

## Oh the Possibilities!!!

# One of our very "OWN" is running for the Pennsylvania House of Representatives!! Can you believe it?

When Anthony Tezak was born with severe hemophilia on November 22, 1983 in the small town of Steelton in central Pennsylvania, his parents never thought they were holding a future member of the Pennsylvania General Assembly! Well what parents would? In 1983, the hemophilia community was sitting in the middle of a nightmare, the HIV epidemic. The national community of patients, reliant on factor replacement therapies, was not looking to the future, they were focused on an unfolding tragedy, caused by decisions of the past. Their sacrifices would be immense, their losses monumental and their lives would be torn apart on every level. And the impact would go on for decades. And the isolation of it all still does, for those who would somehow survive. Anthony's parents were not focused on the possibilities for a little baby in Steelton, Pennsylvania. They were praying for his survival.



As Anthony puts it "I was diagnosed at nine months with severe hemophilia. When I was little, my mom made sure I never received factor concentrate. I would sit on the couch with ice on my bleed for weeks at a time until it would finally resolve. I have a big extended family, so my parents set up an elaborate system of family donors to keep a ready supply of cryoprecipitate for me and for my brother, Josh (ditto on hemophilia for Josh, as well). Looking back, my parents have faired pretty well, even though they had to work so hard to make sure Josh and I had the best

me possibilities. I went on to college at Penn State University and will be graduating this year with a communications degree. Now, as an employee of a large insurance company working in pharmacy prior authorization, I can see the struggles of people in Pennsylvania who have chronic expensive diseases. Patients must sometimes choose between paying their heating bill or getting their medicine. It bothers me to see policies of insurance companies that are negatively affecting the lives of real people. Restricting access to needed medicine because the medicine you need is not on an insurance company's "formulary" is becoming common practice. I don't like Medicare Part D because basic medications are not covered. People in Pennsylvania deserve better.

Insurance companies in Pennsylvania should not deny patient access to medicines and services when they are reporting

care in the safest way.

Although I have less than 1% factor VIII, I didn't have my first joint bleed until I was twelve years old. Josh and I stayed in shape by working out at the Hetrick Center in what was breakthrough technology ...a treadmill in a pool which helped build our joints and muscles to be strong enough to resolve bleeds quicker because our muscles and joints were incredibly strong.

Home treatment for my hemophilia gave

# The Winning Spirit

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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 2006 participating company by meeting the high standards set by Hemophilia Patient and Program Support, Inc.

Meet these companies by going to our website <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 informed consumer and get the information you need to make informed decisions affecting your life.

This year, we are adding links to the sites of clotting factor manufacturers. This new feature will allow 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 at our office e-mail: hemophilia@navpoint.com.....we love to hear from our readers!!

*We still need your help!*

**HB 1705 UPDATE!!** At the writing of this newsletter, we are still waiting for a scheduled vote for "The Hemophilia Healthcare Act," HB 1705. Although close on several occasions, Members of the Pennsylvania House of Representatives have not yet had the opportunity to vote on this important bill. Access to factor and home supportive services are challenged each day in our area and we need the protection that this legislation can provide. Please call your PA House Member and ask them to urge the House leadership to move HB 1705 to a vote!! We have lists of Members and their phone numbers if you need that information. You have all done an outstanding job of supporting this important project up to this point! We still need the efforts of each of you who understand why HB 1705 needs to pass! Please call the DVC office right away and be willing to make just that one important phone call! You can do it! We can help! (215-885-6500)

*We Gratefully Acknowledge...the pledge of support from the following manufacturers for 2006*

Baxter Bioscience  
Recombinate  
Hemofil M  
Proplex T  
Feiba VH  
Bebulin VH  
Albumin (Human)  
Advate

Bayer Corporation  
Kogenate FS  
Koate-DVI

Grifols  
AlphaNine SD  
Alphanate  
Profilnine SD

Wyeth  
BeneFIX™  
ReFacto

Novo Nordisk  
NovoSeven™

ZLB Behring  
Monoclate-P  
Mononine  
Helixate FS  
Humate-P  
Stimate  
Gammar-P I.V

## April

30 Moose Nigh!!

## May

9 Family Dinner!!

## June

5 Carlino's Golf!!

## September

15-17 Family Camp!!

18 Golf Classic!!

## October

12-15 NHF Meeting!!

## November

3 Oktoberfest!!



Join Chapter supporters and employees and friends of Carlino's Specialty Foods in Ardmore, PA for **"Moose Night" on Sunday, April 30th!** The fun starts at 5:00 pm at Our Lady of Good Counsel in Bryn Mawr! Great food, music and tons of fun!! All proceeds go to the DVC for its important work!! For information or directions, call the office (215-885-6500).

**The DVC Golf Classic** will have a new home this year!!!! It will be held at the Radnor Valley Country Club in Villanova, PA on **Monday, September 18th!!** Please come out to support the Chapter and have a great day of golf, as well!!

**THE NHF 58TH ANNUAL MEETING IS COMING TO PHILADELPHIA AND WE ARE THE HOST CHAPTER!!!! YAHOO!!**  
**October 12-15, 2006!! Save the date!!**

We are very excited to be the host site for this year's NHF Meeting. We will welcome more than 3,000 friends from around the United States and around the world to Philadelphia. We will host a special Delaware Valley Chapter party on Friday, October 13th at the Franklin Institute, sponsored by Wyeth!! This annual meeting brings scientists, physicians, program staff and patients together to receive updates on the latest developments in bleeding disorders!! If you have never attended before, this is your chance!! Call the Chapter (215-885-6500) for more information!



The **Annual Family Dinner** will be held on **Tuesday, May 9, 2006** at the Hilton Hotel, 4200 City Avenue, Philadelphia. This year's focus will be "A Community Update." Hear about the status of new products and treatments for the future, the "Cure," HB 1705 and much more!! Call the DVC office for an invitation if you haven't received one from your treatment center (215-885-6500).



**Carlino's Golf** will be a great time on **Monday, June 5th** at Edgemont Country Club in Edgemont, PA. Thanks to Pat and Laura Carlino and John and Kathy DiMichele who make this day so special! Please come out and support the DVC, by being a part of all of it!! Don't golf? Pledge your support by being a volunteer!! We need you!!

**Oktoberfest 2006 (or should we say "Novemberfest?")** will be held on **Friday, November 3rd** at the Hilton Hotel on City Avenue, Philadelphia!! We had to move it a little due to the NHF coming to town!! This great fundraiser has become a fall favorite!! Gaming events, great music and food...this is a night you won't want to miss!! Please plan to be with us! Your support is important to us!!

**Annual Family Camp** will be held at a new site this year, Camp Green Lane in Green Lane, PA, Montgomery County on **September 15, 16 and 17th!!** Housed on 200 acres, this great weekend will feature fishing, boating, arts and crafts, a little education, mini golf, rock climbing and so much more!! This is a great weekend for the whole family!

Meet other families who share your challenges and make a friend or two!! Look for registration materials in your summer newsletter!

Save the date!! This is the best weekend of the year!!



Barbara Konkle, MD, Medical Director, Penn Comprehensive Hemophilia Program, Philadelphia (right, front) with Senator Ted Kennedy with The American Society of Hematologists, Washington, DC.

## The ABCs of Medicare's Part D By David Linney

On January 1, Medicare introduced its new Part D prescription drug coverage that is available to everyone with Medicare.

Private companies provide Part D prescription drug coverage and Medicare recipients can choose from a number of plans that provide benefits and pay the corresponding premium. These benefits are provided through two types of plans:

- **Prescription Drug Plan (PDP)** provides separate drug coverage only.
- **Medicare Advantage**, a managed care plan that provides drug coverage in addition to all Medicare covered services (including factor products).

Under the "standard benefit" design, recipients pay a premium (approximately \$37 per month in 2006) and part of drug plan costs. Drug costs that recipients are responsible for include an annual deductible and either co-insurance or co-payments. Plans can either offer the standard benefit or an alternative benefit that is "equivalent" to the standard benefit. Here's a breakdown of what recipients can expect to pay out of their pockets:

**2006 annual premium costs (about \$37 per month) = approximately \$444**

**2006 annual cost-sharing amounts for drugs:**

**Deductible = \$250**

**Plan pays 75% and recipient pays 25% of the next \$2,000 in drug expenses;**

**recipient's maximum liability = \$500**

**Plan then pays 95% and recipient pays 5%**

**(i.e., recipient pays 5% of charges after paying \$3,600)**

### Facts To Know

Make sure you are aware of the ins and outs of the new Part D. Much information has been distributed over the past several months to those who are on Medicare, so it's good to know the major points:

#### Future Costs

Amounts that recipients will have to pay after 2006 for premiums and their portion of drugs will increase (based on a Medicare drug benefit spending index).

#### Assistance for Low-Income Recipients

There is no premium or cost-sharing for individuals with Medicare and Medicaid. For other recipients with lower income, an application can be made for premium and cost-sharing assistance; eligibility is determined by an income and asset test.

#### Enrollment

Many with Medicare have already enrolled in Part D and many more will enroll in the coming months:

For Medicare recipients who choose to enroll in Part D, initial enrollment began in November 2005 and will continue through May 15 of this year. Late enrollment will involve a financial penalty of approximately 1% of the premium amount for each month after the end of the initial enrollment period.

Individuals with Medicare and health insurance with drug coverage through a former employer that meets or exceeds the government's standards do not need to enroll in Part D while such coverage is in effect. If, when former-employer drug coverage ends, an individual can enroll in Part D with no late enrollment fee.

Medicare recipients who also have Medicaid will either enroll themselves or have been automatically enrolled in Medicare Part D as of December 31, 2005.



## Covered Drugs

Medicare drug plans must provide at least two drugs in each classification of drugs.

## Ability to Change Plans

Once enrolled in a Part D plan, an individual can change plans once a year during open enrollment from November 15 through December 31. New coverage will then begin January 1. You can also change plans if you move out of the service area of the current plan. A new plan that serves the new area can be selected.

## Considerations

The new Medicare coverage is a good thing. Now, for the first time, there is prescription drug coverage. However, keep in mind:

- Enrolling in Part D is advisable. If an individual has no drug coverage, then the benefits of having Part D coverage will usually far outweigh the cost of premiums. Also, even if a recipient has low drug costs now, future costs could be very high.
- If you have Medicare and other health plan coverage, check whether your other plan has drug coverage and if it continued after January 1. This will help you to determine if you need Part D. If you have other drug coverage, ask if your plan is a qualified prescription drug plan based on Part D criteria. If so, then you have the ability to enroll in Part D at a later date without being charged a late enrollment fee.
- Review Part D plans that are offered in your area. Compare your premiums, deductibles, co-insurance and co-pays. Also, review each plan's formulary (the list of covered drugs) to see if the drugs you use are listed.
- If you have Medicare and Medicaid, drug coverage will be provided through Medicare Part D in 2006. There will be no premium, no deductible and very little out-of-pocket cost.
- If you have Medicare (but not Medicaid) and are of lower income, apply for assistance. Your premiums, deductibles and co-pays could be lowered.

## To Learn More.....

For more information about Medicare Part D, you can call Medicare 24 hours a day at 1-800-633-4227 or visit the website at [www.medicare.gov](http://www.medicare.gov). The booklet "Medicare & You 2006" has a special section dedicated to Medicare Part D.

*Previous article taken from HemAware, a publication of the National Hemophilia Foundation, January/February 2006 issue.*

## For Your Information

**Baxter recently announced two research collaborations with Nektar Therapeutics and Lipoxen Technologies to pursue the development of longer-acting therapeutic forms of blood clotting proteins. These agreements focus on further advancing FVIII therapy, with the objective of decreasing the frequency of infusions and improving the lives of people with hemophilia A.**

# New Infectious Agents Pose new Risks for People with Bleeding Disorders, Jefferson Hematologist Says

PHILADELPHIA, PA—February 14, 2006—An international team of scientists, including a hematologist from Thomas Jefferson University in Philadelphia, has concluded that people with bleeding disorders such as hemophilia remain at risk from emerging infectious agents in plasma and blood transfusions. For this reason, recombinant therapies, that is, those produced in the laboratory, must always be an option.

Writing January 21, 2006 in the journal *Lancet*, hematologist Jamie Siegel, MD, clinical associate professor of medicine at Jefferson Medical College of Thomas Jefferson University in Philadelphia, Christopher A. Ludlam, professor of haematology and coagulation medicine at the Royal Infirmary, Edinburgh, Scotland, UK, and colleagues say that coagulation-factor concentrates (CFC) from the blood plasma, used for individuals with bleeding disorders, are now deemed safe from most known infectious agents, such as hepatitis B and C viruses and HIV, in contrast to two decades ago. But challenges from new agents mean plasma-derived products will continue to remain at risk.

The authors point out that an alternative – recombinant products, which are made by expressing genes for clotting factors in the laboratory tissue culture dish – lessen the likelihood of contamination by infectious agents.

“There will always be emerging pathogens and we won’t always know what they are,” says Dr. Siegel, who is director of the Hemophilia Center at Thomas Jefferson University Hospital. “We know that these pathogens may be in the blood supply and if we have a population dependent on plasma-derived products, they are always at risk.”

She contends that infectious agents called prions, which are behind diseases such as new variant Creutzfeldt-Jacob disease (“Mad Cow disease”), may be the most worrisome of all because they are difficult to detect. She is concerned about them affecting mostly young children and their effects decades later. “We don’t know if we can get rid

of prions,” she says. “Currently, there is no available method to diagnose and deal with them effectively.”

The continued debate about the safety of the blood supply and the use of blood-derived versus artificial products for those with bleeding disorders is under the constant threat of emerging infectious agents. Blood-derived products work better in clotting blood, but carry the caveat of potential exposure to infectious agents in the blood supply. Recombinant clotting products made in the laboratory may not be quite as effective, but are virtually risk-free from contamination.

Up until now, decisions on using blood-derived versus recombinant blood products have been left to patients and physicians. Safety studies have not definitively made the case for either.

But Dr. Siegel is concerned. “Today, the doctor reviews treatment options with the patient and together they choose the product to be used.” According to Dr. Siegel, Pennsylvania is the first state to have challenged the idea that recombinant products are safer than plasma-derived products for blood clotting disorders. In addition, the state has established a preferred drug list, she says, noting that blood-derived products may cost half the price. For now, all hemophilia drugs are listed as preferred drugs, but she is worried about the long term.

“It means you could create a two-tiered system and medical assistance patients may get plasma-derived products and potentially not get the same care as those with private insurance,” Dr. Siegel says. “It means they may have limited access to the safest treatments.”

Dr. Siegel says that she is more confident in the safety of recombinant products with respect to infectious agents and doesn’t want individuals with hemophilia to again be the victims of unsafe blood products as they were in the beginning of the AIDS epidemic in the early 1980s

*SOURCE: Thomas Jefferson University Hospital*

## For Your Information

*Following is a brief summary of an article appearing in “Molecular Therapy” March 2006 issue*

**University of Florida scientists say an ancient form of DNA found in fish might be useful in fighting hemophilia. The researchers say the discovery brings them closer to finding a safe way to spur production of a missing protein in patients with the most common form of the hereditary bleeding disorder.**

**Using a dormant strand of DNA that’s existed in fish for millions of years, the researchers successfully replaced the faulty gene responsible for the disease in neonatal mice.**

**“The degree to which these patients have problems from hemophilia stems from how much of this protein, factor VIII, is missing,” said Dr. Bradley Fletcher, an assistant professor of pharmacology and one of the lead authors of the study. “If they have very low levels of it, they have lifelong problems of bleeding...”**

The following was written in response to an article in

“The Wall Street Journal,” Thursday, December 1, 2005

Written by Dana Kuhn, PhD, President Patient Services Inc., Midlothian, VA

“I take issue with your portrayal of Patient Services Inc. as a money making scheme for drug makers and your portrayal of drug makers as developing and pricing drugs beyond the affordability of most Americans, capitalizing upon the misfortune of the chronically ill [“Support System: Through Charities, Drug Makers Help People-And Themselves,” Page one, December 1, 2005].

Patient Services Inc. (PSI), a bona fide charity, operates independently from the influence of drug makers and isn't a “pass-through organization.” With our positive Office of Inspector General's opinion, PSI championed advocating for charities to satisfy the Medicare part D “donut hole” out-of-pocket for beneficiaries. Using donated dollars to help people with expensive chronic illnesses afford their co-payments for prescriptions is our mission. Drugs are expensive, insurance premiums have skyrocketed and health insurance fails to provide sufficient reimbursement for the average American. As a result, millions of Americans with chronic illnesses are uninsured, in debt, or have gone bankrupt. Our health-care system, insurance reimbursement model and the high cost of prescription drugs represent a derisory system. PSI is the “golden standard” solution for this dilemma.

Drug makers incur research and development costs to produce state-of-the-art drugs and treatments that society aggressively demands. While these drugs provide better health, longevity, improved quality of life and partial

cures, the costs can force difficult financial sacrifices for patients. Drug makers understand this derisory system and in order to help mend it, they become altruistic and donate to charities like PSI.

The healthcare and reimbursement system needs to be reformed. Until then, PSI is offering an independent, legal and unique solution. Instead of questioning the legitimate way PSI independently uses donations from drug companies and their motives, kudos should be given to altruistic donors and charities trying to fix the system and focusing on saving lives.”

#### ABOUT PSI

**PSI, a national nonprofit organization that serves all 50 states, locates health insurance policies and subsidizes the high cost of health insurance premiums, pharmacy and treatment co-payments. PSI also assists with Medicare part D co-insurance.**

**Those who suffer from chronic illnesses, including patients with hemophilia, are eligible to apply for assistance from PSI, regardless of income. Dana Kuhn founded PSI in 1989. Dana has severe hemophilia A.**

**For more information or to apply for assistance from PSI, call 800-366-7741. The Delaware Valley Chapter provides financial support to Patient Services Incorporated for the good work they do on behalf of patients with bleeding disorders in the Delaware Valley area.**

*continued from page 1*

## running for the Pennsylvania House of Representatives!!

record profits in their health insurance divisions. Is it the rising cost of healthcare really...or is it rising profits? We need good legislation in Pennsylvania like HB 1705.... legislation that will protect patient access to factor therapies, home supportive services and appropriate medical care. Is that really asking too much?

Property tax reform is also on my radar screen and if elected to the 103rd legislative district, it will be a focus of my efforts. The primary election is May 16th and the general election is November 7th. As the Republican candidate, I am hopeful that I will make a difference if elected. Thanks to the dedication of my family and the advent of treatment for people with hemophilia like me, the possibilities of what I can do are endless.”

Post note: The 103rd legislative district covers the City of Harrisburg, Steelton, Highspire and Wards 1 and 3 of Swatara Township (Enhaut, Oberlin and Bressler). Anyone wishing to volunteer on election day at the polls or work in the campaign headquarters can do so by calling 717-704-0119 or you can visit Anthony's website <electtezak.com> and click on the “contract” link. Donations can also be made via secure PAYPAL on the site or by sending a check/money order to:

Committee To Elect Anthony J. Tezak, Jr.  
101 S. Front Street  
Steelton, PA 17113

*Have a question or issue for Anthony? Call him at 717-704-0119. You may just give him another idea for a POSSIBILITY!!!*

As you grow up, you may learn that even the one person that wasn't supposed to ever let you down, probably will. You may have your heart broken more than once. You will break hearts too, so remember how it felt when yours was broken. You'll fight with your best friend. You'll blame a new love for things an old one did. You'll cry because time is passing too fast and you'll eventually lose someone you love. So take too many pictures, laugh too much and love like you've never been hurt, because every sixty seconds you spend upset is a minute of happiness you'll never get back.

*Author Unknown*



## For Your Information

**The Hemophilia Foundation of Michigan (HFM) is the recipient of a grant from Baxter Healthcare Corporation to provide national distribution of AdvoyMobile hand-held computer devices to improve access to the AdvoyCare electronic bleeding and infusion data system.**

**AdvoyCare, developed by Baxter Healthcare Corporation, is an easy-to-use electronic therapy and data management tool that allows patients to record bleed and infusion details. It eliminates the need for paper records and offers convenient communication and data access and storage for patients and health-care providers.**

**AdvoyMobile provides access and logging capability for patients with or without Internet access using hand-held devices that can be synchronized via a personal computer or telephone line with the same secure database used by Advoy Care.**

**AdvoyMobile devices can be obtained free of charge by all patients nationwide, regardless of what product is used, as long as care for their bleeding disorder is provided at a treatment center that has registered and been trained on the use of Advoy. Order forms are available on the HFM website at [www.hfmich.org](http://www.hfmich.org) and can also be obtained from treatment center providers.**