

# HEMOPHILIA RESEARCH:

**THE ROAD TO A CURE.....WHERE WE ARE, WHERE WE'RE GOING** By Bruce Goldfarb

The 21st century wasn't supposed to be like this. What happened to the hovering jet cars we were promised? Where are the domestic robots to relieve us of household chores? Most important, where is the cure for hemophilia?

Although there's no remedy for post-millennial let-down, researchers and experts in the field have a response for people with bleeding disorders demanding answers: Gene therapy is still on the horizon—the goal researchers around the world aspire to reach. It won't be easy or quick; the initial enthusiasm for gene therapy has been tempered with the reality of scientific hurdles. In the meantime, advances in treatments offer promise for important improvements in the lives of people with bleeding disorders.

"The expectations for the pace of working toward an eventual cure for hemophilia are more realistic than they were 10 years ago," says Paul Monahan, MD, attending physician at the Comprehensive Hemophilia Diagnostic and Treatment Center at the University of North Carolina at Chapel Hill.

The lives of people with hemophilia have improved dramatically since the bleeding disorder was described as the first recognized inherited disease thousands of years ago. The history of bleeding disorders is marked by huge leaps forward and small steps back; dramatic improvements in the treatment followed by obstacles as new challenges and issues arise.

First there was life-saving blood transfusion, followed by plasma, cryoprecipitate and most recently, recombinant clotting factor. The bleeding disorders community was struck by the emergence of the human immuno-deficiency virus (HIV) 25 years ago, as well as by the hepatitis C virus. Processes to screen for and inactivate such viruses have vastly reduced the risks of contracting them from the nation's blood supply, but concerns about the next blood-borne disease are ever present. In addition, the emergence of inhibitors is becoming an increasingly recognized problem. In contrast, von Willebrand disease (VWD) and other bleeding disorders aren't recognized early enough by health professionals and the public.

Experts in hemophilia and other bleeding disorders say that research is proceeding at a rapid pace that is expected to produce more great leaps in the near future.

## GENE THERAPY

The holy grail of hemophilia—using gene therapy to restore normal production of clotting factor—is tantalizingly close, but still beyond our grasp.

When the first human gene therapy trials were announced in the early 1990s, many believed that the long-sought cure for numerous diseases was within reach, not just for hemophilia, but also for cystic fibrosis, muscular dystrophy, severe combined immune deficiency and other inherited diseases.

The principle sounds elegantly simple: viruses, stripped of their disease-causing components, are used to deliver a therapeutic gene. In practice, gene therapy turned out to be much more difficult. "There was an unreasonable expectation that a genetic cure was just around the corner," Monahan says.

The emerging field was dealt a tragic setback in 1999, when Jesse Gelsinger, an 18-year-old, died at the University of Pennsylvania Medical Center in Philadelphia after receiving gene therapy for a rare genetic liver disease.

When gene therapy trials resumed in 2000, more safeguards and precautions were built into research protocols. Researchers now report steady progress in gene therapy, including approaches with safer viruses and even non-viral gene delivery systems.

"If we could figure out a non-viral gene therapy, that would solve so many of the toxicities associated with the viral vectors," says Glenn Pierce, PhD, MD, of Bayer HealthCare-Pharma. He co-chaired the National Hemophilia Foundation's Eighth Workshop on Novel Technologies and Gene Transfer for Hemophilia in 2006. "So far, we haven't been able to figure it out." ("Gene Therapy Update" in HemAware Clinician, see page 84.)

Research in the field of gene therapy for hemophilia is "very encouraging," says David Lillicrap, MD, of Queens University in Kingston, Ontario, who studies gene therapy and other treatments in dogs with hemophilia.

"Gene therapy is not simple and it's not straightforward," Lillicrap acknowledges. "We thought there would be challenges and we met those challenges. I would still be cautiously optimistic that this area of research will be successful at some point in the future."

## BETTER GENES, BETTER PROTEINS

Some researchers are taking a different approach to correcting a "nonsense mutation," a type of genetic variation of hemophilia that results in instructions provided by the gene to prematurely stop creating a factor protein. A shortened, nonfunctional protein is produced.

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# The Winning Spirit

**Quarterly Newsletter**

**National Hemophilia  
Foundation**

**Delaware Valley Chapter**

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# Delaware Valley Chapter News & Notes

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## FROM THE EXECUTIVE DIRECTOR

Each Spring we introduce you to the HPPS participating companies for the coming year!! Each of these companies provides pharmacy and home nursing support to local patients with bleeding disorders and has qualified as a 2007 participating company by meeting the high standards set by Hemophilia Patient and Program Support, Inc.

Meet these companies by going to our website [www.hemophiliasupport.org](http://www.hemophiliasupport.org) and clicking on the companies' logos. You will be linked directly to their site where you can see detailed information on the services that each company provides. Be an educated consumer and get the information you need to make informed decisions about choice of pharmacy provider.

Additionally, [www.hemophiliasupport.org](http://www.hemophiliasupport.org) links to the sites of clotting factor manufacturers. This feature allows you to get information about the products offered by U.S. manufacturers that make our life-sustaining therapies.

By the way, if you have suggestions for our website, send them to us.

e-mail: [hemophilia@navpoint.com](mailto:hemophilia@navpoint.com).....we love to hear from our readers!!



### CHAPTER CALENDAR CHANGE!!

Heads up....all you golfers and supporters!!! The DVC Golf Classic has just moved to June 18th at the Radnor Valley Country Club!! Two great ways to support the DVC in June "on the links!!"

- #1 Carlino's Golf Outing...Edgemont Country Club, Monday, June 4th!!!!
- #2 DVC Golf Classic...Radnor Valley Country Club, June 18th!!!!

# Chapter Happenings



Families and supporters  
at the Fashion Show,  
Family Camp and  
DVC Golf Classic!!

On **May 8, 2007**, the DVC will host our **Annual Family Dinner** at the Hilton Hotel, City Avenue, Philadelphia. This is always a special night bringing patients, families, industry exhibitors and hemophilia program staff together. This year we will dedicate the evening to a celebration of our young members with bleeding disorders. And what a night we have planned!! If you haven't received an invitation from your treatment center, call the DVC office right away (215-885-6500). The evening is FREE and you won't want to miss it!!

On **May 18, 19 and 20, 2007**, we will host our first ever **"Women's Retreat"** for women in families with von Willebrand disease (VWD). This weekend retreat will provide information to women about VWD at the beautiful ACE Conference Center in Lafayette Hill, Pennsylvania. Located just beyond historic Chestnut Hill at the north end of Philadelphia, this fabulous facility provides a spectacular setting for a weekend retreat for women.

The retreat lodge sits in the middle of 300 acres of luxurious woodland and has luxury hotel rooms and fabulous food!! All costs for the weekend will be covered by a generous grant from CSL Behring! We have just a few spaces left, so call us (215-885-6500) if you would like to attend!! Be a part of this informative and relaxing weekend dedicated to women affected by VWD!

Get ready! Get set for **Family Camp Weekend** on the weekend of **September 28, 29 and 30, 2007!!** We will be back at Camp Green Lane again this year, but with our wonderful old food service (that we used at Variety Club Camp for so many years)! Karen Kephart and her wonderful employees will be cooking up a storm (and we plan for perrrrrrfect weather)!! We will have the camp completely to ourselves this year and we have unlimited sleeping space and cabins with all new bathrooms. We will be sending out registration materials with the summer newsletter, but

you can call us anytime to get a registration directly from the DVC office (215-885-6500)!! This is about the best event we do all year....families just being together!! It doesn't get any better than that!!

The **Fall Gala** will be held on **Friday, October 26th** at the City Avenue Hilton Hotel, Philadelphia!! Lookin' good and havin' fun!! This is an important night to raise money for our mission of support to so many people and we hope you will be a part of it!! Wyeth is our event sponsor for the evening....great food, gaming events, dancing!!!! Please join the DVC family of friends and supporters for this spectacular night!!

Mark your calendars now for the **DVC Annual Holiday Party** at Jefferson!! That's right, it will be here before you know it!! The date is set for **Saturday, December 8, 2007!!** Plans are underway!!! This is just the best time!!

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

**a** **June**  
4 Carlino's Golf!  
18 DVC Golf  
Classic!

**I** 30-July 6  
Dragonfly Forest  
Camp

**e** **July**  
12-17 Woods  
Camp#1!

**n** **August**  
5-10 Woods Camp  
#2!

**d** **September**  
28-30 Family  
Camp!

**a** **October**  
26 Fall Gala!

**r** **November**  
1-3 NHF Annual  
Meeting!

# CHANGES IN THE MARKETPLACE...

**More Consumers will have to get Factor Product from Specialty Pharmacies in 2007** By David Linney

*The following information pertains primarily to individuals with employer-sponsored insurance plans. Medicaid, specialty pharmacy programs are not addressed in this article. This article appeared in the September/October 2006 issue of HemAware, a publication of the National Hemophilia Foundation*

In 2007, insurance companies will require more consumers with bleeding disorders to obtain their factor products from specialty pharmacies. In 2008, those numbers will be even greater.

Specialty pharmacies provide biotechnology drugs that are very expensive. Most biotech drugs are either infused (intravenous) or injected (intramuscular). As a category, these drugs are commonly referred to as "specialty pharmacy drugs." Factor products are specialty pharmacy drugs.

Specialty pharmacies sometimes are associated with drug plans known as pharmacy benefit managers (PBMs) and a limited number of health plans. Specialty pharmacy services which focus on the effective cost management of high-cost specialty pharmacy drugs (through efficient purchase, supply and programming), are marketed to payers.

Payers, including employers and insurers who pay for pharmacy bills, have become very interested in using specialty pharmacies to try to reduce their overall drug costs. Interest has risen in direct response to the large number of specialty pharmacy drugs expected to enter the marketplace over the next few years. Payers are concerned that their drug costs will increase dramatically as these new therapies become available.

Until a few years ago, factor products were covered almost exclusively as a health plan benefit. While this is still common today, there is a strong, growing trend to change factor products coverage to a separate drug-plan benefit. Many payers have determined that it is easier to manage drug costs through a drug plan than through a health plan because it is quite difficult to track and manage specialty pharmacy costs through the medical claims review process of a health plan.

## Types of Specialty Pharmacies PBM Specialty Pharmacies

A PBM is a pharmacy benefits manager. For consumers, a PBM is a drug plan that provides pharmacy benefits separate from the health plan.

PBMs contract with employers and insurers to be the fiscal managers of drug benefits for the group's members. They develop and manage formularies (listings of approved drugs). PBMs typically have a network of retail pharmacies to

supply prescription drugs and a mail order pharmacy that may supply up to several months' worth of regularly prescribed drugs.

As more PBMs pop up in the marketplace, a number of them either have or are developing a specialty pharmacy to supply drugs like factor products. The three largest PBMs, in order of size based on covered lives, are Caremark, Medco and Express Scripts Together, they serve more than 200 million policyholders, or approximately two-thirds of the marketplace. Each has its own specialty pharmacy.

Caremark's self-named specialty pharmacy became an even more significant force after it acquired AdvancePCS in 2004. Medco acquired Accredo Health, Inc., in 2005 to create its current specialty pharmacy services, including Hemophilia Health Services, which is dedicated exclusively to hemophilia care. Express Scripts acquired CuraScript Pharmacy and CuraScript PBM Services in 2004 and Priority Healthcare in 2005, creating CuraScript, its specialty pharmacy.

Having a drug plan, though, does not mean it will automatically cover your factor products. Currently, factor products remain more commonly covered under health insurance plans.

The sponsor of the health insurance plan—commonly, the employer or an insurer—decides if it will include specialty pharmacy drugs, including factor products, as a benefit of the drug plan (If the sponsor does not include specialty pharmacy as a drug-plan benefit, then the factor products usually will be covered under the health plan.) The outlook for 2007 is that more employers and insurers will contract with PBMs to supply specialty pharmacy drugs, including factor products.

So if you have a drug plan in 2007, it's very important to verify coverage and supply of factor products for the coming year. Look at your insurance card(s) and call the drug plan number on it. (Most of us have either a health insurance card with a drug plan listed or a separate drug plan card.) For further assistance, contact your hemophilia treatment center (HTC), physician or factor product vendor.

## Health Insurance Plan Specialty Pharmacies

Some health insurance plans that provide

pharmacy benefits in addition to health benefits have established their own specialty pharmacies. Three of these are Aetna, Cigna and WellPoint. Aetna requires the use of its own specialty pharmacy or an Aetna-approved HTC factor product program. Cigna urges—but does not exclusively require—the use of its specialty pharmacy, Tel-Drug. WellPoint's specialty pharmacy, Precision Rx, is its exclusive option.

If you have Aetna, Cigna or WellPoint, be sure to check out the company's required use of specialty pharmacies associated with the health plans in 2007. Call the plan number on your health insurance card. For further assistance, contact your HTC, physician or factor product vendor.

## IMPACT FOR CONSUMERS

The trend toward coverage of factor products as a drug benefit brings both positive and negative changes for consumers.

### PROS OFTEN INCLUDE:

- No lifetime limit.
- Low out-of-pocket expenses (many drug plans only have a co-payment).
- Potential use of a PBM that provides a high-quality service supplying factor products to consumers.

### CONS MAY INCLUDE:

- Decreased ability to select a factor product vendor (i.e., a homecare company), as payers likely will increasingly require the use of specialty pharmacies.
- Little or no recourse in having to use a specialty pharmacy (unless, perhaps, quality of service is below accepted standards).
- Decreased ability to use current factor product vendor if that vendor is an HTC factor product program or another factor product vendor that is not a PBM.
- Newer specialty pharmacies with little experience supplying factor products. Follow up with your HTC or physician to advocate for a reputable, high-quality service and contact both your local chapter and the National Hemophilia Foundation.
- HTC factor product programs likely will lose some of their customer base, which will decrease critical revenue used to support essential HTC services.



# 2006 FRIENDS OF THE DVC

**FACT: In 2006, the Delaware Valley Chapter provided more than \$400,000 in direct support to local patients and programs!!**

In December, the Delaware Valley Chapter mailed out a request for financial support to its members with the 2006 DVC Annual Report. We were amazed at the number of people in our area (and beyond) who responded so generously. Following is a list (incomplete and some anonymous) of those who donated within the designated categories. We extend a sincere thank you to our supporters.....many who contribute several times during the year. Their support will help us to address the needs of patients and programs in 2007!!! Thank you from the bottom of our hearts!!!

## Gold Star

\$25,000  
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# HEMOPHILIA RESEARCH:

THE ROAD TO A CURE.....WHERE WE ARE, WHERE WE'RE GOING By Bruce Goldfarb

PTC Therapeutics, a New Jersey-based biopharmaceutical company specializing in orally-administered drugs, is testing a drug called PTC124 that makes the gene read through the premature stop and produce a normal protein. PTC124 is “a promising development,” says workshop co-chair Katherine High, MD, a gene therapy researcher at The Children’s Hospital of Philadelphia.

Currently, PTC124 is being tested in people with cystic fibrosis, an inherited disease of mucus and sweat glands that affects breathing and digestion, and in a trial with Duchenne muscular dystrophy, a genetic disease characterized by rapid progression of muscle degeneration that occurs in young children. “If their trials for cystic fibrosis and muscular dystrophy don’t show any safety problem, they’ll probably go on to hemophilia,” High says. “A person with a specific mutation causing hemophilia A or B may be a candidate for PTC124. It isn’t for everybody, but if it works in you, then great.”

Until genes can be corrected, other researchers are turning their attention to improving clotting factor proteins. Their goal is to make them more effective or last longer in the bloodstream so people won’t have to take them as often, or to engineer protein molecules that lessen the problem of inhibitors.

Improved factor proteins “have taken on more importance as it becomes apparent that the timeline for gene therapy has become extended,” Pierce says. “Technologies are available to modify those proteins and make them better. That’s where the field is going over the next decade.”

Through molecular engineering, researchers are devising versions of factor protein that are less likely to trigger inhibitors or less vulnerable to their neutralizing effect.

Although drug companies and research laboratories typically hold their cards close to their vests, Bayer and other companies are reportedly investigating sustained-release formulations of clotting factors and methods of delivery that don’t require injections.

“There are a variety of new protein therapies being developed now that will nicely bridge the time to an ultimate genetic cure,” Monahan says. Researchers are developing “longer-acting formulations of factor protein that may allow prophylaxis for a greater portion of the population.”

Pegylation of a protein, combining it with polyethylene glycol, a large substance, allows factor to avoid inactivation and clearance out of the body.

Or a protein can be wrapped into tiny bubbles of fat known as liposomes that slowly dissolve in the body. Either of these approaches may allow more constant and sustained factor levels and reduce the frequency of infusions for a person with hemophilia, from every few days to once a week.

Ideally, people with hemophilia would like to avoid infusions altogether and take factor by mouth or inhale it with a nebulizer. This year, the Food and Drug Administration approved an inhaled form of insulin that could pave the way for other therapeutic proteins such as clotting factor. Taking a pill would be even simpler for patients, but it presents additional technical problems.

Oral formulations of factor would make adherence to factor therapy easier, especially for children, Monahan says. “We would also love to eliminate dependence on central venous access devices such as ports while maintaining adequate therapy,” he continues. “Some of these new strategies will make it to the market and hopefully relieve some of the burden of hemophilia until gene therapy comes along.” But Pierce adds a note of realism. “One has to remember that the stomach and intestines are extremely harsh environments,” he says. “Their purpose is to digest proteins, not keep them intact. There are still delivery issues with oral factor formulations.”

## TAILORED THERAPY

One of the buzz phrases in healthcare today is individualized medicine—tailoring therapy to an individual’s genetic characteristics. Using genetic tests, scientists have found variations in breast and prostate cancer, for example, based on patients’ genetic makeup, or genotype. Some respond well to certain drugs, while others do not. For them a different kind of treatment is required.

This tailored approach has not been applied to hemophilia despite the fact that the hemophilias were among the first diseases to be understood at the genetic level. Hemophilia is categorized by severity, based on an individual’s percentage of circulating factor, which is also used to calculate factor therapy. But hemophilia isn’t that simple.

Within the severe category [of hemophilia], they aren’t all bleeders,” says Kathleen Brummel-Ziedins, PhD, biochemist and research assistant professor at the University of Vermont in Burlington, who received a Career Development Award from NHF in 2005 to support a new way to individualize hemophilia therapy. “Some in the

severe category are mild bleeders. It isn’t dependent on their factor levels.”

Brummel-Ziedins and colleagues are looking into a way of describing the phenotype of hemophilia—its particular clinical manifestations—based on a person’s ability to produce thrombin, another protein in the coagulation cascade. The coagulation cascade is the step-by-step process that occurs when a blood vessel is injured. The normal result is a blood clot that creates a barrier over the injury site; in hemophilia, the cascade cannot be concluded because of a lack of clotting protein. “We have some new technologies that we want to apply to the hemophilia population to find a new way to look at their type of hemophilia,” Brummel-Ziedins says.

A phenotype test would be useful for health professionals to tailor prophylaxis for hemophilia. In some extreme cases, it could identify individuals who may need a different kind of therapy. “People with severe hemophilia who cannot be regulated with factor are candidates for gene therapy,” Brummel-Ziedins says.

Other labs are investigating better ways of “scoring” bleeding disorders, which today is mainly based on plasma screening tests that indicate prolonged time to form a clot. These screening tests include the prothrombin time and activated partial thromboplastin time (aPTT). While easy tests to perform in the lab, the screening tests do not provide a full picture of an individual’s tendency to bleed. It is important to take a complete family history. A prolonged aPTT indicates the need to perform specific coagulation factor assays.

Researchers are also devising ways to diagnose VWD more quickly and easily. Currently, a panel of blood tests is required for positive diagnosis.

“It’s a major problem because we don’t diagnose [VWD] early enough,” says Margaret V. Ragni, MD, MPH, a hematologist at the University of Pittsburgh Medical Center. “The tests we have aren’t good enough even if we try to diagnose it, and a lot of people are missed.”

A simple and quick test for VWD would make it “routine to screen for anybody who comes in with menorrhagia (heavy periods),” Ragni says.

Many people hold hope for a recombinant von Willebrand factor (VWF) that will pose less risk than blood-derived products. But informed observers suggest that it is unlikely that a recombinant VWF product will be developed

*continued on page 7*

## WE LOVE TO HEAR FROM DVC AREA FAMILIES!!

### Check this out from a local mom!!

"Thank you so much for covering some of our expenses for the NHF Annual Meeting in Philadelphia, October 2006! My son is fourteen months old now and we found out that he had hemophilia when he was six months old. This is so new to us and there is so much we need to learn. With hemophilia A being fairly rare, you can feel somewhat alone, since we have never known another person with it.

It was so comforting to be surrounded by other families that are dealing with the same things. When we were at the conference, it was the first time we have felt 'normal.' I loved the rap sessions. I learned many helpful tips from other parents. We even had one parent show us her son's port. I had never seen one before and the concept isn't as scary once you see what it really is. The insurance seminar was helpful too.

My sister just had a son four months ago and he has severe hemophilia A also. Apparently, it is in our family, but we never knew that before. She and her husband also attended the conference. We all agreed that this helped us so much that we are planning to attend the 2007 conference in Orlando, Florida. The hemophilia community has really been wonderful in supporting us as we try to understand how to manage this each day.

Our son is treated by Dr. Blatt and Deb Cebenka (nurse)...they have been a lifeline for us this year! Deb is always there to answer a question or listen to our concerns. At this point, we can say 'so far, so good!' Thank you again for covering the expenses. It was a great help to us!!"

Sincerely,

K.H., Landenberg, Pennsylvania

### Report Out.....Region III Annual Meeting A Consumer's Perspective

The Delaware Valley Chapter sponsored my attendance at the Annual Meeting of Hemophilia Treatment Centers in Region III (Pennsylvania, Delaware, Maryland, Virginia, West Virginia and the District of Columbia) on March 1st and 2nd. I really appreciated this opportunity to represent the DVC and listen to informative discussions about real issues for patients with bleeding disorders.

The sessions were very informative. There was a great presentation on ER issues for patients with bleeding disorders. Regina Butler, RN, from The Children's Hospital of Philadelphia, has developed a "pathway" (what the procedure should be when a patient with hemophilia or VWD ends up in the Emergency Room of a hospital). Having had a couple of ER experiences myself in hospitals both in and out of the HTC network, I was glad to see that procedures are being put in place so the Emergency Room staff know what to do, and in what order, when a patient with a bleeding disorder arrives.

Other great sessions included the consumer breakout group, non-hemophilia causes of pain in the upper body and especially the session on conflict of interest issues. This session resulted in lively audience participation and was very enlightening. I want to thank the DVC for giving me the opportunity to attend this meeting.

Sincerely,

Hal Muschek

#### SAVE THE DATE!!!

The 2007 NHF Annual Meeting  
will be held in Orlando, Florida,

November 1-3!!!

Visit the  
NHF website  
[www.hemophilia.org](http://www.hemophilia.org)  
to get more details!!

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anytime soon for two main reasons—cost and the small size of the target population. Launching a biotech production line costs hundreds of millions of dollars and with an estimated 300 or so people with severe VWD (type III VWD), the economics are difficult for a drug company to take on.

#### LOOKING FORWARD

Improvements in the treatment of hemophilia notwithstanding, members of the bleeding disorders community—treaters, researchers and those with hemophilia—know that much remains to be done.

Reports from laboratories hold promise of better therapies with fewer complications. But it is important to go slowly and cautiously, so that no person with hemophilia is exposed to needless risk, and resources are allocated to the most promising avenues of research.

Toward this end, NHF formed a new research initiatives and cure committee that will develop a white paper on the appropriate direction for future research funding.

Overseeing clinical research will help focus attention on the most promising work while ensuring the least risk to people with hemophilia.

"There are so many exciting things going on, a lot of neat ideas and exciting approaches," Ragni says. "Look where we are today. Lifespan is approaching normal. We have products that appear to be safe. We have eliminated the risk of infection with recombinant products. We're already avoiding bleeds, already avoiding disability. Our current level of success with treatment of hemophilia raises a whole host of questions about what level of risk you're willing to take."

*This article appeared in the September/October 2006 issue of HemAware, a publication of the National Hemophilia Foundation*

# Just a Thought

Life's  
most  
persistent  
and urgent  
question is,  
What are  
YOU  
doing for  
others?

Martin Luther King, Jr.



## FYI

## DVC SCHOLARSHIP PROGRAM NEWS!!!!

### TRUE OR FALSE

The Delaware Valley Chapter provides more college scholarships each and every year to local students with bleeding disorders than any other Chapter in the United States!

**TRUE!!!!** AND we are very proud that we do!!!! Here's an update on the DVC College Scholarship Program and some of the changes beginning in 2007!!

### Program Guidelines

The Delaware Valley Chapter can provide an annual college scholarship up to \$1,000 every 12 months to local college students who have a bleeding disorder and live in the DVC geographic area. The student must be treated at a local hemophilia program in Pennsylvania or Delaware, as well. To apply, the student must write a letter of request for support including all pertinent information (like your name, address, phone, etc), a copy of your class registration and tuition bill.

### HERE'S WHAT'S NEW ABOUT THE SCHOLARSHIP PROGRAM.....

As a scholarship recipient, the DVC will ask you to make a donation of your time and creativity through volunteering. Volunteers help us carry out our mission of service and help us reduce costs, making our Scholarship Program and other programs possible! The DVC has countless needs for fund-raising and volunteer work. In recent years, young volunteers have organized dinners, volleyball marathons, concerts, golf outings, dances, tennis tournaments, selling awareness bracelets and just about any activity you can think of...to raise money for bleeding disorders research and patient needs. We also need volunteers for our events or as helpers in the DVC office, making phone calls or preparing mailings!

You will be asked to come up with an idea of how you could help us..... so we can help others! Creativity is encouraged!! There is no deadline for requesting scholarships, but you can only apply once in a twelve month period.