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HFA Visits Land of



This year's HFA Educational Symposium in Albuquerque was larger than ever! With over 600 attendees and 30+ industry exhibits, we had a full house at the Albuquerque Embassy Suites and spilled over into area hotels. The weekend was packed with great speakers and presentations. Attendees were able to hear about the most current issues affecting the bleeding disorders community from medical, government, advocacy, and industry experts from across the country. Children participated in their own

awesome programs and made new friends. Families attended an authentic barn dance/southwestern barbeque which included entertainment by Native American and Hispanic dancers in glorious costumes. Both young and old joined in dancing with the entertainers and a local country & western band. New and old friends of all ages left armed with new information and fond memories. Look inside for photos and more about our journey to the Land of Enchantment!



MESSAGE FROM THE PRESIDENT

What difference can I make? Well, more than you think. One person can and has made a difference.

There are stories of an individual calling or writing their elected official to voice their opinion and that elected official becoming the swing vote, passing or defeating a piece of legislation. There is the old adage of “the last straw” or “the straw that broke the camel’s back.”

In the bleeding disorder community, we have seen one visit or one phone call have an impact on someone being involved. There are people deeply involved with HFA because one person asked them to get involved. Over the years, Jan Hamilton, HFA Advocacy Director, has asked people to be involved and they have done so and gone on to be Presidents, Vice Presidents, board members, Committee Chairs, and other leaders. Don’t believe you can make as much of a difference as someone like Jan? You won’t know if you don’t try.

Being involved can be defined in many ways. You may have various talents that can be used locally or nationally. You can be involved at many different levels of commitment. Sometimes, involvement takes as little as five minutes.

How? On HFA’s on-line Legislative Action Center! Only five minutes and knowing your own zip code can send an e-mail to your Congressperson. You can spend an hour at your local organization helping stuff envelopes, or helping with childcare at an annual meeting. We at HFA want you to be involved in your local member organization, first. We believe HFA is strong and successful due, in part, to our strong member organizations.

We, the bleeding disorders community, need to be involved and united because, unfortunately, no one looks out for us and does for us, like us.

- Carl Weixler

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Mission

The Hemophilia Federation of America is a national non-profit organization that assists and advocates for the blood clotting disorders community.

Vision

The vision of the Hemophilia Federation of America is that the blood clotting disorders community has removed all barriers to both choice of treatment and quality of life.

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HFA RECOGNIZES OUTSTANDING MEMBERS

The HFA 2007 Ron Neiderman Award was presented posthumously to Donald E. Colburn (1951-2006), who died in July 2006 of complications from lung cancer. Donald was chosen for his outstanding community service to the bleeding disorders community. He lived with severe Hemophilia A and was committed to the creation of a better world for the bleeding disorders community. Donald's volunteer leadership activities in support of quality hemophilia care spanned the last 35 years and included his years as Executive Director of the New England Hemophilia Association (NEHA). In 1989, he and his beloved wife Kathy Ann Keenan founded AHF, Inc., a homecare pharmacy whose mission is to serve the needs of the bleeding disorders



Pictured above are Susan Swindle, Jan Hamilton, Mark, and Carl Weixler

community by supplying life-giving medications and support to individuals and families. Donald will always be remembered for his community strength, advocacy, and comprehensive approach to bleeding disorders treatment. Mark Zatyryka, of AHF, Inc. accepted the award on behalf of

his late uncle.



The HFA Volunteer of the Year Award was presented to Melinda Clark by HFA Administrative Director, Susan Swindle. Melinda has been involved in the hemophilia community her entire life and, since 2002, has been a member of the HFA Board of Directors. Melinda has been

a very active member of HFA, having served on the Teen Connection Committee, and as co-chair, and presently, chair of the HFA Focus on the Feminine Committee. In 2005, she was elected to the HFA Executive Committee as at-large member. Melinda facilitated the Focus on the Feminine break out sessions at the HFA Educational Symposiums in St. Louis and Albuquerque. Last year, she spearheaded the development of the HFA Focus on the Feminine educational project, bringing specific information about women's bleeding disorders and treatment resources to the general public by exhibiting at women's shows across the nation. This year, she was elected HFA Secretary.



Carl Weixler presented **The HFA President's Award** to Paul Brayshaw for special recognition of his valuable advocacy work. Paul serves as a board member for the Hemophilia Foundation of Maryland and voluntary Chair of the Advocacy Committee for the Hemophilia Federation of America. He also holds a gubernatorial appointment to the Virginia Hemophilia Advisory Board. Paul works in the health sector of Factor Support Network Pharmacy. He founded the non-profit Blood Buddies, Inc. to help improve the quality of life for individuals with bleeding disorders through physical activity.

HFA Board of Director Appreciation Awards were presented to outgoing board members Judy Igleman, from Hemophilia of North Carolina; Linda "Lew" Wyman-Collins from the Texas Central Hemophilia Association; and Michael Morse of the Oklahoma Hemophilia Foundation. Each of these volunteers served a six-year term on the HFA Board of Directors and all pledged to remain involved in Federation activities.



*Judy Igleman
North Carolina*



*Lew Wyman-Collins
Texas Central*



*Michael Morse
Oklahoma*

HFA Elects New Officers

The Hemophilia Federation of America elected the 2007 Executive Committee at its annual Board Meeting in Albuquerque, New Mexico. New officers include Carl Weixler, President; Chad Stevens, First Vice President; Donald Akers, Jr., Second Vice President; Melinda Clark, Secretary; and Tom Vaclavik, Treasurer. Other executive committee members include Barbara Chang, Past President; Peter Bayer, At Large.

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Kids learn in the land of



enchantment

Children and teens from across the country came together for an action-packed weekend at the HFA 2007 Symposium in Albuquerque, New Mexico. While adults learned about current issues affecting the bleeding disorders community, their children, from 5 to 18 years of age, participated in comprehensive Children's Programming provided by HFA volunteers.

Our Teen Connection Program was organized and facilitated by HFA Board Members Zuiho Taniguchi (NoCal), Jim Dawdy (SoCal), Maria Rubin (FL) and Lee Hall of Global Health Society. Friday, teens banded together in playing "Southwest Survivor: All One Tribe". Activities included tribal flag design, henna totem tattoos, an introduction to advocacy training led by Kim Bernstein. The day's events ended with a tribal feast.

Bobby Wiseman, Global Health Society, and volunteers Beau Reinegger, Obinna Chama and Antoine Trice ran the PreTeen Program, where our Preteens (9 thru 12 year-olds) played games, personalized t-shirts, created authentic Native American Dream Catchers and other craft projects. All enjoyed meeting their peers from across the country.

Both groups jointly participated in Saturday's off-site activities which included visits to the New Mexico Museum of Natural History and the Explora! Center. There, HFA teens and preteens explored dinosaur exhibits, a planetarium, viewed an IMAX movie, created computer-operated robots, made animated movies, rode a high wire bicycle, and engaged in over 250 hands-on

science activities.

The HFA Kids program was facilitated by our dedicated Board Members Joyce "Granny Goodfood" Donlan (NE) and Judy Igleman (NC), along with volunteers Shannon Cook, Mona Costantini, art therapist; Lana Bienvenu, yoga therapist; and Debbie Couvillion, massage therapist. Children, ages 5 through 9, were treated to a variety of fun art activities. They created their own stuffed teddy bears in HFA's "Bear with It Clinic" and learned basic yoga positions in the Movement Studio. They also learned how to make nutritious snacks that were fun to eat.

This year, HFA Kids received a visit from Stuff, an 8-foot tall, blue-haired doll who helped kids learn "where does the food go after you eat it". This Explora! Center Outreach Program taught kids about various body organs and how to stay healthy.

Later, the Flying Eagle Dancers, a Native-American family from Taos Pueblo, presented a wonderful program that allowed the children to view beautifully costumed dancers perform traditional Native American dances, and to actually learn and participate in the Friendship Dance. Both the children and their parents also enjoyed the chanting, drumming and flute playing of 62 year-old Chief Joseph Flying Eagle and his athletic dancing ability.



“Take Good Care of Yourself”

Dr. William Klinger and Charles Gilbert, II, both from Penn State College of Medicine, kicked off this year’s HFA Symposium with an enthusiastic and humorous presentation regarding exercise, nutrition and emotional well-being. Dr. Klinger described health as each individual’s choice, and it is important that we choose wisely because “the first wealth is health.” Dr. Gilbert went on to explain five essential elements of a healthy lifestyle.

Be physical. It is important to exercise and eat the right foods to maintain a healthy body. Exercising can increase lung and heart efficiency, flexibility, weight loss, and muscular strength. It can also help to decrease stress, weight, personal injuries, illness and loneliness.

Be emotional. Expressing emotions helps individuals to live life now instead of in the past.

Be social with others. Friends can offer support, personal growth, companionship, laughter, perspective and strength. The Hemophilia Federation of America offers many programs to help people in the hemophilia community to become socially involved.

Be spiritual. Spirituality provides healing, strength, wisdom and fellowship.

Be cognitive. Your brain needs exercise, too! Read, do crosswords, puzzles, brain teasers, learn a new hobby, anything to train your brain. Learning throughout your lifetime is the best way to keep your brain young.

It is important for people to make improvements in their lives. By incorporating this model, anyone can enjoy a fun, healthy and balanced lifestyle. Bill & Gil finished by praising HFA for offering programs that address various aspects of this whole



package.

REIMBURSEMENT CHALLENGES AND HOW THEY AFFECT YOU

Moderator: Jan Hamilton, HFA Advocacy Director

Speakers: Ken Trader, Terry Rice, Julie Birkofer, Ryan Faden

Ken Trader, of Hemophilia Health Services, discussed recent changes to Medicare reimbursement for plasma therapies (Average Sales Price + 6% + \$.14/unit) as a result of the Deficit Reduction Act (DRA), and the impact those changes will have on drug prices, service delivery (clinical and home care), and overall industry transparency. With the change in reimbursement, cost utility is being replaced with changes in cost benefit, limiting the ability of consumers to make health care choices.

Terry Rice, of Factor Support Network, explained that to help preserve the current model, we must be proactive as a community to educate our elected officials about the specific needs of the bleeding disorders community. Further, as individuals we must respond to patient utilization requests (i.e., logs) and various other disease management tools to ensure payers understand our consumption is legitimate.

Ryan Faden and Julie Birkofer, with Plasma Protein Therapeutics Association (PPTA), addressed the need for advocacy in making state legislatures aware of the need for plasma products and a high level of quality care. Ryan stressed that this education should include the following: there should be no substitution of prescription without physician approval, home nursing services are essential, and there must always be advance notice of out-of-pocket costs to the patient. Julie also stressed the need for screening women with bleeding disorders, raising the profile of the bleeding disorders community and continuing grassroots advocacy to insure a pro-active status, rather than a reactive response to issues.

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HFA Roasts Jan Hamilton

Jan Hamilton, HFA Advocacy Director, announced her upcoming retirement at the HFA Annual Board of Directors Meeting at the 2007 Educational Symposium in Albuquerque, New Mexico. Carl Weixler, HFA President, made the official announcement at the Friday Evening Dinner where she was the subject of a light-hearted “roast” by members of her extended HFA family and her immediate family.

Corey Dubin began with a hilarious recap of his first encounter with Jan and her renowned driving abilities. Don Akers told of his experiences in finding a “scooter-friendly” taxi ride with Jan in D.C. Don also described a top-secret Las Vegas mission that he and Jan’s late husband, Dr. Chuck, were sent on. The pair had to navigate through the women’s apparel departments of various up-scale clothing stores in an embarrassing search for women’s pants.

Tom Vaclivik, in honor of Jan’s nickname “Crash”, gave her a pink cycling helmet for use with her scooter. It was lovingly autographed by HFA Board Members and staff. Susan Swindle told of her experience with Jan’s great sense of direction when they ended up on the runway of Houston International Airport and watched the passengers of a passing plane wave to them on the tarmac. Jan’s daughter sent a hilarious tribute to her mother via video.

Bob Marks ended the banter with heartwarming and sincere thanks to Jan for her years of devotion to the bleeding disorders community. The audience joined him in giving Jan a standing ovation.

Shawn Decker & Gwen Barringer “Adult Responsibility and Personal Relationships”

Shawn Decker, author of “My Pet Virus” (www.mypetvirus.com), the story of his life with hemophilia, HIV and Hep C, spoke at the HFA Symposium, along with his wife Gwenn. Shawn described his experience of speaking to a group of his peers as “surreal”.

Shawn wrote the following in his blog:

“The talk that Gwenn and I gave was a rarity. Most of the 50 people in the room had hemophilia, and a good portion also had HIV. More than once, a young guy about my age came up to me and said, ‘I’m in the Triple H Club, too!’ (Hemophilia, HIV, hepatitis C) Usually when we speak at universities and colleges, I’m the only diagnosed person in the room, which means inevitably I am representing the community to ‘negatoid’ audiences.

Not so in Albuquerque. I was in a room with all generations of ‘thinbloods’, including my own—the guys who contracted HIV as children, had to go through puberty with HIV, and have survived into adulthood. Often times, there haven’t been too many answers, mainly because we didn’t want to ask the questions that needed to be asked. Trial by fire.”



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Hepatitis C - Transplants

Victor J. Navarro, M.D., Medical Director of Liver Transplantation at Thomas Jefferson University, Philadelphia PA, gave a clear, informative presentation on the current status of Hepatitis C (HCV) in the hemophilia community. He focused on current treatment options and rates of success/failure, symptoms associated with the various stages of HCV disease progression, and future treatment options.

According to Dr. Navarro, 90 percent of hemophilia community has been exposed to HCV, 75%-80% have chronic hepatitis, and 20% have liver cirrhosis (scarring). Dr. Navarro recommended combined pegylated interferon & ribavirin as treatment-of-choice. For those with more advanced stages of hepatic illness (ascites, elevated PT/INR), and who have not had success with combination therapy, future treatment options include protease inhibitor medications.

Transplants are considered a final option for those who have exhausted all other treatment remedies. The transplant procedure is extremely expensive and can be life threatening. However, transplants are a possible solution to the long-term effects of HCV. He explained that a liver transplant does not cure HCV as the HCV virus remains in the body. However, a successful liver transplant can slow HCV's progress dramatically.

HIV co-infection, its effects on treatment outcomes, and the future of liver disease treatment were discussed in detail and led to a robust question and answer session. Audience members left with a greater knowledge of Hepatitis C and treatment options available to the bleeding disorders community.



Pain Management Panel: John Valusek, Ph.D., Bob Marks, Jamie Seigel, MD.

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The Silent Problem of Pain Management By: Michael Morse

At the Annual HFA Educational Symposium in Albuquerque, Jamie Siegel, MD, John Valusek, PhD and Bob Marks, a co-infected severe Factor VIII hemophiliac, presented three different perspectives on the often troubling and silent problem of pain management.

Dr. Siegel, director of the HTC in Philadelphia, shared some of her experiences in working with the hemophilia community. She is cautious in writing prescriptions for her HTC patients. As everyone's pain is different, so should be their methods of coping with it. Dr. Siegel recommends sending patients with pain to a qualified Pain Clinic and letting that physician to individually tailor pain management to that patient's need.

Next to speak was Bob Marks. Born in 1959, he lived through the plasma-cryoprecipitate days and has some of the associated joint damage common during those pre-factor days. Bob became dependent on pain meds during the 1980's HIV crisis, and, again, while enduring Hepatitis C treatment in 2004. He has conquered his substance abuse: the first time through the 12 Step program, then once again, with the help and support of his wife, close friends and the 12 Step program. Since then, working with a hematologist, he has been able to monitor his pain management, proving to himself that his "daily reprieve" will continue.

Our last speaker was Dr. Valusek, retired staff psychologist from the Wichita area, who discussed psychosocial issues. In sharing some experiences with patients, he explained how modifying the way you talk to your brain about pain can bring about very dramatic changes in the way you feel that pain. To him, the rage of feeling helpless drives one to additive behavior: modify the rage and modify the drive.

Some of the ways to help control pain are laughter (10 minutes of belly laughs equal two hours of reduced pain), meditation relaxation techniques, diet and exercise. Having listened and laughed with Dr. Valusek in the past, I was ready for his almost "stream of consciousness" way of speaking to an audience. What I did not anticipate was the four-hour pain relief I felt after laughing with him for 20 minutes. I proved most of my friends' opinion of me wrong (as I must have a brain because Dr. Valusek talked to it)!

Our panel agrees that pain management in the hemophilia community is an obtainable goal, but you really have to want it and work hard for it.



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Research Data and Data Collection By: Lynne Capretto (N Ohio)

Sally Owens, Health Scientist, Center for Disease Control (CDC), and Diane Aschman, President and CEO of the American Thrombosis and Hemostasis Network (ATHN), presented a very informative general session on the latest developments in research data and data collection.

The CDC is a congressionally mandated universal data collection center. It has cooperative agreements with 140 HTC in 12 regions. Approximately 83 percent of hemophilia patients are enrolled. The hemophilia data set was established in the 1980s to track the number of patients for three purposes: (1) to monitor blood safety; (2) to track the extent and progression of joint disease; and (3) to identify issues for further study. The CDC's data set is a surveillance program that collects routine clinical data; it is not able to monitor the progress of people who are already infected.

CDC's Lab Tracker is the software system used by 80 percent of the HTCs. Data from office visits is transmitted electronically. This is important to the community because it monitors blood safety and tracks mortality and hospitalization rates. It has the capacity to identify new infections, such as West Nile virus. It is also tracking joint disease and the impact of obesity. CDC data demonstrates that people treated outside of HTCs have a 60 percent higher mortality rate and 60 percent more hospitalizations than HTC patients.

CDC supports the concept of expanded research, such as that which is being proposed by ATHN. Current CDC data is acceptable for surveillance, but inadequate for research. Hemophilia is a rare condition with rare complications. Meaningful research requires large sample sizes, available only through national and international collaboration.

ATHN is a newly formed (2006) operating foundation. It is a public/private partnership organization that proposes to fill the gaps in CDC data. It intends to collaborate with CDC and not duplicate data collection. Its purpose is to provide stewardship of a secure national database, which will be used to support clinical outcomes, research and advocacy. Some of the data gaps that ATHN proposes to study are the tracking of treatment and product outcomes and the development of inhibitors. ATHN is in the process of establishing its data policies and procedures and is committed to an open and transparent process.

It is expected that consumers will benefit by having secure, transferable and accessible health information. HTCs will benefit from secure, timely and structured patient records held at two secure locations. Data will be collected only once. Updates and maintenance will be centralized.

(The information in this report was culled from the actual presentations and does not necessarily reflect the opinions of the author or the HFA.)



Noon Breakout Sessions Address Specific Needs of the Community

HFA 2007 Symposium attendees could choose to participate in a noon breakout session that addressed the specific needs of three different populations within the bleeding disorders community. Men had the option of attending the HFA Dads in Action or the HFA Blood Brotherhood presentations, while women could attend the Focus on the Feminine session. Participants in all sessions felt more comfortable discussing some of the topics in a same-sex audience.



Joey Privat and Tom Vaclavik facilitated the Dads in Action breakout. They gave a brief introduction into the Dads in Action Program. Charlie Gilbert spoke to the group on the importance of fathers in the lives of their children.



Melinda Clark facilitated the Focus on the Feminine Session. She began with a short presentation on the program and its activities. A guest panel comprised of Ruth Ann Kirschman, RN and Jill Williams, patient and VWD specialist, answered audience questions on topics concerning bleeding disorders in women (medications, carrier-issues, testing available, etc).



Wayne Cook facilitated the Blood Brotherhood session which included a talk by Dr. John Valusec. Designed for men with bleeding disorders, this breakout allowed the men attending to discuss specific issues that go along with growing older. Participants praised this opportunity to talk openly and honestly to other men who are living with hemophilia.

“What Are My Rights in School and the Workplace”

This current topic was addressed at the 2007 HFA Symposium by Anthony Lujan, New Mexico Department of Vocational Rehabilitation; Don Molter, the Indiana Hemophilia and Thrombosis Center; and Sally Hunter, RN, with the Albuquerque Public Schools System.



Anthony Lujan spoke about the history of vocational rehabilitation and the specific goal of providing consumers with a choice of vocations and employment outcomes in order to be integrated into society via employment. Don Molter stressed the need for becoming one’s own advocate, emphasizing that being well- educated is equal to being well-armed. He showed how advocacy was necessary in transitioning a child from the various stages of the school environment to the workplace.

Sally Hunter provided an overview of the Federal “Section 504” rights of individuals in the educational system and the responsibility of the school system to provide individualized educational plans for those with special needs. One attendee’s comment stressed the need for dissemination of this information, as he, a retired educational administrator, was completely surprised to learn of the existence of “Section 504” and its mandate.

It was obvious from the number and level of questions posed to this panel that the special needs of those with bleeding disorders in school and the workplace is a relevant topic. Both attendees and professionals were left with a new understanding and direction for their future. Hopefully, the audience will take this knowledge and put it into practice at home, school and the workplace.

Baxter Healthcare Awards HFA \$100,000 Grant



Pictured from left: Pete O’Malley, Jan Hamilton, Susan Swindle, Carl Weixler, Meredith Zerbe

Baxter Healthcare recently awarded a financial grant in the amount of \$100,000 for support of the Hemophilia Federation of America (HFA) activities in 2007. The grant was awarded at HFA’s Annual Board Meeting and Educational Symposium held February 28 thru March 4, in Albuquerque, New Mexico. Pictured above from left to right are: Pete O’Malley, VP & General Manager, Baxter BioScience; Jan Hamilton, HFA Advocacy Director; Susan Swindle, HFA Administrative Director; Carl Weixler, HFA President; Meredith Zerbe, Group Manager, Payer Relations Baxter BioScience.

The HFA appreciates Baxter’s support of its Educational Symposium and ongoing advocacy efforts.



2007 HFA EDUCATIONAL SYMPOSIUM EXHIBITORS



EXHIBITORS CONTINUED...



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HFA Advocacy in Action

2007 has been a very busy year for the HFA Advocacy team. There are many significant issues impacting the bleeding disorders community, including:

Medicare Co-Pay: 24 States offer supplemental (Medigap) health insurance coverage for the 20 percent co-insurance required by individuals on Medicare

due to disability. To help respond to this discrepancy and require that all 50 States offer similar coverage, the HFA Advocacy team participated in D.C. meetings with Members of Congress and other government officials in January, February, and March. A vast majority of the House and Senate visits were supportive of the issue and its merits. Stay tuned and keep checking the Legislative Action Center on our website (www.hemophiliafed.org) to see what you can do to help in this effort.

Senate bill 1955: Also known as HIMMA, the Health Insurance Marketplace Modernization and Affordability Act, was sponsored by Senator Michael Enzi from Wyoming. This legislation attempted to offer insurance to the working poor and employees working for small companies. The bill was contentious because it preempted state mandates, which offer valuable protections in some states for members of our community. The bill was opposed by a consortium of about 1300 health based groups.

Reimbursement Issues: Ongoing activities involve efforts to prevent single source providers, prior authorization, preferred drug lists, and limits on choices of products, providers, and physicians.

If you are having problems with these issues or others in your state, contact Jan Hamilton, HFA Advocacy Director at jan.hamilton@cox.net for assistance. She and Advocacy co-

chairs Paul Brayshaw and Bob Robinson will be happy to assist you to understand the coverage you need in your state.

Texas State Capital Raises Bleeding Disorder Awareness

Nationally, March is recognized as a time to raise awareness about hemophilia and bleeding disorders. On March 15, 2007, the bleeding disorder community converged on the Texas State Capital building in Austin, Texas. Representatives of the Texas Central Hemophilia Association (Dallas) spearheaded the exhibit and were joined by representatives of the Lone Star Chapter (Houston), the National Hemophilia Foundation (NHF), the Hemophilia Federation of America (HFA) and the Committee of Ten Thousand (COTT). Because it was Spring Break, many tourists were visiting the Capitol building that day, and tour guides even brought groups right through the exhibit's center.

Throughout the day-long event, people were made "AWARE" of bleeding disorders through handouts, "Seeds of Hope" wildflower seeds, "United in Blood" bracelets and personal stories. Besides the public, the exhibitors were approached by at least fifteen Legislators from the 80th Legislative Session now in progress. It was the group's goal to make those House and Senate members aware of the challenges our families face due to the phenomenal expense of these disorders.

Advocacy efforts made by the bleeding disorder community during this legislative session have addressed such challenges as Lifetime Maximum Benefits on health insurance. Through their advocacy efforts, the community was thrilled to gain support from Texas House Representative Senfronia Thompson (Houston), Senator John Carona (Dallas) and Senator Robert Deuell (Greenville) to sponsor a Bill (HB 1600/ SB 730). This bill concerns a study to be conducted by the Texas Department of Insurance regarding eliminating or raising the Lifetime Maximum Benefits on Health Insurance. For further information on these efforts, please contact the Texas Central Hemophilia Association at (214) 351-4595 or visit their website <http://www.texcen.org>.

This article was edited with permission of original author, Christy Argo of the Texas Central Hemophilia Association. You can read it in its entirety at



The "Medigap Access Improvement Act of 2007," H.R. 1282, seeks to require that Medicare supplemental coverage is made available to ALL Medicare recipients, not just those over age 65. This is important to the bleeding disorders community, as many members under age 65 are on "Medicare Disability." In 26 of our 50 states, a supplemental policy is not made available to persons who are on Medicare due to disability as opposed to those on Medicare due to age. H.R. 1282 would require, by federal law, all insurance companies that offer

Medicare supplements to make them available to all Medicare recipients.

More co-sponsors for this bill are signing on every week, but your support is greatly needed. In just 5 minutes, YOU can make a difference by going to the HFA Legislative Action Center on our web site (<http://www.hemophiliafed.org>) to send a letter to Congress. Just scroll down the page and click on the picture of the US Capitol. Many thanks!

(Ed. Note: This article has been reprinted in its entirety with permission of PPTA from The Source, Spring 2007, pp22-23.)

States continue to attempt to address their budget deficits by focusing on health care expenditures. Rising prescription drug costs continue to account for a large portion of those increases. Although, PPTA recognizes the fiscal dilemma faced by the majority of states, the Association in unison with its stakeholders has long maintained that doing so should not be at the expense of patient access to lifesaving plasma protein therapies (collectively, "plasma-derived and recombinant analogs"). PPTA and its stakeholders are ever vigilant that changes in reimbursement in state Medicaid programs do not diminish access to plasma protein therapies and also maintain access to providers that deliver comprehensive quality care.

A recent example of a State in economic trouble turning to health care expenditures for relief is Alabama. Although Alabama's latest attempts to control costs could have impacted the bleeding disorders community, it is important that the community responded because such precedents that could negatively impact patient access must be vigorously opposed and, in the best interest of preserving patient access, defeated. It is also important to constantly focus on differentiating plasma protein therapies from traditional pharmaceuticals in all aspects of the continuum of care. Such as orphan populations served, fragile, rare often chronic diseases; lack of interchangeability among therapies, no generic alternatives; importance of maintaining the sanctity of the physician/patient relationship; the lengthy and cost intensive manufacturing process and robust regulatory environments to name a few.

BACKGROUND

Section 602 of the Veterans Health Care Act of 1992 ("VHCA") enacted the 340B Drug Pricing Program. That statute requires drug manufacturers, as a condition for federal funds to be available to purchase their products under both Medicaid and Medicare Part B, to enter into an agreement with the Secretary of the Department of Health and Human Services (HHS) to provide discounted prices on covered outpatient drugs to a list of "covered entities." In fact, the 340B program was created to encourage pharmaceutical manufacturers to offer discounts to these covered entities that are outside the Medicaid program and thus not able to obtain Medicaid rebates under a Medicaid Rebate Agreement. Under this 340B Drug Pricing Program, a manufacturer enters a Pharmaceutical Pricing Agreement with HRSA in which it agrees to charge covered entities no more than the "PHS ceiling price" for its products.

WORKING TOGETHER FOR PATIENT ACCESS

On November 28, 2006 the Pharmacy Director of Alabama Medicaid sent a letter to hemophilia distribution providers announcing a change in the reimbursement methodology for hemophilia factor concentrates. This methodology would have been based upon Public Health Service (PHS) pricing. PPTA and stakeholders contended to the agency that implementing a reimbursement mechanism preventing providers who do not have access to PHS pricing from the 340B drug discount program from servicing Medicaid beneficiaries would not be in the best interest

of Alabama Medicaid beneficiaries and not consistent with the purpose and intent of the 340B program.

Beneficiaries receiving services from Alabama Medicaid and other government health care programs should not be denied timely access to the treatments they need to keep them alive and functioning. Utilizing PHS pricing could cause numerous providers of hemophilia therapies to decide to discontinue providing hemophilia therapies to their patients. Such approaches may result in single source provider situations. PPTA working in conjunction with stakeholders (Ed. Note: representatives of community organizations such as HFA, NHF and COTT.) has long maintained the policy that single source provider arrangements adversely affect access to the full range of therapies. Specifically, the single provider may choose to furnish a limited selection of therapies. According to the Medical and Scientific Advisory Council of the National Hemophilia Foundation, access to the full range of licensed hemophilia therapies is essential for optimal treatment (MASAC Recommendation #168; Regarding Access to Care for Patients with Bleeding Disorders). Delayed access to the appropriate clotting factor for the patients' unique condition can cause painful and crippling injury to a hemophilia patient's joints and organs. Such complications also often lead to increased costs for medical assistance programs for hospital, skilled nursing and other specialty services.

Patients and their physicians make informed decisions regarding the particular therapy they will utilize. Hemophilia therapies are not interchangeable and open access to all products should remain unimpeded. Each therapy has been approved by the federal Food and Drug Administration (FDA) for specific clinical indications. These are branded therapies, with no generic substitutes. Different therapies may require different dosages and regimens, and may be appropriate only for specific populations. Further, the effectiveness of particular therapies may vary with different populations or with specific individuals. Failure to maintain open access to this full range of licensed therapies could result in the adverse health outcomes discussed above.

OUTCOME – ACCESS RESTORED

On January 5, 2007, the Medicaid Agency stated in a letter to interested parties that "in response to the comments we have received regarding this proposed rule, the Agency will not move forward at this time with the proposed hemophilia reimbursement change." This was a victory for the whole community. Additionally, as other states choose to pursue similar reimbursement changes this year, the actions undertaken in Alabama by industry, patients, and providers represent a blueprint for the community.

1) 42 U.S.C. § 1396r-8(a)

Currently, the Alabama Medicaid Agency is considering other approaches to address reimbursement for hemophilia factor concentrates. One possible reimbursement methodology under discussion would be based upon the Medicare Part B formula which is defined as Average Sales Price + 6% plus a furnishing fee of approximately \$.15 per unit.



HFA of Montana and the Dakotas (HFMD) Participates in NHF Washington Days By: Jim Paist, E.D., HFMD

The National Hemophilia Foundation (NHF) hosted its annual Washington Days community advocacy effort March 7-9, 2007 on Capitol Hill. This was truly a collaborative event with strong representation from the three most prominent organizations representing the bleeding disorders community: The NHF, Hemophilia Federation of America (HFA) and the Committee of Ten Thousand (COTT). Nearly 250 people from coast to coast attended to speak with one voice in building support for federal legislation to help the bleeding disorders community.

Washington Days 2007's primary goal was to recruit House Co-sponsors and Senate Authors for the Medigap bill HR1842 and for the Genetic Non-discrimination bill, HR493. In addition, a "Dear Colleague" letter from Representative Tammy Baldwin (WI) was offered in each meeting to gain congressional support for increased HTC funding from the Centers for Disease Control (CDC). Volunteers from the Great Lakes Hemophilia Association inspired Representative Baldwin to write this letter urging more federal funding for the HTCs.



Washington Days opened the evening of March 7th, with an overview of the legislation we are trying to advance. Helpful tips on how to most effectively approach legislators and their staff were shared, followed by a casual reception.

The big day on the "Hill", was March 8th. Our large group of bleeding disorder community members was divided so each state had a constituent delegation to meet with the state's Representatives and Senators. Some states had a big delegation of ten or more community members, while other small delegations, like Minnesota, were teamed up with another state. Our Minnesota delegation featured HFMD volunteer Denise Cadwell, HFMD Executive Director Jim Paist, and former HFMD President, Eileen Bostwick. We were teamed up with the Missouri delegation, which included Nancy Phelps and Chris Burke. Together we visited Congressional offices from Minnesota and Missouri to build more support for the bills to pass.

Most of the House and Senate staffers we met seemed receptive to the need for Medigap coverage and a genetic non-discrimination law. We had the pleasure of meeting directly with Congressman Jim Ramstad (R-MN), who has been a strong ally of the bleeding disorders community in Washington D.C. The meeting with Congressman Ramstad allowed us the opportunity to thank him for the key support he gave us in 2006, co-authoring the initial Medigap and Genetic Non-Discrimination bills. He also had been among the first to co-sponsor both bills in this session. Congressman Ramstad has been a real champion on health care issues throughout his congressional career, and particularly has been helpful to the bleeding disorders, and the larger chronic illness communities with his ongoing efforts to help pass these important bills.

Several other elected officials whose offices we visited also have co-sponsored the Genetic Non-Discrimination bill and have indicated they will be signing onto the Medigap bill as well. We would like to applaud NHF for all of their hard work in organizing and hosting this annual national gathering on Capitol Hill!

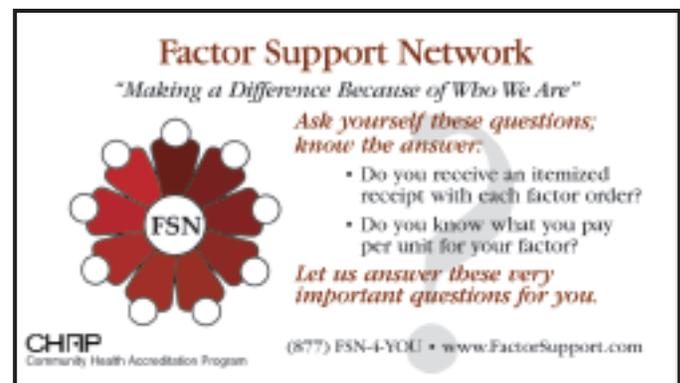
The HFMD is following up with the offices we met with during Washington Days and we'll be meeting with the local Congressional offices in Bismarck and Sioux Falls later this summer. We urge everyone in the bleeding disorders community to get involved to help pass this important federal legislation. One quick and easy way is to go to the HFMD (www.hfmd.org) Web site and click on to the HFA Legislative Action Center link. There you can e-mail a form letter to your Congressional representatives and check the list of bill sponsors to see if your Representatives have signed on. There is positive momentum moving ahead in the House of Representatives, and we also need the support of the six U.S. Senators in our tri-state area. If you have time to call them or write a more personal letter, it makes an even bigger impact. If they have already signed on, it helps to write or call with a nice thank you. We encourage you to contact HFMD or your local chapter to discover other ways to get involved with local efforts. Together, we can really make a difference!



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First Parenting Book on Inhibitors

Families of children with hemophilia and inhibitors have long been ignored educationally in the bleeding disorders community. Attending the first Novo Nordisk Inhibitor Summit meeting in the fall of 2005, author and mother Laurie Kelley witnessed their deep pain and need for education and mutual connection. "I had not seen such collective anguish in over ten years in our community," she says. "It was a well kept secret." Even good friends who had children with inhibitors had managed to hide their struggles. Such summits bring education to the many who can attend, and Laurie knew it was time to reach everyone with inhibitors, everywhere. Laureen A. Kelley is President of LA Kelley Communications, Inc., a Massachusetts-based company providing educational materials to the hemophilia community (www.kelleycom.com).

This year, Laurie will begin writing the world's first parenting book about inhibitors, titled *Raising a Child With Inhibitors*. Funded with an unrestricted grant from Novo Nordisk, this book will cover all inhibitor aspects, from diagnosis to teen years, from the medical to the psychosocial, in a language parents can understand. The book will contain practical information, advice, actual stories from families, and resources.

Laurie is requesting stories—and she would like any parent of a child with an inhibitor, or patient with an inhibitor, to contact her to share their story. These collective stories will form the backbone of the book, addressing directly what parents want and need to know, based on what parents and patients tell her. If you'd like to be a part of this project, contact her at once at laurie@kelleycom.com or 800-249-7977.

HRF, Inc. Assists Hemophilia of North Carolina

HRF, Inc. is a US-licensed Source Plasma Center located in Raleigh, North Carolina. HRF, Inc. was founded in 1985 by four people with Hemophilia. Their goal was to establish a Source Plasma Center where people with Coagulation Disorders could market their plasma in an international market. HRF, Inc. is still owned and operated by people with coagulation disorders. Our staff includes a Hematologist who serves as Scientific Director. Our 2200 sq.ft. facility hosts four donor beds and a modern laboratory for processing the plasma at time of donation.

Participants in the donor pool travel to the HRF, Inc. facility located in Raleigh, North Carolina to participate in a process known as "Plasma Pheresis." This process separates the donor's plasma from the whole blood and is done through a manual procedure. The donor's plasma is used internationally as a "non-injectable" product for manufacture into various "In-Vitro Diagnostics Products." The plasma is also used in Research and Development of "Clotting Concentrates."

HRF is presently searching for new donors and will pay well above the usual donor fees associated with other centers.

Your Hemophilia World - We know it

You live in that wonderfully off-the-wall world of bleeding disorders, where you know the unexpected is bound to happen.
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HRF supports many state and national Hemophilia programs and associations. Jeff Harper, co-owner of HRF, said "We believe in giving back to the Hemophilia community, which is our main mission behind the company." HRF, Inc. continues to expand its operation to meet the ever-increasing international demand for specialty "non-injectable" human plasma. HFA would like to thank Jeff Harper for HRF's assistance in mailing the winter issue of *Dateline Federation* to the North Carolina chapter members.

Interested persons should visit www.hrfinc.com for more information or contact HRF, Inc. at 1-800-356-8123.

FDA Approves New Product to Treat Von Willebrand Disease

The U.S. Food and Drug Administration (FDA) has announced the approval of Antihemophilic Factor/von Willebrand Factor Complex (Human), Alphanate. The product is approved for patients undergoing surgery or invasive procedures with von Willebrand disease (vWD) in whom the hormone desmopressin is either ineffective or contraindicated. It is not approved for patients with severe vWD (Type 3) who are undergoing major surgery. The disease is the most common inherited bleeding disorder, affecting about one percent of the U.S. population.

Alphanate is the first biologic product approved for treatment of surgical and invasive procedures in patients with vWD. Alphanate is already approved for the prevention and control of bleeding in patients with Factor VIII deficiency due to hemophilia A or acquired Factor VIII deficiency.

"This approval is an important advance for patients and their surgeons, providing them access to a proven preventive therapy that can make needed surgery possible and safer," said Jesse L. Goodman, M.D., MPH, director of FDA's Center for Biologics Evaluation and Research.

Men and women are equally affected by vWD, which is caused by a deficiency or defect in certain plasma proteins critical to blood clotting. In most affected people, the disease is mild, and treatment usually is not required to stop bleeding. However, about 2,000 people in the U.S. each year suffer from moderate and severe forms of the disease in which bleeding can be excessive if not treated.

Successful management of surgery or invasive procedures in mildly, moderately and severely affected individuals routinely requires correction of the bleeding defect. In the absence of correction of the bleeding defect, patients may suffer from prolonged bleeding and delayed wound healing.

Alphanate is purified from pooled human plasma from carefully screened and tested U.S. donors, and contains the clotting proteins deficient or defective in vWD, which are Factor VIII (also known as Antihemophilic factor) and von Willebrand factor. Alphanate undergoes two separate steps for viral inactivation to reduce the risk for transfusion-transmitted viruses. However, the potential risk for the transmission of blood-borne viruses, and theoretically variant CJD, while very low, cannot be totally eliminated.

In clinical studies with Alphanate, 120 major, moderate and minor surgical procedures were performed in 76 patients. Based on predefined criteria for efficacy, more than 90 percent of patients had favorable outcomes. In these clinical studies, 15.8 percent of subjects and 5.7 percent of infusions were accompanied by adverse reactions, most commonly itching, pharyngitis, paresthesia (a sensation of numbness and tingling on the skin), headaches, swelling of the face, rash and chills.

Alphanate is manufactured by Grifols Biologicals, Inc., Los Angeles, Calif.

HFA Member Organizations

- Bleeding Disorders Association of the Southern Tier (New York)
- Florida Hemophilia Association
- Gateway Hemophilia Association (Missouri)
- Hemophilia Association of the Capitol Area (Maryland)
- Hemophilia Foundation of Arkansas
- Hemophilia Foundation of Idaho
- Hemophilia Foundation of Illinois
- Hemophilia Foundation of Maryland
- Hemophilia Foundation of Minnesota/Dakotas
- Hemophilia Foundation of Nevada
- Hemophilia Foundation of Northern California
- Hemophilia Foundation of Southern California
- Hemophilia of Indiana
- Hemophilia of North Carolina
- Hemophilia of South Carolina
- Hemophilia Outreach of El Paso (Texas)
- Lone Star Chapter of NHF (Texas)
- Nebraska Chapter of the NHF
- Northern Ohio Hemophilia Foundation
- Oklahoma Hemophilia Foundation
- Sangre de Oro, Hemophilia Foundation of New Mexico
- Snake River Hemophilia & Bleeding Disorders Association (Idaho)
- Tennessee Hemophilia & Bleeding Disorder Foundation
- Texas Central Hemophilia Association
- Tri-State Bleeding Disorder Foundation (Ohio)
- United Virginia Chapter
- Utah Hemophilia Foundation

One Last Look at the HFA 2007 Educational Symposium in Albuquerque, NM...



Member News



FLORIDA HEMOPHILIA ASSOCIATION

Events

June 29 - July 1

24th Annual Family Education Symposium - Deerfield Beach Resort

July, 1, 2007

Submission Deadline for the Daniel L. Carlin Memorial Scholarship Fund

October 1, 2007

Swing for the Kids Golf Tournament - Jacaranda Golf Club

December 1, 2007

Holiday Picnic, CB Smith Park - Pembroke Pines, FL

FHA's Compassionate Care program provides emergency assistance funds for individuals and families impacted by bleeding disorders. These funds can be utilized for emergencies affecting basic living requirements, such as rent/mortgage payments, utilities, food, and phone card to call the treatment center. If you like to learn more, please visit our website at: <http://www.floridahemophilia.org/>

HEMOPHILIA FOUNDATION OF NEVADA

May 18th

Art Kane Memorial Golf Tournament - Las Vegas

May 20th

Blood run - Las Vegas

June 2nd

Junior National Championship (CLS Behring)

July 12th-15th

Camp Independence - Las Vegas

August 9th-12th

Camp Eagle Spirit - Elko

September 15th

Consumer Expo Meeting - Reno

September 16th

Blood run - Reno

October 13th

Consumer Expo Meeting - Las Vegas

October 20th

5k Run/1 Mile Walk - Las Vegas

GATEWAY HEMOPHILIA ASSOCIATION

Spring 2007

General Membership Meeting

April/May

GHA Bowl-a-thon (Sponsored Event)

June 29th – July 1st

Family Education Weekend & General Membership Meeting - Country Club Hotel & Spa, Lake of the Ozarks, MO

July

Camp Barnabas

July 30th – August 4th

Wilderness Camp - Lawson, MO

Fall 2007

General Membership Meeting

September 24th

“Tee Off for Hemophilia” Golf Tournament - Annbriar Golf Course, Waterloo, IL

October

Halloween Hayride (Sponsored Event)

December

Christmas Party & General Membership Meeting

HEMOPHILIA FOUNDATION OF MARYLAND

January 1st

We moved to the address below. Our telephone numbers remain the same:

Hemophilia Foundation of Maryland
13 Class Court, Ste 200
Baltimore, MD 21234

May 19th

Spring Bull Roast & Silent Auction - Oregon Ridge Banquet Hall, Cockeysville, MD

June 2nd

HFM Walk for Hemophilia, Clarence “Du” Burns Arena

NORTHERN OHIO HEMOPHILIA FOUNDATION

May 11th

Hearts for Hemophilia Gala • Windows on the River

July 30th

17th Annual Ron & Tim Mattero Memorial Golf Outing • Quail Hollow

HEMOPHILIA FOUNDATION OF SOUTHERN CALIFORNIA

Semi-Annual Events

Regional Educational Seminars (for families with hemophilia & other bleeding disorders) Dates to be announced

May 9th & 16th

Hemophilia Council of California Couples Retreat -
Asilomar Center, Monterey

September 28th-29th

Camp Malibu

Man/won Program (for adults w/bleeding disorders,
spouses, partners & siblings)

Mentoring Program (for children, teens, young adults with
bleeding disorders)

Call HFSC for more information

1-800-371-4123 or 626-793-6192

OKLAHOMA HEMOPHILIA FOUNDATION

May 28th

Board Meeting - OKC

June 14th -18th

Camp Independence

July 13th -14th

OHF Annual Meeting

August 27th

Board Meeting - OKC

September 24th

Board Meeting - Tulsa

September

OHF Golf Classic - OKC

October 13th

Fall Festival - Glenpool

October 22nd

Board Meeting - OKC

December 1st

Christmas Party - OKC

**TEXAS CENTRAL HEMOPHILIA
ASSOCIATION**

May 7th

Greg McKinney Memorial Golf Tournament - Bridlewood
Golf Club, Flower Mound, TX

September TBA

Jokers Are Wild Casino Night/Gala

NEBRASKA CHAPTER OF THE NHF

August 10-12

Annual Meeting and Educational Conference in Lincoln

September 10

James Hollrah Memorial Golf Tournament - Wilderness
Ridge in Lincoln

October 7

Vala's Pumpkin Patch

HEMOPHILIA FOUNDATION OF ILLINOIS

May 5th & 6th

Our Statewide Family Education & Fun Weekend, Grand
Bear Resort - Utica, IL

July 22nd-28th

Camp Warren Jyrch - Leaf River, IL

September 19th

Annual Golf Outing - Cantigny Golf Course, Wheaton, IL

November 16th

Holiday Wine Auction & Dinner

HEMOPHILIA OF INDIANA

New Address:

5170 E 65th Street - Indianapolis, IN 46220

Phone Numbers: 317-570-0039

Main #: 317-570-0057

Patient Dental Service: 800-241-2873

Fax: 317-570-0058

SOUTHERN TIER ASSOCIATION

We have some of our events planned for 2007. In April, we are planning our 3rd annual family weekend which has been a very good informational event for everybody. Of course we will continue with sending our Kids to Camp High Hopes for boys and Camp Little Oaks for girls. Our Dads in Action committee is working on its event schedule for 2007 and we will keep you informed as each is scheduled. We are also planning our annual BDAST picnic followed by our golf tournament and wine event. The BDAST wishes everyone a happy holiday season.

**THE HEMOPHILIA FOUNDATION OF
ARKANSAS**

A Hemophilia Awareness Day is now an Arkansas State Law. On the afternoon of March 5, 2007, Governor Mike Beebe signed into law HB 1289, which states that the first day in the month of May of each year is designated as a Hemophilia Awareness Day in the state of Arkansas. It is our hope that with the Hemophilia Awareness Day we can bring about more knowledge, understanding and compassion to Hemophilia and related bleeding disorders. Plans for this event are in the making!

Events for 2007

March 31

Bowling Bash - Fort Smith - Bowling World, 3:30 - 7:00

May 1

Hemophilia Awareness Day - To be announced

June 17

Annual Membership Meeting -- Wild River Country
Waterpark - N.L.R., 10:00am - to close

July 22-27

Camp Nopokamee "Christmas in July" - Ozark
Conference Center - Morrilton

For kids ages 7-18 years old who are affected with
bleeding disorders, are carriers of hemophilia or are
siblings.

August

Matthew Parnell Golf Tournament - Maumelle Country
Club - TBA



December

Annual Christmas Party

Date, Time, and Place to be announced

Member News Continued on pg. 20

The Hemophilia Foundation of Arkansas exists to lend support, education and services to the bleeding disorders community in Arkansas. Special programs include summer camp, educational meetings, patient financial assistance and more. For additional information, please contact Donna Tozer toll-free at 888-941-HEMO or email at donna.tozer@yahoo.com.

TENNESSEE HEMOPHILIA & BLEEDING DISORDERS FOUNDATION

Thursday, May 17, 2007

Music City Golf Classic - Hermitage Golf Course, Old Hickory, TN

Saturday, June 2, 2007

Dart Tournament - Tupelo, MS

Monday, August 20, 2007

Blues on the Green Golf Tournament - Memphis, TN

September 22, 2007

Sporting Clay Tournament, TBD

October 6, 2007

Gala, Liberty Hall, The Factory at Franklin

November 19 - December 14, 2007

Poinsettia Sale

TRI-STATE BLEEDING DISORDER FOUNDATION

April 21

Wine Tasting - Richmond

April 27th-29th

Teen vWD program - Williamsburg

May 12th

Moms Night Out - Charlottesville

May 25th-27th

Family Weekend - Charlottesville - Camp Holiday Trails

June 2nd

Batter Up Event - VA Beach area

June 2nd

UVA Hem/Onc Reunion

June 8th

Harborfest - Norfolk Fest Event

June 15th

Chapter Reception - Richmond

June 16th

Annual Meeting - Richmond Science Museum

June 23rd

Family Fishing Outing - SW area of VA

June 24th

Bayou Boogaloo - Norfolk Fest Events

July 29th-Aug 3rd

Camp Youngblood at Camp Holiday Trails

August 18th

20 • Dateline Federation • Spring 2007

Von Willebrand Disease Women's Adult Retreat -
Homestead - SW area of VA

September 8th

Sleeping with the Fish - VA Beach area

Fishing Trip - Adult Retreat - VA Beach area

October 1st

Golf Tournament - Richmond

October 6th

Junior National Championship - Richmond

December

Holiday Parties - Hosted by UVA, VCU, and CHKD
HTC's

SNAKE RIVER HEMOPHILIA & BLEEDING DISORDERS ASSOCIATION

June 8th

Annual Education Day

August 11th

Swim Day

HEMOPHILIA OF NORTH CAROLINA

June 2nd

HNC Annual Meeting, Cararrus Arena & Event Center,
Concord, NC

June 22nd

HNC Annual Golf Tournament - The Preserve at Jordan
Lake, Chapel Hill, NC

June 10th-16th

Camp Rainbow

July 22nd-28th

Camp Carefree

July 30th-August 4th

Victory Junction Gang Camp



SANGRE de ORO/HFNM

April 26th-28th

Bi-Regional VIII and X Meeting - Springdale, UT

June 8th & 9th

CIT Training - Camp Oro Quay

June 10th-15th

Camp Sangre Valiente - Camp Oro Quay

June 30th

Nilo Duran Poker Run - Questa, NM

August 27th

Golf Tournament - Arroyo del Oso

October 26th-28th

Bowl-a-Thon/Family Weekend - Albuquerque, NM

HEMOPHILIA ASSOCIATION OF THE CAPITOL AREA

April 14-15

Couple's Retreat at Airlie Center - Warrenton, VA

April 22nd

Pool Party at George Mason University Aquatic Center -
Fairfax, VA 3:30pm-6:30 pm

May 14

12th Annual DC Hemophilia Open at Heritage Hunt Golf Club - Gainesville, VA. Shotgun start noon

Member News Continued on pg. 21

HEMOPHILIA FOUNDATION OF MN/DAKOTAS

April 13-14, 2007

HFMD Annual Meeting Ramada - MOA (formerly the Thunderbird), Bloomington, MN - Saturday Evening Activity: The Grand Lodge & Water Park

July 14-20, 2007

Summer Camp - Courage North Lake, George, MN

July 27-29, 2007

Dakota's Retreat - Black Hills, SD (Watch for more details in upcoming months)

September 10, 2007

HFMD Golf Tournament Indian Hills Golf Club - Stillwater, MN

November & December

Poinsettia Sales begin at HFMD

HFA member organizations are encouraged to post announcements and events by emailing the information to sandy.a@cox-internet.com.



IN MEMORIAM

RICHARD CHARLES NAGLER, 53, died peacefully in his sleep at his home in Ft. Collins, CO on January 9th, 2007. Mr. Nagler spent the majority of his life in Alexandria VA where he was a Virginia Senior Probation and Parole Officer and noted volunteer for the Hemophilia Association of the Capitol Area. After his retirement in 1999, Richard moved to Colorado with his wife, Mary. He is survived by Mary and his brother, James Sr.

Mr. Nagler was a very active volunteer in several hemophilia-related groups both in the Washington, D.C. area and nationwide. Through his work on Capitol Hill, he helped to secure a safe blood supply for future generations by testifying before the Academy of Sciences Institutes of Medicine, as well as being an advocate for people affected by Hemophilia, HIV and HCV. He helped raise money for and awareness of the problems facing people afflicted with these diseases. He is featured along with other people with hemophilia and HIV and their family members in a book titled "Dying in Vein".

RANDI PALTROW, Director of National Relations at Patient Services, Inc. (PSI), died January 20, 2007 after a year-long battle with pancreatic cancer. Dana Kuhn, PhD, PSI president and founder and a close friend of Randi's, expressed his company's deep regret at her loss and the creation of an endowment called the 'PSI Randi Paltrow Fund' to keep her legacy alive. (www.hemophilia.org/NHFWeb/MainPgs/MainNHF.asp)

Randi was a devoted advocate of the hemophilia community. Randi served as Executive Director of the Northern Ohio Hemophilia Foundation from 1999-2003. She served as Director of the Board of the AIDS Task Force of Greater Cleveland and at the Cleveland United Way. From 1992-1998, Randi worked at the American Red Cross in Northern Ohio. As the Manager of the West Service Area Office and a Blood Donor Consultant she increased the number of donor collections and program donations, and recruited volunteers.

In announcing Paltrow's death, Laurie Kelly wrote that Randi "dedicated herself to the important issues of insurance reform . . . (and) downplayed her cancer. She was energetic, bursting with ideas, and determined to not let her illness get her down. With her typical can-do attitude, she always made you believe that she would overcome any obstacle. I hope our community adopts that attitude as her legacy, as we say good-bye to a true friend." (www.kelleycom.com/blog/2007/01)

Randi was also a longtime friend of the Hemophilia Federation of America and those of us who worked with her had these comments:

"Very sad news indeed...she will be missed!" Maria Rubin

"I will miss her greatly . . . It is for those of us who remain to carry on the mission and make sure that what she believed in and what we all fight for will never be forgotten." Bob Marks



Two Research Collaborations to Develop New Hemophilia B Products

Wyeth Pharmaceuticals announced two new research collaborations to discover, develop, manufacture and market novel biopharmaceutical products to treat hemophilia. The research partnerships are with Nautilus Biotech in Evry, France, and MediVas, LLC in San Diego, Calif.

Nautilus has developed a patented technology that makes minimal and specific changes to the amino acids in order to slow the breakdown of the factor IX protein in the body. MediVas will employ its unique polymer-based drug delivery system to develop novel formulations of recombinant factor products.

Both Nautilus and MediVas will apply their proprietary technologies in an effort to extend the half-life of recombinant hemophilia therapies. If successfully developed, a product with an extended half-life might allow patients to reduce the number and frequency of treatments.

Wyeth Receives FDA Approval for New BeneFIX Features

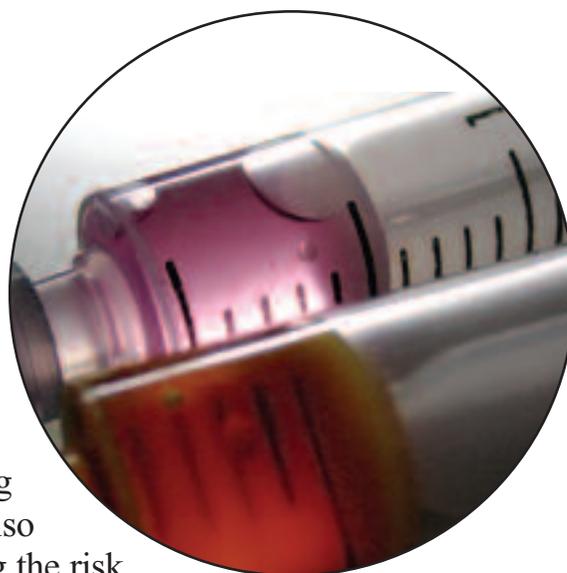
Wyeth Pharmaceuticals announced that it has received approval from the U.S. Food and Drug Administration (FDA) for new convenience enhancements for BeneFIX® Coagulation Factor IX (Recombinant) that will offer patients a simpler and more convenient preparation process compared to the original BeneFIX preparation process.

The FDA approved the following four convenience enhancements for BeneFIX: a 2000 IU vial, a needle-less reconstitution device, a prefilled diluent syringe and a reduced diluent volume for the 1000 IU dosage strength.

The new BeneFIX features allow patients to use a lower volume of diluent to administer the product for the most commonly used dosage size (1000 IU), leading to a lower total volume of infused product. BeneFIX also offers a new needle-less preparation process eliminating the risk of needle-sticks during reconstitution. The 2000 IU vial will be the largest unit dosage vial offered for hemophilia B treatment.

Wyeth expects to begin offering BeneFIX with these new enhancements in mid-2007.

Please see full Prescribing Information at www.hemophiliavillage.com. For a copy of the Prescribing Information or for more information about BeneFIX, you can also call the Wyeth Hemophilia Hotline, 1-888-999-2349.



Mission Statement

The Hemophilia Federation of America is a national non-profit organization that assists and advocates for the blood clotting disorders community.



Vision Statement

The vision of the Hemophilia Federation of America is that the blood clotting disorders community has removed all barriers to both choice of treatment and quality of life.

WHY JOIN THE HFA?

Your membership in Hemophilia Federation of America helps to support the

- Grassroots Advocacy
- Educational Symposium
- Helping Hands
- Dads in Action
- Focus on the Feminine
- Blood Brotherhood
- Comprehensive Children's Programming
- Teen Connection
- Educational Scholarships
- Consumer Directory
- Informative Website
- Educational Resources
- Community Chat Rooms

To join, visit our website at www.hemophiliafed.org or complete and return the membership form found on the back cover of this issue.

BECOME A MEMBER OF THE HEMOPHILIA FEDERATION OF AMERICA

IN ONE OF THE FOLLOWING WAYS:

Visit our website at www.hemophiliafed.org, use Paypal to send payment

or

Complete the information below and mail to address listed below.

I would like to become a partner of the Hemophilia Federation of America. Please accept my donation in the following category.

- Corporate Angel Partner (\$100,000)
- Corporate Diamond Partner (\$50,000)
- Corporate Platinum Partner (\$25,000)
- Corporate Gold (\$10,000)
- Corporate Silver (\$5,000)
- Corporate Bronze (\$2,000)
- Corporate Friend (below \$2,000)
- Chapters (\$750)
- Individual Diamond (\$1,000)
- Individual Platinum (\$500)
- Individual Gold (\$100)
- Individual Silver (\$50)
- Individual Bronze (\$25)

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Please make checks payable to: Hemophilia Federation of America.



**Hemophilia Federation of
America**

1405 W. Pinhook Road, Suite 101
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