

NHF/DVC THE WINNING SPIRIT

Quarterly Newsletter, National Hemophilia Foundation, Delaware Valley Chapter, Spring 2011 – Volume 18 #2



National Hemophilia Foundation
Delaware Valley Chapter

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PSI

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

www.hemophiliasupport.org/fyi.htm

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

PA STATE REPRESENTATIVE LAWRENCE CURRY CONTINUES HIS FIGHT TO HELP HEMOPHILIA PATIENTS

PRESS RELEASE, February 14, 2011: HARRISBURG - State Representative Lawrence Curry (D-154) has reintroduced The Hemophilia Standards of Care Act (HB 635) that would create a standard of care for Pennsylvanians with hemophilia and other bleeding disorders.



“This bill is necessary to protect the quality of life that people with bleeding disorders deserve,” said Curry, D-Montgomery/Philadelphia. “It will protect access to state-recognized hemophilia programs that allow people with bleeding disorders to treat their disease effectively at home, rather than enduring lengthy, expensive hospital stays.”

Before scientific breakthroughs, hemophilia patients were hospitalized for painful internal bleeding episodes. Now, most administer intravenous blood-clotting products in a home setting. Curry said this advancement in home treatment, together with medical management by the seven state-recognized hemophilia centers, has enabled most people with hemophilia to lead healthy, independent lives.

“Centers for Disease Control and Prevention studies show a 40 percent reduction in mortality and morbidity for patients seen at Hemophilia treatment Centers. But as insurance companies look to cut costs, many patients fear they will lose access to these centers, and be forced to see ‘approved providers’ who may not be experts in treating bleeding disorders,” Curry said.

H.B. 635 would preserve access to the following services:

- 1) Medical services provided by the seven state-recognized hemophilia programs;
- 2) The clinical coagulation laboratories associated with the seven state-recognized hemophilia programs;
- 3) All FDA-approved blood clotting products;
- 4) Full-service home care pharmacies that can provide home nursing care; and
- 5) Require medical screenings for bleeding disorders for women prior to undergoing certain surgical procedures.

Hemophilia is a hereditary, chronic, incurable bleeding disorder that affects at least 1,700 Pennsylvanians.

Curry has been working since 2007 to set hemophilia standards of care. The bill he sponsored last legislative session passed unanimously in the House, but the state Senate failed to take action on it.

Curry received the National Hemophilia Foundation Awards of Excellence Advocate of the Year 2009 for his work championing the plight of hemophilia patients in Pennsylvania.

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National Hemophilia Foundation

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We gratefully acknowledge the pledge of support from the following manufacturers for 2011.

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Each spring, we introduce our readers to the HPPS participating companies for the coming year!! Each of these companies provides pharmacy and home supportive services to local patients affected by bleeding disorders and has qualified as a 2011 participating company. Each company meets the very high standards of service set by Hemophilia Patient and Program Support, Inc (HPPS).

2011-2012 HPPS Participating Companies

Accredo

CVS/Caremark Specialty Pharmacy

Coram Specialty Infusion Services

Factor Support Network

National Cornerstone HealthCare Services

Walgreens

Meet these companies by going to our website www.hemophiliasupport.org and clicking on the companies' logos. You will be linked directly to their site where you will find detailed information on the services that each company provides. Be an educated consumer and get the information you need to make informed decisions about what you need in a pharmacy. If you or your family member has a bleeding disorder and you haven't registered with the HPPS program in the past, e-mail your contact information to hemophilia@navpoint.com. By registering, you will be informed of important issues and events throughout the year.

Hemophilia Patient and Program Support, Inc. is dedicated to providing support to patients and programs within the geographic boundaries of the DVC. Become a member today!!

2011 Chapter Calendar

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

April

9 Annual Fashion Show!

29-5/1 Women's VWD Retreat!

May

3 Annual Family Dinner!

14 Broad Street Re-Run!

June

6 Carlino's Golf

11 BBQ Cookoff/Grilling for a Cure!

25 Hershey Speaker Series: Inhibitors & Aging!

July

7-12 Dragonfly Forest Camp!

18-23 Woods' Camp: Session #1!

August

3-8 Woods' Camp: Session #2!

27-28 Perk Up Half Marathon!

September

9 Healthcare Reform/ Plymouth Meeting!

20 Annual Golf Classic! REVISED DATE!

23-25 Annual Family Camp!

October

1 DVC Walk/Run!

8 Plymouth Meeting Speaker Series: Inhibitors & Aging!

21 Fall Gala!

November

10-12 NHF Annual Meeting!

December

3. Annual Holiday Party!

CAMPAIGN FOR OUR FUTURE

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Research is our future

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NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

CHAPTER HAPPENINGS

HERE'S WHAT'S BEEN HAPPENING

NHF Washington Day, February 17, 2011!

Patients and volunteers from around the country met in Washington, DC to educate members of Congress about issues affecting the bleeding disorders' community. Top on the list: National Healthcare Reform and continued federal funding in support of the Hemophilia Treatment Centers. Thanks to all of our local volunteers for participating and a special, big hug to the Hamstead family for being there. What a great picture of Cole and his parents visiting Senator Tom Carper (DE)! Our gratitude to everyone who participated.

Bowling for Fun, Saturday, February 26, 2011!

We had the best time at this family event!! Parents and kids all over the place with lots of prizes and pizza!! Thanks to Kim Bayer, Pat and Chuck Felthaus, Cheryl and Keith Littig and our wonderful volunteers from LaSalle University Sorority!! What a blast!!



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

Women's VWD Retreat on the Hill, April 29-May 1, 2011!

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

Annual Family Dinner, Tuesday, May 3, 2011!

Join other families at the Annual Family Dinner, held at the Hilton Hotel, City Avenue, Philadelphia. An informative night that provides updates and a program of interest for local Chapter members. *Together We Can Make a Difference* (our theme for this year) will feature presentations on treatment in other parts of the world for people with bleeding disorders. Don't miss this spectacular evening! Call the Chapter for an invitation.

Broad Street ReRun, Saturday, May 14, 2011!

This 5-Mile Run, ½-Mile Kids' Run and 1-Mile Family Walk is in its third year! Join us at the Pavilion Shopping Center in Lansdale, PA on South Broad Street. Bring the whole family and join Super Mario and Luigi from Nintendo at this fantastic event to benefit the DVC!! Great food and goodie bags to all pre-registered...register now at www.broadstreetrerun.com.

Carlino's Golfing for a Cure, Monday, June 6, 2011!

Sponsored by Carlino's Foods in Ardmore, PA, this is one of the nicest events of the year! This will be held at the Edgemont Country Club in Edgemont, PA. Food, fun, golf. What could be better?



CHAPTER HAPPENINGS



BBQ Cookoff/Grilling for a Cure & Family Fun Day, Saturday, June 11, 2011!

Two great events in one and both for a great cause! Bring a team to BBQ if you think you are up for this cooking challenge or sign up as a team to play horseshoes or just come out and spend the day. Games, music, tons of food. All you can eat Pig Roast & DJ. Bring the family. Fun begins at noon! To register or find out more, go to: www.bbqcookoff4acure.com.

All Day Education Program, Hershey Lodge, Saturday, June 25, 2011!

Two wonderful sessions (lunch included) at the beautiful Hershey Lodge in Hershey, PA.

Understanding Inhibitors, Joanna Davis, MD

University of Miami School of Medicine

Who is likely to develop an inhibitor? What is the role of immune tolerance? Current strategies for minimizing the risks of inhibitor development. Research and more.....

Aging in Hemophilia: The Issues, Christopher Walsh, MD

Mount Sinai School of Medicine

Cardiac Issues, Joint & Mobility Issues, Pain Management, Research and more.....

To register for this day of education, call the DVC (215-885-6500) or email Kim Bayer at the office (kimb@hemophiliasupport.org). Don't miss this!!



The Perk Up 1/2 Marathon (that is 13.1 miles of running for the non-running crowd), Saturday, August 27 & Sunday, August 28, 2011!

Save the date as this event is going to need all hands on deck!! The DVC has partnered with the Upper Perkiomen Valley Chamber of Commerce for the 1st Annual Perk Up 1/2 Marathon. The event will start and end at the exclusive Perkiomen School situated in the beautiful Upper Perkiomen Valley. This quiet corner of Montgomery County, Pennsylvania has exceptional natural beauty with rolling hills and flowing waters. The course is beautiful! Not up for the 13.1 mile running challenge? Sign up to be a volunteer! For more information, go to www.perkuphalfmarathon.com or call Christine Rowe @ the DVC (215-885-6500) or email to: christiner@hemophiliasupport.org.

5k Run/Walk and 1/2 Mile Kid Run, Saturday October 1, 2011

Join all of us on Saturday, October 1st as we walk or run and raise funds to help find a cure for hemophilia and von Willebrand Disease. All funds raised will stay local and benefit the Delaware Valley Chapter of the National Hemophilia Foundation. Become a fundraiser today and form a team! Visit www.active.com.

The 5k Run/Walk and 1/2 Mile Kid Run will take place on the beautiful Pfizer Pharmaceutical Campus located at 500 Arcola Road Collegeville PA 19426. Both events will begin at 9:00 a.m. and registration will open at 7:30 a.m. The cost for each participant is \$20.00 or \$10.00 for the kids. Price increase will take effect closer to the event. To register for the walk/run, visit www.active.com/donate/gohemophilia click on "Register for this Event" at the top of the page or visit www.hemophiliasupport.org to download the "Mail In Application." Not able to attend the event? Help support one of our families by making a donation to their child's site by searching the child's name in the box.

Like to win a trip to Orlando?

How about some other great prizes in addition to that trip to Orlando? It's simple. Just become a fundraiser today by visiting www.active.com/donate/gohemophilia and click on the top of the page "Become a Fundraiser" and create your own fundraising site! Help us reach our goal of \$135,000 this year and make a difference in the lives of all families living with bleeding disorders. Need help? Contact Christine Rowe at 215-885-6500 or email at christiner@hemophiliasupport.org.



FIGURING OUT HEALTHCARE COSTS FOR YOUR CHILD

Severe hemophilia is one of the most expensive medical conditions to treat

By David Linney

For parents of a child newly diagnosed with a bleeding disorder, medical costs and insurance coverage instantly become big concerns because of the high cost of clotting factor.

Severe hemophilia is one of the most expensive medical conditions, averaging \$200,000 yearly. Annual costs for moderate hemophilia and severe von Willebrand disease are lower but still significant, ranging from \$10,000 to \$100,000 a year on average. Total costs for each diagnosis can be higher if there are complications. However, costs for newborns and very young children will usually be only a small portion of these average costs.

Where your child will receive treatment for his bleeding disorder depends on the treatment plan determined by your child's physician. For the first couple of years, treatment sites may include the emergency room, which is often affiliated with the hemophilia treatment center (HTC); the HTC infusion clinic; a doctor's office; and your home, with a homecare nurse. Clotting factor may be billed as part of a hospital bill or separately from a specialty pharmacy that distributes it.

If your child has health insurance through an individual or family plan or an employer family plan, coverage will vary from policy to policy. The most common medical services your child may need are:

- Emergency room visits
- Hospitalization
- Doctor visits
- Outpatient lab work and X-rays
- Drugs
- Clotting factor concentrates

It is important to understand your benefits coverage for these services. Review the printed insurance plan summary from your insurance company or employer, and call your insurance company or visit its web site. Your HTC staff can often verify coverage for you. In addition, the National Hemophilia Foundation's information resource center, HANDI, can help explain basic coverage (but not your individual insurance plan) and provide you with resources.

Project Out-of-Pocket Costs

Understanding your child's projected medical service needs and estimating the highest amount your insurance will not cover—your maximum out-of-pocket cost—will help you with financial planning.

Out-of-pocket costs include:

Deductible: the dollar amount that the policyholder is liable to pay (often on an annual basis) before insurance will provide coverage.

Co-insurance: the percentage of costs paid by insurance (for example, 80%) and the percentage of costs that the policyholder is liable for (for example, 20%), often after a deductible is met.

Co-payment: the dollar amount charged for each medical service, such as an inpatient hospitalization, a doctor or physical therapy visit or a prescription.

Co-Insurance Limit: the maximum annual out-of-pocket dollar limit that a policyholder is liable to pay for co-insurance costs (for example, 20% up to \$2,000).

Out-of-Pocket Limit: the maximum annual out-of-pocket costs for the deductible and co-insurance limit.

Coverage can be affected by which medical providers and pharmacies you use. Insurance plans contract with providers to be "in network." If you use out-of-network providers, the treatment may not be covered or may be only partially covered. Coverage can also be affected by insurance plans that require authorizations, which are special approvals to provide coverage for certain medical services or medications.

Healthcare Reform

Under new healthcare legislation, by September 22, 2011, no insurance plan will have a lifetime limit (the amount an insurance plan will pay in benefits for an individual during the lifetime of a policy). By January 1, 2014, no insurance plan will have an annual limit on benefits.

For parents of a child covered under Medicaid, the coverage rate for medical and pharmacy services is usually very high. Many state Medicaid plans may require small out-of-pocket payments to providers for each medical or drug service received. Medicaid has no lifetime limits. Medical and pharmacy providers must be Medicaid approved for you to receive care and service. (Almost all hospitals are Medicaid approved.) Medicaid authorizations may be required for specific medical services or medications.

Understanding your insurance coverage while you're trying to comprehend your child's new diagnosis can be overwhelming, but by becoming familiar with what services and products are covered, you can plan for your family's medical costs.

Previous article taken from HemAware.org, an online publication of the National Hemophilia Foundation, February 2011.

Winning Spirit Newsletter GOING GREEN!!!

If you would like to receive your quarterly Winning Spirit via email (rather than through the mail), contact the Delaware Valley Chapter (hemophilia@navpoint.com) and let us know. Provide the following information in your email:

- Name
- Current mailing address

- Home and cell phones
- The email address you would like us to use

You will begin to receive your newsletter via your email.
NOTE: IF YOU ARE A PATIENT REGISTERED AT AN AREA HTC, YOU WILL CONTINUE TO RECEIVE A HARD COPY VIA YOUR TREATMENT CENTER.

If you are a patient with moderate to severe hemophilia A (factor VIII deficiency) or the parent/caregiver of a person with moderate to severe hemophilia A, you are eligible to receive a \$50 Visa gift card by participating in a brief, online survey (about 30-45 minutes) assessing how the management and treatment of hemophilia affects patients and parents/caregivers. The survey can be taken from any computer with internet access.

If you choose to participate, you will receive a \$50 Visa gift card for your time completing the survey and if you are a parent/caregiver, your child with hemophilia will also receive a \$50 Visa gift card for completing their portion of the survey. Depending on the child's age and ability, the parent/caregiver may have to help the child complete his portion of the survey.

To find out how to register to participate, contact the DVC Office (215-885-6500).



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PA STATE REPRESENTATIVE CONTINUES HIS FIGHT TO HELP HEMOPHILIA PATIENTS

Post Note from George Levy, DVC Board Member

The Delaware Valley Chapter and you, its members, have made a big effort to secure passage of health care legislation to both preserve and improve our access to essential, life-sustaining medical care. Our efforts have spanned three separate legislative sessions and six years, but we have not succeeded. It is very disappointing, but we have still accomplished something important. We have raised the awareness of many members of the state legislature that hemophilia is an extraordinary disease which deserves the special remedy of dedicated legislation. We enjoy a base of support within the legislature that will serve us in the future, as we struggle to defend our vital access to health care.

As you know, in 2009 we succeeded in achieving the unanimous passage of our bill, the Hemophilia Standards of Care Act, in the Pennsylvania House of Representatives. We then focused on repeating the same success in the Pennsylvania Senate, but we did not succeed there. The reason we could not move the bill to the floor of the Senate for a vote is because one powerful senator, Patricia Vance, Chairperson of the Senate Health & Welfare Committee, vehemently opposed our bill and refused to release it from her committee. Unfortunately, the fact that the chairperson of a committee can kill a piece of legislation, even when it enjoys significant support, is a very un-democratic aspect of our democracy. If Senator Vance had released this bill, it most assuredly would have burst out of the Health & Welfare Committee and made its way to the Senate floor, where we had a clear majority of support. This bill

would have passed and been signed into law by former Governor Rendell.

However, that is not what happened. In this new legislative session, 2011-12, our bill has been re-introduced by Representative Curry in the House of Representatives, as noted in the press release above. We also believe there is interest in re-introducing this bill on the Senate side. This is a most difficult time to advance health care legislation, even urgently needed legislation to address patient access to essential medical care. Pennsylvania, like most other states, has a budget crisis, which is a hangover from the national financial crisis. Fiscal discipline will be the focus of this legislative session – how to handle a \$4 billion deficit. Moreover, the current House and Senate are more conservative. Yes, we have been shouting for six years that the Hemophilia Standards of Care Act will not cost the state a dime; it may even save money for the Commonwealth's Medicaid patients. Unfortunately, health care legislation is still going to be on the back burner of issues.

This does not mean we should abandon the cause, but it is likely to take longer than we anticipated to address our issues in a legislative fashion. Each of you should continue to make your elected state representatives and senators aware of our need for legislative relief. [If you have problems with your insurance company, please continue to forward the details to the Chapter office.](#) We will continue to gather and save the "evidence," so that when conditions are friendlier we will again push hard to enact the Hemophilia Standards of Care Act. Thank you.

The following was provided by Barry Haarde who grew up in Bethany Beach, Delaware in the 1960's. Barry and his brother John were both treated at the Children's Hospital of Philadelphia Hemophilia Program and the Cardeza Foundation Hemophilia Center at Jefferson. We take a look back at the Delaware Valley Chapter...



HEMOPHILIA NEWS

DELAWARE VALLEY CHAPTER OF THE NATIONAL HEMOPHILIA FOUNDATION
1321 WESTERN SAVINGS FUND BUILDING • PHILADELPHIA, PA. 19107 • PE 5-1566

VOLUME 3, No. 1

CAMPAIGN ISSUE: 1969

Einstein Project Seeks Total Rehabilitation

A pilot research project, designed to demonstrate the effectiveness of the team approach to rehabilitation of hemophiliacs is currently under way at the Albert Einstein Medical Center under the direction of Dr. Irving Woldow, Senior Attending Hematologist. Dr. Woldow is also a member of the Delaware Valley Chapter's Medical Advisory Board.

The eventual aim of the project, Dr. Woldow pointed out, is not only to reach the more than 500 hemophilic patients currently registered as members of the Delaware Valley Chapter, but all those hemophiliacs who are not registered. For the time being the number of patients has been limited to those currently being treated in the Hematology Out Patient Department of the hospital.

Dr. Woldow said, "We are trying to design a program in which the hemophiliac will be brought into the mainstream of our society and show that a patient needs more than a place where he can go and be treated. He must be made to realize that he can become an active and useful member of society."

Some 12 patients are participating in the initial group. The patients and their families were first given interviews to ex-

(Continued on page 2)

Danny Johnson Named Area Poster Boy

Danny Johnson of 2662 Elbridge St., Philadelphia is only four years old. But already during his short life he has been hospitalized six times.

The reason for Danny's frequent hospitalization is he has hemophilia. Despite this affliction, Danny has been able to lead a "pretty active, normal life," according to his mother, Mrs. John Johnson. For the next several months, however, the youngster's life will be more active than normal, for Danny has been named Philadelphia area poster boy for the 1969 campaign.

"Danny is typical of youngsters born with hemophilia and it is because of him and all the children like him that this campaign is so urgent," said Chairman Tom Gola.

Danny, whose father, John, is a machine operator at Standard Pressed Steel

(Continued on page 4)

24,000 Volunteers Sought For Hemophilia Campaign

As the month of March—Hemophilia Month—approaches, efforts are well under way to make this the most successful campaign ever.

Some 24,000 volunteers, 6,000 more than last year, are being recruited for the March of the Life Brigade door-to-door campaign which will begin March 15. State Representative and LaSalle Basketball Coach Tom Gola, 1969 campaign chairman, said this year the goal for the Delaware Valley Chapter will be \$140,000.

He said he hoped the majority of the goal would be realized through the door-to-door campaign and the Special Gifts phase, which is already under way with special activities being planned in each area by Division chairmen.



State Representative and LaSalle Basketball Coach Tom Gola, 1969 General Campaign Chairman for the Delaware Valley Chapter, and four-year-old Danny Johnson, Philadelphia area poster boy.

The Banner Day street corner campaign, another phase, will take place on March 29.

Mr. Gola said volunteers are still needed in every community and neighborhood throughout the campaign area to make the 1969 campaign a success. "It is up to the volunteers to carry the drive to their neighbors and friends and thus give us the funds that are so vitally needed if we are to eventually gain victory over this dreaded disease," Mr. Gola said.

This year two new areas have been opened up as part of the Delaware Valley Drive. They are Camden County and Lower Bucks County.

William Peter Johnson III



"Pete" Johnson died on December 15, 2010 and he left a strong legacy of advocacy and support, most especially to local patients with bleeding disorders. Pete worked for most of his adult life to make life better for the hemophilia community. The Delaware Valley Chapter has established the "Pete Johnson Memorial Scholarship" in memory of a great man and a true friend. This scholarship will help deserving college-bound students with hemophilia realize their dream of a higher education. To apply, interested students should contact the Delaware Valley Chapter.

The following was sent to the DVC from A Grateful Father.....

Over the course of his 71 plus years, William Peter Johnson III has been called many things. "William" by his parents, "Bill" by family and close friends and "Pete" or "Mr. Pete" by almost everyone else he came in contact with. I called him "Pete" or "Big Guy" because although he was slight in stature, after just one time meeting him, you knew he was "The Man."

Over the last 13 years, I have come to know Pete as a very kind, giving and demanding man. Not that he wanted things done for himself, but he was very diligent in getting things done for the young men in the hemophilia community. For as long as I knew Pete, I don't recall ever hearing him lament about his state in life.

My son was one of the many boys with hemophilia that Pete took under his wing. Pete treated him like a son and tried to help him with the many difficulties associated with a bleeding disorder. He also treated our entire family like we were next of kin. Pete was available 24/7 to answer questions and concerns from any of us, or even just to discuss our everyday lives.

I personally am grateful that I had the opportunity to get to know Pete and I will forever be in his debt. Of all the things that William Peter Johnson III was called, I am most proud to have called him FRIEND!



Delaware Valley Chapter Support Network

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

Delaware Branch
Gail & Luke Vannicola
302-378-1278

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

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

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