



Dateline Federation

NEWSLETTER OF THE HEMOPHILIA FEDERATION OF AMERICA

Spring 2005

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- Past President Reflections
- Advocacy and our Community
- Volunteer Awards
- Board Member Rotations
- Kids' Day in Nashville
- The Teen Point of View
- Dads In Action
- Women's Pampering Session
- Capitol Advantage
- Treating the Whole Patient
- Mentor of the Year
- Chapter Chat
- Thank You to our Sponsors

Nashville 2005:

Successful Infusion Accomplished!

By Donnie Akers, Co-Chairman
HFA Symposium 2005

HFA sought to create a “Music City Infusion” at its 2005 Educational Symposium, and by all accounts, a successful infusion was accomplished. Families, industry and health care providers gathered along with HFA members and volunteers April 1-3 at the Music City Sheraton in Nashville, Tenn.

In keeping with the “focus on the community and family,” the Sheraton Music City Hotel’s intimate and inviting setting was an ideal place for interaction, sharing and the forging of bonds among the members of the community, a hallmark of HFA events.

Comments of “First-Time Attendees” supported that ideal:

- *“This is the first time I have attended a Federation meeting, and I thought it was really a much better forum to learn and talk to others about hemophilia.”*
- *“First timers...teen program was enjoyed by big brother, and he learned a lot about his sister’s illness and how other teens feel. ... Great place to meet and have fellowship with other families. Feel we are not alone.”*

Comments of “parents of small children” indicated:

- *“The support for the children was great because it allowed the parents/adults to focus on the speakers and other activities.”*
- *“We met a lot of other parents who we could relate to. We learned things that we didn’t know yet that will benefit us with our son. ... It was also nice to have someone to infuse my son on site. He is 7 months old, and it has been so hard to find someone to do it right.”*

Comments of “Exhibitors” reinforced the HFA focus:

- *“My second HFA meeting (first was Houston in 2003). ... As I found true then, it remains so. I enjoy the difference in atmosphere, greater intimacy and focus on families than I usually find to be the case. ... For my consumer families that were able to attend, the experience was a revelation because it was the first community event either had been able to attend.”*
- *“The HFA experience is nice because it is a more intimate environment. The rooms and exhibit halls were nicely located.”*

In presenting a forum for learning and doing, HFA provided the opportunity for one person to infuse his brother for the first time, fostering a greater bond and connection as a result of this significant and emotional event. A new attendee, with minimal prior community involvement, experienced his larger hemophilia family for the first time as an adult and was infused with a greater reality and desire for involvement.

Once again, the programs presented by HFA were designed to infuse information, knowledge and a sense of belonging into the entire community. All who attended were infused with the latest knowledge regarding their treatment, their resilience and alternate therapies. All segments of the clotting disorders community were infused with new energy regarding the critical need for action and advocacy to ensure and maintain their choice of treatment and quality of life.

The “HFA Kids” were infused with all sorts of fun, learning and magic centered on the “HFA Teddy Bear Hospital.” “HFA Teens” were infused with enthusiasm and a sense of responsibility for their future by interaction between their peers and mentors.

New families were infused with comfort and hope, learning from those before them who have experienced their challenges firsthand. They were encouraged upon seeing that their lives can be normal.

“HFA Dads in Action” were infused with proactive tools to become integral partners in the lives of their children. HFA’s women, our sometimes forgotten heroines, were infused with fun and reinvigorated with a pampering session that was richly deserved.

The past, present and future were represented at the HFA Symposium, from the moving documentary “An Unexpected Life” to songs from the children before everyone enjoyed the closing night dinner and “bluegrass” sounds for a “grassroots” group.

Families, volunteers, presenters, sponsors and exhibitors were infused with factors such as hope, courage, resilience and determination to make the 2005 Nashville “Music City Infusion” an important success in the continuing mission and vision of HFA.

A sincere thanks to all who made it possible and who continue to work diligently for the entire clotting disorders community. ■

Remembrance Wall Project

If you are interested in submitting a name for the HFA Remembrance Wall Project, please submit your family member name and year of death to HFA at info@hemophilafed.org

About This Publication

Dateline Federation is a publication of the Hemophilia Federation of America (HFA). It is published four times a year. The Material in Dateline is provided for your general information only. We do not give medical advice or engage in the practice of medicine. The HFA recommends that you consult your physician or local treatment center before beginning any form of treatment. Send all comments, suggestions, and article submissions to: Dateline Federation, 1405 W. Pinhook, Ste. 101, Lafayette, LA 70503.

Mission Statement

The Hemophilia Federation of America is a national nonprofit 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.

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Past President Barbara Chang reflects on 2004

It hardly seems possible that a year has passed since I was selected to accept the office of President for this wonderful organization. There have been several trials and tribulations along the way, but they have been outweighed by the great feelings of accomplishment.

A look back over the year brings one particular word to mind—transition:



- We transitioned to becoming a stronger organization with firm accounting practices verified by an independent financial audit.
- We transitioned our physical location to office space that allows for better organization and expansion.
- We transitioned to establishing a new position of Advocacy Director, which demonstrates our priority in dealing with issues of advocacy. We experienced changes in staff without losing sight of our goals.
- We transitioned to developing a budget that reflects the separate needs of core programs apart from additional programs desired to more completely fulfill our Mission and Vision.
- We transitioned to an elevated awareness of the need to expand our outreach to funding sources.
- We transitioned to more interaction with other organizations whose values align with our Mission and Vision. We have increased our member organizations to 22.
- We transitioned to become more focused on a few select programs rather than maintaining a broad-brush approach. This has allowed key programs to continue, such as Helping Hands, Scholarship and Symposium, while developing new areas such as HFA Dads in Action.
- We transitioned to becoming an organization with an enhanced public image with our improved and more useful and user-friendly web site. We now provide a tool (Cap Wiz) to allow necessary, rapid and efficient communication with local, state and national legislators and key governmental offices. We have gathered information for and printed the HFA Hemophilia Consumer Choice Directory, a unique compilation of resources to assist our families.

We have enhanced our strong presence in Washington. There is consolation in knowing that HFA is recognized throughout the halls of government leadership, and in knowing there is an understanding of hemophilia and its consequences by the citizens of the United States.

We have many battles to continue to fight and many more hills to climb, but we will continue to be there as a representative for the blood clotting disorders community.

Our passion continues. ■

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Advocacy Is The Key To Protecting Our Community

By Jan Hamilton
Advocacy Director



The opening session of the Hemophilia Federation of America 2005 Symposium featured a panel that discussed how members of the community can be effective advocates for access to care on all levels. Jan Hamilton moderated the panel and launched the discussion with an overview of the activities of the HFA Task Force on Medicare 20 percent co-pay and its effect on families within the hemophilia community.

The Task Force consists of members of all hemophilia organizations with a national scope, industry representatives, home care, and the Plasma Protein Therapeutics Association (the manufacturers' trade association). The members who sit on the Task Force all have expertise in dealing with the effects of a 20 percent co-pay upon our families. The purpose is to collect data and create a White Paper that will provide background statistics on the community, sample financial pressures caused by the co-pay, and develop a series of suggestions to correct the situation that are affordable, reasonable and fair.

Upon completion of the White Paper, it will be presented to the MMA (Medicare Modernization Act) Reform Task Force at the request of Rep. Jim Gerlach, R-Pa., who sits on that Task Force. At that time, we will be asking for help from the community to get congressional approval of a change that would alleviate the major financial pressures caused by the current system.

Other members of the panel included Jim Romano, Director of Government Relations and Advocacy for Patient Services, Inc., who presented the Washington perspective; Michael Bradley, Senior Director of Health Care Economics for Baxter BioScience, who presented the industry perspective; Michelle Rice, Executive Director of Hemophilia of Indiana, who gave the grassroots perspective; and Tony Garr, Executive Director of the Tennessee Health Care Campaign, who spoke on the major problems with reimbursement in the state of Tennessee.

Romano, chair of the HFA Advocacy Committee, discussed the general atmosphere in Washington today, where major emphasis is on terrorism and the war in Iraq. He indicated that it would be very difficult to make any major strides in improvement of Access to Care issues that have a price tag attached. Therefore, our task is an enormous one, and as we outline a plan, we will be calling on the community to get involved both through visits to Washington and the use of the wonderful legislative tool found on the HFA web site through our Legislative Action Center. The web site address is www.hemophliafed.org.

Michael Bradley discussed how the payers are affecting delivery of quality care to members of the hemophilia community. Bradley explained the difference between the AWP formulary we had and the ASP pricing structure plus 6 percent plus the 14-cent administrative add-on. There is just not enough "wiggle" room left for companies to be able to absorb the 20 percent we can't collect, and this is causing many of the smaller companies to sell out to larger ones and/or just go out of business because of insufficient cash flow.

An advertisement for The Baxter Factor. It features a black and white photograph of two young boys, one with his arm raised. The text reads: "SHARE OUR VISION A Whole New Outlook for People with Hemophilia and Their Families". Below the photo is the logo "The Baxter Factor" with the tagline "HERE FOR YOU" and the website "WWW.HEMOPHILIAFED.ORG". The Baxter logo is also present.

Our Deepest Sympathies are extended to the family and friends of Jack M. Moore, Jr. 39, of Bridgeton, NJ, died on March 3, 2005, during a brief visit to Salvador, Brazil, from complications of hemophilia. He was the loving son of Rachel Faye Bishop Moore of Spartanburg, and the late Jack Marion Moore.

Memorials may be made to the Hemophilia Federation of America at www.hemophliafed.org or Covenant Presbyterian Church, 880 W. O. Ezell Boulevard, Spartanburg, SC 29302

He also explained the dangers of whatever happens in Medicare and Medicaid trickling to private pay. Just because a person is not currently on Medicaid or Medicare, he must not become complacent, because some of the private pay companies are already following examples already in place in Medicare and in some states with Medicaid.

Bradley also pointed out the dangers of competitive bidding, sole-source providers, preferred drug lists, prior authorization, and some PBMs (Preferred Benefit Managers.) In summary, we must be vigilant and continue to advocate for a reimbursement arena that is both affordable and fair for our community.

Michelle Rice gave an account of how Hemophilia of Indiana has stepped in to meet with insurers, state Medicaid personnel and others to tell the story of hemophilia and why we are a unique community.

Hemophilia of Indiana has mounted a terrific grassroots effort to educate the people who make decisions regarding reimbursement for their families. They have a blueprint for success. However, Rice pointed out that even when we win

a battle, we cannot sit back and relax, because there is always another obstacle waiting around the corner.

Tony Garr has been in the trenches of advocacy for some three decades. He gave an overview of some of the pitfalls we face and some suggestions for how to get around the obstacles. All in all, it takes perseverance and strong determination. Just because someone tells you "no" is not cause for taking our marbles and going home. We just have to continue knocking on doors, making phone calls, and sending e-mails and faxes.

Later in the sessions, HFA made petitions available for people to sign against Single-Source Provider practices. The petitions will be collated and used in our efforts against those practices in every state where it becomes a problem. Community members are urged to contact the HFA Advocacy Office as soon as state problems arise so that we can make our Legislative Action Center available as a tool to overcome the problems. ■

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HFA Recognizes Outstanding Volunteers

At ceremonies on April 1, the Hemophilia Federation of America announced its outstanding volunteers for 2005. HFA consists of many individuals who very graciously give their time and talent to the organization. We are thankful and appreciative of the hard work and dedication of those who received these awards.



The 2005 Michael Davon Community Service Award was presented to **Star Tyree**. Star has served as an independent board member of HFA since 2002. She has served HFA for the last two years as symposium co-chair. Star has been active in the hemophilia community for many years, including serving as Indiana Chapter Executive Director for 12 years. Star is currently employed as National Director, Community Resource Coordinator, for Curative Critical Care Systems.



The HFA 2004 Volunteer of the Year Award was presented to **Angie Knight**. Angie has dedicated a week of her time each year for the past three years to HFA in an effort to help us prepare for the upcoming symposium. She also stops in at the national headquarters several times a year to help out with whatever task is at hand. Other community involvement includes serving on the Board of Directors of the Arkansas Chapter for six years. She served as chapter president for three years. Angie has a 25-year-old son with severe Hemophilia A.



Each year, the HFA president has the opportunity to select a person believed to merit special recognition. This year, **The HFA President's Award** was presented to **Tom Vaclavik** by outgoing president Barbara Chang. Tom joined HFA's board in 2004 as the seated member from the Indiana Chapter. He currently serves as co-chair of HFA's Dads in Action program. He has been an active board member of the Indiana Chapter for four years. Tom has custody of an eight-year-old grandson who has severe Hemophilia A.



The HFA Past President's Award was presented to **Barbara Chang** by incoming president Carl Weixler. Barbara has served on the HFA board since 2000 and was elected to the executive Board in 2001. She has also served as HFA's Educational symposium co-chairman for two years.

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Two HFA Board Members rotate off, but do not walk away!



Donnie Akers (left), Alan Converse (right)

The heart and soul of the Hemophilia Federation of America (HFA) as an organization is its board of directors and other volunteers, and that heart and soul is definitely held together by the staff and how well they keep the board organized and in communication with one another. According to the By-Laws of the HFA, every six years a board member must rotate off the board for a year, and that is what just occurred this past April in Nashville.

Alan Converse and Bob Marks both believed with, and gave, their heart and soul to the Federation for six years in various capacities. They both sat on the Executive Committee the past few years and gave countless hours of their time in many capacities. Alan faithfully manned our booth at every HFA and NHF convention we attended. If you wanted to find Alan, you would look at the booth where you always found him giving of himself to serve as an informational conduit between our organization and the consumer at these meetings.



Bob Marks (left), Mike Morse (right)

Bob Marks dedicated many long hours to his role as president of the Board of Directors for two years. He also volunteered many hours behind the scenes with the Dateline newsletter and our web site as publications committee chair.

We would love to write about all of the generous time and energy these two individuals shared with HFA. Unfortunately, however, we do not have the time or the space to fit it all in this short article. Suffice it to say that they will be sorely missed in their roles on the Executive committee and elsewhere within the Federation. As with all individuals who rotate off of the board, they will be allowed to step down for a year but they will not be allowed to sit idle and avoid the important work they still have to perform for the HFA.

We take this opportunity to thank Alan and Bob, and we wish both of them all of the best. We will be talking to them real soon about their continued volunteer work for the Federation. As it says in the title, they can rotate off but they are not allowed to walk away! ■

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HFA Kids' Day Was Magic In Nashville

The magic of music was this year's theme for the Hemophilia Federation of America's Kids' Day, and it was magic for the more than 35 children sharing Imagination Station at the HFA Educational Symposium 2005 April 1-3 in Nashville.

There was magic everywhere, from Bear Clinic to Granny Good Food's place. "Granny Good Food Has the Blues," and in song and play she taught the children that eating good food can be fun.

With the help of the children, Granny (Joyce Donlan, HFA board member from the Nebraska Chapter) magically converted five pans of blue Jell-O into the most beautiful edible bouquet of flowers and branches of blueberries and marshmallows. She had blue nacho chips with salsa and blue juice, and she taught the children their songs for the wonderful closing performance when everyone made it to the stage to wave good-bye to the attendees.



The five pans of Jell-O magically showed up on Saturday morning, thanks to the kindness and generosity of Nashville newlyweds Mr. and Mrs. Stephen Lawrence, and we thank them so much. The magic of the volunteers was really great. Blueberries appeared out of nowhere. All the volunteers gave beyond their limits, and we want to thank everyone.



volunteers, the children sewed the talents into their designer bear.

These bears have magically scattered all across the country, and they will carry their special spirit with them wherever they have gone. Volunteers John Jarrett and Kim Hoagland can attest to this. We thank them for the gift of their time that they gave the children.

The magic of Bill Hoagland entertained and captivated the attention of all the children. He was funny, and he knew what clotting disorders were and taught the children how to do their own magic tricks. Bill, who has a son and two brothers-in-law affected with clotting disorders, came all the way from Connecticut and magically made the children laugh and amazed them. The children were included in the show, which was so great. Everyone enjoyed the show, and we thank Bill for sharing his talents with us.

Lana Bienvenu magically took the children to the highest level of yoga and shared her gift with them extensively during the two-day session. Lana brings a special calmness to the program.

Bob Graham and Chad Blair from Camp High Hopes in New York did an excellent job with the action sports. Jeff Kallberg, a physical therapist, taught stretching exercises. We thank them for their excellent job.

Lynn Capretto, HFA alternate HFA board member from Northern Ohio Hemophilia Foundation, gave tirelessly in keeping track of everyone. We are very grateful to her and to everyone who was there. If you were there and we have neglected to mention you specifically, I think you understand why, and I hope you will accept our heartfelt gratitude for all you have done. ■

It really was magic.





The Teen Point of View

By "Z" Taniguchi



As I walked into the hotel suite and glanced around the room, I was surrounded by more than 30 teen-agers staring at me. Some were smiling and some looked hostile, while others had the painful look of not wanting to be there.

I quickly thought to myself, "Why did I agree to be the teen chair coordinator for HFA?" I'll get back to that question later.

After a few minutes of brief introductions and icebreakers, I dived right into the program by explaining some of the subjects I wanted to discuss. Communication workshops, lifetime caps and peer pressure were among the many things we covered over the weekend.

Again, the look of boredom spread across the room. However, as the program went along, I started to notice a change. Were these guys and gals starting to warm up to the adults?

By the end of the symposium, I looked around and observed what was happening. Some teens were running around getting their t-shirts signed, some were listening to music and chatting away, while others were hanging out enjoying themselves. It was then I realized why I agreed to take over as teen chair coordinator.

The need for teens to be heard is greater now than ever. They've seen and experienced much more than most of us did in our adolescent years. When this program first took off, I didn't realize just how important it was for the teenagers to speak their minds in a comfortable setting. Many times, it seemed there was a look of relief on their faces after they got to speak and be heard.

The biggest joy still comes when they leave the room knowing they left with more than what they came with. Many of them left feeling more confident about themselves, and many left with more friends than before.

In these next months, HFA will be organizing a teen group consisting of young men and women across the country. This group will design programs for other adolescents and for the rest of the bleeding disorders community. More information will follow later. Thank you to all who helped out with this year's program, and thank you to all who attended. ■



Jan Hamilton, HFA Advocacy Director, Susan Swindle, HFA Administrative Director, Donnie Akers, HFA 2nd VP & Symposium Co-Chair, Barbara Chang, HFA Past President, Pete O'Malley, VP & General Manager, Baxter Healthcare Corporation. HFA would like to gratefully acknowledge Baxter Healthcare Corporation for their 2005 "ANGEL" corporate sponsorship.

HFA Dads In Action

About 40 persons attended the “Dads in Action” session hosted by co-chairs Joey Privat and Tom Vaclavik that was held at the recent HFA Educational Symposium. The group heard about the new program and how to start one in their own local areas. Joey and Tom introduced other fathers in the audience who were starting the program in their areas and encouraged everyone to get information and call for help.

Both co-chairs shared their personal journeys as a father and grandfather dealing with a child with hemophilia. Tom shared his experiences with his grandson and how he has learned to help his grandson live an effective life. Joey relayed a moving incident in which his son’s life was threatened by an automobile accident. Had it not been for Joey educating himself on the medical needs of his child with hemophilia and informing his child’s friends about what to do in case of an emergency, his son may not be here today.

Joey introduced Edgar Guedry, LCSW, who had the participants break out in groups of four or five to discuss a scenario addressing children’s behavior. Each group had to answer their scenario with what course of action, if any, they would do as a father. The exercise was geared toward helping each participant understand the many factors involved in fathering a child, especially one with hemophilia. The groups performed the exercise well, generating much discussion.

Joey and Tom informed the group of the next training session July 8-10, in Lafayette, La.

“Dads in Action,” a program of the Hemophilia Federation of America, trains fathers to take an active role in their child’s life and be a part of the solution. It is geared toward getting fathers to become proactive in teaching, serving as a role model, mentoring and providing support for other fathers. “Dads in Action” program support is provided partially through a generous grant from Factor Foundation of America, who recently announced their continued support for 2005. ■



Women's Pampering Session

By Melinda Clark

Manicures, massages and hair styling: All these and more are what greeted the women who attended the "Women's Pampering Session" at the Hemophilia Federation of America's 2005 Symposium in Nashville.

Women from across the country came together to listen to the motivational story of Barbara Forss, a woman with factor VII Hemophilia and founder of the Lady Bugs support group. She shared with the women the journey she traveled in becoming an empowered woman with a blood clotting disorder. Barbara spoke about how support groups such as hers help women network and share information and stories. In doing so, they empower themselves.



The women then had a chance to give themselves manicures, receive chair massages, have their hair styled by professional braiders, and enjoy chocolate-covered strawberries.

While this sounds like all fun and games, it was also therapeutic. While pampering themselves, women felt at ease in sharing their stories and networking with each other. New friendships were formed. New resources were found.

Walking around the room, you could find a patient sharing with a young mom what a bleed feels like, giving her a new perspective when trying to empathize with her son. You could hear an older mother telling a younger mother how different things were "back in the day," bringing generations together.

Thanks to the Feminine Focus committee and the event coordinator, Sheila Timura, for a wonderful event! Special thanks go to Debra Couvillion and Beth Weixler, who pitched in at the last minute to lend us their professional services.

Although this year's event can be counted a success, it is time to begin planning for the future. The Feminine Focus program is still in its infancy. We would love to hear your thoughts, ideas and suggestions. If you would like to share them with us, or would like to volunteer to serve on this committee or any other HFA committee, please contact our office at (800) 230-9797 or fax us at (337) 261-1787.



Look for more information on Feminine Focus in the future. We look forward to seeing you in 2006. ■

HEMOPHILIA FEDERATION OF AMERICA ANNUAL MEETING AND EDUCATION SYMPOSIUM

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Capitol Advantage—Our Gateway To Congress

By Jim Boudreaux, HFA Webmaster



On Friday, April 1, at HFA's Educational Symposium 2005 in Nashville, HFA President Carl Weixler and I demonstrated the use of Capitol Advantage's Legislative Action Center.

The session was made possible through the generosity of American Homecare Federation, Inc. (AHF), this web-based advocacy system makes it fast and easy for you to contact your United States senators, representatives and state legislators regarding issues important to the bleeding disorders community.

The Legislative Action Center, also known as Cap Wiz, streamlines the process of effective communication with those who make our laws. Instead of having to write a letter, put it in an envelope, then stamp and mail it, you can achieve the same results just by visiting the Cap Wiz page of our web site and following the directions there. This unique advocacy tool became a reality to HFA in 2004 by the generous donations from the following donors: American Homecare Federation, Cyril Homecare Pharmacy and Curative Pharmacy Services.

A prewritten letter, which you can edit, is provided for a specific issue. Then, with just a few mouse clicks and possibly an edit or two, your letter is on its way to the appropriate parties via e-mail. Alternatively, you can print out the letter for direct mailing or faxing. For direct mail, the addresses are provided. The format of the letter to be sent is set up for communication with members of Congress or state legislatures. The correct protocol for salutations, such as Honorable, Mr. Speaker, etc., is automatically provided. A spell check feature may also be used. The system is constituent-based. When you send an e-mail to Congress, only the member or members in your district receive this mail.

Anyone may use the Legislative Action Center feature of our web site. Some personal information, such as your name and address, is requested, but no e-mail will be sent to you unless you opt to join our mailing list. For us to track the effectiveness of the Legislative Action Center and send e-mail alerts of new issues in our Community to the user, you must opt to join the mailing list.

Please note that e-mail addresses added by joining are NOT released for use by third parties. They are used ONLY to automatically notify members when new alerts are posted.

A useful way to orient a potential Cap Wiz advocate is by example. Currently, one of our issues is the continuing

funding in 2006 by the federal government of the National Institute of Health (NIH) and Medicaid.

For funding to continue, Congress must include it in the budget. Our appeal asks Congress to do this, and users send letters to their U.S. Senators and members of the House of Representatives. The steps to doing this are provided below:

1. Visit our web site, www.hemophiliafed.org, and click on Legislative Action Center, either on the side menu or on the photo of the Capitol Building in the middle of the home page.
2. When the Legislative Action Center page appears, you will see a box titled "ACTION ALERT!" Inside this box, click on the link to Support Continued Funding for NIH and Medicaid."
3. When the Action Alert page appears, read the text provided and follow the instructions, providing your contact information. In most cases, you may choose to have the letter printed as well. If you are not yet a member, the option "Sign me up for the Action E-List" may be selected. The message may then be edited, if needed, and previewed.
4. After previewing the message, you may go back and edit, or click SEND to send it to your members of Congress. If you had chosen the option to print earlier, you may print the letter for direct mailing or faxing.

Cap Wiz makes it simple, easy and effective to communicate with lawmakers on issues pertinent to our community. However, for our office to be able to effectively track use of the Legislative Action Center and to automatically send Action Alerts, it is most important that you JOIN. All you need to do is click on any link that says "Join Our Action E-List."

We are fortunate to have the Legislative Action Center as a tool to communicate with those who can be of great help to our community. Please help us by visiting our web site, clicking on Legislative Action Center, and joining by going to any link that says "Join Our Action E-List." ■



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Treating The Whole Patient

By Donnie Akers, Co-Chairman
HFA Symposium 2005



"Treating the Whole Patient" was the theme for Saturday's schedule of programming at HFA's 2005 Symposium in Nashville, and HFA was honored to have expert presenters in a number of disciplines.

In keeping with HFA's focus on patients and their families, these professionals addressed the audience members on their level and not that of the clinician/practitioner. The result of these presentations was a powerful partnering of both the experts and community members in an exchange of valuable and insightful information essential to all.

Charles Gilbert II, ACSW, BCD, Director of Education for the Central Pennsylvania Psychiatric Institute of the Department of Psychiatry at Penn State College of Medicine, Hershey, Pa., and a psychiatric social worker for more than 33 years, provided a captivating presentation on "Resilience" of chronic disease sufferers. Many of those in the audience were able to find validation and commonality in their own experiences as shared by others and demonstrated by Gilbert.

The "Resilience" presentation was followed by a panel discussion facilitated by Dr. Jamie Siegel, Clinical Associate Professor of Medicine at the Cardeza Foundation for Hematological Research and Division of Hematology, the Director of Hemophilia and Thrombosis Center, and Medical Director of the Cardeza Foundation Special Hemostasis Laboratory in Philadelphia. Seigel is a valuable member of HFA's Medical Advisory Panel and provides countless hours of support to HFA and the entire bleeding disorders community.

In keeping with the topic, the conference attendees were introduced to Jeffrey Kallberg, PT, a graduate of the

University of Minnesota whose practice focuses on treating children and adults with bleeding disorders through his employment with CoaguLife; and Cherys Zimmerman, RN, Nurse Coordinator of the East Tennessee Comprehensive Hemophilia Center and Coordinator of Hemophilia Services.

The panel was enhanced by the inclusion of community members Wayne Cook, a severe Hemophilia B patient and longtime hemophilia advocate who serves as HFA's newly elected treasurer and represents HFA member organizations for the Bleeding Disorders Association of the Southern Tier of New York; and Chad Stevens, also a severe Hemophilia B patient and banker who hails from Newdale, Idaho, and serves on the HFA Board of Directors representing the Hemophilia Foundation of Idaho.

The blending of health care professionals and community members provided each segment an opportunity for personal development and understanding of one another. All were able to peek inside the special perspectives of each presenter as they dealt with the ongoing crises and burdens in their daily lives as well as the strength and joy they have discovered in their own journeys.

The panel members discussed their biggest challenges in life, the benefits they have realized as a result of their challenges, the significance of the bleeding disorder in their lives, and their hopes for the future. The power of coming together in such a group setting and sharing experiences, thoughts, ideas and feelings is what HFA's symposium seeks to accomplish and this panel hit the mark admirably and effectively. This panel exemplified the power of the HFA symposium as a super-sized support group for the community.

HFA was especially pleased to provide its symposium audience with the expertise of Dr. Donna DiMichele, Attending Physician and Medical Director of the Regional

Comprehensive Hemophilia Diagnostic & Treatment Center, Associate Professor of Pediatrics in the Department of Pediatrics and Director of the Special Coagulation Research Laboratory at the New York Presbyterian Hospital-Weill Medical College of Cornell University in New York City. She is one of America's distinguished physicians working for the care of individuals with bleeding disorders. DiMichele spoke about her work with immune tolerance and inhibitors to eager and attentive audience members who experience the trials and tribulations of these problems on a continuing basis.

He's always there when needed, and once again the community was the recipient of the invaluable services of Dr. Christopher E. Walsh, Associate Professor of the Department of Medicine at Mt. Sinai School of Medicine and Director of the Mt. Sinai Hemophilia Center in New York City. Walsh is a renowned hemophilia expert, practitioner, researcher and author who, as an integral part of HFA's Medical Advisory Panel, can always be counted on. Walsh not only provided symposium attendees with the current state of research and development or "what's new" in hemophilia, but also spoke at the pre-symposium Coalition for Hemophilia B breakfast meeting held in conjunction with the HFA event.

Psychosocial and medical issues were not the only fare in HFA's treatment of the whole patient. HFA's resident wearer of many hats, Carole Lancon, MA, ATR, who has served the HFA as a staffer, volunteer, symposium presenter and HFA Teen Program Director, moderated the "Alternate Therapies" breakout sessions, which focused on various means of coping, stress management and related topics pertinent to those with chronic conditions and their caregivers.

The "Alternate Therapies" sessions were designed to provide a holistic approach to living and healing and included a presentation by HFA newcomer Debra Couvillion, a Master/Teacher in the Healing Art of Reiki as well as a Massage Therapy instructor from Baton Rouge, La. Couvillion introduced the concept of Reiki, a Japanese healing art that uses the laying of hands in its quest for

deep relaxation and other desired effects. Couvillion also spoke of her work in development of "Sound Therapy" and the use of voice along with massage to facilitate deeper levels of healing for clients.

HFA veteran Lana Bienvenu, BA, Registered Teacher of Integrated Yoga Therapy from Little Rock, Ark., provided participants with her special brand of "chair yoga" especially designed for those with mobility impairment, which is prevalent in our community. Her deep breathing and relaxation methods are continuously enjoyed and are inspiring to her audience members, with many continuing the practices they learn at symposium.

Additionally, Bienvenu provides specially designed yoga sessions for the HFA Teens and HFA Kids programs that are highly successful components of those symposium programs.

Having introduced the concept of "Art Therapy" to the HFA community at its 2002 Cleveland Symposium, HFA again provided that form of education and support to those in attendance seeking personal insight and transformation. On the heels of her HFA debut at Las Vegas in 2004 as the facilitator of the "Bear Clinic" of the HFA Kids programming, Mona Constantini, MA, ART, Doctor of Ministry degree candidate and faculty member of the Graduate Institute in Connecticut, continued the HFA tradition of introducing interested attendees to the healing and life-enhancing creative process of art as a therapeutic tool.

HFA is pleased to be able to achieve the cooperation and support of so many professionals and experts in a number of disciplines who never hesitate in their response to serve the community of those who have bleeding disorders.

HFA is grateful to all of the professional contributors for their dedication and service to those who might not otherwise have an opportunity to benefit from their work, knowledge and expertise. ■

What Was That Award “Z” Received at the HFA Banquet This Year?

By Brian and Kelly Craft

We thought you'd never ask!

At the 2003 Hemophilia Federation of America symposium in Houston, Carl Weixler had everyone sing “Happy Birthday” to a grand man turning the big 5-0. He was slight of build with all the quirky little bends in the joints we older guys are noted for.

His name was Don Paul Lucas. He and his wife, Jackie, had been, and Jackie still is, very involved with the hemophilia community. They were especially involved with the youth of our community. They created their own summer camp for the kids left out of the mix in northwestern Pennsylvania.

In December 2003, Don Paul went to live in that Area Code we can't dial after enjoying a fine holiday season with his family and counting his great fortune of a life well lived.

Upon hearing of his passing, all of us at Comedy Lifeline International wanted to create a way to remember the Don Pauls of our community, so we came up with the **“Don Paul Lucas Mentor of the Year”** award. The award is designed to recognize the outstanding commitment to the mentoring and guiding of the youth in our community. The first year, 2004, it was given to Don Paul posthumously and to his wife Jackie, who accepted it at the dinner.

This year, a unanimous decision was to honor Zuiho Taniguchi, aka “Z.” He has worked in many summer camps, is the leader of the youth program for the HFA, and always has time in his schedule and room in his heart to help our next generation of leaders.

If you'd like to submit a name for consideration as Mentor of the Year or be on the selection committee, please call Brian or Kelly Craft at (949) 515-3404. We'd love the help and input. This is not a heavy time-consuming committee; we get nominations and decide on the best candidate in one or two e-mail sessions or phone calls.

Congratulations again, “Z.” Keep your funny side up. ■



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Baxter to Purchase Plasma From American Red Cross Under a New Long-Term Supply Agreement

Baxter Healthcare Corporation and the American National Red Cross (Red Cross) recently announced that they have signed a new, long-term plasma procurement contract. Under this new agreement, Baxter will purchase plasma from the Red Cross, effective July 1, 2005. Based upon a strategic review of its Plasma Services business, the Red Cross informed Baxter that it intended to exit the plasma therapeutics business. As a result, the parties agreed to terminate their long-standing, contract manufacturing arrangement for the processing of plasma products. To view the announcement in its entirety, please go to HFA's website www.hemophiliafed.org Industry News section.

CDC Foundation Announces \$3 million Grant to Fund Hemophilia Study from Wyeth Pharmaceuticals

The CDC Foundation has received a \$3 million grant from Wyeth Pharmaceuticals to study why some hemophilia patients do not respond to the drugs currently used to stop or prevent a bleeding episode. The three-year grant will provide funding for scientists at the Centers for Disease Control and Prevention (CDC) to study the risk factors associated with this serious problem.

“CDC scientists have long wanted to determine how and why certain hemophilia patients develop this inhibitor, but have not had the funds for a comprehensive study,” says Charles Stokes, president and CEO of the CDC Foundation. “With the help of Wyeth Pharmaceuticals, CDC can now take the first steps toward ultimately finding a solution to this problem.” To view this announcement in its entirety please visit HFA's website at www.hemophiliafed.org, Industry News section.

Thank You to



Also thanking sponsors whose pictures were unavailable: Novo Nordisk Inc., New Life Home Care Inc., The Coalition for Hemophilia B

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Chapter Chat

HEMOPHILIA OF NORTH CAROLINA

The annual meeting will be held on Saturday, May 7, at the Victory Junction Gang Camp. This state-of-the-art camp in Randleman, N.C., was established by the Kyle Petty family in memory of their son, Adam, and is part of the Paul Newman Hole in the Wall Camps, the world's largest group of camps for children with serious illnesses and life-threatening conditions.

The daylong meeting will include a tour of the facility as well as discussions of many topics of interest for the community, including a presentation by the North Carolina Division of Vocational Rehabilitation on career opportunities for people with blood clotting disorders.

The camp is setting aside one week for children with blood clotting disorders this summer, and this will give the children and families an opportunity to preview the facility.

On June 13, there will be a golf tournament held at the prestigious Prestonwoods Country Club in Cary, N.C. All proceeds will go to the Hemophilia of North Carolina chapter. For additional information, please call 336-495-2017.

TENNESSEE HEMOPHILIA & BLEEDING DISORDERS FOUNDATION

Upcoming Events:

June 3-5: Annual Meeting in Nashville.

August 26: Blues on the Green Golf Tournament in Memphis.

Additional information regarding these events, please contact the TN Chapter at 615-373-0351.

HEMOPHILIA ASSOCIATION OF THE CAPITAL AREA

Upcoming Events:

May 1: Blood Buddies - An Introduction to Yoga.

May 4: Teleconference - "Recombinant Products for the Treatment of Factor 8 Deficiency."

May 16: DC Hemophilia Open Golf Tournament.

May 22: Town Hall meeting for women affected by bleeding disorders.

June 10-16: Summer Camp at Hole in the Wall Gang Camp, Ashford, Conn.

July 9: Women's Day Out.

July 24-29: Summer Camp at Victory Junction Camp, Randleman, N.C.

Sept. 24: Annual Educational Symposium and Annual Meeting.

Oct. 8: Blood, Sweat & Gears Annual Bike-a-Thon.

Call the Chapter at (703) 352-7641 if you are interested in attending any of these events.

HEMOPHILIA OF INDIANA

2005 Wheels for Winning: Hemophilia of Indiana, Inc., has announced plans for its annual Wheels for Winning Biking & Walk-a-Thon to be held Sunday, Aug. 28, at the famed Indianapolis Motor Speedway. Admission to the grounds is free, and the event is open to the general public beginning at 9 a.m. Biking and walking will take place on the famed 2.27-mile track. A festival atmosphere promoting a healthy lifestyle will provide a fun-filled afternoon for the entire family, with rides for the children, sponsor exhibits and giveaways, concessions and on-track activities for biking enthusiasts of all skill levels.

For additional information, call (800) 241-2873 or log on to www.hemophilaofindiana.org/events-wheels.asp.

TEXAS CENTRAL HEMOPHILIA ASSOCIATION

2005 Calendar of Events

March-Seeds of Hope for Hemophilia

All month we will be selling Wildflower Seed Packets to "spread" the word about Hemophilia. They are \$2 a packet.

May 09-The 14th Annual Greg McKinney Memorial Golf Tournament

Bridlewood Golf Club, 4000 Windsor Drive, Flower Mound TX. Registration begins at 12:00PM

June 11-Texas Central Hemophilia Annual Meeting

American Airlines Training Center in Fort Worth & Hurricane Harbor-Arlington, Texas

A splash of a good time! Begins at 9:00 a.m.

September 10-Bowling for Hemophilia

Benefiting Camp Ailihpmeh - 2 p.m. to 4 p.m.

AMF Lewisville Lanes-Lewisville, Texas.

Teams of 5 or individual players welcome. Registration is \$20 per person or \$80 per team.

October 1st -JOKERS ARE WILD-Casino Night/Silent Auction

Westin Park Hotel-Dallas, Texas - 7 p.m. to midnight

Dress is black-tie optional. \$75 individual ticket/ \$125 a couple

December 4 – ANNUAL HOLIDAY PARTY

Southwest Airlines Corporate Headquarters- Dallas, TX

1:00pm – 4:00pm.

For additional information regarding these events, please contact TX Central at 214-654-4595.



HEMOPHILIA FOUNDATION OF ARKANSAS

Camp Nopokame will be held July 17th to the 23rd at the Ozark Folk Center in Morrelton, AR.

Family retreat will be held August 26th & 27th at Camp Winomacka in Arkadelphia, AR

For additional information please call the Chapter at 501-851-3109.

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