provide financial assistance with your insurance premium.

Contact PSI at 1.800.366.7741 to request an application.

A Client Service Representative will guide you through the enrollment process.



THE HEMOPHILIA 5K RUN AND FAMILY WALK

The Delaware Valley Chapter of the National Hemophilia Foundation

MARK YOUR CALENDARS!!

SATURDAY, OCTOBER 2, 2010

COLLEGEVILLE, PA

Go to: hemophiliasupport.org to register

CAMPAIGN
FOR OUR FUTURE



PHASE II:

Research is our future

Visionary Partner and Lead Benefactor



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NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders