

dateline

# FEDERATION

Issue 16 Volume 10 • Summer 2008

2008 Symposium

## Getting Our Ducks in a Row

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INSIDE



# Educational Symposium 2008

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

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

This year's Educational Symposium allowed members, member organizations and the hemophilia community at large to come together to get "Our Ducks in a Row". The over 500 attendees of the Hemophilia Federation of America's 14th Annual Educational Symposium met in Little Rock, AR May 1st - 3rd to organize and define objectives for the 2008/2009 operating year and to help each other navigate barriers ranging from insurance to employment.

With over 30 exhibitors, information and access to health care providers allowed guests to have their questions answered on a one-on-one basis. The presentation offerings were wide and diverse. Each session and its presenters shared particular expertise on a variety of topics and issues affecting the hemophilia community, from health care delivery to insurance and payments, as well as pain, therapy and emergency room care.

The Blood Brotherhood program took center stage as over 40 Blood Brothers, many of whom were first-time symposium guests, met to train and initiate the Blood Brotherhood program in six pilot sites all over the country.

Little Rock provided a great backdrop for the families of the HFA to enjoy the mild, if often stormy, weather of middle America. The Peabody Hotel hosted the HFA and our guests, and provided an always exciting march of the ducks twice daily. From the scenery of the location on the river to the ability to walk to a number of "Flying" restaurants Little Rock offered symposium attendees plenty of entertainment including a closing at the Museum of Discovery.

In addition to the children's programming in Little Rock, the HFA teens traveled to Perryville, Arkansas to the Heifer Ranch for the first ever overnight camp in HFA history.

The HFA Board met on May 30 to make some important decisions about the future of HFA, as well as elect a new slate of Board officers. Important programmatic and administrative issues were decided and the future of HFA is bright thanks to the progress made in this meeting!

More information about the individual sessions and news from the symposium can be found throughout this issue of *Dateline Federation*. We would be remiss in reflecting on the 2008 Symposium without thanking the generous sponsors of our sessions and the volunteers and staff who made the event happen!



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# A Message from the HFA Board

Former HFA Board President Carl Weixler passed the torch to Chad Stevens, incoming Board President at the 2008 Symposium. The Board and Staff of the Hemophilia Federation would like to thank Carl for his commitment to the HFA as we proudly welcome Chad!



**Outgoing Board President  
Carl Weixler**

## TITLE OF THE ARTICLE

Amy Lynn James, 30-years-old, of Maumelle, Arkansas died Sunday, October 28, 2007, at Hospice Home Care in Little Rock after a lifelong battle with diabetes. A past President of the Hemophilia Foundation of Arkansas, Inc. Amy was very

active in diabetes and hemophilia research. Amy was the proud mother of two sons to whom she devoted her life. Both Christian James and Jordan Baker were born with hemophilia and required her constant care. She is survived by both sons and a host of family and friends whose lives she touched.

Following a private memorial held in her memory, Amy's body was donated to medical research in an effort to find a cure for diabetes. The family requests that, in lieu of flowers, gifts or memorial contributions be sent to a trust fund set up for her children through First Service Bank, P.O. Box 430, Greenbrier, AR 72058, (501) 679-7300.

The Board of Directors and staff of the Hemophilia Federation of America would also like to extend its condolences to family and friends of Donna Riling, who passed away on December 14, 2007. She was a past Associate Executive Director serving on staff for the Tennessee Hemophilia & Bleeding Disorders Foundation (THBDF) for 11 years until her retirement six years ago. After Donna's retirement, she continued to be an active volunteer, advocate and friend for the community that she so dearly loved.

Save One Life is a 501(c)3 registered charitable organization who's vision is a sponsor for every person with a bleeding disorder who lives in the developing world and needs aid. One who offers compassion, friendship, direct financial support and a future filled with hope. Just \$240 annually provides food, vitamins, clothing or an education a young person with a bleeding disorder who would otherwise have to go without. To learn more about Save One Life visit their website at: [www.SaveOneLifeInc.org](http://www.SaveOneLifeInc.org).

In a recent letter, Molly M. Evers, a recipient of the 2007

**Incoming Board President,  
Chad Stevens**

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*The 2007-2008 HFA Board tours North Little Rock after their board meeting on April 30th, 2008.*

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# Outstanding Members Recognized - 2008 Award Recipients

## Outgoing Board of Directors Recognized

During the opening luncheon of the 2008 HFA Educational Symposium incoming Board President Chad Stevens, thanked six board members for their over thirty combined years of service to the HFA. As Chad noted, board members serve tirelessly during their terms but never their skills and volunteer commitment are taken from the community. As we thanked the board members for their service, *Joyce Donlan*, or “Granny Goodfood,” was recognized for her voice of reason and commitment to establishing, maintaining and growing the HFA children’s programming. Although *Erick Johnson* will continue to drive membership to the HFA, his thoughtful contemplation of ways to improve the community will be missed. As symposium board chair *Donald Akers, Jr.* has solidified his role as a member of the bleeding disorders community even though blood tests would not confirm the same. Donnie will continue to offer sound advice and legal help as he assumes the role of General Counsel. Always impeccable, *Joey Privat* leaves the board where he first impacted the community through his tireless work to establish the HFA’s Dads in Action Program. Although they were absent from the luncheon, *Star Tyree* and *Barbara Chang* were recognized for their commitment to the HFA. *Star Tyree’s* care and commitment to HFA at large has always been driven by her commitment to the individual. Finally, the HFA board will bid farewell to *Barbara Chang*, a former HFA President whose role as a volunteer and resource had a great impact on the progress the HFA has made in the past few years. Although the HFA will miss these board members, we find joy in the fact that they will continue to be a part of the community.

**President’s Award: Barbara Chang**

2007 President Carl Weixler spoke about Barbara Chang and her commitment to the Hemophilia community. “Although Barbara is not a member of the community, she has been adopted into the family because of how special she is,” said Carl. Barbara’s longtime commitment extends through a number of roles in the HFA including but are not limited to tireless advocate, volunteer and friend. Her consideration of the individual and her willingness to be a resource to Carl Weixler earn the President’s Award.

## Volunteer of the Year: Tabby Mayhan

Executive Director Susan Swindle presented Tabby Mayhan with the 2008 Volunteer of the Year award. Tabby’s commitment to the HFA began when, without pause, she her own child and our own HFA President for the first time during an annual symposium. Tabby provided much-needed assistance in preparing for the 2008 Symposium, which is why she was honored with the Volunteer of the Year Award.

## Carl Weixler, President 2005-2008

The HFA would like to thank outgoing HFA President Carl Weixler for his service to the organization. Under Carl’s tenure as president from 2005-2008, the HFA has accomplished a great deal. Carl’s commitment to this organization for the past three years as president was highlighted by his willingness to talk to anyone at any time about anything. Chad Stevens presented the award to Carl and expressed his thanks for taking him under his wing. Chad concluded with the sentiment that he “is proud to call Carl a mentor, blood brother and friend.”

## Ron Neiderman Humanitarian Award given to Kim Bernstein

Kim Bernstein was honored with the Ron Neiderman Humanitarian Award for her service to the bleeding disorders community through her profession. This award, in honor of Ron Neiderman, is given to a person whose desire, tenacity and kindness to the community matches Mr. Neiderman. Our community lost Ron Neiderman but continues to honor him with this award. Kim has been active

in the community since 1992, where she serving as an advocate, voice and educator for the community at large. Kim’s reminder to focus on the question “What is your why?” has encouraged members and advocates alike to speak on behalf of the HFA on the numerous trips to Capital Hill.

*Pictured-From Top Left to Bottom Right: Joyce Donlan, Erick Johnson, Chad Stevens and Donnie Akers, Joey Privat and Chad Stevens, Carl Weixler, Tabby Mayhan and Susan Swindle, Chad Stevens and Carl Weixler, Kim Bernstein and Carl Weixler*





## Enduring the Dynamics

The first session of the HFA symposium, titled *Enduring the Dynamics of Living with a Chronic Bleeding Disorder: Healthcare Delivery Today and in the Future*, provided a variety of sources for advocating on behalf of patients with bleeding disorders. Paul Brayshaw, HFA Advocacy Co-Chair, and Kisa Carter, HFA Public Policy Director, facilitated the session, which allowed the panel participants to explain their individual companies' roles and challenges in the community in which they serve.

The discussion covered a range of issues associated with managing the cost of care while maintaining access to care. The session gave attendees an explanation of the variety of factors that exist in the world of bleeding disorders treatment, care and payment. The speakers encouraged the attendees to advocate for themselves as patients with bleeding disorders.

A discussion of the hemophilia payer mix offered examples of how the healthcare environment is changing and how it affects people with hemophilia. The healthcare environment continues to change, and there are a number of resources available to patients and families with bleeding disorders to point patients in the right direction to advocate for themselves. (For a full listing of patient advocacy groups and resources, visit the resources section of the HFA web site [www.hemophiliafed.org](http://www.hemophiliafed.org))

Panel participants represented a variety of products, distributors, insurance carriers and information providers including Joe Pugliese (Executive VP, Hemophilia Alliance Group Purchasing Organization), Gary Mull (VP Client Relations, AHF) Glenn Mitchell (Area VP, Chronic Sales, CVS Caremark) and Michael Bradley (Baxter Healthcare).

The changing cost market of hemophilia treatment and insurance reimbursements has been unequal at best in recent years. The cost of producing factor, although expensive, has gone down in recent years, but so has the reimbursement given to patients. In a volatile insurance and medical reimbursement environment, this session provided answers to questions regarding specific factors, insurance plans and treatment mechanisms.



## Insuring Survival

Insurance issues vary according to individual patients with specific bleeding disorders. Navigating the maze of insurance options, rights and responsibilities can be complicated for a person with a bleeding disorder. However, the *Insuring Survival* session with panel participants provided a number of options to persons in our community. Sally McCarty (Insurance Advocate, Hemophilia of Indiana), Dana Kuhn (Patient Services Incorporated), Cheryl Fish-Parcham (Deputy Director, Health Policy, Families USA), Jeff Gabardi (Senior Vice President, State Affairs, America's Health Insurance Plans) each explained the options provided by their organizations.

The purpose of each of the presenting organizations is to provide access and accessibility to health care for persons with bleeding disorders. Each organization's representatives suggested self-advocacy but also offered a range of support to people in our community. Issues discussed included lifetime caps, being labeled "uninsurable," issues affecting retirement, and family and employment changes. Being a part of an individual plan, small group plan or large group plan can affect each patient's insurance rights, and the session focused on the risks and benefits of being a part of each of these plans.

National healthcare concerns are more complicated for persons with bleeding disorders because treatment costs for specialty injectables and treatment of bleeds can be costly. Cheryl Fish-Parcham suggested three needs of the bleeding disorders community as they relate to insurance: "We need rules. We need adequate benefits. We need to spread the costs." The needs of the bleeding disorders community, however, are not that far outside of those in the national scope of insurance coverage. In addition to suggesting that HFA partner with other disease groups to advocate for insurance rights, Sally McCarty noted that in the bigger picture, "We need a President and a Congress that are brave enough to step on some toes to solve this problem."



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# Program Updates *Hemophilia Federation of America*



HFA's newest program, the Blood Brotherhood, kicked off in Little Rock with fun, learning and team-building, as over 45 members of the pilot Blood Brotherhood groups convened during the Symposium.

The Blood Brotherhood was created earlier this year with funding from the Centers for Disease Control. The CDC wanted to address the needs of adult men with bleeding disorders, and HFA put together a winning plan that included group meetings, an online chat room, community projects and plenty of opportunities for sharing experiences, all with the objective of helping the "older" generation live healthier lives.

In its first year, the Blood Brotherhood has established core groups at six pilot sites around the country. All six--Oregon, Indiana, Tennessee, Texas, Illinois and Maryland--were represented in Little Rock. "I enjoyed renewing old relationships, and meeting people whom I have met online and now can put a face and a joint problem with," John Reed observed.

While the Brotherhood's site coordinators were in a training and brainstorming session, the Blood Brothers competed in a Wii tournament refereed by program co-chair Carl Weixler. After a couple of hours of good-natured competition, the team of Greg M., Kevin S., Jim M. and Jarrod Y. emerged as champions. "We'll be doing more Wii contests, both at sites and online, because it's such a fun way to stay active and keep moving," program coordinator Dan Bond said. The Blood Brotherhood will be providing Wii's to all 6 pilot sites to keep the competition going. Bob E. from Illinois took home the tournament Wii as the prize for being the oldest Blood Brother in attendance.

During Saturday's breakout session, Dan Bond provided a brief overview of the program. Wayne Cook, Blood Brotherhood co-chair, did a short presentation on Continuous Infusions and joint replacements. HFA attorney Donnie Akers spoke to the group about wills and trusts. "I learned more this weekend than I have in years," James L. of Texas said.

Everyone left Little Rock with a new or renewed sense of Brotherhood, and new ideas for fostering collaboration and sharing among the seasoned veterans in the bleeding disorder community. Each site will be meeting several times during the year, along with "meeting" and sharing ideas online.



Dads in Action Co-Chairs Joey Privat and Tom Vaclavik, along with Dad's in Action trained leaders from a variety of states, led the Dad's in

Action Session at the 2008 Symposium. The group of almost 40 men met to talk about situations that affect dads and their personal concerns, problems and victories as dads of children with a bleeding disorders.

The dads group shared their experiences from infusions to healthcare coverage and from sports to day-to-day life with a bleeding disorder. The Dad's in Action program provides fathers with training and comradeship as they build strong bonds with their children. The group which allows dads to give other dads support, helped one father, who said, "I am used to taking care of problems myself, but there are some things you just can't - Dad's in Action helps with that."

The session allowed the men to introduce themselves and tell about their families, who live in over 13 states. Despite geographic differences, the dads left the session knowing that there were some others in their corner. One veteran dad described every day as a learning experience, with programs like Dads in Action allowing men not to stand alone in that experience.

*Above: from left to right - Joey Privat, Stanford Murray, Lance Cleghorn and Sean Kaercher share a lighthearted moment with the attendees of the Dad's in Action Breakout Session.*

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Hemophilia Federation of America  
**FOCUS** ON THE *Feminine*

Candy Whirley will join the HFA 2008 Symposium as a presenter of the Focus on the Feminine breakout session entitled "Let Me Guess... Too Much Stress?" Candy will bring the Symposium attendees on a roller coaster ride with her high-energy, innovative training activities and her contagious sense of humor.

Candy specializes in breaking down barriers so that people will work better together, learn to deal with change, improve communication, and become more creative. Her interactive style includes stories and engaging activities that not only make learning fun, but bring meaning to the topic and help the participants retain and apply what they have learned.

Through speeches and workshops, Candy shares over 20+ years of expertise to help professionals from the Hawaiian Islands to London, England improve their job performance and achieve their personal goals. Currently Candy serves as President of the Kansas City Chapter of the National Speakers' Association. She graduated Cum Laude from Missouri Western State College with a B.S. in Speech Communications, with a Human Relations emphasis. Candy earned a Masters in Management from the University of Phoenix. A former Kansas City Chiefs



BY: LEE HALL, GLOBAL HEALTH SOCIETY, INC.

The 2008 Hemophilia Federation of America's (HFA) Annual Symposium Teen Connection was marked by a pivotal event, the first camp program "All One World . . . A Heard to be Heard." HFA joined forces with Global Health Society, Inc (GHS) collaborating together at Heifer's International Ranch located in Perryville, Arkansas just forty-five minutes northwest of Little Rock.

This exuberating event was sponsored by the generous support of WYETH and was attended by twenty-two teenagers, one hematologist, one physical therapist and two nurses, who were part of the GHS Medical Team, and five counselors from the teen connection committee and GHS.

The camp consisted of many uplifting and experiential activities conveying the truths of international issues surrounding poverty, diseases, morbidity and global factor consumption. Activities were conducted in a barn where the floor was painted as a global map to simulate the visual concept of the global consumer census, spending and explorations into cultures spanning the continents. Does this sound like a new twist on a camp? Well it was.

The interactive educational activities on Friday took the campers on a journey into four of the six Heifer villages; simulating living situations in Guatemala, Zambia, Thailand and the Urban Slum. The youth and adults were randomly divided, unevenly, to assist in this process of the exploration of life and poverty in underdeveloped regions.

*Continued on Page 8: "A Herd to be Heard"*



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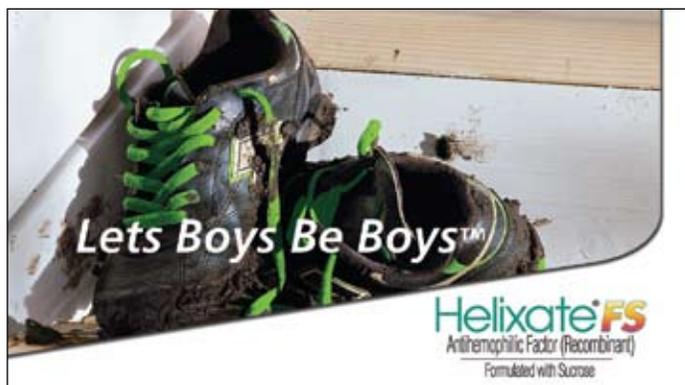


**Jesse Mayhan** – Pushes his own factor for some time now. Great



## **Spencer Duggan**

– From Chantilly, VA was invited to sing in John Rutter's Mass of the Children in Carnegie Hall on April 20th. Spencer is a member of his high school's Music Honor Society, Tri-M, and the Fairfax Choral Society in the Master Singers. He has been accepted in the music program at Shenandoah Conservatory which he will attend in the Fall. He will major in Music Education and minor in Voice Performance.



## *HFA Teen Connection* myPlace

*Jim Munn* reflects on his recent experience at the HFA Teen Program Camp in Perryville, AK with "ALL ONE WORLD" By Jim Munn, RN

When I was first contacted by Lee Hall from Global Health Society (GHS) about helping with an educational program for teens at the HFA Annual Meeting I was intrigued by the fact that we would be conducting a "mini camp" that engendered a global perspective. Once I received word of the program's title -- "All One World . . . A Herd to be Heard" -- and that it would be conducted at the Heifer International Ranch, I couldn't help but think I was at risk for stepping into something that can be used as a fuel source. My preconceived notion could not have been less accurate.

Although we did see several bovine behemoths (and some "fuel paddies" drying in the sun) what transpired over the course of one and a half days in Perryville, AR, on May 2nd and 3rd, was one of the best "camping" experiences I have worked. As part of a health center team comprised of a physician, two nurses and a physical therapist, I can attest to the fact that we had as much fun as the campers and learned much in that short time. Based on the premise we all share one world, the programming set forth by Heifer International was eye-opening and relevant to the education Lee and his staff developed. The entire camp became a part of the global village and we learned what it may be like for families around the world to subsist for a day. Lee and the other GHS staff members were able to weave into the Heifer International program the bleeding disorders experience from a global perspective as well. I don't believe anyone came away from that weekend untouched by the interconnected life experiences we shared.

Several educational sessions and fun activities were conducted; each enriching the desire to expose the campers to something larger than they are. With slides depicting life with hemophilia in Peru and Romania provided by Susan Zappa, R.N., and Lee Hall, the nurses had the unique opportunity to explain to the campers how treatment is given in other areas of the world and some of the consequences their "blood brothers" experience because of lack of factor and a paucity of other simple care measures. Accompanied by a heart-warming letter from Maria (last name here)'s cousin who lives in Venezuela, we learned to be thankful for our bounty and cognizant of the challenges still faced by approximately 75% of the world's people affected by bleeding disorders. By the looks on campers' faces, the willingness to participate in all components of the camp, and the comments shared with family members and HFA meeting attendees on return to Little Rock, I can safely say the program was a huge success! I know it was for me!

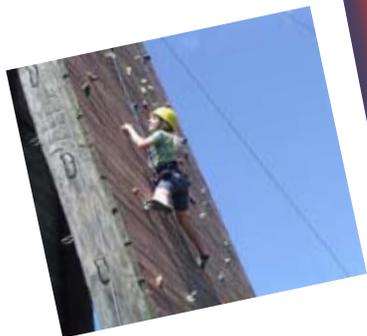
*Industry News*  
*Just for Kids*

**BioRx announces its 2009 Kids Hemophilia Calendar Contest**

CINCINNATI, Ohio (April 17, 2008) – BioRx seeks artwork from children under the age of 18, who either have a bleeding disorder or have a sibling or parent with a bleeding disorder. Children should submit artwork relating to experiences in living with hemophilia, along with an entry form by September 2 to: Bio Rx • Kids Calendar Contest • 10829 Kentwood Road • Cincinnati, OH 45242. An entry form can be obtained by visiting BioRx's website at [http://biorx.net/wp/wp-content/uploads/2007/11/2009\\_calendar\\_contest.pdf](http://biorx.net/wp/wp-content/uploads/2007/11/2009_calendar_contest.pdf). For a copy of the article in its entirety, please visit [www.hemophiliafed.org](http://www.hemophiliafed.org), Industry News Section (Information provided by Bio Rx).

**Step Up Reach Out applications announced for 2008 by Fleishman-Hilliard Inc.**

(April 7, 2008) – A leadership program for young men with hemophilia called Step Up Reach Out is currently seeking applicants to participate in this year's class. Applicants must be between 18 and 22 years old with a diagnosis of hemophilia A or B and proficiency in English. More information and an application form are available at [www.stepupreachout.net](http://www.stepupreachout.net). (Information provided by Michelle Slattery Tuoy, Fleishman-Hilliard, Inc.).





## Therapy Advances from Bayer and CSL Behring

Bleeding disorders medications manufacturers were invited to present the latest in medical testing advances in the Therapy Advances Session of the HFA Symposium. The HFA welcomed Jurg M. Sommer, Ph.D, Hematology Research, who spoke on Research and Development of Longer Acting Factor VIII Products for Hemophilia A Treatment. Although Hemophilia A affects a small group of people, Bayer is committed to finding a longer acting treatment. In addition, CSL Behring is coming up with treatments and special factors for rarer forms of bleeding disorders. Kilmartin presented information on Humate P, "Beriplex" or prothrombin complex contrite.



## More in Industry News

**Bayer HealthCare Receives Gold Award for [www.livingwithhemophilia.com](http://www.livingwithhemophilia.com) - Best Educational Web Site for Patients**

BERKELEY, Calif. (April 28, 2008) – The Health Information Resource Center has recognized Bayer HealthCare for excellence in Web site development of its hemophilia patient education Web site, [LivingWithHemophilia.com](http://LivingWithHemophilia.com). The site received the highest award for patient education information as part of the 2007 annual World Wide Web Health Awards competition, a program that recognizes the best Web-based health-related content for consumers and professionals. *For a copy of the article in its entirety, please visit [www.hemophiliafed.org](http://www.hemophiliafed.org), Industry News Section (Information provided by Bayer HealthCare).*

**Dr. Hani Atrash appointed Director of the Division of Blood Disorders (DBD) in the National Center on Birth Defects and Developmental Disabilities (NCBDDD)**

Effective Jun 2008, Dr. Atrash will assume his new role as Director of the DBD in the NCBDDD. Over the last couple of years, under the direction of Dr. Roshni Kulkari, the DBD has expanded its vision and continued to lead in our community. Dr. Atrash's expertise in program development and in execution of large public health programs will combine with the strengths of the DBD's scientists and staff to enhance and expand the divisions excellent programs in blood disorders, and to increase DBD's collaboration with other divisions at CDC, with partners at state and local health departments, and with private organizations. *(Information provided by Dr. Ed Trevathan, Director, National Center on Birth Defects and Developmental Disabilities).*

<p><b>John Reed RPh</b> <b>Cliff Marshall RPh</b></p>  <p><b>Pharmacist's specializing In Bleeding Disorder Products</b></p>	<p><b>Cyril Home Care Pharmacy</b></p> <p>214 Missouri PO Box 676 Cyril, OK 73029</p> <p>Phone: <b>1-888-258-2453</b> Fax: 1-877-464-3108 Email: <a href="mailto:jbreed@tds.net">jbreed@tds.net</a></p>
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## Omissions and Edits

*Corrections from PAGE 13 of the the Winter 2008 Dateline Federation:*

*Information on the Caremark Eric Delson Memorial Scholarship can be found at <http://healthresources.caremark.com/topic/prchemophilia>.*

*Information on the COTT Scholarship can be found at [http://www.cott1.org/news.html?topic\\_id=11](http://www.cott1.org/news.html?topic_id=11)*

*Information on the NuFACTOR Eric Dostie scholarship can be found at <http://hemophiliafed.org/site54.php>*

# Employment, Retirement, Insurance- The Basics



Avi Kumin, a partner in Katz, Marshall and Banks, LLP, along with Dana and Mandy Kuhn of PSI, Inc., presented the basics of rules and regulations of employment and how it affects insurance, retirement and hemophilia treatment. To better help members of the bleeding disorders community navigate issues with

their employers and their family members' employers as they work regulations and rules of the Family Medical Leave Act (FMLA), Americans with Disabilities Act (ADA), Rehabilitation Act, Employee Retirement Income Security Act (ERISA), HIPAA and COBRA were discussed as they relate to the members of the Hemophilia Community.

In order to ensure job stability while dealing with a family or personal medical issue, Avi Kumin, an expert in employee rights, suggested that an employee understand the FMLA, meet the eligibility requirements for FMLA, and fulfill the reasons for leave. In order to request leave, Kumin suggested that there were "no magic words" necessary but to protect oneself employees should (1) specifically ask for "family and medical leave," (2) do it in writing and keep a copy and (3) connect the leave request to a serious medical condition.

The Americans with Disabilities Act (ADA) protects qualified individuals with a disability from discrimination in the workplace. In addition, the ADA permits disabled employees to request workplace accommodations to allow them to do their jobs. Although the ADA does not provide absolute protection from firing, there are rights when a person is approved for coverage under the ADA. To qualify for the ADA a patient must be regarded as being or have a record of being substantially limited in a major life activity.

ERISA is a federal law that applies to employer benefits plans, such as health care benefits and pension benefits. ERISA provides protection to the patient because it rules that an employer cannot terminate an employee with Hemophilia because his/her use of health care benefits is expensive.

Mandy Kuhn of PSI, Inc. explained the need to be open to HIPAA and COBRA options when changing employment. Our speakers all encouraged for persons with bleeding disorders to be relentless and become their own advocate when facing employment concerns.

There are a number of resources available to persons with bleeding disorders and employment concerns and issues:

Avi Kumin, Partner, Katz, Marshall and Banks, LLP

Dana Kuhn, Mandy Kuhn, PSI, Inc.

ACCESS Program part of Hemophilia Health Services when it comes to social security and SSI call 880-700-7010

Bleeding Disorders Hotline in TX if you have a problem while you are working call 800-520-6154

*PROTECT YOURSELF  
against barriers to  
employment:*

- Make requests in writing*
- Keep documentation*
- Email description of events to yourself*
- Don't give them any other excuse to fire you!  
(tardiness/attendance issues), (performance problems) (insubordination)*

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## Emergency Room Care



According to the attendees of the Navigating the ER session, emergency room visits can range from pleasant to terrible depending on the hospital, the doctor and the regulations for treating hemophilia. Chris Walsh, MD, from the Mt. Sinai School of Medicine, advocates preparedness, and working together with your HTC or personal doctor and the treating physician.

Walsh noted a need for an emergency medicine-approved and disseminated list of guidelines for treatment of bleeds in the hemophilia community. The discussion focused around what patients feel is needed from emergency rooms. Patients with hemophilia present a unique case for emergency room doctors—they are particularly well educated and experienced in their disease and its treatment. Sometimes, but not always, ER doctors have little experience with management of bleeding episodes. Walsh calls the relationship between bleeding disorders patients and emergency room physicians a “paradoxical situation [which] often leads to frustration for both.” He adds, “...it need not be this way.”

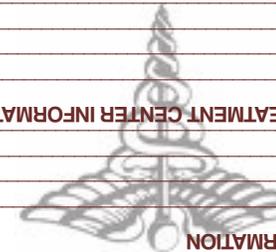
The session’s question and answer portion revealed a number of

### Patient Rights and Responsibilities in the ER

- Your knowledge of your disease is your best weapon.
- Carry a medical alert bracelet indicating your condition.
- Carry a card with your HTC information.
- Stress the need to contact the HTC.
- Carry and bring your own factor to the ER/Hospital.

ways that patients can notify doctors and officials about their specific factor deficiency. The key to preparing for a bleed is to call ahead. Your local EMS director and ER can provide specific regulations, notifications and other information on your treatment ahead of time. If you can educate the health professionals in your area emergency room, you will be more able to get good treatment from them.

*Fill out this “In Case of Emergency Card,” cut along the dotted lines, fold it in half and place it in your wallet so that your HTC and ER Doctor can be on the same page. This small card and your medical alert bracelet will be of great help in case of emergency.*



**HEMOPHILIA TREATMENT CENTER INFORMATION**

Phone 2: \_\_\_\_\_  
 Emergency #: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 First, M.I., Last: \_\_\_\_\_

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**PHYSICIAN INFORMATION**

First, M.I., Last: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 Emergency #: \_\_\_\_\_  
 Phone 2: \_\_\_\_\_

**IN CASE OF EMERGENCY**

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**IN CASE OF EMERGENCY**

**PATIENT INFORMATION**

First, M.I., Last: \_\_\_\_\_  
 DOB: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 Phone 1: \_\_\_\_\_

**MEDICAL INFORMATION**

Primary Conditions \_\_\_\_\_  
 \_\_\_\_\_  
 Known Allergies \_\_\_\_\_  
 Medication (include dosage and frequency) \_\_\_\_\_  
 \_\_\_\_\_



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## The Seven C's of Advocacy

BY: JIM BROWN

Through my advocacy experiences, I have discovered that certain elements and qualities are vital to successfully advocating on behalf of yourself and the bleeding disorders community. Throughout my professional career and volunteer experiences, I've advocated on behalf of various groups of people at several legislative and administrative levels. I've provided testimony at state and federal legislative committee hearings, drafted new legislation or amendments to current legislation, met with legislative aides responsible for health care issues, written numerous letters, position papers and made phone calls on significant health care issues. My involvement in organizing events such as, "Day at the Legislature" has been a successful way for members of our local hemophilia chapter to meet with their legislators and advocate on behalf of the bleeding disorders community.

Advocacy will always be a critical piece to our future as individuals with bleeding disorders and to the community. I hope the following suggestions will aid in your quest to become a great advocate.

1. **CLEAR** - Provide clarity when discussing hemophilia and establish your purpose for the visit. It's possible to meet with someone unfamiliar with hemophilia, the treatment process or other aspects of bleeding disorders. Use resource material from HFA, NHF, manufacturers, home care companies and others to supplement the discussion and provide further understanding. Know what you are asking for! Are you asking for legislation to be introduced? Co-sponsorship of legislation? A vote for or against proposals? A change to administrative policies? Be sure to present strong clear points that emphasize your position.

2. **COMPLETE** - Provide complete information. Talking points, fact sheets or additional material to leave behind should be presented at the onset of your meeting. Your goal is to become a primary source that provides complete information. Prepare yourself to address the opposition's viewpoint which provides a thorough picture of the issue from all sides.

3. **CONCISE** - It's best to be concise when presenting your position. Time is often limited during these meetings. Key facts, terminology, bullet points, main issues and a concise view of the "big picture" are a good place to start.

4. **CORRECT** - It's essential that you provide accurate and factual information. Correct and reliable information makes the person comfortable and confident in advocating on behalf

of your issue. Furthermore, it makes you a reliable, trustworthy source to contact.

5. **CURRENT** - Provide the latest data, updates, statistics or status of your issue. It is important to provide a history of your personal situation; however current information will give a better sense of how to advocate on your behalf. Ensure you address whether immediate action is necessary or if the issue is not quite as pressing. Timing can be critical to success or failure!

6. **COMPELLING** - Personal stories are a very compelling way to tell someone about the issue. It is especially critical for the bleeding disorders community to convey these stories because of the profound impact it can have on creating or changing public policies. Personal stories put a "face" to the issue and can often impact changing an issue from a low priority status to an issue that needs immediate action.

7. **COMMITTED** - Show your commitment to the issue! Demonstrate your willingness to help through follow-up letters or emails, letters of support, testimonies at hearings and anything additional that will help support your issue. Your long term commitment is a reflection as to how important the issue is to you and the community you represent.

Success can be achieved. Recently, Senator Byron Dorgan of North Dakota introduced legislation that will raise the lifetime cap on private insurance policies. Success for introduction of this legislation can be credited to the mother of a hemophiliac who fought five years to see introduction of this legislation. This powerful example illustrates the importance of remaining committed to an issue for the long haul.

### Jim Brown

*Jim Brown has severe Factor IX hemophilia and is also a Hepatitis C and cancer survivor. He is particularly committed to advocacy, because he now has a grandson with severe Factor IX hemophilia. Jim serves on the Board of Directors for Hemophilia of Iowa and The Hemophilia Foundation of Minnesota/Dakotas where he also co-chairs the Industry Relations Committee. He is a Past President of the Nebraska Chapter of NHF, and remains active in their activities.*

*His work experience includes being an Instructor on the faculty of a school of nursing, supervisory positions in medical services in a state Health and Human Services agency, several years as Executive Director of a state-wide health care organization, partnership in a small law firm where his practice focused on health care law, college instructor in a paralegal studies program and CEO of a multi-million dollar corporation with several health care facilities in five states. Currently he works for a hemophilia home care company.*

*Jim has co-authored health aide courses, articles for professional journals and newsletters, and has presented over 75 workshops and seminars on health-related topics and legal issues in delivering and accessing health care. His education includes graduation from Nursing School as an RN, a B.S in Health Occupations Education from the University of Nebraska and a Law Degree from the University of Nebraska College of Law.*



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## Focus on the Feminine Q&As

Send questions to [info@hemophiliafed.org](mailto:info@hemophiliafed.org), re: FOFMQA

Dear Jill:

Should young women be put on birth control for heavy, prolonged periods? My daughter is miserable and embarrassed about her bleeding.

Idaho

*Dear Idaho:*

*Many girls with bleeding disorders have a tough time when they begin menstruating. Although their first few periods may be light, often girls experience heavy flows (sometimes accompanied by clots) which interfere with school, family life, hobbies and other activities. It is not unusual for periods to last longer than 10 days.*

*Therefore, it is important to take your daughter to your Hemophilia Treatment Center for evaluation of her menstrual bleeding. Birth control pills are one option for regulating menstrual flow. Some girls require additional treatments such as Stimat® or plasma-based clotting factor.*

*Your health care team at the HTC will work with you and your daughter to find the best solution for her menstrual issues. Some HTCs work with OB-GYNs who are familiar with bleeding disorders – so they might refer your daughter to such a physician.*

*Heavy periods can cause teenagers to feel embarrassed and depressed. If you feel your daughter is feeling overwhelmed by her menses, contact the social worker at your HTC for a consultation.*

Jill

Dear Jill:

I heard last year that some kind of big report on VWD was coming out. Whatever happened to that?

California

*Dear California:*

*Good news! “The Diagnosis, Evaluation, and Management of von Willebrand Disease” was published in December, 2007, by the National Institutes of Health (NIH), the U.S. Department of Health and Human Services, and the National Heart, Lung, and Blood Institute (NHLBI). This important document provides the United States’ first clinical guidelines for the diagnosis, treatment and management of VWD.*

*The original document was written for medical professionals. Now, a document with consumer-friendly language is being released. It will make the report findings more accessible to those who are not comfortable with medical language.*

*You may order copies of the report or download a PDF file at: [www.nhlbi.nih.gov/guidelines/vwd/](http://www.nhlbi.nih.gov/guidelines/vwd/)*

Jill

## Jill Williams

A woman with von Willebrand disease, Jill Williams works as a vWD Specialist for Critical Care Systems. She is a long-time advocate in the bleeding disorders community, and has authored numerous national articles, pamphlets and booklets on the medical and psychosocial issues of women with bleeding disorders.

### Disclaimer

*This material is provided for general information only. The HFA does not give medical advice or engage in the practice of medicine and recommends that you consult your physician or local treatment center before beginning any form of treatment.*

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## 2008 HFA Educational Symposium Exhibitors



HFA educational  
2008 symposium  
little rock • arkansas

2008 Educational Symposium Exhibitors provided a welcome break from conference activities in their information and fun-filled booths. Employees and volunteers representing 34 companies and organizations shared in the fun. The groups represented were: Inalex Communications, Bayer Healthcare Pharmaceuticals, Coram Inc., Factor Support Network, Matrix Health, HPC International, Hemophilia Alliance GPO, Talecris Biotherapeutics, NewLife HomeCare, Inc., ARJ Infusion Services, CoAg Therapeutics, PPTA, AHF, INC., Baxter BioScience, Hemophilia Health Services, Paragon Hemophilia Solutions, Specialty Therapeutic Care, Homecare for the Cure, CVS Caremark, Grifols USA, Biomed Pharmaceuticals, National Cornerstone Health Svcs., BioRx, CSL Behring, Critical Care Systems, Novo Nordisk Inc., Walgreens-OptionCare, Care for Life, Wyeth Pharmaceuticals, Medex Biocare Pharmacy, Factor Health Alliance, Hemophilia Federation of America, Patient Services Inc., Coalition for Hemophilia B, Am. Thrombosis & Hemostasis Ntwk, Hemophilia Foundation of Arkansas



## 2008 HFA Educational Symposium Exhibitors



**Thank you  
for your  
support!**

## Historic Bill Passed by Senate



### Senate Passes Historic Bill on Genetic Information Nondiscrimination: Americans Can Take Advantage of Health Advances without Fearing Discrimination.

WASHINGTON, DC— (April 24, 2008) – With overwhelming support the Senate today passed by a vote of 95-0 the Genetic Information Nondiscrimination Act (S. 358). The bill is a testament to a strong bipartisan effort. The Coalition for Genetic Fairness commends the members of the Senate for its commitment to affording comprehensive protections against genetic discrimination.

The Genetic Information Nondiscrimination Act (GINA) paves the way for the responsible use of genetic information while protecting against discrimination with respect to health insurance and employment.

“We are grateful for the bipartisan efforts of our sponsors in the Senate – Senators Edward Kennedy (D—MA) and Olympia Snowe (R—ME) as well as the tremendous support of Senator Michael Enzi (R—WY). They are our champions and are making history today,” said Sharon Terry, President and CEO of Genetic Alliance, and President of the Coalition. “Fears that genetic information could be misused hurts individuals, researchers, clinicians, and associated industries. Today, our fears have been addressed.”

Marla Gilson, Director of the Washington Action Office of Hadassah, said, “Just 10 years ago, only 100 genetic tests existed. Today, that number has grown to over 1,000 and everyday these tests are helping diagnose thousands of health conditions. Given the Jewish community’s historical experiences with genetic issues, we worked hard to see that this bill was passed.”

The Coalition has worked for thirteen years toward the passage of legislation to eliminate the misuse of genetic information. Discrimination on the basis of genetic information had led individuals to shy away from genetic testing that could help them manage their health proactively. It also has caused many to opt out of clinical trials for fear that their genetic information would be used against them. This lack of participation has slowed the research and development of treatments and beneficial drugs.

“We now have a huge task ahead of us,” said Kathy Hudson, director of the Genetics and Public Policy Center at Johns Hopkins University, “to make sure that doctors, researchers, and the public are aware of the new protections GINA provides.”

S.358 protects Americans from discrimination by health insurers or employers based on genetic information by:

- Prohibiting group health plans and issuers offering coverage on the group or individual market from basing eligibility determinations or adjusting premiums or contributions on the basis of genetic information. They cannot request, require or purchase the results of genetic tests, or disclose genetic information.
- Prohibiting issuers of Medigap policies from adjusting pricing or conditioning eligibility on the basis of genetic information. They cannot request, require or purchase the results of genetic tests, or disclose genetic information.
- Prohibiting employers from firing, refusing to hire, or otherwise discriminating with respect to compensation, terms, conditions or privileges of employment. Employers may not request, require or purchase genetic information, and may not disclose genetic information. Similar provisions apply to employment agencies and labor organizations.

*(Information Provided by: Coalition for Genetic Fairness)*

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## Navigating Pain and Dental Care



**R**andy Riley, MD, Joseph Yale, DDS shared their professional expertise in navigating pain and dental care issues as a person with a bleeding disorder.

In a mid-morning session Riley shared his experience with treating pain as it relates with hemophilia gleaned from his roles as pharmacist, medical doctor and currently as he treats patients at the Indiana Hemophilia and Thrombosis Center.

Riley explained that pain is “always subjective”. Patients each deal with pain differently and it is important for a patient to work with their treatment team to relieve the pain. Treating pain can be greatly altered if it is not described correctly. Riley suggests patients describe pain in their own words, explaining what the pain feels like and how that pain makes you feel. By using the chart below, Riley suggested the doctor will be able to more easily assess your pain in comparison to other pain. If trying to treat intermittment or a range of pain doctors prescibe keeping a pain log. By documenting symptoms and the reaction to differing types of treatment, your physician can more easily communicate with you.

Through his presentation, Riley described a number of methods for relieving pain. First, he suggests you work with your healthcare team to better understand your pain. Always try activity/exercise as a way to treat pain- as Dr. Riley said “you are meant to move”. Additionally Riley did not discount other non-medical methods to treat your pain, but cautioned against using FDA unapproved treatments in case they can react with your hemophilia treatment medications.

When appropriate medication can be the next step in treating pain. When these options have been exhausted Riley suggests sharing feelings of pain with a counselor. He says, “Think of it as a team approach- if you have more people on your team and they are working together, that is the ideal situation.”

The final session of the 2008 HFA Symposium dealt with the sensitive topic of dental care. Dr. Joseph Yale explained the treatment protocol for persons with bleeding disorders as two-fold: (1) the dentist must determine the severity of the bleeding disorder (if it is severe, moderate or mild) and (2) the invasiveness of the dental procedure needed.

Yale described patient dental needs from birth through adulthood and as those treatments relate to persons with bleeding disorders. The speaker first advocated preventative dental care and early treatment. From the first dental office visit at one year-old through adulthood Yale explained that normal dental care for a person with a bleeding disorder should be nothing to be afraid of. Dentists have the ability to determine the invasiveness of the procedure and if need be, procedures can be performed in a hospital if they are particularly complicated and the patient’s bleeding disorder is severe.

Both professionals agreed that preparation and prevention are key to the complications of navigating pain and dental care as a person with a bleeding disorder.

