

Chapter Events

2 Chapter News & Notes
3 Chapter Happenings
3 Chapter Calendar
3 We Say Goodbye...

7 Legislative Update

Hepatitis C Advocacy:
Taking the Fight to the Hill
and Beyond By Paul Haas

8 Viewpoint

A Dad's Perspective

4 On the Health Front

Healthy Skepticism By Bruce
Goldfarb

Step Therapy for the Treatment of Hemophilia A...

A Step Forward?

A Step Backward?

Okay, here we go.... Webster's Dictionary defines step therapy as "the practice of beginning drug therapy for a medical condition with the most cost-effective and safest drug therapy and progressing to other more costly or risky therapy, only if necessary. The aims are to control costs and minimize risks. Also called step protocol."

An insurance company in Pennsylvania has proposed step therapy for the treatment of patients with hemophilia A on Medicaid. Following is their proposal. See what you think.

Step 1: Take Kogenate FS...and if that product fails to work, then

Step 2: Take Refacto,...and if that product fails to work, then

Step 3: Take any of the following: Advate, Helixate FS or Recombinate

Hmmm..... first of all, each of the above factor products has demonstrated efficacy (effectiveness) and is licensed for the treatment of hemophilia A in the United States. All have a demonstrated record of safety, as well.

As a result of the HIV epidemic many years ago, pharmaceutical companies invested in the research and development of recombinant factor products (not plasma-derived). Today, in addition to plasma-derived factor replacement therapies, we have a few choices in the first and second generation of products and one third generation recombinant factor product. Maybe you are wondering why the only "third generation" factor product is down on that step three, understanding that it is the only product made with no human or animal albumin. Go figure.

continued on page 6



Winter 2005

Volume 12

Number 1



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

Board of Directors

Keith W. Moore, *President*

James R. Lindquist, *Vice President*

Andrew B. Serrill, *Treasurer*

Cheryl A. Littig, *Secretary*

Board Members

Alicia Blackshear

Diane Brown

Laura Carlino

Clifford B. Cohn, Esq.

Kathy DiMichele

Patricia Felthaus

Adam Gusdorff, Esquire

Elaine Jones

Carl Lampe, Jr.

Steven Lampe

George Levy

Robert Romano

Kathleen Sell

Pauline Tache

The Winning Spirit is published quarterly by the National Hemophilia Foundation, Delaware Valley Chapter. The contents of this newsletter may be reproduced freely, but please attribute the source. The material in this newsletter is provided for your general information only. The Delaware Valley Chapter does not give medical advice or engage in the practice of medicine. DVC under no circumstances recommends particular treatments for specific individuals, and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment. Graphic Artist: www.chaley.com

From the Executive Director

As we waved goodbye to 2004, we said farewell to an old friend, *Hemalog Magazine*. The Delaware Valley Chapter has been distributing this wonderful magazine for many, many years and our readers just loved it. The publication was supported by a grant from ZLB Behring for thirteen years and the grant is no longer available. We will miss it.

With this issue, we are enclosing another publication (just this one time), *Parent Empowerment Newsletter*, produced by LA Kelley Communications. We thought the November 2004 issue was very informative about issues we are facing right now, particularly in Pennsylvania and we want to thank Laureen Kelley for sending us 2,500 copies!

NHF Board Names New CEO

The National Hemophilia Foundation (NHF) Board of Directors has announced the selection of Alan Kinniburgh, PhD, as the foundation's new CEO. Current plans are for the appointment to take effect on January 17, 2005. Kinniburgh comes to NHF after several years of service at the Leukemia and Lymphoma Society, where he was the senior vice president of research. The decision to appoint him to the NHF position was the result of a nationwide search conducted over many months. The search was led by a diverse committee of volunteers working closely with professionals from Korn-Ferry, an international executive recruitment search firm.

"I am extremely pleased that Alan Kinniburgh has agreed to become our CEO," said NHF President Paul Haas. "The search committee looked at a group of very well-qualified candidates and I believe they have done an excellent job in identifying this outstanding leader. Alan brings significant scientific, organizational and fundraising experience to the position and I believe his leadership will help NHF and this community move to a higher level."

In his role at the Leukemia and Lymphoma Society, Kinniburgh oversaw a research program with a budget of more than \$45 million annually, including a broad range of grants to nationally known scientists and prestigious institutions around the country. He was also a frequent spokesperson for the organization and a commentator for the media on blood-related cancers. Prior to working at Leukemia and Lymphoma, he held a variety of other significant organizational, scientific and academic positions, including serving as the founding director of the Roswell Park Cancer Institute's Laboratory of Molecular Diagnostics.

As CEO, Alan will oversee all foundation staff and operations, with the overall responsibility of fulfilling NHF's mission. "I'm extremely excited to have this opportunity to work with the National Hemophilia Foundation and help make a difference for people affected by bleeding disorders," Kinniburgh said. "This is a very passionate, dedicated and hard-working community with a proud history. It is my hope that through our collective efforts we will continue to build our advocacy, research and education programs so that we may improve the lives of patients and their families."

John R. McCabe was a DVC member, an educator and a man with hemophilia. As a teacher, John was encouraged by watching young people strive to achieve their hopes and dreams and he did much during his lifetime to help young students accomplish their goals. After John's death, his son, Keith, established an annual music event, in honor of his father to support the Chapter's Scholarship Fund. "In My Father's Name," has contributed to the DVC's Scholarship Fund for the last two years...and Keith has plans to continue his important efforts. Last year, the Delaware Valley Chapter was able to award more than 80 scholarships to deserving students with bleeding disorders in southeastern PA and Delaware. If you would like to contribute to this important fund, please call the DVC office (215-885-6500).

We Gratefully Acknowledge...the pledge of support from the following manufacturers for 2005.

American Red Cross
Monarc-M

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

Bayer Corporation
Kogenate FS
Koate-DVI
Konyne-80

Grifols
Alpha Nine SD
Alphanate
SD/HT
Profiline SD

Wyeth
BeneFixTM
ReFacto

Nabi
Autoplex T
WinRho

Novo Nordisk
NovoSevenTM

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

16 Fashion Show!
New Location!

March

Hemophilia
Awareness Month
9-11 NHF
Washington Days

May

17 Family Dinner!
New Location!



We were all dressed up and lookin' good for "Oktoberfest" held at the Adam's Mark Hotel on Friday, October 15, 2004, sponsored by Wyeth! What a great night of food, music, gaming events and a terrific



live auction with our dear friend, Frank McCraghan and company! Diane Brown (DVC board member) provided the live entertainment and we danced the night away! Our thanks to Bob Romano, Megan McEnroe (Wyeth) and their wonderful committee for planning this great evening for us! The funds raised at this event will help the DVC provide needed support to our members and programs throughout the year. Don't miss Oktoberfest 2005 next fall. It just gets better and better!



DCV delegation in Dallas.

The 56th NHF Annual Meeting was held on November 4-6, 2004 in Dallas Texas. This is the only meeting in the United States completely focused on bleeding disorders and two DVC leaders were honored at the Awards Luncheon... Kathy Sell (DVC board member) was acknowledged by the NHF President for her outstanding volunteer service to our Chapter and her leadership on several key committees. We want to thank Kathy for all she does for us and congratulate

her for an honor well deserved!

William "Pete" Johnson was presented with the 2004 NHF award for "Meritorious Service." Pete has been an outstanding local and national leader for...well...most of his life! His mom was a key figure in the early days of the DVC and Pete has continued his family's tradition of helping people with bleeding disorders in many, many ways! Thanks, Pete, for being such an important person in our lives!

On Saturday, December 11, 2004 local families attended the Annual Family Holiday Party at Jefferson Alumni Hall in Philadelphia. Santa was there, with presents for everyone. We had a great lunch and a chance to reconnect with old friends and meet new families, as well. Many thanks to Pete, Pat and Patti Johnson and their great committee for planning absolutely everything and for making sure we all had the best time ever! We'll see you next year!!



Spring is just around the corner and we can't wait till Saturday, April 16th and our Annual Fashion Show and Luncheon! The famous Ladies' Committee had to move this event to a NEW LOCATION (The Jefferson House closed)! This year, we will see all of our dear friends and supporters at the DREXELBROOK IN DREXEL HILL, PA for a wonderful day of fashions and fun! You will have a chance to meet that famous anchor Rick Williams from WPVI-TV, Channel 6!! Rick will be our honored guest at the luncheon. Oh...by the way...please support the annual raffle that you should have received in the mail sometime in January. We really need your support each year!

Plan to be with us on Tuesday, May 17, 2005 for the Annual Family Dinner AT A NEW LOCATION...THE CITY LINE HILTON HOTEL!! Our old friend, the Adam's Mark Hotel has closed so we have moved this event just a few blocks away to a beautiful location. This year, we have a new twist to our family night... that will be "over the top!" Mark your calendars now and plan to be with us!

We Say Goodbye....

to a wonderful, wonderful nurse, Margaret Wagner, RN. Margaret has been the nurse coordinator at the Christiana Hospital Hemophilia Program in Newark, Delaware for a long time and has been such a help and support to Dr. Philip Blatt, MD, medical director of the program. Margaret has retired after many years of dedicated service to families in the greater Delaware area. Margaret and Dr. Blatt have worked together as the "Christiana team" helping



patients with bleeding disorders in every imaginable way. We will miss you, Margaret, and we can't thank you enough for everything you have done for your families! Happy retirement!!

As we say goodbye to Margaret, we welcome a new and very experienced nurse to the hemophilia program at Christiana.

Deb Cebenka, RN, MSN is the new nurse coordinator. When we interviewed Deb, she said, "I don't have a resume...I've only had one employer...Christiana Care Health Services for 30 years!" Wow!! Deb has a lot of experience in the management of chronic illness. She was the manager for patient education at Christiana and the coordinator for the Adult Muscular Dystrophy Program. "I understand when a patient speaks about 'my nurse, my program'...there is a very close relationship between staff and patient, when the relationship is built over many years. Muscular dystrophy and hemophilia impact the whole family. In fact.... the patient defines the family. Our job as medical providers is to provide current, correct information so that patients can make informed decisions." Welcome, Deb...you have big shoes to fill!!

P.S. All contact information remains the same for the Christiana Hemophilia Program (302-733-3542).



Healthy Skepticism *By Bruce Goldfarb*

Like many parents of a child with hemophilia, Ziva Mann watches her 2 and a half year old son's health closely. Diagnosed with severe hemophilia A, the toddler receives regular medical attention and prophylactic Factor VIII to keep the disorder in check.

But when her child has symptoms of croup or some other minor illness, Mann is more likely to first reach for the kitchen spice rack to make a tea imbued with healthful properties.

"My goal is to avoid medication when it isn't necessary," says Mann, a graduate student at Harvard who resides in the Boston area with her husband. Using traditional herbal remedies "give us a sense of control, that we can handle the little things," she says.

The fastest-growing type of healthcare in the US isn't routinely offered at most hospitals or doctors' offices. Americans, particularly baby boomers and those younger, are wading outside of the medical mainstream in record numbers.

Interest is increasing in complementary and alternative medicine (CAM), a general term for a variety of healing systems and remedies that fall outside of conventional medical care. CAM runs the gamut from acupuncture to massage, from herbal remedies to therapeutic touch.

Although often used interchangeably, alternative and complementary don't mean the same thing. A complementary remedy is used in addition to conventional medical care, such as a person who does relaxation therapy along with medication for high blood pressure. Alternative medicine is a different school of thought and practice that is used instead of traditional medicine, for example homeopathy or naturopathy.

By definition, CAM remedies are unproven. However, clinical studies are beginning to show benefits from interventions that were once dismissed out of hand. For many CAM approaches, the scientific jury is still out. Some may be proven safe and effective, while others are not.

Health Trends

Depending on which definition is used, between 10% and 43% of Americans report using some kind of CAM remedy.

According to a landmark study by Harvard researcher David Eisenberg, MD, Americans make more visits to CAM practitioners than they do to primary care physicians and spend more out-of-pocket for CAM remedies than for conventional medical care.

CAM has become big business. Growing numbers of medical doctors, nurses and hospitals have embraced integrative medicine, combining elements of conventional care with complementary and alternative treatments. More health plans cover CAM services, such as acupuncture and chiropractic.

Folk medicine has a long history in the US, but in recent years some forms of CAM have gained a degree of respectability. In 1991, the National Institutes of Health (NIH) formed the Office of Alternative Medicine, now the National Center for Complementary and Alternative Medicine

(NCCAM), to foster research and disseminate authoritative information to the public and health professionals.

Smart Health Shopping

American consumers take their purchases very seriously. When in the market for a digital camera or personal computer, people will seek recommendations from friends, read comparison charts and user reviews in consumer magazines and spend a lot of time at the store examining the features and prices of various models.

This is smart shopping. You want value for spending your hard-earned money. You want to be sure it's the right product for your needs, that the features work for you as promised and that it's a good deal.

Yet when it comes to the most important decision, our health and well-being, reason often goes right out the window. Few patients actually shop around for a doctor or know what questions to ask to learn about experience and qualifications. People who regard their body as a temple, avoiding cigarettes and red meat, will gulp down over-priced dietary supplements of unknown purity and dubious value.

Particularly vulnerable to the baseless claims of CAM remedies, experts say, are those with chronic or progressive conditions, such as cancer, cardiovascular disease, acquired immune deficiency syndrome (AIDS) or chronic pain.

Whether considering the claims of an over-the-counter cold remedy, care from a New Age therapist or cardiac bypass surgery, it's critically important to make decisions based on information that is accurate, reliable and relevant.

Here are some of the most popular forms of CAM:

Chiropractic

Chiropractic is one of the most popular alternative health care choices in the US. More than 31 million Americans, or about 11% of the population, seek chiropractic care annually. Chiropractic is now the fastest-growing licensed health-care profession in the nation.

Invented by magnetic healer David Palmer in 1895, chiropractic centers around the function of the nervous system and usually involves "adjustments," manipulations that cause an audible popping. "Straight" chiropractors limit their practice mainly to spinal adjustment, while "mixers" often include homeopathy, acupuncture, naturopathy or some other CAM approaches.

Clinical research suggest that chiropractic may be useful for some musculoskeletal problems, particularly back and neck pain, as well as headaches and certain other conditions. But many chiropractors make unsupported claims, suggesting that adjustment is effective for muscular dystrophy, asthma, diabetes, epilepsy and other conditions ordinarily under medical care.

When shopping for a chiropractor, it is important to talk with the provider to make sure his or her philosophy is in synch with your own.



Acupuncture

Acupuncture is a form of traditional Chinese medicine (TCM), a philosophy and art that includes herbal remedies, dietary modifications, physical exercises, meditation and massage. Originating in China more than 2,000 years ago, acupuncture is one of the oldest and most commonly used therapies in the world.

Today, Americans have more than 5 million acupuncture treatments every year. According to a 2002 survey, nearly 1 in 10 Americans, about 20 million people, have received acupuncture treatment.

Acupuncture is based on the belief that disease is the result of an imbalance of energy, or Qi, that runs along lines of meridians in the body. The insertion and manipulation of slender metal needles into specific points along the meridians redirects Qi and restores energy balance to the body.

People with hemophilia should avoid treatment with acupuncture needles. Variations of acupuncture include acupressure, a method of healing by the application of pressure and massage at points along the meridians and laser acupuncture, a type of light therapy in which a laser beam is directed at acupuncture points on the skin.

Although the study of acupuncture has produced an uneven track record of research, some clinical trials suggest therapeutic benefits for pain control, substance abuse and other conditions.

When performed by a competent and well-trained person, the risks of acupuncture are low. Considering the large number of acupuncture treatment performed every year, reports of serious complications are rare.

Naturopathy and Naturopathic Medicine

Naturopathy is an umbrella term, encompassing a wide variety of interventions, including herbal remedies, nutrition, homeopathy, acupuncture, hydrotherapy, magnetic therapy and hydrotherapy. As an alternative health system, naturopathy is aimed at using natural forces to help the body fight illness and reach an optimal state of health.

The naturopathic approach is characterized by a holistic view that includes the whole person. Naturopathy holds that health and disease result from the interaction of a person's physical, mental, emotional, genetic, environmental and social components.

Aromatherapy

The olfactory bulb, located in the roof of the nasal cavity, is the most exposed nerve in the human body. Covered with a layer of tissue so thin that odors can pass through, the olfactory nerve is a quick and direct route to the bloodstream and brain. The nose is an efficient route for administering drugs. Proponents of aromatherapy suggest that the body is also affected by active agents contained in aromatic compounds.

Mind-Body Medicine

Mind-body medicine recognizes the connection between health and emotional or psychosocial factors. The approaches found in this area include hypnosis, biofeedback, visualization or imagery, meditation and relaxation therapy and cognitive-behavioral therapy. Research indicates that certain mind-body approaches offer benefit for such conditions as headache,

chronic pain, anxiety, insomnia, depression and hypertension. Clinically, hypnosis is used for smoking cessation, weight loss and other conditions.

Herbs and Dietary Supplements

With roots in age-old folk medicine, dietary supplements are one of the fastest-growing areas in CAM. Once relegated to obscure health food stores or a modest shelf in retail pharmacies, dietary supplements have gone mainstream. Today, vitamins and herbs are a multi-billion dollar business.

More than 150 million Americans, more than half the population, report taking dietary supplements, producing more than \$19 billion in sales annually.

Consumers expect that products sold in this country are safe and work as claimed. Yet dietary supplements are not subject to the same standards of safety and efficacy required of drugs. Although clinical studies show that some herbal remedies can have beneficial effects in certain situations, consumers should know that tests show dietary supplements vary widely in quality and consistency. In some cases, products have little or no active ingredient. At the same time, many people assume that because a product is natural it is safer or harmless. Herbal remedies may contain active ingredients that can cause side effects and interact with prescribed medication.

Energy Therapies

Energy Therapies are based on the idea that illness and disease are due to disruptions in the flow of energy through the body. This includes the Asian art of Ayurveda and therapeutic touch.

BEFORE YOU TRY

If you're interested in exploring CAM remedies, here are some things to keep in mind:

- Talk with your doctor first before trying anything different. Make sure you include any over-the-counter remedies or dietary supplements as well.
- Consider the claims of CAM remedies with skepticism. Is there good research to back up a claim?
- Don't stop taking prescribed medications.
- Only use pure, standardized products from reputable companies.
- Seek out companies that invest in clinical research to show that their products are safe and effective, companies that are less likely to make unsupported, outlandish health claims.
- Try only one remedy or product at a time. Trying more at the same time, raises the risk of adverse interactions and makes it difficult to sort out causes if a problem develops. Trying one at a time lets you determine your body's response without any interference.
- Don't assume that natural means safe. Many CAM remedies have active ingredients that can interfere with prescribed drugs or blood clotting or make our physical condition worse. Just as there may be beneficial effects, there may be negative effects as well.

Previous article taken from HemAware, Volume 9, Issue 6. HemAware is a publication of the National Hemophilia Foundation.



continued from page 1

Step Therapy for the Treatment of Hemophilia A...

Following is the National Hemophilia Foundation (NHF) response to step therapy for hemophilia.



December 20, 2004

Daniel J. Hilferty
President and Chief Executive Officer
AmeriHealth Mercy Health Plan
500 Nationwide Drive, Suite 100
Harrisburg, PA 17110

Dear Mr. Hilferty:

I am writing on behalf of persons with bleeding disorders who receive Medicaid benefits in the State of Pennsylvania to question the prior authorization requirement implemented by Keystone Mercy Health Plan for clotting factor products. The National Hemophilia Foundation (NHF) believes the protocol developed by Keystone places the lives of individuals with bleeding disorders in danger by forcing these individuals to demonstrate for Keystone the inability of certain factor products to provide the necessary level of clotting needed to prevent spontaneous internal bleeding, joint damage, trauma, and death.

In the bleeding disorders community's experience, this protocol will not result in the costs savings anticipated by Keystone. Excess factor will be required by individuals as they attempt to manage their bleeds with the clotting factor mandated under the "step therapy" rather than the product selected by their treating physicians. Increased hospitalizations will occur as factor replacement falls below recommended levels when individuals are forced to use a factor product that does not provide them with the best factor recovery. Longer term, the joint damage rendered to individuals can not be reversed except through expensive surgery, and there is an increased chance of the development of inhibitors by some patients as a result of the product changes. In short, this protocol is counter to the ethical practice of medicine and quality hemophilia care. More troubling, all of these costly and adverse outcomes are avoidable.

In evaluating the "step therapy" protocol for hemophilia, it is clear that drug price was the only factor considered by Keystone. As an example, Kogenate FS® and Helixate FS® is the same product manufactured by Bayer Biologicals and repackaged under the Helixate FS® name for ZLB Behring. A medical review would have placed these products on the same "step."

Furthermore, "step therapy" is a term used in medicine to explain a protocol of using drugs of an increasing strength, such as antibiotics, to treat a persistent infection. More recently, so-called "step therapy" programs have been used to promote the use of lower cost generic or brand drugs before "stepping up" to a more expensive brand. Such protocols may be appropriate when drugs are recognized as therapeutically equivalent. Clotting factor drugs are not therapeutically equivalent or interchangeable. In fact, potentially dangerous consequences have resulted in the past from assuming that these products can be substituted for one another.

Your immediate attention is required to address this issue before further damage is inflicted by this poorly constructed protocol. NHF requests a meeting as soon as possible to discuss the Keystone protocol as well as other challenges recently faced by individuals with bleeding disorders in Pennsylvania who are enrolled in the Keystone plan. We are contacting your office to arrange the details.

Sincerely,

Paul F. Haas, Ph.D.
President

Keith Hoots, MD
Chair
Medical and Scientific Advisory Council

If you are experiencing problems with your insurance company, with regard to your choices of homecare pharmacies or factor products or you have any questions or problems, call the Delaware Valley Chapter right away. State officials are working on insurance problems for patients with hemophilia in Pennsylvania right now. Let us know what's going on and how we can help you (215-885-6500).



Hepatitis C Advocacy:

Taking the Fight to the Hill and Beyond

By Paul Haas, PhD, President, National Hemophilia Foundation

It isn't necessary to provide a detailed history of hepatitis and its impact on the bleeding disorders community. The community knows the price it has paid and is continuing to pay in terms of HIV/AIDS and hepatitis. Today, blood factor products are dramatically safer than those used before 1992. Nevertheless, the need for advocacy on behalf of those who are infected with HIV/AIDS and hepatitis is still present. Such a need will not disappear until there is a cure for these two devastating viruses.

In terms of hepatitis C (HCV), the NHF has worked closely with the National Institutes of Health (NIH) to ensure HCV programs and clinical trials are accessible to persons with bleeding disorders. To date, NIH has funded 64 HCV clinical trials, with 35 of these trials currently recruiting patients. NIH also currently funds seven hemophilia-specific research studies on HCV. Four of these studies address coinfection issues and seek to better understand the differences in immune response between coinfecting persons and persons with HCV only.

On the legislative front, NHF, along with Hemophilia Federation of America and other organizations working with people who have hepatitis, has endorsed the Hepatitis C Epidemic Control and Prevention Act (S.1143/H.R.3539). Nearly 4 million Americans have HCV and approximately 400,000 have contracted hepatitis through blood transfusions. Yearly, HCV costs have already reached an alarming \$15 billion. That figure is expected to skyrocket to \$26 billion by 2021.

The Hepatitis C Epidemic Control and Prevention Act is groundbreaking legislation. It would establish a comprehensive program for HCV public awareness campaigns, screening and counseling, early detection, professional education and research.

The bill directs the Secretary of Health and Human Services, in consultation with the directors of the Centers for Disease Control and Prevention (CDC) and NIH, to develop a plan for prevention, control and management of HCV. Other elements in the plan would include strategies for education, databases, early detection and research and a biennial assessment of the plan. The bill authorizes appropriations of \$90 million for FY 2004 and such sums as may be necessary in FY 2005 through FY 2008. The bill would also require the director of NIH to create a Liver Disease Research Advisory Board. The legislation mandates additional resources and a more coordinated federal

approach for improving HCV prevention, treatment and disease management.

The bill is sponsored in the Senate by Kay Bailey Hutchison (R-TX) and Edward Kennedy (D-MA), and in the House by Heather Wilson (R-NM) and Ed Towns (D-NY). H.R. 3539 has been referred to the House Committee on Energy and Commerce. Currently, there are 27 cosponsors in the Senate and 39 cosponsors in the House. Activity on this bill is expected to continue once the new Congress returns.

Timing of Compensations Efforts

In terms of advocacy for HCV compensation in the United States, NHF has opted to follow its success with the Ricky Ray compensation for those with HIV/AIDS. NHF is aware of and respects the recent efforts of affected individuals in the bleeding disorders community in pursuing introduction of legislation that would provide federal compensation for HCV. However, NHF believes significant groundwork must be completed prior to the consideration of federal compensation because the private sector plays a much greater role in healthcare in the United States than in other countries. The findings regarding the federal government's role in the spread of HCV have not been documented in an authoritative manner, nor have the results of various litigated court cases provided a strong base of advocacy on this issue. Introduction of legislation without a strong substantive foundation leaves the community vulnerable to failure and dims prospects for future Congressional consideration.

To this end NHF is committed to seeking support for an independent review of the federal government's responsibility in the spread of HCV through blood and blood products. The Institute of Medicine's report on HIV and the blood supply provided needed information for the community's HIV compensation campaign. An independent review is a first and necessary step toward any future federal HCV compensation effort.

In the United States, most activities to date have consisted of individual or class action lawsuits on behalf of affected individuals. Information regarding worldwide compensation for HCV, when available to NHF, has been reported to the community via HemAware, eNotes (NHF's electronic newsletter) and on the NHF website, www.hemophilia.org.

Previous article taken from the November/December issue of HemAware, a publication of the National Hemophilia Foundation.

A Dad's Perspective

The following was sent to the Delaware Valley Chapter by a local dad.

I was giving some thought to the changing face of hemophilia care and all of the issues that we, as families, face in our life walk with hemophilia and other bleeding disorders. When my son was born with severe hemophilia, more than twenty years ago, with no family history, I took comfort that there was a team behind me to face the challenges. The team consisted of my Hemophilia Treatment Center, the Delaware Valley Chapter and my homecare company. The whole team worked together for the benefit of my son, but what a difference in today's world.

I now watch as manufacturers negotiate directly with insurance companies to have their product be the "preferred" product for the treatment of hemophilia. My insurance company says my son must use that product, or I pay out-of-pocket or, worse yet, my insurance company won't "approve" any other factor product other than that one product.

I have watched a major homecare company suggest to a state Medicaid department that, one way for the state to save money would be to "sort patients with bleeding disorders out...those that already have hepatitis or HIV would not be able to take a recombinant factor...they would use a plasma-based factor. The only patients who would be eligible to receive recombinant factor therapies would be those of us who had minimal or no exposure to these deadly viruses...a class system. This would be against the guidelines of the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation.

I see Hemophilia Treatment Centers, as part of large hospitals, becoming "for profit centers." Patients get little to no choice of homecare providers. Many of the HTC's have factor programs and they keep the patients with good insurance, sometimes charging more for the factor than what we would pay a full service homecare company that provided a lot of services to us. I see insurance companies entering into contracts with a single pharmacy provider, usually not one that can give any real homecare service and insurance companies wanting to only pay for a single factor product...no choice...all for the bottom line.

This team that I took so much comfort in now spends more time bickering over patient numbers and profits and not choice and care. At what point will my son and his well being be more important to this team than the money that my son can generate for them. Let's not leave out Chapters. My local chapter is fighting to effect laws for my son, to protect his rights and options in his care. The work that lies ahead of us all in these changing times, is too great not to work together. Boy...would it be refreshing to see all of us work together to solve the problems. Not all HTC's, manufacturers or homecare companies act like this, but it is enough of you that my son has become a dollar sign and not a human being. You know who you are. So my urgent plea is that we all start working together again for a standard of care that benefits our children and not someone's pocketbook.

Just a Dad

If you think you are beaten, you are.
If you think you dare not, you don't.
If you'd like to win, but think you can't,
It's almost a cinch you won't.

If you think you'll lose, you're lost,
For out in the world we find
Success begins with a fellow's will.
It's all in our state of mind.
If you think you're outclassed, you are.

You've got to think high to rise.
You've got to be sure of yourself before
You can ever win a prize.

Life's battles don't always go
To the stronger or faster man,
But soon or late the man who wins
Is the man who thinks he can.

Walter D. Wintle

