

NHF/DVC THE WINNING SPIRIT

Quarterly Newsletter, National Hemophilia Foundation, Delaware Valley Chapter, Summer 2011 – Volume 18 #3



National Hemophilia Foundation
Delaware Valley Chapter

IN THIS ISSUE

- 2 – From the Executive Director
 - Chapter Calendar
- 3 – Chapter Happenings
- 4 – Chapter Happenings
- 5 – VIEWPOINT: As I See It
- 7 – Christine Rowe accepting contribution from Dan Reavy
- 8 – Actively Aging
 - DVC Support Network

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.

GOVERNOR CORBETT PROPOSES A STATE BUDGET THAT WILL PUT THE PENNSYLVANIA BLEEDING DISORDERS' COMMUNITY AT RISK!!

At the writing of this newsletter, the Governor of Pennsylvania has proposed a 2011-2012 state budget that will cut state support to the seven hemophilia programs by 43%. A cut at that level will gut the programs that have improved the quality of life and the medical outcomes for more than 2,000 Pennsylvania patients with hemophilia and von Willebrand Disease for more than 30 years.

Here's the story.....

Funding for the State Hemophilia Program has been lumped into one line item called "Special Medical Programs" and then the overall proposed allocation will be cut by 43% (of current levels). This appropriation includes services for Children with Special Needs, Hemophilia, Adult Cystic Fibrosis, Cooley's Anemia, Home Ventilator Care, Adult Spina Bifida and Sickle Cell Disease.

The proposed allocation for the next budget year 2011-2012 is \$2.9 million for all of these programs. That is down from \$5.38 million. This represents a 43% decrease in funding available to the collective group. Over the past four years, funding to support services for these special medical conditions has been reduced by 25%. And it is unclear how much of the reduced proposed support will actually be allocated to provide care for patients with bleeding disorders in Pennsylvania. This could spell a disaster.

In 1973, Pennsylvania was the first state to enact a State Hemophilia Program. This model of care for Pennsylvanians with hemophilia, a rare bleeding disorder, became the model for a national network of Hemophilia Treatment Centers across the United States put in place by a federal act of Congress in 1975. This system of care has been providing comprehensive care for people with hemophilia and von Willebrand Disease ever since.

The hemophilia line item within the Pennsylvania Department of Health budget ensures that patients with bleeding disorders have access to a multidisciplinary team of skilled care providers, highly specialized laboratory tests and factor replacement therapies which are necessary to prevent repeated life and limb-threatening bleeding episodes. Comprehensive services include diagnosis, clinical management, orthopedic and dental care, patient education, counseling and home factor infusion training and supervision. This model of care has increased the independence of these patients and reduced the overall costs of medical care and the need for state-funded assistance programs.

According to the Centers for Disease Control and Prevention, patients who receive their care from one of these centers of excellence, have better medical outcomes than patients treated outside this comprehensive care model. Hemophilia Treatment Centers have reduced not only complications for patients, but have reduced the costs of their

continued on page 6

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

Kim Bayer, Administrative Assistant

Christine Rowe, Fund Development Coordinator

Board of Directors

Thomas D. Galvin, President

William L. Widerman, Vice President

Andrew B. Serrill, Treasurer

Cheryl A. Littig, Secretary

Board Members

Leonard Azzarano

Robert Babb

Patricia Felthaus

James Flood

George Levy

Lynn Lindquist

Christopher Marozzi

Kathleen Sell

Jonathan Worthington

Noel A. Fleming, Esquire

Legal Counsel

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

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

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

CLINICAL TRIALS: SHOULD I? SHOULDN'T I?

Choosing to participate in a clinical trial is an important personal decision. It is often helpful to talk to a physician, your HTC, family members or friends about deciding to join a trial. After identifying some trial options, the next step is to contact the study research staff and ask questions about specific trials.

What is a clinical trial?

Although there are many definitions of clinical trials, they are generally considered to be biomedical or health-related research studies in human beings that follow a pre-defined protocol. ClinicalTrials.gov includes both interventional and observational types of studies. Interventional studies are those in which the research subjects are assigned by the investigator to a treatment or other intervention and their outcomes are measured. Observational studies are those in which individuals are observed and their outcomes are measured by the investigators.

Why participate in a clinical trial?

Many people with hemophilia and von Willebrand Disease participate in clinical trials. Why? Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available and help others by contributing to medical research.

Who can participate in a clinical trial?

All clinical trials have guidelines about who can participate. The factors that allow someone to participate in a clinical trial are called "inclusion criteria" and those that disallow someone from participating are called "exclusion criteria." These criteria are based on such factors as age, gender, the type and stage of a disease, previous treatment history and other medical conditions.

Before joining a clinical trial, a participant must qualify for the study. Some research studies seek participants with illnesses or conditions (like hemophilia or VWD) to be studied in the clinical trial, while others need healthy participants. Inclusion and exclusion criteria are not used to reject people personally. Instead, the criteria are used to identify appropriate participants and keep them safe. The criteria help ensure that researchers will be able to answer the questions they plan to study.

To find out more about clinical trials currently enrolling patients with hemophilia and von Willebrand Disease, visit ClinicalTrials.gov, a service of the U.S. National Institutes of Health. Then ask your HTC about participating in a clinical trial before you try to enroll.

CAMPAIGN
FOR OUR FUTURE

PHASE II:

Research is our future

Visionary Partner and Lead Benefactor

novo nordisk

NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

2011 Chapter Calendar

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

July

7-12 Dragonfly Forest Camp!

18-23 Woods' Camp: Session #1!

August

3-8 Woods' Camp: Session #2!

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/Chicago!

December

3. Annual Holiday Party!

CHAPTER HAPPENINGS

Here's what's been happening!!

Annual Fashion Show and Luncheon, Saturday, April 9, 2011!

This was a wonderful day of fashion and fun! Our honored guest was Dr. Bruce Main, President of UrbanPromise in Camden, NJ. A big thank you to Jennifer Sawyer and Lynn Lindquist, Co-Chairs, and their wonderful committee that made this day so spectacular. We can hardly wait for this great event in 2012!



Annual State Capitol Awareness Day, Tuesday, April 26, 2011!

231 patients, parents, medical providers and volunteers participated in our Annual State Awareness Day to voice our concerns about proposed state funding reductions to the State Hemophilia Program and to let our legislators know why HB 635 is so needed. Thanks to all who participated. We couldn't do this without your help!



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

This wonderful weekend conference provided education and resources to women in families affected by VWD! The event was made possible by a generous educational grant from CSL Behring. Thank you for supporting such an excellent conference!



Annual Family Dinner, Tuesday, May 3, 2011!

Together We Can Make a Difference was the theme this year for our Annual Family Dinner. Highlights included a presentation from Mike Rosenthal, World Federation of Hemophilia, a tribute to Dr. Frank Shafer for his many years of dedicated work at St. Christopher's Hospital for Children in Philadelphia and comments by The Honorable Lawrence Curry (D-154), sponsor of *The Hemophilia Standards of Care Act, HB 635*. What a great night!



CHAPTER HAPPENINGS

Broad Street ReRun, Saturday, May 14, 2011!

This 5-Mile Run, ½-Mile Kids' Run and 1-Mile Family Walk was a super success and a lot of fun too! Held at the Pavilion Shopping Center in Lansdale, PA on South Broad Street, families and supporters spent the morning running and walking to benefit the Delaware Valley Chapter. Super Mario and Luigi from Nintendo were there and more than 1,000 kids and adults participated. If you loved this event, be sure to register for our Annual Walk and Run (October 1) at www.hemophiliasupport.org!! Get in shape and have a blast!



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

Sponsored by Carlino's Foods in Ardmore, PA, this was one of the nicest events of the year! This event was held once again at the Edgemont Country Club in Edgemont, PA. A big thank you to Carlino's Specialty Foods, Inc. in Ardmore, PA for sponsoring this annual event and a special thank you to owners, Laura and Pat Carlino and their very generous employees and Kathy and John DiMichele for making this day possible!

BBQ Cook-Off & Horseshoes for Hemophilia, Saturday, June 11, 2011!

Over 25 teams competed from four different states for the best in ribs, chicken and chef's choice! What a delicious day it was! Teams also competed in the horseshoe tournament to be crowned the best ringer! Special thanks to Tom Rowe for organizing and serving some of the best food!

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



The Perk Up ½ Marathon (that is 13.1 miles of running for the non-running crowd), 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 Inaugural Perk Up ½ 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 ½ 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! To form your team visit www.active.com/donate/gohemophilia or call Christine Rowe at 215-885-6500 for more help! We have enclosed a sample team page to get you started!

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 or \$10 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? **We will be giving away a trip to Orlando for an entire family (up to four members) so you won't want to miss the opportunity to possibly win!** 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 to christiner@hemophiliasupport.org.

NHF Annual Meeting, November 10-12, Chicago!

Each year, in the late fall, people affected by bleeding disorders around the United States attend the National Hemophilia Foundation's Annual Meeting. This conference provides information and resources to patients and families and is a great way to meet people from other Chapters. There is even a Youth Program, so the kids stay busy while parents attend sessions! To find out more go to: www.hemophilia.org. See you in Chicago!



AS I SEE IT

By Bill Jamison

As a community of individuals with bleeding disorders, all of us are uniquely different and we all have our own thoughts as to what we need individually from a health care perspective, in order to have positive medical outcomes.

As a person with severe hemophilia type “A,” I have had the opportunity to meet with others like myself from all over the country and some from abroad. We “swapped stories,” some good and some bad and compared “notes” on our individual medical outcomes. Subjects such as joint replacements, restrictions of mobility and just trying to live with hemophilia on a day-to-day basis have been the usual topics of discussion. One subject we have all agreed on was the need for overall comprehensive care from our hemophilia treatment centers.

When I was born in the early 1950’s, hemophilia treatment was nearly non-existent. Life expectancy of 5-10 years was the norm for a patient diagnosed with severe hemophilia back then. Treatments consisted of whole blood, fresh frozen plasma and lyophilized plasma. Long stays in the hospital for weeks and even months were very common. Health complications such as severe joint damage and muscle damage were just part of living with a bleeding disorder during those times.

The psychosocial issues related to hemophilia were many. Not being able to go to school or go out and play with your friends or go to work all had an impact on our lives. These were not good times for the patient with a bleeding disorder. Simple things like just trying to find a doctor to treat hemophilia were sometimes impossible. There was a definite need for centers of excellence to treat this very demanding condition.

As time passed, it was clear to the medical community and even clearer to the patients that there was a need to establish some kind of health care system to meet the treatment needs of individuals with hemophilia and other bleeding disorders.

Time passed and in 1973, the bleeding disorders community in conjunction with the National Hemophilia Foundation, embarked on a two-year effort to establish a network of comprehensive centers of care for the hemophilia community and their families.

Since 1975, this network has grown into what we have today... 141 federally-funded, and in Pennsylvania and many other states, state-supported Hemophilia Treatment Centers (HTC’s) across the United States.

People with hemophilia and other bleeding disorders have as many commonalities as they have differences. This is where the specialized treatment plan from a hemophilia treatment center comes into play. So, what is comprehensive care?

Comprehensive care at a hemophilia treatment center has time and time again, proven to be the best course of treatment for someone with a bleeding disorder. Treatment teams vary from HTC to HTC. Some offer a full range of services that can include pediatric and adult hematologists, hemophilia nurse coordinators, physical therapists, orthopedists, social workers, occupational therapists, psychiatrists, nutritionists and dentists. Remember, not

all HTC’s provide all of these services. It is always best to check with your HTC to determine what services are available to you.

In order to minimize potential negative medical outcomes from a bleeding disorder, it is not just up to your treatment team. It is vitally important that you as the consumer take an active part in following the treatment plan your HTC has provided to you. You need to be a participant in your care so the potential for a positive medical outcome can be achieved.

The importance of fully understanding your bleeding disorder can never be understated. It is imperative that you and your family be educated consumers. Learn as much as you can about your bleeding disorder so you can work towards the best health outcome for your condition. This gives you the knowledge base to be able to ask questions of your treatment team and be an integral part of your plan of care.

In today’s world of budget cuts and spiraling health care costs across the nation, many HTC’s have needed, in many instances, to cut their operating costs significantly. The federal and state monies that have been available throughout the years to support HTC’s do not go nearly as far as they did even five years ago, resulting in the loss of needed services to the bleeding disorder patients and their families. It is so, so important that you take an active part in always advocating for needed services provided by all the Hemophilia Treatment Centers across the country.

Looking back over the last 50 or so years, I and so many others of my generation have endured the pain, suffering and crippling effects of living with a bleeding disorder. Many survived just to be infected with HIV and hepatitis viruses. Our community paid dues that no one should ever need to pay. The bleeding disorder community, hemophilia chapters and groups, along with many other of the unseen volunteers fought many battles over the years. They helped to make living with a bleeding disorder a little better, a little easier to give future generations more opportunity and a better way of life in order to just be “normal” and do all the things that other people do.

Hemophilia treatment centers and comprehensive care have enabled many people with hemophilia to be able to integrate themselves into society, be productive citizens and more importantly, able to give something back to society at large.

Comprehensive, proactive hemophilia care does work. It’s proven. It’s a fact. As a community, we must step forward to fight the issues that impact our care and our health outcomes. You must get involved with your community, hemophilia organizations, your legislature and other interested parties to ensure hemophilia treatment centers throughout the United States continue to receive adequate funding to provide the expertise in treating this condition called hemophilia. We cannot go back to the way hemophilia was treated in the 1950’s and 1960’s. We owe this to our future generations until a cure is found. Educate, communicate and advocate. Get Moving!

continued from page 1

GOVERNOR CORBETT PROPOSES A STATE BUDGET THAT WILL PUT THE PENNSYLVANIA BLEEDING DISORDERS' COMMUNITY AT RISK!!

care across the United States. Patients rely on this expert care to sustain their lives. Today, there are 140 such centers in the United States and there are 7 programs in Pennsylvania providing comprehensive care to more than 2,000 Pennsylvanians with hemophilia.

As a result of the care provided by Pennsylvania's Hemophilia Programs over the last 37 years, hemophilia care has dramatically changed from supporting disabled children and adults to promoting individuals in achieving full, active, healthy and productive lifestyles.

This proposed 43% reduction in funding for The Pennsylvania Hemophilia Program will eliminate or reduce this model of care recognized by both the state and the federal government and will have disastrous results, including:

- Reduced services to a very vulnerable population in Pennsylvania.
- Reduced services will result in poorer outcomes.
- Reduced services will result in loss of quality of life.
- Reduced services will fracture and dismantle coordinated

care, the lynchpin for hemophilia care.

- Reduced services will drive patients to emergency rooms and increase complications, death rate and costs of care.
- Reduced staffing, a direct result of loss of state support, will put the seven programs out of staffing requirements to receive federal support.

The end result will be that the system of care that has reduced complications and costs of care to patients with hemophilia will be dismantled. The disastrous result of this will be increased Medicaid roles, as the hemophilia community will once again, become a community of crippled individuals, needing government support at an increasing rate.

This patient population cannot be serviced through emergency rooms or hematology offices in the Commonwealth without disastrous effects on the health and welfare of individuals with hemophilia. The following article from 1976 clearly outlines the strong leadership of then Governor Shapp (of Pennsylvania) and the General Assembly regarding Pennsylvania's responsibility to this vulnerable community.

The following article was taken from The Pennsylvania Department of Health Bulletin Summer 1976, Volume 37, Number 2.

"Hemophilia is a disease that affects hundreds of Pennsylvania residents. Effective treatment has been developed to permit hemophiliacs to lead reasonably normal lives, but without State financial support, only the wealthy could afford proper treatment and care.

The State (of Pennsylvania) became involved in helping the plight of hemophiliacs and their families in 1972 when Governor Milton J. Shapp first learned of the difficulties a Camp Hill family was having in providing money for the treatment of their son, Kevin Marshall. The family had exhausted all private savings and donations and could no longer afford the \$1,000-a-month hemophilia treatments. The family's effort to obtain state aid was turned down by the Department of Public Welfare unless the father quit his job.

Governor Shapp learned of the situation through news stories early in November of 1972 and arranged for free treatments for Kevin at Hershey Medical Center. Only a month later, a bill providing for \$250,000 for hemophiliac treatment (ACT 59A) passed the legislature and was signed by Governor Shapp to provide free, state assistance for 800 hemophiliacs in the state.

Hemophilia, for readers unfamiliar with the term, is an inherited disease in which the blood lacks certain clotting factors. Victims are sometimes called "bleeders." The condition lasts throughout one's lifetime—it doesn't go away, nor does it improve. Victims bruise easily; bleed from the kidneys, into joints and also bleed excessively when injured and after operations. They know when they are bleeding, experiencing swelling and pain in the area affected.

Until recently, no treatment was available for such persons, except to splint bleeding joints and rest. This meant time off the job or out of school—which alone marked them as "different." Chronic bleeding into joints causes severe arthritic crippling, preventing normal usage of limbs. Operations and dental work were out of the question—bleeding complications could result in death.

Act 59A was passed in December, 1972, and implemented in March, 1973—probably faster than any other bill ever passed. Input to the program was received from governmental agencies, the Pennsylvania Chapters of the National Hemophilia Foundation, interested physicians, patients and parents of patients.

Nine hemophilia centers were established to care for patients. The centers provide evaluation and reevaluation of registered patients and supply blood products needed by them for blood coagulation. Most of the centers will also train patients or their parents in the techniques for treating themselves, if sufficient medical indication exists for home treatment.

continued on next page

The centers are responsible for determining treatment for patients, be it on an outpatient basis, at home, in the emergency room or for a surgical procedure. Most hemophiliacs are outpatients at one of the nine centers. However, home treatment is gaining in popularity.

Persons enrolled in the home treatment program have considerably more independence than those who are outpatients. Because of their ability to administer self treatment, there are fewer visits to the clinics and/or emergency rooms for treatment, more immediate treatment, more self assurance—all resulting in the patient's ability to lead a more independent life in better health, with much less time off from work or school and fewer hospital and doctor bills.

Before the scientific breakthroughs of less than ten years ago, hemophiliacs died at the average age of 11. Then researchers developed a way of isolating the necessary clotting factors in blood to make concentrates of blood plasma clotting factors. Mild hemophiliacs can take the concentrates only when needed to stop bleeding. Moderate or severe hemophiliacs are usually put on regular regimens of the concentrates.

However, some individuals develop inhibitors or antibodies to the concentrates which makes the concentrates relatively ineffective. Other medications are then used in treating these people.

Aside from the possibilities of developing inhibitors, the major problem thus far associated with the blood product concentrates is the danger of hepatitis. Because large pools of blood donors are required for making the concentrates, it is possible, even with the most sensitive tests and procedures, that the hepatitis virus is present in the concentrates. Though donors are carefully screened, the risk remains high.

The cost to the State for operating the hemophilia program was approximately \$1,480,000 in fiscal year 1974-75.

State funds are used after all other applicable financial sources have been exhausted: private insurance, Federal Title XIX benefits and limited family resources. About 30 percent of those enrolled are required to share part of the cost of concentrates. Their share can range from \$50 to \$1,500 a year. About 600 of the approximately 800 hemophiliacs in the state are registered in the State Program.

Although hemophiliacs don't usually really bleed to death, slow physical and mental deterioration can take place. Medication helps the body, but psychological support is needed from family, friends and the medical professionals in close day-to-day contact with the hemophiliac.

PENNSYLVANIA'S LEADERSHIP IN PROVIDING HELP TO HEMOPHILIA VICTIMS HAS BEEN CITED BY THE NATIONAL HEMOPHILIA FOUNDATION AS THE BEST IN THE NATION. The program now serves as a lifeline for more than 600 patients whose medication alone can run as high as \$12,000 a year."

Christine Rowe accepting contribution from Dan Reavy



Thank you to Dan Reavy and the Verizon Foundation for the generous contribution of \$5000.00 to the DVC. With contributions from generous donors like Verizon, the DVC can continue to help families affected by hemophilia and help make life a little easier!

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.

ACTIVELY AGING

Maximize your health as you age with hemophilia

By Patrick F. Fogarty, MD

Thanks to comprehensive care at hemophilia treatment centers (HTCs), improved safety of clotting factor concentrates and effective treatments for hepatitis C and HIV, men with hemophilia today are experiencing the joys—and the aches and pains—of a life lived into middle age and beyond. Because of their bleeding disorder, however, men with hemophilia have to pay particularly careful attention to their health as they age. Here are some things I encourage my mature patients to do:

Find a good primary care physician (PCP). It's really important to make sure your PCP is a good fit and that you see him or her regularly. Your PCP coordinates age-related health maintenance, such as screening for high cholesterol and certain cancers. If possible, try to have a PCP in the same health system as your HTC, which will greatly enhance communication between your clinicians.

Pay attention to unusual bleeding. This is defined as bleeding that isn't usual for *you*. Blood in the urine or stool may occur occasionally in men with hemophilia, but bleeding also can be the first sign of an age-related malignancy, such as colon cancer. Remember that many conditions are more easily treated if they are identified earlier, so don't delay telling your PCP and HTC about new bleeding.

Undergo age-related tests. Sometimes routine screening tests for age-related conditions, such as a colonoscopy, or diagnostic procedures, such as a prostate biopsy, are thought to be too risky for men with bleeding disorders. These tests might be delayed or

not performed. Aging men with hemophilia should undergo screening and diagnostic procedures as recommended for men without a bleeding disorder. It's also important to insist that your HTC be contacted and that it supplies a regimen for factor replacement (and any other treatments) to minimize the risk of bleeding.

Inform your HTC of new diagnoses or medicines. Finally, treatment of certain conditions that are more common in older men may require medications that can increase the risk of bleeding. Involving your hematologist in these discussions is essential, so make sure your HTC is aware of any new diagnoses or medications.

With a good primary physician, attentiveness to unusual bleeding and involvement of your hematologist in managing age-related medical conditions, you'll meet the challenges—and joys—of growing older head-on.



Patrick F. Fogarty, MD, is Director of the Penn Comprehensive Hemophilia and Thrombosis Program at the University of Pennsylvania Medical Center in Philadelphia.

Previous article taken from the Spring 2011 issue of *HemAware*, a publication of the National Hemophilia Foundation.



THE HEMOPHILIA
5K RUN AND FAMILY WALK

The Delaware Valley Chapter of the National Hemophilia Foundation

Mark Your Calendars!!

Go to: hemophiliasupport.org to register
Saturday, October 1, 2011
Collegeville, PA



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