

WHY DO WE NEED HB 1105

The Hemophilia Standards of Care Act IN PENNSYLVANIA?

If you have been reading prior issues of *The Winning Spirit* over the last three years, you already know the answer. For our newer readers, however, we thought it might be good to review why we need this legislation in Pennsylvania, legislation that will protect patient access to all factor replacement therapies, our hemophilia programs in Pennsylvania, and other needed services and options in pharmacy and home supportive services. It seems so simple and cost effective to the bleeding disorders' community, people affected by hemophilia and von Willebrand disease. If we maintain access to what we really need to stay healthy, then costs for our health care go down over the long haul and our productivity goes up. Theoretically, when we get what we need, we need less intervention for complications and problems. Make sense to you?

Let's review. All patients with bleeding disorders need access to a few basic things.

1. Access to medicine and factor replacement therapies (factor products).
2. Access to our designated hemophilia treatment centers in Pennsylvania. There are seven of them now, with the closing of The Reading Hospital Hemophilia Program this year.
3. Access to the coagulation laboratories connected to our seven hemophilia programs where we get our blood work done right, the first time.
4. Access to options in pharmacy and home supportive services, in case we need more than just our medicine or factor.

There's a fifth point of HB 1105, which has to do with screening women who may potentially have a manageable bleeding disorder, prior to a physician recommending a hysterectomy. We'll get to that later.

On the first four points of HB 1105

We surveyed the seven hemophilia programs in Pennsylvania and asked the program staff to outline some real examples of problems patients are having. Here are a few of the hundreds of examples submitted by the centers:

- A 26-year-old patient with severe VWD. Insurance will not pay for factor to use at home. Must go to the ER when he needs factor.
- A 53-year-old male with moderate hemophilia required surgery. 1. Insurance did not allow for full-service homecare. It was difficult to find a visiting nurse agency that would administer the patient's factor product which was supplied by an outside pharmacy. 2. In-home lab arrangements were made with the insurance approved lab. Coagulation samples were sent to the Florida lab. Results were not available for at least 48 hours. This caused a delay in making medication adjustments. 3. The specialty pharmacy supplied the Sharps container but would NOT make provisions for the proper disposal of the contaminated supplies.
- A 25-year-old patient with severe hemophilia. Insurance company requires that this patient use an outside lab for his blood work. Four times in the last year, the results came back "no evidence of a bleeding disorder." Patient has had hemophilia all of his life.
- A 27-year-old pregnant woman was tested by an outside laboratory, not connected to one of our state-recognized hemophilia programs, and she was given a diagnosis of possible factor VIII deficiency. Confirmatory testing at the hospital coagulation lab was negative, but because of the original results from the outside laboratory, it was necessary to re-test this patient and family members several times, and genetic analysis was also required to evaluate for hemophilia carrier status. Extremely costly. In addition, the baby boy was not circumcised because of the possibility of a bleeding disorder diagnosis. The baby was repeatedly tested. The erroneous original result from the outside laboratory unnecessarily complicated the proper evaluation and also INCREASED the costs for the insurance company.
- A 54-year-old female with moderate hemophilia on home infusion therapy suffered a hip bleed. Only a limited amount of the patient's prescribed factor VIII replacement product was authorized

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The Winning Spirit

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National Hemophilia Foundation DELAWARE VALLEY CHAPTER

222 S. Easton Road, Suite 122, Glenside, PA 19038
Phone (215) 885-6500
fax (215) 885-6074
e-mail: hemophilia@navpoint.com

Ann Rogers
Executive Director

Sue Stinger
Program Coordinator

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James R. Lindquist, *Vice President*
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A YOUTH LEADER'S STORY

Written by Seth Scicchitano

presented by Seth at the 2007 Delaware Valley Chapter Family Dinner

I am a 16-year-old boy who has severe hemophilia. Living with hemophilia has had its negative and positive effects on me and my family. Hemophilia has changed the way my family lives. Hemophilia has made my family realize the truly important things in life. We have always had to be careful in what we do but have also learned to enjoy life and be thankful for many things. We have been through a lot of bumps, bruises, cuts and trips to the hospital.

As a young child, my hemophilia held me back and kept me from doing a lot of things young children do. I can remember painful injuries and terrible bruises. But as I grew older, and the treatments I received improved, I can now live a pretty normal life as a teenager should live. Because of my bleeding disorder, I am and have always been especially careful whenever I engage in any kind of physical activity. I know what my limits are and how far I can go.

My knowledge of hemophilia has grown a lot. I know that when I have an injury I need a treatment right away and that helps to prevent further bleeding and a lot of severe damage to my joints. Hemophilia does not keep me away from partaking in what I love to do. I am currently involved on my high school's varsity basketball and baseball teams. I have never looked to take the easy way out. I use my bleeding disorder to motivate me to use all the talent I have and be thankful I can even be doing the things I am doing.

The way I view myself is that I can do anything anyone else can. I like to be a leader in whatever I am doing. I do not shy away from the sacrifice and time it takes to be a leader. In everything I do I try my best to be at the top and I always strive for excellence. I feel that I can do anything I set my mind to, whether my bleeding disorder affects the outcome or not. I hope to be an important person in whatever I do when I am older. I will always push myself to be the best I can be.

It is almost every boy's childhood dream to be a professional athlete, president or astronaut. As a child, my dream was to play professional basketball. I can remember my doctors telling me I was lucky to be playing basketball at all. They would tell me to try a sport with less contact, such as swimming. But I will never steer away from playing basketball. Though I now know that my once childhood dream of dunking in front of millions of fans is, well, a dream, I now dream of becoming a person of importance to someone, in my career, community, or family. I dream about raising a family and providing them with whatever they need and want. I have my goals set – graduate high school, attend college, receive a degree and have a wonderful family. These goals are more practical than being the next Michael Jordan, though I still have that dream.

I have always had the **best** doctors and medical staff. They have done so much for me and my family. When I would be hurt, they would always be there to take care of me, make me laugh, or, as a baby, hold me down while I received the needle for my treatment. They spent countless hours helping me, teaching my family about hemophilia and for that I am very grateful.

I plan to become involved in activities to share experiences that have helped me grow into a self-sufficient and positive person. I plan on joining the Delaware Valley Chapter to help call on our legislators and lobby for hemophilia issues.

I would encourage others with bleeding disorders not to let their disorder hold them back. You can still live a normal life. Do what you love and love what you do. Do not be ashamed with your disorder. Get involved with groups that deal with others with a bleeding disorder. Always strive to do the best you can.

The DVC is always looking for volunteers to help us in the Chapter office. We are located in Glenside, PA, just one block from the commuter train and on a major SEPTA bus route. If you ever have a few hours to help us out, please call the DVC!!!

Just a few hours of your time can make a big difference for us!! Students welcome!!

Chapter Happenings

We had two great Patient Information Nights in September.

September 7th: *The Future of Treatments & The Cure!*

Glenn Pierce, MD, PhD, a man with severe hemophilia and a noted authority in research investigating advancements in next generation products and gene therapy gave a great presentation to families and local medical providers. This update focused on new factor replacement therapies currently in development. Dr. Pierce reported on longer acting factor products, products that could potentially be effective for a few weeks, rather than a few hours. He talked about products with a "longer half life." He summarized current research on gene therapy and gave us great hope that hemophilia will be one of the first major diseases to have a sustainable cure. Thank you to Bayer HealthCare for providing a generous grant to the DVC that made this evening possible!!

September 14th: *Insurance and Advocacy!*

Rob Dash, Payer Relations Manager East, Baxter BioScience, provided a great evening of information on how insurance companies cover bleeding disorder products and services. Additional topics included a review of COBRA, HIPPA and how to deal with obstacles and problems you may encounter with your health coverage. Thanks, Rob, for a great presentation and our gratitude as well, to Baxter BioScience for providing a generous grant to the DVC that made this evening possible!!

The family of Marco Marozzi and the Delaware Valley Chapter invite you to join us for **Marco's Race to Cure Hemophilia**, a 5K race and 1 mile family fun walk on Saturday, **October 6, 2007** in Bangor Park, Bangor, PA!! This is a family affair, so bring the whole family and walk or run to help find a cure for hemophilia. Strollers are welcome in the 1 mile walk. To register, call Gina @ 908-237-1624 or email: gje1099@earthlink.net. Come on out to support this great event!!



The National Hemophilia Foundation will hold its **59th Annual Meeting in Orlando, Florida on November 1-3, 2007**. This year's theme is Join Us for the Journey! Sessions will focus on education, workshops, advocacy updates and social events. This conference is the largest yearly gathering of our entire community, including patients affected by bleeding disorders, their families, members of related industries, noted scientists and medical providers from around the United States and the world!! Mark your calendar now for the next two NHF Annual Meetings!!

NHF's 60th Annual Meeting
 November 13-15, 2008
 Denver, Colorado
NHF's 61st Annual Meeting
 November 19-21, 2009
 San Francisco, California

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- October**
- 6 Bangor 5K Run!
- 19 Joint Disease & Surgery Info Night!
- 26 DVC Fall Gala!
- November**
- 1-3 NHF Annual Meeting in Orlando!
- December**
- 8 Holiday Party!
- March**
- 29 Bowling for Fun!!
- April**
- 5 Fashion Show & Luncheon!
- 25-27 VWD Retreat Weekend!
- May**
- 6 Family Dinner!
- 10 Rowe Run!

An Evening at the **Lucky Hearts Casino**, our fall gala event this year, will take place on Friday, **October 26, 2007** at the Hilton Hotel on City Avenue, Philadelphia! What a great evening of food, fun, gaming, dancing and so much more!! Proceeds from this event support local patients and programs right here in the Delaware Valley!! For more information and tickets, call the DVC office @ 215-885-6500!! We'll see you there!!



The following article appeared in the fall 2007 edition of *Quest*, a publication of Coram Hemophilia Services. The article is reprinted here in its entirety with permission.

We thank Coram for allowing us to share this wonderful tribute to our dear friend, Art Stinger.

Art Stinger: The Dad of Hemophilia

"There's a saying that goes 'the job of a parent is to give your children roots, then give them wings.' Sue and I agreed with that. It wasn't always easy with Matt, but that was our goal, to get him independent. Now his future is bright and there are no boundaries in his world. So our suggestion to other parents is to give your children love and roots, but don't forget those wings!" — Art Stinger

When Art Stinger married his childhood sweetheart 33 years ago, he had no idea that he would one day leave a legacy as "The Dad of Hemophilia". Hemophilia? There was no history of hemophilia in his or his wife Sue's families, and their first son, Patrick, was fine. Then Matt was born three years after Patrick, and he was diagnosed with severe hemophilia A. That changed everything for the Stinger family. Over the years, Art's approach to the challenge of hemophilia has changed the lives of hundreds.

"At that time there wasn't an Internet, so we went and looked up definitions, and talked to people," Sue recalls. "We took charge because we were adamant that we were not going to treat Matt different from Patrick."

Art and Sue immediately got involved in the Delaware Valley Chapter of the National Hemophilia Foundation, which is one of the oldest in the country. They also found support at Children's Hospital of Philadelphia. Art sat on the board of the Delaware Valley Chapter close to six years after Matt was born; Sue works there today.

"Art always said it was the team — the community — that raised Matt," Sue says. "He was right there with me from day one. A lot of times the fathers leave the infusing to the mothers. But Art said Matt wasn't my child, he was our child. We both infused Matt, and when we had to go to the ER, Art would leave work and come up from Philadelphia. Even Patrick came. We were a family."

Patrick was the older brother, the one who kept an eye on Matt when they were at the pool with friends.

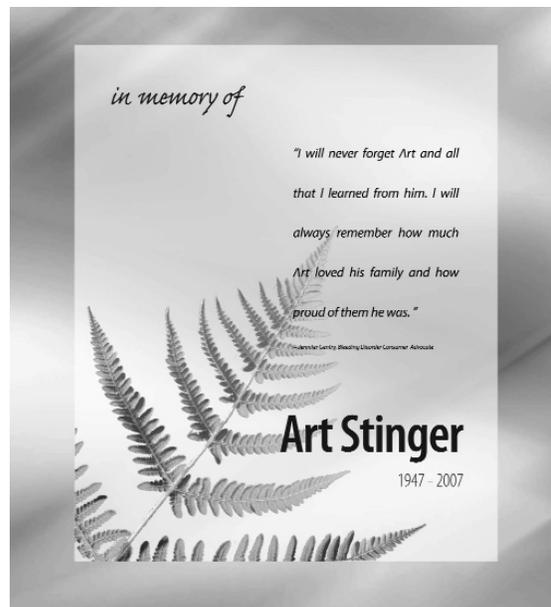
"Just the reality of it — going to the ER every week — that wasn't something my other friends were doing," Patrick shares. "But the thing is, the way my father treated it, and thus the way I treated it, was that the hemophilia wasn't a big issue. We just did what we had to do."

Art kept the family's approach to Matt's hemophilia pragmatic and grounded. He told Matt that he could go sleep over at his friend's house when he learned how to infuse himself.

"I picked it up pretty quickly when he told me that," Matt says. "And because he taught me to manage it, I was able to go on vacations when I got a little older."

"The care and compassion my father gave me is the reason I'm in the nursing field now," adds Matt, who comes into contact with hemophilia families in his job as an ER and trauma nurse at Children's Hospital of Philadelphia. "He was with me at every single appointment I ever had, every ER visit I ever had. I had an orthopedic appointment six months ago, and he had chemo the same day, and he came down with me. His healing hands made everything feel better and not that big a deal. That's what I want to pass along to my children."

Patrick, an architect in Philadelphia, also bears the stamp of his father's influence. Without saying as much out loud, Art knew that Patrick needed one-on-one Dad time sometimes. When Patrick acted out, Art would take him to Philadelphia on a



weekend afternoon. They would park at the Philadelphia Electric Company (PECO) where Art worked and walk.

"We would walk from one river to the other," Patrick says. "It was a long walk. We would just talk, just hang out. A lot of lessons were taught along the way. I have no doubt that that's what put the bug of architecture in me, his love of the city and sharing that with me."

Art worked at PECO as a senior systems analyst for 29 years. When they downsized, he went into business with his brother-in-law; four years ago he became an Advocate for Coram. Advocacy became his passion. Just as his zest for life and generosity of spirit impacted his sons' lives, so did they impact the entire hemophilia community. He became deeply immersed in the Hemophilia Federation of America's Dads In Action program, urging other fathers to get involved.

"Art was an active member and strong advocate for The Delaware Valley Chapter of NHF, as well," says Ann Rogers, the chapter's Executive Director. "I first met Art when his family was very young. From that very moment, there wasn't anything he wouldn't do to help the chapter or other affected families. He was a rich example of action and compassion. He held many leadership positions on the NHF committees and sat on its board twice. He volunteered for anything and everything. His passion for helping others was demonstrated at every level of his life. He was courageous and strong and not about himself. I don't know if I have ever met a person so committed to making a difference in the lives of others. We already miss Art. We are all better people because he touched our lives. He leaves a strong legacy and will never be forgotten."

Art also developed a PowerPoint presentation that chronicled Matt's walk with hemophilia, the progress in products over the years, and Matt's promising future today.

"Art absolutely loved being an Advocate," Sue remembers. "He loved it! When he showed his presentation to manufacturers, he'd tell them, 'You guys make the medicine, but you don't know what the families go through.' He would talk to

young families and assure them their sons would be alright. He had patients he would call in the evening just to see how things were going, ask how their child was doing in school. Art even knew the names of their family dogs. He was everybody's friend."

Art fought a brave battle against cancer. Sue thought they might win it, because he was so strong and determined. The last visit to the hospital took her by surprise.

"I thought he probably had an infection and maybe we'd be in the hospital a couple of days," she says. "On Thursday he was laughing and joking and gave Matt a big hug. But by Saturday we had the whole family there, his mother and sisters. The boys and I always said that if it happened, we wanted it to be quick."

More than 400 people crowded into the facility for the funeral service. Sue and the boys stood for two hours greeting people whose lives had been touched by Art Stinger. They received more than 200 sympathy cards.

"I was amazed by the number of people at the service," says Patrick. "I grew up with my brother having hemophilia, but I did not grow up in the hemophilia community. My father talked about it briefly, but it was never the focus of our relationship. Ours was something different. It was astounding for me to see the number of people that he touched and helped, and to realize he never once bragged about that."

*Dear Art,
We wish you God speed on your journey. Mind your manners and don't forget to wash behind your ears. You are still our little boy. At our age it is inevitable that we will be joining you sooner rather than later and will be able to check to see that you are behaving. You would moan and groan every time Dad gave his famous toast. Well, here it is again. "Here's to it to do it and to do it again. If you can't get to do it you may never get to it to do it again." We love you and miss.
Mom and Dad
(Harry and Flo)
— Florence Stinger*

*What a wonderful man to have as a special friend. Art touched my life and my family's lives in many ways. He taught me a lot about our job, one he was very proud to have. He was a great advocate because of his knowledge, but mostly because he was a very caring person. I still want to pick up the phone and call him just to talk. I will never forget Art and all that I learned from him. I will always remember how much he loved his family and how proud of them he was. We were all blessed to be part of Art's wonderful life.
— Jennifer Gentry, Bleeding Disorder Consumer Advocate*

Art was a shining example of what the word advocate truly meant. He was "the Dad" of hemophilia, the dad that could get other dads to understand how to "step up" for their sons and daughters, wives and extended families. When you were around him you could not help but share his enthusiasm. I have worked with many great and passionate advocates, but Art was a standout. He was bigger than life when it came to his passion. He was simply the father of a boy with hemophilia who left a very big footprint in the hemophilia community and here at Coram. He lives on in many hearts.

— Nancye Buelow, National Director of Consumer Advocacy and Program Development, Coram

"He was my best friend and role model," Matt says. "I miss him so much, but I'm going to carry on every single thing he has taught me. I'm going to do my best to be like he was. He used to say, 'I don't want you to be like me. I want you to be like you.' But in reality, there's nobody else I'd rather be like."

"In the guest book, one of the Bayer drug reps put in a poem, and it is Art to a T," Sue adds. "He fought the battle, and I think the good Lord said, 'It's time to come home.'"

God Saw You Were Getting Tired

*God saw you were getting tired
And a cure was not to be
So he put his arms around you
And whispered come to me
With tearful eyes we watched you
And saw you pass away
Although we loved you dearly
We could not make you stay
A golden heart stopped beating
Hard working hands at rest
God broke our hearts to prove to us
He only takes the best.*



Art Stinger, 1947 - 2007

*Art,
Your contributions to our lives were so very many. You were such a dedicated person. You were funny, sympathetic, generous of spirit, a dedicated father and husband and just one of the best people I have ever met. You were such an integral part of the Delaware Valley Chapter. You were truly a member of our family and touched other families in very real ways. You provided comfort and hope when we couldn't find it. You helped give us direction and purpose and above all, you did it with joy and compassion. We miss you daily and know that you can see we have our arms wrapped tightly around Sue and Matt and Pat.*

— Ann Rogers, Executive Director, DVC of the NHF

Art was a wonderful man. He was a great mentor, friend, husband and dad and meant a lot to my family. He changed my life by helping me get this job and leading my husband to a Dad's in Action program. The program changed the way Robert looked at being the father of a child with hemophilia and the importance of that role. Art was the most unselfish person I have ever met. He loved his family so much and spoke of them often. He was a great example for all of us to follow.

— Kelly Champagne, Bleeding Disorder Consumer Advocate

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WHY DO WE NEED HB 1105 *The Hemophilia Standards of Care Act* IN PENNSYLVANIA?

by the insurance company. Continued treatment with the medication required a progress report every 48 hours, before further authorization of additional medication shipments would be given. Insurance company would not allow adequate supply of factor at home. This interfered with implementing standards of care practice for treating a bleeding episode in a patient with hemophilia.

- A 17-year-old patient with hemophilia. Insurance will not allow blood work to be done in the coagulation lab at the hospital. The results from the outside laboratory are often inaccurate, and there is an unreasonable delay in getting test results.
- A 30-year-old patient with severe hemophilia and a high titer inhibitor needs an adequate supply of factor at home to be safe. Insurance will not allow him to have more than 5 doses at one time shipped to his home. His co-pay must be paid for each shipment of 5 doses, and there are instances when he has NO factor at home.
- A 23-year-old patient with severe hemophilia. His new insurance company rejected his claim for the payment of factor. Reason stated at the bottom of the denial and signed by the insurance company medical director: "authorization is denied because factor VIII is not indicated for the treatment of hemophilia."
- A 33-year-old male with hemophilia who can self infuse at home. Insurance company denied factor for use at home. Reason for denial: "Patient must be infused by a home infusion company or in a facility. Factor products should not be self-administered."
- A 42-year-old male with severe hemophilia. Insurance only covers the cost for factor if he is at a facility. Factor at home must be paid for out-of-pocket.
- A 55-year-old patient with hemophilia. Insurance will not pay for factor to be administered in his home. He must go to the ER or to an out-patient treatment area when he needs factor. He is losing his job because of too much time lost from work.

These are real examples of why we must obtain passage of the Hemophilia Standards of Care Act!

- An 11-year-old patient with hemophilia. Insurance will not allow patient to receive a certain brand of factor prescribed by his physician, even after the hemophilia physician wrote a letter of medical necessity. The insurance company has a "preferred product for the treatment of hemophilia."
- A 48-year-old patient with severe hemophilia. His insurance required him to switch to a mail order pharmacy chosen by the insurance company. The pharmacy does not always ship the correct supplies and in the amount prescribed by the hemophilia physician.
- Several patients at our treatment center have had to change their home care pharmacies and are now required to use the pharmacy owned or designated by the insurance company. These patients also cannot have laboratory studies or receive treatment at one of our state-recognized hemophilia programs. We have been unsuccessful at getting an out-of-network referral. Denied each time.
- A 43-year-old patient with severe hemophilia was switched by his insurance company to the pharmacy owned or designated by his insurance company. He treats on demand and needed factor urgently because of a significant bleed. It took the insurance company pharmacy one week to deliver factor, despite many phone calls. Before delivery, this patient ended up in the ER and was then admitted. All of this could have been avoided had he received factor promptly!
- A 15-year-old female complained of bruising and heavy menstrual periods. Her brother has severe factor VIII deficiency. Her insurance would not allow proper coagulation studies done at the hospital. Lab studies were referred to a large pharmacy not connected to a state-designated hemophilia program. She was erroneously diagnosed as a symptomatic carrier for four years. Activities were restricted, education was provided, and then further studies were completed by the hospital coagulation lab. On two samples, she was found to have perfectly normal factor VIII levels. She is

not at risk for bleeding, she is not a symptomatic carrier, and the anxiety and confusion she and her family experienced could have been avoided by allowing the use of a specialized coagulation lab connected with a local hemophilia program.

- Ongoing laboratory issues for our hemophilia program: we have blatant and repeatedly incorrect coagulation test results from outside laboratories. If followed, this could have life-threatening consequences for our patients.
- We also have at least one referral a month for a patient who has a potential bleeding or clotting disorder diagnosis, but it is a laboratory issue and not a patient issue. We are having trouble with four insurance companies at this time regarding the issue of obtaining approval to use our own coagulation laboratory to perform necessary blood tests.

These are real examples of why we must obtain passage of the Hemophilia Standards of Care Act!

On the fifth point of HB 1105

According to the National Hemophilia Foundation (NHF) and The Centers for Disease Control and Prevention (CDC), more than 30,000 unnecessary hysterectomies are performed in the United States each year due to undiagnosed bleeding disorders in women. Women should be screened for a possible bleeding disorder prior to a physician authorizing a hysterectomy or other invasive procedure when a woman presents with menorrhagia (excessive menstrual bleeding). Bleeding disorders require medical management, not potentially unnecessary surgery. Women with bleeding disorders need unrestricted access to the comprehensive care model provided by Pennsylvania's state-recognized hemophilia programs.

In December 2001, The American College of Obstetricians and Gynecologists issued recommendation 263, "von Willebrand disease in Gynecologic Practice." This recommendation calls upon OB/GYNs to refer a female patient for proper screening for bleeding disorders such as VWD prior to performing a hysterectomy, when the woman has symptoms of excessive bleeding.

PLEASE E-MAIL YOUR INSURANCE STORIES TO US.

WE WANT OUR VOICES TO BE HEARD!!!

hemophilia@navpoint.com

Legislative Update

PENNSYLVANIA HEMOPHILIA PROGRAM DIRECTORS SUPPORT HB 1105 *The Hemophilia Standards of Care Act*

The following letter was sent to Representative Anthony DeLuca, Chairman, PA House Insurance Committee. A great big "thank you" to Dr. Barbara Konkle (Penn Comprehensive Hemophilia Program) for coordinating this terrific letter!!! We very much appreciate this strong endorsement from every hemophilia medical director!

THANK YOU!!!!!!

Dear Chairman DeLuca:

We the Directors of the Hemophilia Treatment Centers in the Commonwealth of Pennsylvania are writing to indicate our strong support of The Hemophilia Standards of Care Act, HB 1105, currently under consideration by the House Insurance Committee. We confront the issues addressed in this bill on a daily basis and recognize the impact these issues have on our patients. We support the position of the National Hemophilia Foundation, whose letter you have received. As physicians who care for patients with hemophilia, we look to the Medical and Scientific Advisory Council (MASAC) of NHF for the medical standards of care for our patients with bleeding disorders. Two Pennsylvania Hemophilia Center directors, Dr. Margaret Ragni from the Hemophilia Treatment Center of Western Pennsylvania in Pittsburgh and Dr. Catherine Manno from The Children's Hospital of Philadelphia serve on this council, attesting to the excellence in hemophilia care available in the Commonwealth.

We would like to briefly point out the critical issues affecting our patients. They have spontaneous bleeding, at times life threatening. Although we support

cost-effective medical care, the use of mail order pharmacies and large commercial laboratories does not work for patients with hemophilia and other congenital bleeding disorders. Because bleeding is often unpredictable and serious, quick access to factor therapies is critical. Support of home therapy, which our programs provide, is immediate and cost-saving. If patients cannot get the medication they need on a timely basis nor have the support they need for home infusion, costly hospitalizations and poor outcomes, including death, may occur.

Further, although large commercial laboratories perform many tests in an excellent manner, specialized coagulation testing requires sample handling and techniques that large commercial laboratories cannot consistently provide. Such an approach can result in delays in diagnosis, incorrect diagnoses and treatments and costly repeat testing. These difficulties jeopardize patient safety and interfere with timely treatment, unacceptable options for bleeding patients.

As the examples above illustrate, the current approach by many insurers does not meet the needs of this population and often results in additional costs in their care. As Hemophilia Center program directors, we

strongly urge the passage of HB 1105. It will improve the quality and lifespan of residents of Pennsylvania with bleeding disorders.

On behalf of the HTC Directors listed below, who mightily support HB 1105, I have signed this letter and encourage you to contact any of us for more information.

Sincerely yours,

Barbara A. Konkle, MD *Penn Comprehensive Hemophilia Program, Philadelphia*

M. Elaine Eyster, MD *Hemophilia Center of Central Pennsylvania, Hershey*

Catherine S. Manno, MD *The Children's Hospital Hemophilia Program, Philadelphia*

Margaret Ragni, MD *Hemophilia Center of Western Pennsylvania, Pittsburgh*

Jamie E. Siegel, MD *Cardeza Foundation Hemophilia Center, Philadelphia*

Lloyd E. Barron II, MD *Lehigh Valley Hospital Hemophilia Program, Allentown*

Frank E. Shafer, MD *St. Christopher's Hospital for Children Hemophilia Program, Philadelphia*

SANDOR SHAPIRO, MD *His Passions: Medicine and Music*

The following excerpt was taken from an article by Sally A. Downey, Staff Writer The Philadelphia Inquirer, August 19, 2007

Dr. Shapiro of Haverford, a research professor at the [Thomas Jefferson] University who specialized in the study of blood and an accomplished violinist, died July 21, five days before his 74th birthday. He suffered a heart attack while biking in Acadia National Park in Maine, where he was vacationing.

For almost 40 years, Dr. Shapiro served on the staff of Jefferson's Cardeza Foundation for hematologic Research and was director from 1985 to 2001. The Foundation is devoted to the study and diagnosis of blood diseases and blood-related cancers, such as leukemia and to the care of patients with platelet, bleeding, clotting and bone-marrow problems.

In 1973, Dr. Shapiro established the Foundation's Hemophilia Center [The Cardeza Foundation Hemophilia Center]. The Center developed innovative treatments for patients with hemophilia, including home infusion therapy that significantly improved their care.

Patients with hemophilia must take clotting medicines [some] made from plasma to prevent uncontrolled

bleeding. In the 1980s, many patients with hemophilia were sickened by medicines made from blood contaminated by the AIDS virus. Safer but more expensive medicines were introduced and Dr. Shapiro advocated additional government funding for the medicines and for hemophilia centers.

"These centers are vitally important," he told a newspaper reporter in 1988. "We have seen the tripling of services we provide because of AIDS."

Dr. Shapiro received research funding from the National Institutes of Health, served on the editorial boards of several professional journals and was a visiting scientist at prominent research institutes in Israel, Britain and France.

"He was an internationally-known leader in the field of bleeding and blood clotting," said Paul Bray, director of the Cardeza Foundation. He said Dr. Shapiro had invented a test that is used all over the world to diagnose a condition that puts subjects at high risk for clotting disorders. "His patients loved him," Bray said.

A native of New York, Dr. Shapiro earned a bachelor's degree and a medical degree and completed postgraduate training at Harvard University. He then was a National Institutes of Health Fellow at the Massachusetts Institute of Technology before joining the Jefferson faculty in 1964.

His lifelong passions were science and music, said his son, Alan. He was concertmaster of his high school and college orchestras and later performed in recitals as a soloist and in chamber groups. This month, he was scheduled to give a concert in Burlington, VT, where he had a summer home. He served on the board of the Philadelphia Chamber Music Society. He was planning to devote more time to music when he retired from Jefferson next year, his son said.

Post Script
Dr. Shapiro was a dear friend of the hemophilia community and the Delaware Valley Chapter. "Sandy" was a staunch supporter of our mission to support patients and programs over the years and was an active member of our Chapter. His contributions to science and treatment were immense. He was a wonderful physician, research scientist and man. His memory lives on in the hearts of all of us who knew him so well. Farewell, dear friend.

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



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 three 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!!

Birdsboro Branch
Tina & Jeff McMullen
610-582-1731

Camp Hill Branch
Shannon & Jay Penica
717-975-2897

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

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

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.