



Dateline Federation

NEWSLETTER OF THE HEMOPHILIA FEDERATION OF AMERICA

Spring 2004

Volume 9, Number1

Federation Celebration!

By: Barbara Chang, Symposium Co-chair

What did I see as I looked around?

- Friends greeting friends
- Lots of hugs and kisses
- Folks helping one another
- People crying while listening to speakers
- Kids laughing
- People taking notes
- Lucky ones cashing in and collecting their winnings

We celebrated, met new friends, and heard unbelievable inspirational stories, learned about hepatitis C, ER Triage programs, pain management, and government relations. We interacted with company professionals who shared their time and talent with us. We sat and talked with the thought leaders and caregivers who keep us informed about the latest issues affecting our community. We shared experiences with members of the blood clotting disorder community from all over North America. We watched a few of our brothers and sisters try their luck at gambling and believe a few dollars actually landed in our pockets. We watched our children interact and teach us a few things. Everyone was able to go home with something be it tangible or not. I had fun, how about you?

The people arrived from across the nation and Mexico too! It was amusing when new folks shared their surprise about the simple and quick registration process. (Thanks to our efficient and hard working staff and volunteers). The bags we all received will continue to be useful long after the symposium. The meeting rooms were all conveniently located, with the exhibit hall right next door to the general session room across the hall from the break-out session rooms. The vendors seemed pleased with the amount of people who visited the exhibits, exchanged information and picked up some goodies.

Those who were fortunate enough to attend the pre-symposium workshop for Chapter Development were blessed with a valuable compilation of facts and ideas to bolster the local chapter. Jan Hamilton and Star Tyree provided an excellent road map for success.

The two motivational speakers, Ray Hollister and John Foppe, were absolutely amazing. We are truly inspired to cope with any "condition" that we are born with or encounter along life's path. These speakers touched each of us in a personal way that we will have embedded in our memory. We heard about the latest legislative issues from our representatives in Washington DC - Dale Dirks, James Romano, and Julie Birkhofer.

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Christy Argo hosted a new families reception to meet and greet with our youngest community arrivals. We all enjoyed a wonderful dinner together at the Top of the Riviera. We celebrated a few award winners including Sue Dill, Jim Romano, Jamie Siegel, Bob Marks and Barbara Chang.

Dr. Jerry Powell brought us the very latest reports of tests and therapies for hepatitis C. We listened to the plans for a national educational program to assist persons with a blood clotting disorder when they visit the ER presented by Jan Hamilton, and Doctors Chris Walsh and Jamie Siegel.

All of the break-out sessions were well attended. The evaluations indicated the value of these workshops with a few suggested areas for improvement. Joey Privat lead the Dads in Action session where they laid the groundwork for the future by preparing a draft mission and vision statement. The Dads also set preliminary dates for the next training program to be held in Lafayette in June 2004. The other break-out sessions included Pain Management, John Mulder MD; Research Update, Chris Walsh MD; Family Communications, Tricia Hensarling, M.S.; Alternative Therapies, Brad Lewis MD; Women with Bleeding Disorders, Jamie Siegel MD; Home Infusion Techniques, Lew Collins RN; Sports & Hemophilia, Disabled Adventure Outfitters; Strategies for Family Finances, Greg McClure LSW; Orthopedics, Mauricio Silva MD.

A few special moments occurred when an eight year old boy managed his first "stick" (venipuncture) and a teenager learned to administer factor for her Dad.

It was a joy to visit the infants and toddlers being gently rocked by the child care "grannies". The young children's room was vibrant, messy, colorful, musical and bustling with activities. The children were engaged in arts and crafts, games, stories and preparing nutritional snacks. They were entertained by a visiting Troubadour who taught them some new songs. Our children had a chance to visit the Circus Circus across the street. Brian and Kelly Kraft had the teenagers engaged in a mixture of activities which included the exchange of thoughts and ideas as well as serious future plans. We were all treated to a summary of the children's activities during the Sunday breakfast when they shared their music and their ideas with all of us.

Does this sound like a jam-packed weekend? You bet it does. Perhaps you should plan to attend the next HFA educational symposium in 2005. ♀

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, 102-B Westmark Blvd, Lafayette, LA 70506.

Mission Statement

They 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.

Officers

Barbara Chang, President
Carl Weixler, 1st Vice President
Donald Akers, 2nd Vice President
Peter Bayer, Secretary
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Wendy Hearne, Administrative Assistant
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Carole Lancon, Teen Program Director

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Bleeding Disorders Association of the Southern Tier
Florida Chapter of NHF
Gateway Hemophilia Association
Hemophilia Association of the Capital Area
Hemophilia Foundation of Arkansas, Incorporated
Hemophilia Foundation of Idaho
Hemophilia Foundation of Maryland
Hemophilia Foundation of Nevada
Hemophilia Foundation of Northern California
Hemophilia Foundation of Southern California
Hemophilia of Indiana, Incorporated
Hemophilia of North Carolina
Hemophilia of South Carolina
Hemophilia Outreach of El Paso
Lone Star Chapter of the NHF
Nebraska Chapter of the NHF
Northern Ohio Hemophilia Foundation
Oklahoma Hemophilia Foundation
Tennessee Hemophilia & Bleeding Disorder Foundation
Texas Central Hemophilia Foundation
Utah Hemophilia Foundation

HFA Welcomes the New Member Organizations



Hemophilia Foundation of Idaho

The Hemophilia Foundation of Idaho is an 11-year old foundation. The greatest challenge over the years has been identifying appropriate participation by industry representatives while maintaining a positive relationship.

Our Foundation was created out of survival. With hemophilia comes the necessity to decipher the complex knowledge and information involved, share that information with others, and the need to discover more information in order to attain adequate medical care. The most positive experience our chapter has had is the inception of a local Hemophilia Treatment Center. It is really exciting to see families having access to care that meets the national standard, the ability to stay in-state for hemophilia services and related medical therapies, adequate infusions and education to go with them, and reliable medical treatment even at the broader level of emergency care. Watching families interact with our own physicians at educational seminars, clinics and other meetings is truly a positive phenomenon. The relationship between physicians and consumers at our HTC is absolutely AWESOME!

We have had many successful annual meetings where we bring families in overnight for a weekend of educational seminars and break-out sessions. The original idea was to have a mini NHF... **We were so successful, we outgrew our original hotel almost immediately!**

Our most successful events are yet to come!! We are continually improving projects on all fronts. Currently we are working on a summer-camp and we have an Annual Golf Tournament that is going into its 10th year.

We are so happy and proud to be an important part of bringing members together with industry and healthcare providers in an improving, vital and healthy interface.

Hemophilia Foundation of Arkansas, Inc.

The Chapter was organized at picnic held at Camp Alders gate pavilion in Little Rock, AR in June of 1994. Approximately 15 people were present, not including children. The group talked about the need for a Chapter in Arkansas and the treatment center employees were willing to mail out letters to all the patients and families to let them know about the

organization. We elected the Board of Directors from the 15 people and selected officers from the Board members.

We began work immediately on getting the chapter mission statement and to be recognized as a nonprofit organization. The mission statement took only one meeting, the nonprofit recognition took 5 years. Our mission is to help all people in the state of Arkansas with a bleeding disorder and to educate ourselves and patients to the best practices for taking care of yourself if you have a bleeding disorder. The chapter began working on a golf tournament as a fund raiser. Since 1995, we have each year done a golf tournament that has resulted in money to help the chapter.

Each year we have, for the families in Arkansas, a Bowling Bash usually held in the spring, a Family Retreat & Membership meeting held one weekend in the summer months, and a Christmas party held in December. As time permits we have picnics, a day at the lake fishing, or go to the water park for fun. The Family Retreat is a really good fellowship for the bleeding disorder community in Arkansas. We have vendors come to meet the people that they usually just talk to on the phone and we try and have a speaker that is familiar with bleeding disorders for an educational time. The children and teens have activities planned so they will not be bored. With the success of getting families together for the Family Retreat, we have outgrown two locations where the retreat was held.

This year we are celebrating our 10th year as a chapter. There is a picnic and fun planned for the membership at Wild River Country in June. We are collecting old photos and memorabilia to display for old members to reminisce over and new members to see how things were back in the beginning.

Hemophilia Foundation of Arkansas continues to grow and help educate people in the bleeding disorder community. We have an all volunteer board with no paid employees. The chapter is working toward getting an executive director in the future. All board members have a full time job outside of working on the board. I feel we have a successful organization.

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What's Your Excuse?



Born without arms, John Foppe's story has touched many hearts and his message has changed many lives. John brought his inspirational message to the Hemophilia Federation of America at our 2004 Symposium in Las Vegas on Sunday, March 28. Born in 1970 with seven birth defects, and not expected to live, Foppe not only beat the odds, but has gone on to lead a remarkable life: one that involves using his feet for everything from shaving to eating to driving a car. He travels around the world motivating others.

John has met a Pope, fired up a pro football team, skied in Austria, and climbed the steep steps of the Batu Cave, a Hindu Temple in Malaysia. He has written a book, earned a master's degree in social work, and been honored by the U.S. Jaycees as one of its Ten Outstanding Young Americans.

Foppe has spent the past 15 years as a professional speaker. Known for delivering high-impact presentations on overcoming adversity and fostering personal growth, he has spoken to businesses, schools, organizations and churches across the U. S. and internationally. John is the author of an inspirational and personal growth book, titled *What's Your Excuse? Making the Most of What You Have*.

Through sharing his heartwarming and humorous stories of overcoming adversity, John educated and encouraged listeners in his Sunday morning presentation. His basic message is: "Our only real handicaps are those mental and emotional ones that prevent us from participating fully in life." He says, "Most people think of a handicap as something physical like a lack of sight or mobility.

Instead, I convince people that negative thoughts, cynical beliefs, and bitter emotions cripple our spirits. When you change your attitude, your life changes."

Foppe states, "I tell people my condition doesn't give me different problems. It just makes me experience the same problems everyone else has more deeply. Everybody struggles with liking themselves, getting along with others, and doing more with less. I simply tell people its OK and give them some ideas to help them cope along the way."

John doesn't allow his condition to hold him back. His willingness to share his own struggles hits home for many audiences. "I acknowledge life is tough, and I still struggle. The tips I offer are grounded in my lived experiences of wrestling with my own problems." When people feel John's sincerity, they instinctively realize that "if John can do so much without arms, then I can do more with what I have".

To hear John speak is an opportunity to be renewed and to move on with a new perspective on life. His audience left with an inspirational message and renewed optimism. 🙏



John is pouring a glass of water with his foot.

Extraordinary! Fantastic! Thank you! Great!

-A response from an attendee-

Disabled Adventure Outfitters



Disabled Adventure Outfitters (DAO) gave an overview of its services during the Sports in Hemophilia Break-out session at the HFA Educational Symposium in Las Vegas. With a mission of *“providing access to fun, adventure, and personal growth”*, DAO’s goal is to provide the

disabled, through a variety of programs from day trips to weeklong camps, with outdoor recreation opportunities in a safe, professional environment. Such activities are fun and life affirming while building self-esteem and self-confidence. Unfortunately, disabled persons usually do not participate in such activities because of limited financial resources, access, or awareness. DAO seeks to overcome these obstacles by providing specialized programs for various disabled groups at little or no cost to the individual through working cooperatively with the organizations representing them and seeking funding from external sources. The hemophilia chapters within California work with DAO to coordinate transportation for youths attending camp.

DAO Adventure Programs enrich the lives of participants via guided, challenging activities which build self-esteem, self-confidence, and positive self-image. Each Hemophilia Adventure Camp for

adolescents and adults with bleeding disorders is a week-long outdoor program for up to twelve affected participants. Campers are placed in unfamiliar and challenging situations that involve problem-solving and team-working skills. Participants are provided with daily networking opportunities in both structured and unstructured settings. Program leaders insure all campers a comfortable environment stressing safety and good judgment.

DAO’s Teen Adventure Camp is designed for boys and girls from ages 13 to 18 and tends to be a little more active than their adult programs. Teens spend the first two days camping at the coast, rock climbing and ocean fishing, then move up to the Trinity River for three days of whitewater rafting and inflatable kayaking. All DAO programs follow the philosophy of “challenge by choice”, encouraging participants to push themselves to the extent they wish, but also supporting them if they decide “that’s enough for now.” Such an atmosphere is quite contagious and, by the end of the week, campers usually form a cohesive, mutually supportive group.

DAO can be reached via email at daoinfo@mindspring.com, by phone at (707)822-1101, by snail mail at PO Box 152, Arcata, CA 95518, or on the web at www.specialadventures.org. ♣

Welcome HFA’s Newest Intern



This spring, the Hemophilia Federation of America welcomed its newest intern, Kaissy Hammer, RN. Kaissy holds a Bachelor of Science Degree in Nursing from the University of Louisiana at Lafayette and, as a Gates Millennium Scholar, recently completed a graduate degree in Education with a concentration in Health Promotion and Wellness. Kaissy presently works as a registered nurse at Women’s and Children’s Hospital in Lafayette, LA. During her internship with HFA, Kaissy assisted with preparations for the 2004 Educational Symposium in Las Vegas. After graduation, Kaissy hopes to become an advocate for the health care community. ♣

Congratulations!



Year 2004 Graduates

May all your dreams
come true!

-The Federation board and staff



Dads in Action

By: Joey Privat

Looking back and reflecting on the Dads in Action session held at the 2004 symposium in Las Vegas, I can truly say I saw a group of committed men working towards a common goal. A goal we set for ourselves in our work, on the golf course, and in many aspects of our everyday life. These are the same goals we so often over look in our family life. We over look the simplest of things such as eating dinner as a family, playing a game of horse, and telling our spouse or children that we love them.

The session was very well attended with 49 persons present. As Director of Dads in Action, I was the facilitator of the program for the day along with two of the trained facilitators sharing their success of the program in the states they represent. Robert Champagne from Dallas, Texas

shared his experience as facilitator. The session in Dallas was a social event which included a pizza party, and a friendly game of Whirly-Ball. The event was attended by dads and their children. This event is a great example of what the purpose of the Dads in Action program is committed to.

At the session, we set our sites on training a new group of dads in Lafayette, LA. June 11th thru 13th. The other major accomplishment was the mission and vision statement put together by the group.

Mission Statement

Dads in Action is a network of involved dads created to encourage, educate and support each other and their families within the blood clotting disorder community.

Vision Statement

The vision of Dads in Action is that our families have developed into educated, involved and supportive members of the blood clotting disorder community.

Overall Dads in Action is evolving into a program that is reaching out to many dads across the country. I see many of them using it as a foundation to build upon in the hemophilia community and within their everyday lives. ♀



2004 HFA Symposium Sponsors

We would like to again thank all our sponsors for making this year's Symposium a great success!

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FRIEND

The Coalition for Hemophilia B
PPTA
Patient Services, Inc.



Celebrating With HFA Kids

By: Joyce Donlan & Judy Igelman



The HFA Kids 2004 program met at Symposium in Las Vegas for CELEBRATION STATION. It was a big birthday party to help HFA celebrate its 10th year of existence. Yellow Ducky (aka Judy Igelman) and Granny GoodFood (aka Joyce Donlan) guided the children through a wide variety of arts and crafts, fun food projects and relaxing social activities.



Some special guests helped us to make it a fun-filled few days. Nick the magical troubadour entertained the group with fascinating old world tales, musical instruments, and games. Dr. Zoolittle showed up with more fun activities. The kids worked with an artist to create small books. Lana Bienvenu taught the kids fun ways to relax with yoga. Other HFA volunteers assisted with caring for the children and are greatly appreciated for their hard work.



The real goal of the HFA Kids Program is to help children from across the country get to know each other and make special friends they won't forget. Those present learned more about living healthy, positive lives and feeling confident in moving forward when a blood clotting disorder affects their lives, either directly or indirectly.



HFA was glad to be able to share the fun with our community's kids. We look forward to seeing many of you again next year. ♡





HFA Teen Connection in Vegas!

Thirty-two Teenagers from across the country spent 2 energetic days together in Las Vegas at our Educational Symposium. Spearheaded by young energetic Chairman Zuiho “Z” Taniguchi and his dynamite Teen Committee (Maria Rubin, Kerry Brooks, Melinda Clark, Sharen Haddad, Carole Lancon, Linda Ohlson, and Laveanne Lovelady), HFA provided a fun-filled weekend for our teenaged audience.



Brian and Kelly Craft of Comedy Lifeline International presented a hilarious program that educated the group on self-advocacy, communication and leadership skills, and assisted the teens in developing a strong group identity. As a professional comedian and actress who have taken their program to hemophilia camps across the country, Brian and Kelly had the group rolling in the aisles with hysterical laughter.



Two new groups met for the first time. Our newly-formed Big Blood Brothers/ Sister, a group of young adults (18 thru 25 years-old) mentoring teens, was there to share their time and talents with the next generation of HFA leaders. The team included Chad Brown, Josh Maul, and Tinsey Grigg. The HFA Teen Advisory Board consists of teens appointed by their individual Member Organizations. Those present at Symposium were Laurie Arnett (Nebraska), Brianna Collins (Maryland), Aaron Craig (Texas Central), Crystal Gomez (El Paso), Sean Jones (Indiana), Meghan Porenta (Utah), Anna Shafer (Southern Tier), Brittany Vega (Gateway), and Kevin Williams (North Carolina).



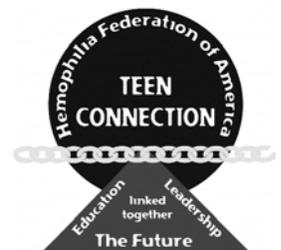
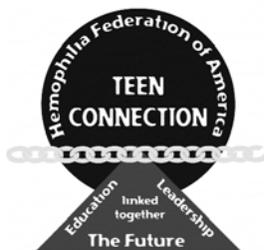
The teen program began Friday afternoon with time for introducing the weekend’s events and getting to know one another through fun activities. Saturday morning, the group dove right into learning more about themselves, their strengths and talents. Teens discussed self-advocacy, peer pressure, relationships, and other issues that today’s teens face. Smaller groups of affected males, affected females, and unaffected siblings/children met and came up with ideas for future projects and activities upon which they want to focus their efforts.



As a reward for working so hard, the group journeyed to the Adventuredome, a 5-acre indoor theme park, on Saturday afternoon. They put their new skills into practice, let off steam and had some fun while developing new friendships with peers! The group finished the weekend with a presentation of their activity and ideas to the General Assembly on Sunday morning.



Those teens attending took lots of photos, exchanged email addresses, and made plans to stay in touch via an HFA Teen Connection Chat Room. They also addressed the possibility of meeting again this summer or fall to discuss ways that Teen Connection can be of service to the larger community. Based on the talent present at Symposium, the blood clotting disorders community’s future is sure to be in good hands! 👤





The Community speaks about 2004 HFA Symposium

The evaluations are in and the community has spoken. Here are a few of the comments shared with us regarding the symposium held in Las Vegas on March 26 – 28 in celebration of our 10th birthday.

“Another round of applause to all. As I sat and watched some of the magic unfold this weekend, there were many different things that came about... We have the chance to start something no other organization has done before.”

“...I am extremely happy with the program. The HFA Kids program was exceptional!!! The speakers were truly inspirational and informative. I am very glad I attended, a true eye opener! Thank you for the opportunity!”

We asked for suggestions for topics and/or speakers for next year and here are a few of the suggestions.

“Parenting kids with hemophilia, Resources for families, Interaction with HTC’s/Drs/Social workers (Dos & Don’ts), or Helping your child transition from pediatric to adultcare”

If you have a topic or a speaker that you would like to see on the agenda for 2005, send us an e-mail or drop a note. For e-mail, you may send your comments to either of our co-chairs:

Donnie Akers dakers@cox-internet.com or
Star Tyree star45@frontiernet.com
Jan Hamilton j.hamilton@cox-internet.com

To mail a comment, send it to:

Jan Hamilton
Hemophilia Federation of America
102 B Westmark Boulevard
Lafayette, Louisiana 70506



HFA Recognizes Outstanding Volunteers

On Friday evening, March 26, during our Educational Symposium Federation Celebration, the Board of Directors was please to recognize some outstanding volunteers in the hemophilia community. Without a dedicated team of volunteers, the many tasks that need to be completed would be impossible to achieve.



The 2004 Michael Davon Community Service Award was presented to **James Romano**. James (Jimmy to us) has worked as a volunteer with HFA since he was a freshman in college and delivered packets of information to members of Congress as we were working on the Ricky Ray campaign. He is connected to the blood clotting disorders community through his three uncles and two cousins who all have hemophilia. His entire family is heavily involved in hemophilia activities. As an employee of the Health and Medicine Counsel of Washington, Jimmy represents us on an ongoing basis on Capitol Hill. However, the time and effort that he puts into working for the cause goes above and beyond his job.

The 2004 Ron Niederman Humanitarian Award was presented to **Jamie Siegel, MD**. Jamie serves as co-chair of the HFA Medical Advisory Professionals Board. In that capacity, she has served as symposium speaker, worked on Emergency Room treatment guidelines and our Emergency Room Triage Educational program. She has also edited the revision of “The Facts” brochure and has been there countless times to answer our questions. After the presentation, she confided that she actually was Ron Niederman’s physician during the last few months of his life, so this award was very meaningful to her.



The HFA 2004 Volunteer of the Year Award was presented to our new President, **Barbara Chang**. Barbara has been on the HFA board since 2000, when she was the representative from our member organization, the Hemophilia Foundation of Southern California. She is now an independent member of the board and has served as co-chair for the last two symposia. She is always there for HFA and the hemophilia community.

Each year, the President has the opportunity to select a person believed to merit special recognition. This year, the **HFA President’s Award** was presented by outgoing President Bob Marks to **Susan Dill**. Susan serves as chair of our popular Helping Hands program which demands a lot of time on her part. She also has served on our Nominating Committee and the Ad Hoc committee for the production of our new Treatment Directory. Susan has no family connection to hemophilia, but is very much a part of the community.



HFA Past President’s Award was presented by Barbara Chang, our new President, to **Bob Marks**. This award was given to Bob for all the services he has done for HFA in the past two years as President.

Three of our board members were recognized for completing a total of six years of service to the HFA board. They rotate off the board this year, but will still be active in committees and projects. They are: Susan Dill, who was an independent member from Michigan; Rich Vogel, from New Jersey and our President before Bob Marks; and Linda Lewis, an independent member from Missouri.

Congratulations and our heartfelt thanks to each of these people for their outstanding service. 🐾

HFA in Washington

By: James Romano



With the election season shifting into high gear this spring, partisanship on Capitol Hill has effectively blocked any real progress on major legislation. This is the environment in which the Hemophilia Federation of America (HFA) is working on Capitol Hill to advance its legislative agenda. During the first week of April, HFA Executive Director, Jan Hamilton, and HFA President Barbara Chang arrived in Washington, DC for a week of numerous activities. This trip served several important purposes, which will be described in more detail in this article.

The first purpose of the trip was to attend the Department of Health and Human Services' Advisory Committee on Blood Safety and Availability, which met in Washington, DC that week. Hand in hand with the Blood Safety meetings is always the Plasma Protein Therapeutics Association's (PPTA) stakeholders meeting which allows voluntary health organizations and the manufacturers of plasma derived therapies as well as recombinant therapies to meet and discuss important issues of mutual interest.

The second purpose of this trip was for HFA to introduce our new President, Barbara Chang to key offices in the California Congressional Delegation on Capitol Hill. The final purpose of the trip provided the Federation with an opportunity to advance a number of our legislative issues. Specifically, HFA followed up on our victory to fund the half cases through some remaining monies from the Ricky Ray Fund and our other important issue of removing the one million dollar lifetime cap on health insurance which affects a number of individuals in our community.

Since Barbara resides in California, she and Jan met with many health care leaders in the California Congressional Delegation. They met with staff from the offices of Senator Barbara Boxer (D-CA), Senator Dianne Feinstein (D-CA), Congressman Henry Waxman (D-CA), and Congresswoman Hilda Solis (D-CA). These meetings were very important in broadening HFA's horizons and contacts on Capitol Hill and educating these congressional offices on the programs and projects of the Federation.

While in Washington, Jan and Barbara also met with the office of Senator Mike DeWine (R-OH). As you already know, Senator DeWine is a champion of our

community. He was the original sponsor for the Ricky Ray Hemophilia Relief Fund Act in the United States Senate. The purpose of the meeting was to discuss the completion of the remaining Ricky Ray claims. Senator DeWine and his staff have worked very hard with HFA to assure that the remaining cases are finished completely and correctly. Because of the language that HFA was able to insert into the report accompanying the Omnibus Appropriations Act for FY 2004, the Health Resources and Services Administration (HRSA), the federal agency charged with administering the Ricky Ray Fund, must submit a report on how it will finish paying off the remaining claims. HFA is patiently awaiting this release of this report.

Jan and Barbara also met with Ms. Jocelyn Moore, Legislative Assistant to Senator John Rockefeller (D-WV) regarding the one million dollar lifetime cap on health insurance which is a continuing problem in the hemophilia community. Ms. Moore recently worked for Senator Robert Graham (D-FL) and was instrumental in working with Senator DeWine to finish the Ricky Ray Fund claims. Now Ms. Moore works for Senator Rockefeller and is looking forward to working with HFA on our legislative agenda. Senator Rockefeller was the Democratic sponsor on the original legislation to remove the cap in the mid-1990s. We are looking forward to working with Senator Rockefeller's office on this issue.

Also while in Washington, Jan reached out to work with other health organizations on a number of issues that affect the hemophilia community. She met with Ms. Shannon Pemberthy and Mr. Paul Haas of the National Hemophilia Foundation. The result of this meeting was an agreement by HFA and NHF to collaborate together on the issue of Hepatitis C Compensation, mainly working to establish an Institute of Medicine review of HCV infection in the hemophilia community along the same lines as the original report into HIV infection. Jan also met with Thelma King Thiel, Executive Director of the Hepatitis Foundation International (HFI). The purpose of that meeting was to discuss ways for HFA and HFI to work together since HCV is a large problem in our community. ♀



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In another effort to expand the concerns of the blood clotting disorders community in matters of reimbursement, we met with a member of senior management with the America's Health Insurance. This group represents health care insurers other than Blue Cross / Blue Shield. We discussed concerns regarding prior authorization, sole source providers, limitations on product, CHOICE, proper coding by hospitals regarding factor therapies, and lifetime caps. We will continue our conversations with this group and with Blue Cross / Blue Shield in these matters.

In the government relations arena, the Hemophilia Federation of America had a very good spring and we are looking forward to advancing our priorities in the coming months. 🐾

Current Patient Notification Registrants:

*GET ON BOARD WITH TECHNOLOGY –
CHANGE YOUR NOTIFICATION TO
E-MAIL*

As of June 11, 2004 express mail will no longer be a choice for notification. If you are currently registered to receive your notification via UPS please contact PNS today at

www.patientnotificationsystem.org or call 1-888-UPDATE-U and change your notification.

*DON'T DELAY – MAKE THE CHANGE
TODAY!*

E-mail is instantaneous, trackable and accessible even on travel



Greetings From HFA President

Here is my first time to officially greet you as the elected HFA President of the Board of Directors. Wow, what a joy, honor and privilege it is for me to be chosen as your team leader!

My first thoughts go toward our history. I am most fortunate to be following our Past President, Bob Marks who has accomplished so much for our Federation. We have seen several major advances in our organization and have been in a period of transition.

We have now reached our 10th anniversary and look forward to the next decade. In my opinion, we are on the threshold of becoming a larger national voice for the Blood Clotting Disorders Community. As our number of member organizations increases and our funding grows, so will our programs and capabilities.

We remain committed to issues of blood safety, reimbursement and legislative issues both on a local as well as a national basis. We will focus on several major programs including ER Triage, a Directory of product and service providers, Dads in Action and the brand new concept of Moms on a Mission.

We remain dedicated toward our Mission and Vision. HFA is a small but mighty group of people who make a significant impact. We represent the people with blood clotting disorders and need every one reading this message to become involved. There is much to be done and it starts with committee work. Come on, get involved, and support your board as we support the community. My door is always open; please contact me in any way you find convenient; you may leave a message at the office 800-230-9797, send e-mail to bchang@hemophiliafed.org or drop a line to Hemophilia Federation of America 102B Westmark Blvd. Lafayette, LA 70506 🐾



HFA Announces the 2004 Scholarship Winners

It was a delight to see the amount of highly intelligent and talented youth in the bleeding disorder community.

Our scholarship committee was certainly challenged by the task of choosing this years' winners. After many hours of reviewing and ranking the applicants, the committee has chosen the following individuals as the winners:

For the Artistic Endeavors Scholarship

Rosa D. Marroquin

Houston, TX

Rosa will be attending the University of Houston.

For the Sibling Continuing Education Scholarship

James D. Ryan

San Antonio, TX

James will be attending Baylor University.

For the Continuing Education For persons with Bleeding Disorders Scholarship

Joseph C. Reichle

Dubuque, IA

Joseph will be attending the University of Iowa.

Ryan S. Monk

Cincinnati, OH

Ryan will be attending the University of Cincinnati.

Joshua J. Friesen

Wake Forest, NC

Joshua will be attending the Southeastern Accredited Seminary.

Thank you to all of you who took the time to apply for our 2004 Scholarship Program. We know our scholarship committee's task of choosing five recipients out of an amazing field of candidates was daunting and they feel these applicants stood out.

We encourage you to apply for our 2005 program. Applications will be sent in the fall of 2005. Please call 800-230-9797 to be put on our 2005 mailing list. Good luck to all of you! 🐾

BON VOYAGE and HFA STAFF CHANGES



Susan Swindle, Administrative Director, loyal staff member and volunteer for the last 4 years, made the difficult decision to leave HFA in order to accept a part time position elsewhere which allows her to spend more time with her family. Our loss is the Swindle Family's gain. HFA and the entire community are extremely grateful for Susan's tireless work on behalf of the community. Susan graciously remained with HFA through our Educational Symposium in Las Vegas and was an invaluable part of its smooth operation and success. The Board of directors expressed a fond farewell and thanks to Susan at the Educational Symposium.



Carole Lancon reluctantly has taken leave as head of HFA Teen Connection Program to fill an interim teaching position, but will continue to remain involved with Teen programming as a member of HFA and will continue to be in HFA offices weekly. Carole is available at her HFA email address and continues her work with Zuiho "Z" Taniguchi, Teen Committee Chair, to get our Teen Chat Room up and running.

HFA Executive Director, Jan Hamilton, along with Desiree Gothreaux, Executive Secretary/Bookkeeper and Wendy Hearne, Administrative Assistant will continue HFA service to the Blood Clotting Disorders Community as additions to staff are made. 🐾

HFA Welcomes two new members to the Medical Advisory Professionals Board (MAP)

The Hemophilia Federation of America is pleased to welcome two new additions to our MAP Board. The two latest additions to this prestigious group are Jonathan Goldsmith, MD and Mauricio Silva, MD.



Jonathan Goldsmith, MD, is currently Vice President of Medical Affairs and Interim President of the Immune Deficiency Foundation in Towson, Maryland. Dr. Goldsmith earned his undergraduate degree from Dartmouth College and graduated from New York University School of Medicine, followed by an Internship and Residency at Vanderbilt University Hospital and School of Medicine. He has held professorships at the University of North Carolina, University of Iowa, University of Southern California and others. Dr. Goldsmith has also been Co-Director and Director of the Nebraska Regional Hemophilia Center and the University of Nebraska Viral Syndrome Clinic.

His other professional accomplishments include serving as Head of the Childrens AIDS Center in Los Angeles, Medical Director and Vice President of Clinical Affairs for Alpha Therapeutic Corporation. He has also held senior positions at Centeon LLC and Questcor Pharmaceuticals. Dr. Goldsmith has published extensively in peer reviewed science and medical journals on hemophilia, AIDS, immunodeficiency and other topics

He is licensed to practice medicine in the state of California and is Board Certified in Internal Medicine and Hematology.



Mauricio Silva, MD was born in Bogotá, Colombia. He studied Medicine at Pontificia Universidad Javeriana, School of Medicine in Bogota, Columbia and served an internship at Pontificia Universidad Javeriana, Hospital Universitario de la Samaritana, also in Bogota. Dr.

Silva completed a Residency in Orthopaedics and Traumatology at Pontificia Universidad Javeriana, Bogota, Colombia and completed a Fellowship in Research in Total Joint Reconstruction at Joint Replacement Institute at Orthopaedic Hospital, University of California at Los Angeles. He also completed a Research Fellowship in Musculoskeletal Complications in Hemophilia, International Hemophilia Treatment Center, Orthopaedic Hospital, University of California at Los Angeles.

Dr. Silva has completed developmental courses on Study of Internal Fixation in Melgar, Colombia and in Knee and Hip Arthroplasty at Anderson Orthopedic Clinic, Alexandria, VA. He is licensed to practice medicine in Colombia and in California.

He is the recipient of numerous awards both in his native Colombia and in the United States, The Netherlands, and Spain.

Currently, he is a Research Fellow at Orthopaedic Hospital, Los Angeles both at the Joint Replacement Institute and the International Hemophilia Training Center. ♀



Advocating for Chronic Conditions, Entitlements and Social Services

A team of dedicated experts helping people with hemophilia and related bleeding disorders explore state and federal entitlement programs and associated health insurance coverage issues.

18 Times To Call A.C.C.E.S.S.

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1. I quit my job.
2. I lost my job.
3. I got a new job.
4. I have reduced the number of hours I work.
5. I'm looking for work.
6. I'm no longer able to work full-time.
7. I'm about to lose my health insurance.
8. I'm about to use up my health insurance.
9. I just lost my health insurance.
10. I can't get health insurance.
11. I just got married.
12. I just had/adopted a child.
13. My child has lots of medical bills that I can't pay.
14. My child just turned 18.
15. My child is about to leave for college.
16. My spouse stopped working.
17. I'm getting a divorce.
18. I'm moving.



Hemophilia of Indiana

Hemophilia of Indiana (HII) is an Indianapolis based not for profit health agency dedicated to assisting individuals and families affected by bleeding disorders like Hemophilia and von Willibrands Disease.

The organization has a 40-year history of providing educational programs, support group development, financial assistance and consumer advocacy. Special programs include unique fund raising events, summer camp for children, scholarships, therapeutic workshops and medic alert identification.

HII is a member of Community Health Charities and is associated with the National Hemophilia Foundation and the Hemophilia Federation of America.

In 2004, Hemophilia of Indiana has added two staff members and is implementing new and exciting marketing campaigns designed to better serve the Indiana hemophilia community while generating more exposure for the Chapter and the hemophilia cause.

For more information, contact us at 800-241-2873

Utah Hemophilia Foundation

The Utah Hemophilia Foundation has existed since 1959 to meet the needs of people with bleeding disorders in Utah. Through education, advocacy, outreach and networking, the UHF empowers individuals and families to lead healthier and more self-sufficient lives.

The Utah Hemophilia Foundation offers a wide variety of educational and networking opportunities throughout the year for those with bleeding disorders. Programs include Camp Valor, a summer camp for kids, ages 8 to 14, with bleeding orders; an annual week-long teen adventure (river rafting and hiking; quarterly teen activities; an adult retreat; a weekend family forum/annual meeting; workshops and seminars and quarterly first-step events for families with affected children between the ages of 0-8. Additionally, the UHF produces a quarterly newsletter, an annual memorial publication, and other written communiqués to keep folks informed and connected. We also maintain an agency website, www.hemophiliautah.org. 📍

In Memory of David B. Madeiros

(June 11, 1956 to February 29, 2004)

As Founder and Executive Director of Factor Foundation of America, David Madeiros was the vision and overall strategic leader of the organization in funneling funds into the bleeding disorder community. David was responsible for overseeing the daily operations, patient care and services; government relations, and patient advocacy for the community. He managed more than 40 employees representing strategic regional locations throughout the country.

David applied his undaunted passion for building cars (preferably Mustangs) and airplanes to his daily life. Born with hemophilia, he stood firm in his convictions that “the disease does not rule the person.” In this manner, he overcame many of the ailments and illnesses associated with bleeding disorders and enjoyed a very happy and fulfilled life with his wife Kim and son Jason. He was a true testament of perseverance and had a will to overcome life’s small obstacles. He committed his time, energy and skills to bestow this same

philosophy and approach to the thousands of people within the bleeding disorders community.

Born on June 11, 1956, in Troy, NY, David was an innovative, driven spirit who eventually owned and operated Charter Concord Development, a commercial development leasing company in Boca Raton. He received his Masters in Business (MBA) from Florida Atlantic University (FAU) (1980), his undergraduate degree at Siena College in New York (1978) and attended Bishop Gibbons High School in New York (1974).

David is survived by his wife Kim and son Jason, brother Robert, sisters Kathi and Pam and mother Ruth Madeiros. David is predeceased by his father Phillip and brother Larry.

The Hemophilia Federation of America sends out our heartfelt condolences to the Madeiros family & the Factor Foundation of America. 📍

Knowing the Factor:

One nurse/mother/sister gives so much to those with bleeding disorders

By Teresa A. Andrasik, BS, RN



Linda Eleanora Wyman Collins, BSN, RN, C, is known by the nickname “Lew” in the NICU of George Washington University Hospital (GWUH), Washington, DC, where she has worked as a full-time nurse for 20 years.

A single mother of three and active in her church, Lew is moving through her life quietly, while making a big difference. She is a member of the board of directors of the Hemophilia Foundation of Maryland (HFM) and a volunteer at the local chapter. In addition, she has worked for the Hemophilia Association of the Capitol Area (HACA) for 12 years. She is the HFM’s representation on the board of directors of the Hemophiliac Federation of America (HFA), a non-profit national advocacy group for people with coagulation disorders. For the past 3 years on the HFA board Lew has continued her work as an advocate, volunteer and lobbyist.

Family History of Bleeding Disorders

Lew, my friend and co-worker, was diagnosed with von Willebrand’s disease (VWD) 11 years ago. She is also a carrier for hemophilia A. “Looking back, I always had a lot of bruises growing up, ulcerative colitis, bleeding with dental work, even undiagnosed joint bleeds,” she remembers. “Beginning in the teenage years I had heavy periods, yet so did my mom, grandmother and aunts. My brothers were born premature and did not live long. My theory is they died of pulmonary hemorrhage or intraventricular hemorrhage. Because of the technology back then, the listed cause of death was hyaline membrane disease. It was not pursued any further. Also, doctors were baffled by my sister’s death; she passed away after a minor closed head injury in a motor vehicle accident.”

The journey toward diagnosis for this family was long and eventful:

In 1981, Lew’s 21-year-old sister mysteriously died the vehicle accident.

Also in 1981, Lew’s firstborn son was circumcised and promptly hemorrhaged. Later, at 17 months old, he woke up from a nap and couldn’t walk. After numerous misdiagnoses, a savvy resident from GWUH discovered abnormal coagulation studies. Further testing revealed the toddler was a severe hemophiliac, type A

In 1984, a second son was born (he was not circumcised!). He was tested and is also a severe type A hemophiliac.

In 1988, Lew’s daughter was diagnosed as a carrier for hemophilia A.

In 1996, a nephew was found to have hemophilia A

In 1997, a niece was diagnosed to be a true hemophiliac. She has factor VIII (hemophilia A) and factor XI deficiency (hemophilia C).

Inherited Bleeding Disorders

Von Willebrand’s (vWD) disease is an inherited disorder that affects 2-3 percent of the population. It is caused by a deficiency or defect in a protein, called von Willebrand’s factor, which promotes blood coagulation.

In fact, vWD is just one of many bleeding disorders. This collection of hereditary bleeding disorders is each associated by a lack of one of the factors needed to coagulate blood. The two most common hereditary bleeding disorders are hemophilia A and hemophilia B.

Hemophilia A, the classic type of hemophilia, is handed down as an X-linked recessive trait and has a lack of coagulation factor VIII. More than 80 percent of patients have type A hemophilia.

Hemophilia B is handed down as an X-linked recessive trait and has a lack of coagulation factor IX. About 15 percent of patients have type B. (A less common disorder is hemophilia C. This bleeding disorder is caused by an X-linked recessive trait and a deficiency of factor XI.)

Approximately 60 percent of patients with hemophilia A and B are severe cases and can have spontaneous bleeding without any precipitating event. Routine problems experienced by those with bleeding diathesis include: significant loss of blood when having simple dental procedures; epistaxis (nosebleed), a common problem with children; and excessive fatigue from chronic anemia. Another complication is that a simple hematoma can become a continuous bleed.

(Continued, page 18)

Continued from page 17

Hemarthrosis (bleeding into a joint) requires extravasation of the blood and can result in scarring of the joint as well as joint disease and permanent disability. Vision can be lost from bleeding into the eye. Women experience abnormal menstrual bleeding that often results in unnecessary hysterectomies. The leading causes of death for those in the hemophilia community at this time are intracranial bleeding or complications of AIDS, transmitted by contaminated plasma concentrates which were being used as treatment for hemophilia in the early 1980s, prior to advanced screening tests for the presence of HIV in the blood.

Coagulation factors in the blood are responsible for the process of blood clotting. There are as many as 20 different plasma proteins or clotting factors that interact in human blood. Factor replacement therapy is lifesaving for those with bleeding diathesis. Some have been duplicated for use in the chronic bleeding community.

Treatment

Difficulties can also arise with the treatment for hemophilia. The top three complications of factor infusion and blood replacement are the potential for the transmission of the HIV virus and hepatitis B and C. (It's the transmission of hepatitis B and C that is the complication. The term "liver disease" is too general and, in fact, not correct. Many other substances such as alcohol, drugs and toxins can also cause "liver disease"). All persons who receive blood products should be immunized against hepatitis B.

Routine lab tests for those suffering an injury or possible spontaneous episode include a CBC and a factor level. Treatment with clotting factors is a percentage correction — treat higher for an injury involving the head or abdominal area. For example, a 40 percent correction will treat a joint bleed. A member of the bleeding community must keep 100 percent correction on hand at all times.

RICE — rest, ice, compression and elevation — is the treatment often prescribed for bleeding injury. An air-filled cooling cuff is an ingenious device that encompasses all the RICE points. It is made of three components, a cuff, a tube and a cooler, which applies pressure to the affected area as well as cooling water to keep swelling down. By lowering the cooler as the body warms the water from the tube, the water is rechilled, making this a convenient method to keep pressure and coolness applied.

An important nursing role is to teach self-infusion to the chronic bleeding patient.

Accessing a vein or existing central line should be done with sterile technique. These skills can become routine for the patient who is properly prepared.

A nurse working with the chronic bleeding patient should teach patients how to articulate and identify their episodes. Is the bleed in a muscle, joint, mucous membrane or soft tissue? The sensation of blood entering a confined space such as a joint results in a dripping feeling. As a bleed progresses it will feel warm to the touch. Treatment should begin before swelling occurs if possible. Patients are taught to take a skin pen and mark the borders of a tissue bleed. The breeching of the border will be a visible sign of continued bleeding or under-treatment

Parents should be conscious of a child who favors an extremity or who refuses to put weight on both extremities. All members of the bleeding community should be encouraged to keep a bleeding log. They will be given guidelines on how to treat injuries in advance, how much factor or desmopressin acetate (DDAVP or Stimata) to infuse depending on the type of injury. By following the prescribed guidelines of their physician, chronic bleeding patients will have more independence.

Finally, patients should be taught to wear medical alert bracelets, carry wallet cards with their diagnosis and keep a letter from their treating physician explaining their personal treatment program. All those with the diagnosis of chronic bleeding should carry a case with their 100 percent factor dose and self-infusing IV supplies when traveling.

Twenty-five years ago the life expectancy of a severe hemophiliac was 40 years; now, with advanced medical treatment available in HTC's, safer factor products and home infusion, the CDC estimates a life expectancy of 64 years. These extra years are necessary if hemophiliacs are to live a healthy life and raise their children.

Community Resources, Treatment Centers

Hemophilia is a rare bleeding disorder, which affects approximately 20,000 people. Speed of treatment is of the utmost priority in saving lives. Specialists who have factor products and DDAVP on hand are needed on standby to support this community. The National Hemophilia Foundation (NHF) was established in 1940 to meet the needs of the chronic bleeding community. Its mission is education, research and advocacy on behalf of people with bleeding disorders.

According to the NHF, more than 70 percent of the hemophilia community participates in one of the 150 centers or hemophiliac treatment centers (HTCs) that comprise this network.

HTCs grew out of concern over dangerous delays in getting coagulation treatment for the chronic bleeding community. Michael Soucie, PhD, at the CDC, who conducted a study to determine if there is any real benefit to the HTCs, said, "Persons who received care in the HTCs were 40 percent less likely to die than those who had not."

HTCs have a hematologist available 24 hours a day, 365 days a year. They are also staffed with physical therapists, orthopedists, social workers, dentists and RN coordinators. HTCs are equipped with CT scans and MRIs, and keep factor products in stock. "Due to the high cost of factor products many emergency departments and hospitals do not stock them. Factor costs per year can be as much as \$250,000-\$500,000. My sons use 2,500-3,000 units per dose of factor, at a cost of \$1.20 per unit," Lew reveals. "Yet all patients in the bleeding community are not insured for access to an HTC. This is a serious health issue that needs to be addressed. Many insurance companies have a \$1 million lifetime cap."

Becoming Politically Active

As a young adult, Lew did not imagine herself in the political arena. Yet living and raising children with a bleeding disorder has opened the door to a serious need for advocacy. As a nurse advocate with intimate knowledge of bleeding disorders, Lew has been influencing change and improving conditions for this population.

She helped gain support lobbying for the Ricky Ray Act, a bill that gave compensation to people infected with the AIDS virus from the blood supply, during a time when the government was aware the virus existed and did not take proper precautions. Lew also lobbied tirelessly to prevent Blue Cross/Blue Shield Care first from converting to a for-profit company that would have caused many HTCs to close.

Lew has also worked to access specialty care and recombinant products, and to identify women in the community with undiagnosed bleeding disorders. When asked what she is currently focused on, Lew immediately answers, "Some insurance companies will not cover the cost of an HTC visit, it is important that a patient bill of rights is implemented to ensure that those in need can see specialists."

In addition to her efforts on Capitol Hill, Lew has applied herself at the grassroots level. She has taught

many families how to be advocates for their own health care. She has educated physicians and school personnel about bleeding disorders. "Education and patient advocacy are important for our quality of life," she states.

Educating Children Too

Not all of Lew's efforts are focused in the adult arena; she makes time to volunteer at Camp Young Blood in Virginia, a place dedicated to helping children deal with a chronic bleeding diagnosis. "At summer camp we teach the children to self-infuse. I have had 5 and 6 year olds successfully self-infuse with good sterile technique," she says. "They are very proud of themselves and are thrilled with the independence they gain from being able to infuse and not be homebound."

In addition, Lew volunteers at a teen retreat in Maryland for adolescents with bleeding disorders. "The retreat makes it possible for young adults to spend time together, relax and share in a comfortable environment. We do activities like a rope course, wall climbing, swimming, archery, horseback riding or just watching movies. It is so healing for them to be with others who have the same or similar diagnosis."

Lew's volunteering is not limited to the land. She volunteered on an overnight outing aboard the U.S. Coast Guard cutter, Taney. This educational trip, which also gives the diagnosed young men and women a chance to be together, just as importantly gives the parents a break from the care of their unique children.

The word hemophilia is of Greek origin, "haima" meaning blood, and "philos" meaning beloved or dear. This is a true definition for Lew Collin's mission. Though she is one person, one nurse, she is making an enormous impact on the lives of others.

Resources

Anderson, K.N., & Anderson, L.E. (1998). *Mosby's pocket dictionary of medicine, nursing and allied health* (3rd ed). Chicago: R.R. Donnelley and Sons Co.

Hemophilia Federation of America: www.hemophiliafed.org; 800-230-9797.

CDC: www.cdc.gov/ncidod. Click on search, then use keyword "hemophilia."

Hemophilia Foundation of Maryland Inc.: www.hemophilia.org; 800-964-3131. (For resource materials call 1-800-42-HANDI)

Hemophilia Association of the Capitol Area: www.hacacares.org. (E-mail address: hacacares@aol.com)

Teresa A. Andrasik is a NICU nurse for George Washington University Hospital, Washington, DC, and a coordinator of the Special Diet Support Group of St. Mary's Hospital, Leonardtown, MD. This article was reprinted from ADVANCE, vol. 5, Issue 20, with permission from the author. ♀

PPTA Presents Plasma Forum 2004

The Plasma Protein Therapeutics Association presents an annual "Plasma Forum" discussing the key issues facing the industry today. This year's event will be held June 9 – 11 at the Grand Hyatt in Washington, D.C.

There are many changes impacting the industry and the 2004 Plasma Forum promises to be a dynamic and thought-provoking meeting. This year's event is entitled: "Consumers, Regulators and Industry: Working Together for Tomorrow." There will be sessions on access to care, recent developments in specialty therapies, trends in donation and therapy manufacturing processes and regulatory developments. The sessions will also address innovative emerging roles for plasma therapies, including counterterrorism, and will provide insight into the challenges the industry faces going forward.

The audience is generally company executives, research directors, marketing managers and regulatory affairs personnel. There are a handful of consumers who attend but this program is always full of very informative topics and it is a wonderful chance to get answers to probing questions.

Once again this year, HFA will have a speaker at this event. Executive Director, Jan Hamilton, has been asked to present issues on Access to Care for the blood clotting disorders community. Others on the panel with Jan are: John Walsh, Alpha-1 Foundation; Jonathan Goldsmith, MD, Immune Deficiency Foundation; John DeHart, Guillain-Barre Syndrome Foundation; and Shannon Penberthy for the National Hemophilia Foundation.

For additional information or to register call PPTA at 202-789-3300. 📞

CAPWIZ™

By: Jan Hamilton



Since the return from the Hemophilia Federation of America (HFA) Symposium in Las Vegas, the legislative program at HFA has become greatly enhanced. The reason for this enhancement is HFA's new contract with Capitol Advantage, a Washington, DC based firm which works with organizations on a state and federal basis to manage grass roots communications with Congress and state legislators effectively. This is done through Capitol Advantage's premier electronic database system named *CAPWIZ™*.

Now in an instant, hemophilia community members will be able to contact their congressional and state representative offices directly through *CAPWIZ™*, because it has both a federal and state mechanism. The HFA Advocacy Committee will identify important public policy issues and pieces of legislation that we will need to identify so that our community can send letters to Congress asking for cosponsorship as well as congressional action. Hemophilia community members will be able to log on to the HFA website and in turn be able to access

CAPWIZ™. This will make it easier to send pre-approved correspondence that will be emailed and faxed over to the offices. Each letter may be sent directly from the site or downloaded to be faxed and/or mailed to the offices.

This tool will further enhance the work HFA does on Capitol Hill because it will allow all of our member organizations and members to contact their legislators directly on issues of importance to HFA and the hemophilia community. All you have to do is to visit the HFA website at www.hemophiliafed.org and go to the Legislative Action site. There are no passwords and it is open to everyone. We also invite chapters and industry to link to the site so that it is more readily available to everyone.

Look for more information about *CAPWIZ™* in the months to come. If you would like to have more information now, call the office and ask to speak with Jan Hamilton, Executive Director. 📞



FYI: Industry News Briefs

CSL Limited & Aventis-Behring Sign Agreement

CSL has acquired Aventis Behring, combining this business with their ZLB Bioplasma operations to create ZLB Behring, a leader in the global plasma products industry. The business will be managed from its head office in King of Prussia, Pennsylvania. Peter Turner, the current head of the ZLB Group business, will run the combined business. Peter Perreault has replaced Joseph Pugliese as General Manager of the Hemophilia Business Unit, North America.

Questions about how this business transaction may affect your relationship and interaction with Aventis Behring may be addressed to Peter Perreault at 610-878-4141 and he will provide answers as they become available.

Bayer AG Seeks Divestiture of Its Plasma Business

Kogenate® Product Line Not Included in Initiative

Bayer AG announced recently it is initiating a process to divest its plasma business which is part of the Bayer Biological Products (BP) division. The recombinant factor VIII blood coagulation business—comprising the Kogenate® product line—is not included as part of this Bayer AG initiative. As this initiative is being pursued, Bayer BP will continue its long-standing commitment to the bleeding disorders community.

Wyeth Closes Plant in United States

Wyeth recently announced that it is closing its St. Louis, Missouri manufacturing facility and consolidating [US: ReFacto® Antihemophilic Factor (Recombinant); EU: ReFacto® (moroctocog alfa, recombinant coagulation factor VIII)] drug substance production to the Stockholm, Sweden manufacturing facility. Manufacture of the company's investigational recombinant factor VIII drug also is transitioning to this facility in Sweden.

As a result, the company has withdrawn its marketing application for this investigational drug from the U.S. Food and Drug Administration (FDA) so that the application can be updated. Wyeth intends to update and resubmit an application after the manufacturing transfer to Stockholm is completed and documents for the Stockholm facility are available for submission to the FDA.

Clinical trials for our investigational drug remain ongoing. Patients and clinicians involved in these clinical trials can be assured that sufficient clinical supply is available to complete the current studies. Wyeth remains committed to the development of this investigational drug, to providing safe and effective recombinant factor products with enhanced viral safety, and to supporting individualized tailored care for the hemophilia community.

Data Analyses Further Support Safety and Efficacy of Baxter's ADVATE for Hemophilia A

First and Only Human- and Animal Plasma Protein- and Albumin-Free

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For Adults, Children with Hemophilia A

Study results on the Baxter Healthcare Corporation's ADVATE Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method (rAHF-PFM) were presented at the 45th Annual Meeting and Exposition of the American Society of Hematology (ASH) these results add to the growing body of data evaluating the therapy's safety and efficacy in patients with hemophilia A. These data are consistent with previously presented study results on ADVATE.

As the first, third-generation recombinant therapy for hemophilia A, ADVATE is also the first hemophilia A therapy to comply with MASAC recommendations that state, "All efforts should be made to remove human albumin from recombinant factor VIII products" and that, "Increased efforts should be made to eliminate human and bovine proteins from the manufacturing process of recombinant products."

An Invitation From Baxter for Hemophilia A Consumers

With a physician prescription, individuals with hemophilia A can receive up to six doses free of charge of the latest breakthrough in factor VIII therapy: ADVATE (Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method) rAHF-PFM. Along with these six complimentary doses of ADVATE rAHF-PFM, patients can also receive a complimentary GoPack—a portable kit that affords the flexibility of infusing factor at home or on the go. Those who have not yet advanced to ADVATE rAHF-PFM are encouraged to talk with their physician to determine whether it is the best therapy option for them.

Bayer Biological Products to Introduce Enhanced Tamper-Evident Packaging Features

Shrink-Banding Marks Latest Phase in Initiative to Enhance Safety of Biological Products

Bayer Biological Products (BP) announced plans to introduce shrink-banding as an enhanced tamper-evident packaging innovation for all liquid products in vials produced at its Clayton, N.C. facility. Additionally, Bayer BP is actively pursuing alternative packaging safety innovations for other Bayer BP products in a manner responsive to product differences and the unique needs of various geographic regions. Current plans to introduce tamper-evident packaging to Kogenate® FS and KOGENATE® Bayer feature a customized over seal with a Bayer logo. 

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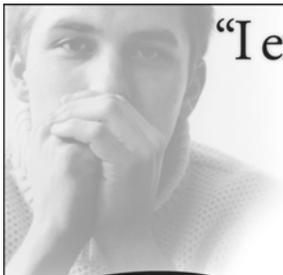
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Community Calendar 2004

June

PPTA Plasma Form will be June 9-11 in Washington, DC.

Dads in Action Training will be held in Lafayette, Louisiana the weekend of 11-13.

Heartland Hemophilia Annual meeting will be held in Omaha, Nebraska on the 26th.

June

9th Annual Polo Tournament & Family Fun Day with Hemophilia Foundation of Southern California on the 27th at Will Rogers State Historic Park.

July

Gateway Hemophilia Annual meeting, Sheraton in Downtown St. Louis, Missouri on the 10-11.

August

Advisory Committee on Blood Safety and Availability Hyatt on Capitol Hill, Washington, DC on the 26-27.

October

HFA Mid-Year Board Retreat will be held in Lafayette, Louisiana the weekend of 10-11.

Congratulations to Judy Igelman, an HFA Board Member, who was awarded the Industry Volunteer of the Year Award by the Hemophilia of North Carolina Chapter.

Editorial Committee:

**Wendy Hearne,
Layout & Design**

**Carnell Chappelle
Jan Hamilton
Bob Marks
Mike Morse
Carl Weixler
Phill Blomquist
Zuiho Taniguchi**

HFA Board Members in Action

Two of our board members are involved in activities that are raising funds for the blood clotting disorder community.

Craig Elledge will be volunteering to help at Camp Heartland, a camp for children and teens with HIV/AIDS, and trying to raise \$1000 toward the camp.

Paul Brayshaw is riding his bike for 184 miles for 3 days along the Chesapeake and Ohio Canal from Cumberland, MD to Washington, DC to raise money for Hemophilia Foundation of Maryland.

If you would like to support these two members of the blood clotting disorder community, please call the office at 800-230-9797 for more information

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