Quarterly Newsletter
National Hemophilia Foundation
Delaware Valley Chapter

The Winning Spirit

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In this Issue

WHAT IS A CURE?

By Martha J. Frase

In 1964, a laboratory breakthrough sent hopes soaring that a cure for hemophilia A and B was a possibility. That was the year Judith Graham Pool, PhD, professor of medicine at Stanford University, discovered how to derive factor-rich cryoprecipitate from human plasma in large quantities. For the first time, blood-clotting factors could be produced cost-effectively and consistently.

Today, researchers have discovered how to manufacture factor products derived from plasma, as well as synthetic factor products using recombinant technologies that do not require human plasma. Factor can be concentrated and mass-produced to create stable products that can be used prophylactically to prevent bleeds.

"Now we have a lifelong replacement therapy," says Steven W. Pipe, MD, associate professor of pediatrics and pathology at the University of Michigan Medical School. He is also pediatric medical director of its Hemophilia and Coagulation Disorders Program. "Patients are liberated from treatment in hospital settings. Now they can self-manage their disease at home. It is not, strictly speaking, a cure, but similar to the way people in the 1920s considered insulin to be a cure for diabetes."

The definition of "curing" a chronic disease varies widely. The question, "What does a 'cure' mean for you?" was posed to consumers attending the 2006 annual meeting of the Lone Star Chapter of the National Hemophilia Foundation (NHF) in Houston by Rita R. Gonzales, NHF board member and the mother of two sons with hemophilia. "It was very informal," says Gonzales. "I surveyed about 20 people and encouraged them to speak freely about their ideas. Their responses were all over the ballpark."

The answers ranged from "getting the body to express factor" to the simple expectation of "my son not having to infuse twice a week" to the hopeful notion of "a permanent fix or reversal of the genetic defect." The latter interviewee added, "But we have to be realistic and ask what is achievable in the near future. There will be steps along the way."

DEFINING MOMENTS

"In my mind, the definition of a cure has changed significantly since our son was born," says Richard Metz, MD, a Los Angeles primary care physician and father of a 20-year-old son with severe hemophilia A. Metz serves on the NHF board. "A long time ago, a cure was thought of as nothing less than changing the gene — getting rid of the deficiency so that subsequent generations would not be affected. But as time has gone on, we've seen so many issues and problems in gene therapy research, and it's taking a lot longer than expected." Meanwhile, many safe, innovative therapies have emerged to improve the lives of those with hemophilia.

When Michael Metz was born in 1987, physicians were just beginning to treat hemophilia with safer, viral-inactivated, plasma-derived concentrates. "Then recombinant products came out, along with safer clotting factor, and that was another huge step toward a cure," says Richard Metz. A major burden was alleviated, and it changed Michael's future. "He rarely bleeds, leads a fairly normal lifestyle and is doing quite well. He is a sophomore at the University of California-Santa Barbara and took a snow-boarding trip during spring break. I see my son as being a healthy person in society."

Eliminating hemophilia won't happen soon, because about one-third of cases involve a random — not inherited — gene mutation, according to NHF. Also, several different mutations can cause low factor levels. "It's not just one disease,

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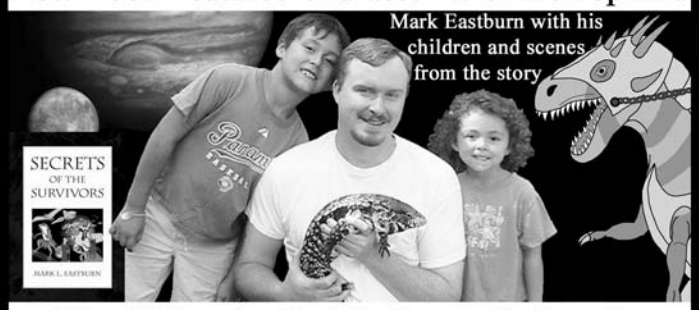
From the Executive Director

The Delaware Valley Chapter Board of Directors welcomes four new board members for 2008-2009: Tom Galvin, Lynn Lindquist, Christine Rowe and Marty Piper. "Each of our new board members brings unique skills and talents that will add to the dimension of our Chapter," said Keith Moore, President. "They are dedicated to our mission of support to local patients with bleeding disorders and the programs that serve them. We are grateful to each new member for giving their time and talent to enhance the work we do on behalf of our members." Welcome aboard, Fab Four!

New Book Features Character With Hemophilia



When NHF member Mark Eastburn decided to write a book, he knew right away that one of his main characters would have a bleeding disorder. "I wanted to create a hero who my children will be able to look up to; someone with hemophilia who is still able to do amazing things," Mark reports. As father of a child with hemophilia and von Willebrand Disease (VWD), a daughter with von Willebrand Disease, and having VWD himself, bleeding disorders have been close to Mark for many years.

Mark Eastburn's novel, titled *Secrets of the Survivors*, has been receiving great reviews from readers of all ages. It is available through the website http://www.aprenden.com and major online bookstores such as amazon.com.

We Gratefully Acknowledge the pledge of support from the following manufacturers for 2008.

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Helixate FS
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Stimate

Novo Nordisk
NovoSeven® RT

Wyeth
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Xyntha

Chapter Calendar

October	**11** Marco's Race!
	24 Fall Gala!
November	**13-16** NHF Meeting/Denver!
December	**6** Family Holiday Party!
January	**24** Men Matter!!
March	**28** Fashion Show!!
April	**9** Bowling for Fun!
	24-26 VWD Women's Retreat!
May	**5** Family Dinner!
	16 Re Run Broad Street 5 Miler!
	25 Liberty to Liberty Triathlon!

Chapter Happenings

Look What's Coming Up!!

Night at the Casbah! Friday, October 24th at the Hilton Hotel on City Avenue. A fantastic night of fun, dancing, gaming, wonderful food, and a live auction to support the DVC's mission of support! For tickets, call the Chapter office: 215-885-6500!

The DVC Annual Holiday Party will be held at Jefferson Alumni Hall in Philadelphia on Saturday, December 6, 2008! To register for this family event, call the DVC office: 215-885-6500! This is a fun day for kids of all ages (and their parents, of course!).

On Saturday, January 24, 2009, the DVC will host a Saturday program "Men Matter." This workshop is being brought to our area by Joe Caronna and Inalex Communications and is made possible by a generous educational grant from Baxter BioScience. The program was created specifically for men affected by bleeding disorders, either as a patient or parent. Some of the highlights include:

- Differences between the way men and women cope with a chronic disorder
- Three steps to emotional fitness
- How bleeding disorders affect relationships, with tools and strategies to cope
- The role of conflict in deepening or weakening relationships
- Creating and sustaining a vision for an intimate relationship

Space is limited to 30 men, so call the DVC office right away to reserve your spot (215-885-6500)!

Inalex Communications
Men Matter: For Men Only! **Saturday, January 24, 2009**

Men Matter is a workshop created specifically for men affected by bleeding disorders as patients or as parents. This workshop will focus on learning skills and developing processes that most men never have a chance to do. It will help men identify and express whatever they are feeling in a healthy way and to be comfortable with the feelings of others.

Too many men don't have the all the information they need in order to achieve success in life. Men deal in facts, figures, procedures and information, not necessarily in emotion. The emotional part is often the most difficult. This presentation is intended simply to serve as a guide to men in understanding how to deal with their feelings.

This innovative workshop inspires discussion and reflection, challenges stereotypes and does it with incredible skill, integrity and humor.

Jack Kakolewski, Facilitator

Jack Kakolewski is a licensed Psychotherapist with over 25 years of professional experience. He has degrees from Seton Hall and Catholic University and received his Masters in Counseling Psychology from Iona University. In addition, Jack has a post-graduate degree in Marriage and Family Counseling from Seton Hall. For the past ten years, he has served on the faculty of the Institute for Psychoanalysis and Psychotherapy of New Jersey.

Jack is a frequent speaker at men's workshops and retreats, helping them re-connect to their emotional needs and learn the skills of coping and understanding. Jack is especially dedicated to helping men affected by bleeding disorders, either as patients or as parents. Jack resides in Ridgewood, New Jersey.

On Saturday, March 28, 2009, The Annual Fashion Show and Luncheon will be held at the Drexelbrook in Drexel Hill, Pennsylvania. Our special guest is Laureen A. Kelley, President of LA Kelley Communications, Inc., a worldwide provider of educational resources and leadership training for the bleeding disorders community. Laurie is the author of eleven books, including Raising a Child with Hemophilia and A Guide to Living with von Willebrand Disease. Plan to join us for this spectacular event!

Join us on Saturday, April 9, 2009, for Bowling for Fun at Thunderbird Lanes in Northeast Philadelphia! Come join the fun! Watch for details in the winter Winning Spirit!

April 24-26, 2009 is the date for the 2009 VWD Women's Retreat on the Hill! This weekend retreat is for women in families with VWD! To receive a registration form, call the DVC office!

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WHAT IS A CURE?

and it's not going to be completely wiped out," says NHF board member Eileen Bostwick, PhD. She is the mother of a college-aged son with severe hemophilia A. "But for a lot of laypeople, this is what they think of when they hear the word 'cure.'"

Deciphering the meaning of "cure" is important to the bleeding disorders community at large, since public support for chronic disease research funding often focuses on eradication. An NHF working group met in 2007 to begin hammering out its own definition of a cure. "We want donors to understand very specifically what we are going after," says Bostwick. With Metz, she served on the panel of researchers, physicians and other parents. Together, they developed a two-part working definition that was adopted by the Board and incorporated into NHF policy documents: A cure, it reads, constitutes "restoration of good health by restoring one's ability to maintain hemostasis without significant, ongoing medical intervention." The second part of the definition notes, "Until a cure is available, there is continuous improvement in the quality of life both physically and mentally for all those afflicted with bleeding/coagulation disorders."

BEYOND BIOLOGY

"It would be nice if we could wipe hemophilia off the face of the Earth, but right now we have good enough treatments so that people who have it can function normally," says pediatrician and hematologist-oncologist Jan van Eys, PhD, MD, professor emeritus at Vanderbilt University School of Medicine in Nashville, Tennessee.

After more than 45 years of treating children with hemophilia, van Eys is convinced that a cure is defined by how well a person functions in his or her life, a concept that is not unique to hemophilia. A cure is part biological, part psychological and part social, he believes. "The idea of a biological cure is what people get hung up on," van Eys says. "But there is enough factor in the world such that people with hemophilia will be able to function well if they have access and are able to use it. So the biological is the least important of the 'cures' in that respect."

Two factors are necessary for functioning well, van Eys believes. "First, you have to be at ease with having or having had the disease, and not consider yourself stigmatized or nonfunctioning," he says. "Second, society has to accept you as having or having had the disease — others expect and allow you to function as well as anyone else."

A psychological and social cure may be more easily achieved by today's newest patients. "The conversation [physicians have] with parents has changed a lot," van Eys notes. "Prophylaxis can start at a very early age, and a child may survive without any real joint damage in his life. So I don't have to warn them about all the crippling that may happen. Hemophilia has changed from a doomsday diagnosis to the potential of a very normal lifestyle."

While a normal lifestyle is now possible for children with hemophilia, Metz notes that achieving a cure in this sense is a deeply personal journey. He says it is affected by a person's experiences of and with the disease. For some, he says, the damage is already done. "A person who's been affected will have the psychological scars and issues of growing up with a disease from early childhood," Metz says. "Even if we had a therapy where a person no longer had to infuse, it won't immediately 'cure' people who have other problems, like joint disease or HIV infection." In his opinion, effective gene therapy would also not have an impact on existing problems. "Even if my son never has another bleed, he can pass the defective gene for hemophilia on to his daughters," says Bostwick. "He has to live with that."

For these reasons, van Eys advocates expanded mental health research and support for the bleeding disorders community. "When we talk about research, it is always a temptation to accentuate the biological cure," says van Eys. "But I believe that it's just as important to tell parents, 'we can make your son a happy, healthy, functioning child, with just one problem: He needs an infusion.'"

SMALL STEPS FORWARD

Today's newly-diagnosed children can look forward to a life unimaginable 20 to 30 years ago — relatively unrestricted and free from worry about life-threatening bleeds and even joint damage. But parents of these newborns will naturally have higher expectations for their child's future — including a day when the disease will be eliminated entirely from his or her body. They are as invested as any generation of parents in the medical advances, such as new drug and genetic therapies that will bring the prospect of a cure even closer.

"The original treatment goal for hemophilia was to save lives, then it was to control bleeding episodes, and then it was to prevent long-term joint disease," says Pipe. "In this way, we are inching toward a cure. Most of what I see on the immediate horizon is continued life improvements, particularly with more convenient therapies like room-temperature, stable factor and variations in vial sizes." In the future, researchers like Pipe expect the availability of factor products with longer half-lives, a reduction in infusion frequency and perhaps an oral delivery system.

Only a few years ago, the goal of altering the gene itself seemed tantalizingly close. But gene therapy research as a whole has undergone recent setbacks as patient safety has been questioned. A handful of human subject deaths in other disease trials has caused all researchers to put on the brakes.

According to Pipe, there are no trials underway involving gene therapy for hemophilia. Five trials have been conducted so far: two by Avigen and one each by Transkaryotic Therapies, Chiron and GenStar Therapeutics. "To their credit, all showed a very good safety record. Those that were not completed were stopped after brief side effects were reported," says Pipe. "That's what makes progress seem so slow. Since these trials have been aimed primarily at the safety of gene

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New Study Will Monitor Postpartum Bleeding in VWD Patients

A new multi-site study will measure postpartum von Willebrand factor (VWF) levels in women with von Willebrand Disease (VWD) to provide clinical data for physicians who, until now, have had to rely on anecdotal evidence. Andra James, MD, Duke University Medical Center in Durham, NC, is the principal investigator of the study. Other sites that will participate include the Mary M. Gooley Hemophilia Center in Rochester, NY, and the Robert Wood Johnson University Hospital in New Brunswick, NJ. Two additional locations will be added later. James and her colleagues will assess how VWF levels fluctuate during the postpartum period and whether decreases in these levels can be linked to hemorrhaging.

Virtually all women experience a rise in their VWF and factor VIII (FVIII) levels during the third trimester of pregnancy. However, within one month postpartum there can be a gradual decrease to baseline levels. According to investigators, this situation contrasts significantly among women with VWD who may experience precariously low drops in their VWF and FVIII levels — below the baseline — during the postpartum phase. While this condition seemingly exposes VWD women to a significantly greater risk for excessive bleeding, the evidence until now has been mostly anecdotal.

The prospective cohort study is designed to compare changes in blood levels of VWF postpartum in an equal number of women with and without VWD. Tests to determine patients' VWF levels will be conducted at periodic intervals in the immediate postpartum period. Investigators will assess how quickly, to what levels and for how long VWF levels drop in the days post-delivery. The data will help establish optimal clinical protocols.

"While we know that decreasing VWF levels following childbirth can result in serious complications for women with VWD, there are very little clinical data available to guide physicians in treating these patients," said Peter Kouides, MD, a principal investigator of the study. He is the Medical and Research Director of the Mary M. Gooley Hemophilia Center. "By studying the patterns in declining VWF levels, we hope to learn whether treatment following birth is needed and the optimum duration of therapy." The study is being funded through a $1.2 million grant provided by CSL Behring.

Previous article provided by the National Hemophilia Foundation.

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therapy — rather than a cure — it's always been back to the drawing board." He gives the example of using bone marrow transplantation to cure some cancers at the risk of triggering other chronic, life-threatening diseases. "We need to be very careful, as we move forward with genetic research, that we don't adopt it so quickly that we introduce another set of complications for patients."

Finding research subjects in the developed world, where there are effective treatments, could pose a challenge, Metz predicts. "Eventually, in a few decades, if we are able to really alter the gene in a safe way with fewer risks, how would you convince people with hemophilia who are leading essentially a normal life to undergo a medical procedure that would carry some risk?" he asks. In developing countries, where people with hemophilia have fewer treatment options and face joint disease and even death, it may be easier to find subjects. However, this creates an ethical problem when researchers disproportionately recruit from populations that lack treatments that are readily available in the US, Metz believes.

Pipe expects clinical gene therapy research on other diseases — muscular dystrophy, immune deficiencies and Parkinson's disease — to yield valuable results for bleeding disorders research. "I don't think people should be so disappointed that they don't see a lot going on in hemophilia trials now," Pipe says. "It's time to concentrate on basic science and animal trials, and look at clinical successes elsewhere."

An additional concern is cost. "This type of research is very, very expensive, and there is no rapid discovery," says Bostwick. "The bleeding disorders community is unlikely to ever raise enough money themselves, so we historically have relied heavily on pharmaceutical companies."

Advocates shouldn't be discouraged or concerned that funders will bypass bleeding disorders to concentrate on other, more life-threatening diseases, van Eys says. "Hemophilia A is a unique disease because it resides within a specific gene, which has always made it attractive to genetic researchers," he says. "I don't worry about the genetic aspects being ignored."

"Another thing working to our advantage is increased awareness of clotting disorders in general, like deep vein thrombosis and pulmonary embolism," says Bostwick. "These disorders are part of the same picture as they are also caused by problems within the clotting cascade." Since they affect a larger number of people, greater resources are being focused on the basic science that can benefit hemophilia research as well.

People with hemophilia and those yet to be born with the disease, can look forward to continued incremental advances toward safer, more effective treatment to prevent bleeding. "The ultimate cure would be if the gene were eradicated, so that for some generation down the road, no one would ever have to worry about it again," says Metz. "Mapping the human genome was science fiction 20 to 30 years ago. I believe it's possible, but it remains the very long-term vision of what a cure could be."

Previous article taken from the July/August 2008 issue of HemAware, a publication of the National Hemophilia Foundation.

Legislative Update

Issue #1

Lifetime Insurance Caps Bill Introduced In U.S. House of Representatives

A DVC CALL TO ACTION!!!!

On Thursday, July 17, 2008, Congresswoman Anna Eshoo (CA) along with Representatives Betty Sutton (OH), Jason Altmire (PA) and James Langevin (RI) introduced H.R. 6528, the Health Insurance Coverage Protection Act, which raises the minimum lifetime cap for private health insurance to $10 million. This bill is identical to the Senate bill (S. 2706) that was introduced by Senator Byron Dorgan in March 2008 during NHF's Washington Days.

H.R. 6528:

- Sets the minimum level of a lifetime cap placed on a group health plan at $5 million for the first two years and $10 million in years three and four.
- Provides for an annual inflationary adjustment to a group insurance plan's lifetime cap based on the consumer price index in subsequent years.
- Exempts health plans offered to businesses with fewer than 20 employees, but would require that health plans meeting the parameters of the bill be offered to a small business at the employer's request.
- Calls for an Institute of Medicine Study to determine the number of individuals who reach their lifetime caps.

If you haven't already done so, please contact your U.S. Senators and Representative to urge them to co-sponsor these important bills!!!!

If you need help from the Chapter office to identify House and Senate Members, just give us a call! We really need your help!

Issue #2

Genetic Information Nondiscrimination Act Passes in House and Senate

On Thursday, May 1, 2008, the United States House of Representatives passed the Genetic Information Nondiscrimination Act (GINA, S. 358) by a vote of 414-1. A week earlier, on Thursday, April 24, 2008, the United States Senate passed the bill by a vote of 95-0. The passage of this historic legislation follows a 13-year effort by a broad coalition of grassroots organizations, including the National Hemophilia Foundation (NHF).

GINA amends the Employee Retirement Income Security Act of 1974 (ERISA) and the Public Health Services Act (PHSA) by prohibiting health insurance issuers from:

- Adjusting premiums on the basis of genetic information;
- Requesting or requiring an individual or a family member of an individual to undergo a genetic test; and
- Using or disclosing genetic information for purposes of underwriting or determining enrollment eligibility.

Additionally, GINA protects employees from having genetic information used against them by:

- Prohibiting employers, including employment agencies and labor organizations, from "requesting or requiring" genetic testing of an individual or his family; and
- Prohibiting employers from using genetic information to make hiring or promotional decisions, or when determining eligibility for training programs.

Issue #3

Update on HB 1105 and SB 1030 *The Hemophilia Standards of Care Act*

As summer winds down, the Pennsylvania Chapters continue their work on The Hemophilia Standards of Care Act, HB 1105 and SB 1030. This legislation, when passed into law, will protect access to care for more than 1,700 Pennsylvanians with bleeding disorders. Local families affected by hemophilia and von Willebrand Disease continue to struggle to maintain access to:

1. All brands of FDA-approved clotting factor
2. The state-recognized hemophilia programs in Pennsylvania
3. The coagulation laboratories connected with the state-recognized hemophilia programs
4. Quality pharmacy and home supportive services

If you have not spoken directly to your state representative about *The Hemophilia Standards of Care Act*, we need your help right now. Call the DVC office to find out how you can help in this important state advocacy initiative (215-885-6500)! We have made monumental strides in the development of our effort in 2008. Highlights include the completion of two, successful public hearings, our annual Bleeding Disorders Awareness Day in Harrisburg and a review by the Pennsylvania Health Care Cost Containment Council. Give us a call and be a part of "history in the making!"

Medical Update

MENORRHAGIA'S LINK TO BLEEDING DISORDERS

By Kurt Ullman

During the past decade, research has shown that many women with menorrhagia have an underlying bleeding disorder such as von Willebrand Disease (VWD) or platelet dysfunction. This has led to a growing movement to change how clinicians diagnose and treat these women.

"The Centers for Disease Control and Prevention (CDC) completed a study four years ago of women with menorrhagia," says Roshni Kulkarni, MD, director of the Division of Blood Disorders at the National Center on Birth Defects and Developmental Disabilities at the CDC's Atlanta headquarters. "Because physicians were not aware that bleeding disorders could be a cause of excessive menstrual bleeding, they were doing little testing looking for these problems. The CDC interviewed 75 women and found an average of 16 years between their first bleeding symptom and diagnosis with a bleeding disorder."

As Kulkarni notes, that finding raised quite a few eyebrows among hematologists and gynecologists. Many of these women were undergoing unnecessary surgery, including hysterectomies, which solved the menstrual bleeding issue but did nothing to treat the underlying bleeding disorder.

"There is no question that the most important development during the last decade is the greater awareness that women who bleed excessively during menses may have an underlying bleeding disorder," says Peter A. Kouides, MD, medical and research director at the Mary M. Gooley Hemophilia Treatment Center in Rochester, New York. "Physicians often used to just pat women with menorrhagia on the back and tell them they had to live with it. It is only more recently that we have had the studies to back up the notion that there may be something we can treat going on."

Kouides points to statistics from the World Health Organization indicating that up to 20 million women worldwide have heavy periods, and between 10% and 20% may have underlying VWD. Another study shows that perhaps as many as half of the remainder may have an abnormality in platelet function.

The nature of the problem means that multiple specialists, including hematologists, gynecologists and primary care physicians, must work together to find and treat these women. The National Hemophilia Foundation (NHF), the American College of Obstetricians and Gynecologists (ACOG) and the CDC have been at the forefront of these efforts. One development is the definition of a normal menstrual period recently published by Jennifer Dietrich, MD, an ob/gyn active in ACOG. She is also an NHF Women with Bleeding Disorders Task Force member.

"We have gotten the word out to gynecologists to consider VWD and other bleeding disorders in the differential diagnosis for having bleeding," says Barbara Konkle, MD, director of the Penn Comprehensive Hemophilia and Thrombosis Program in Philadelphia. "Additionally, we have seen a steady increase in the number of women being referred to hemophilia treatment centers (HTCs) by their family physician or pediatrician."

All three experts agree that while the growing recognition that women with menorrhagia may have VWD or other bleeding disorders is probably the most important change seen in the past 10 years, there have also been major advances in treatment.

"Over the last few years, much of the focus has switched toward trying to find the best way to treat VWD and other bleeding disorders in women," says Kouides. "The CDC has been supportive of studies that have given us scientific and clinical proof on ways to successfully treat these women."

Konkle points to research leading to a better understanding of the uses of hemostatic agents in the treatment of heavy menses, including therapies such as progesterone-covered intrauterine devices.

"Over the last 10 years, a high-purity von Willebrand Factor (VWF) concentrate has been studied, and a recombinant VWF product is under development," Konkle says. "We also have more information on how to use those we do have better and more efficiently."

"Hysterectomy is no longer the only treatment available," says Kulkarni. "We now have viable alternatives that give women an option other than going under the knife. Furthermore, these treatments may preserve and prolong the reproductive years of these women while also improving their quality of life."

To further increase this knowledge base in the future, the CDC is developing a woman-specific section to the Universal Data Collection tool used by all HTCs. This will help track not only the incidence of females of all ages with bleeding disorders, but also the treatment used.

"Now that we have a handle on VWD, those involved with treating menorrhagia and bleeding disorders are going to become more proactive in looking at other factor or platelet disorders that might contribute to heavy menstrual bleeding," says Kulkarni. "This should help us define differences in bleeding disorders by race and also how responses to treatment might vary."

Previous article taken from the May/June 2008 issue of HemAware, *a publication of the National Hemophilia Foundation.*

Bleeding Disorder Legal Hotline

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

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

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

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

Planned Giving

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

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!!

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

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.