



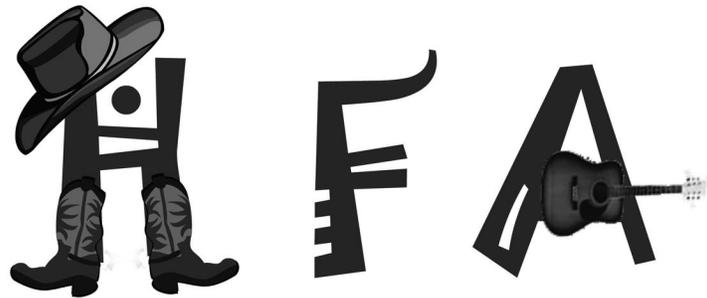
Dateline Federation

NEWSLETTER OF THE HEMOPHILIA FEDERATION OF AMERICA

Winter 2004

Volume 9, Number 4

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MUSIC CITY INFUSION NASHVILLE 2005

HFA invites you to join us for
a boot scootin' good time.

Make plans to attend our
Educational Symposium

April 1-3, 2005

At The

Sheraton Music City Hotel
Nashville, TN.

800-230-9797

www.hemophiliafed.org



President's Patter

As I reflect upon the time since our last issue of Dateline Federation, I realize many things are in flux with our organization. The most notable change is a subjective feeling that we are evolving into a more professional business-like organization with focus

on a few key areas. We are not straying in any way from our mission and vision but rather becoming more adept at keeping our eye on the goals of our organization.

We have lost a dear friend of the organization with the passing of Dr. Charles Hamilton. He was a dedicated member of the community and beloved husband of Jan. He is missed tremendously by everyone whose life he touched. We wish Jan and her family a peaceful readjustment.

The most exciting fiscal news for HFA is the announcement of having conducted a full, official financial audit. Our audit is now complete and we can use this to open doors in the areas of government grants. We have also adopted some new guidelines for our budget to reflect programs which are totally dependent upon outside funding.

One key area of importance to HFA is advocacy and in an effort to focus our attention on this issue we have created a new position. We are extremely pleased to announce that Jan has agreed to return from sabbatical as HFA's first Advocacy Director. She will be working closely with Jim Romano, Advocacy committee chair. Our most notable issues are successful meeting with Mark McClellan at CMS and the position we have taken in regards to sole source providers. We are also taking the first steps to offer collaboration with NHF and other community organizations regarding a united voice to advocate for our community.

We attended the NHF meeting in Dallas Nov 4-6. While there, Donnie Akers and I met with many company representatives to provide an overview of HFA and to request their consideration of support. Susan Swindle, Carl Weixler and Bob Marks joined us on some occasions. In general, we believe everyone continues to recognize the good deeds of HFA and have offered to respond with as much financial support as possible. Everyone seems pleased about our site selection for 2005 in Nashville and our strength in the areas of advocacy.

The HFA Dads in Action program is really taking off! We have a good core group of leadership and are having support groups organized throughout the country. These dads are meeting the challenge of getting involved with their children, taking the kids to activities, educating themselves and infusing their children.

Wishing you a Happy New Year! 🍷

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.

Officers

- Barbara Chang, President
- Carl Weixler, 1st Vice President
- Donald Akers, 2nd Vice President
- Peter Bayer, Secretary
- Randy Ratcliff, Treasurer
- Bob Marks, Past President

Staff

- Jan Hamilton, Advocacy Director
- Susan Swindle, Administrative Director
- Sandy Aultman, Administrative Assistant
- Desiree Gothreaux, Executive Secretary/Bookkeeper
- Jim Boudreaux, Webmaster

Member Organizations

- 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 Illinois
- 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

Washington Update:

At a meeting of leaders of the hemophilia community hosted by NHF in Washington, DC on Monday, January 24, there was a lengthy discussion regarding the issues concerning Medicare reimbursement and the impact current reimbursement structure will have on Medicaid and third party payors. A Task Force was formed including HFA's Advocacy Director, Jan Hamilton to formulate a resolution that would be introduced at the Advisory Committee on Blood Safety and Availability on Tuesday, January 25 by Paul Haas, NHF President and a member of the ACBSA committee.

The resolution formulated by the Task Force was passed by ACBSA and will be sent directly to the HHS Secretary. The following is that resolution along with a strong recommendation from the Committee itself. Please feel free to contact your congressmen and ask them to address this situation and communicate with the HHS Secretary regarding this crucial matter.

WHEREAS the committee is acutely aware of many challenges facing the bleeding disorders community;

WHEREAS the committee has been made aware that one of the foremost challenges to Access to Care is the 20% Medicare patient co-pay;

WHEREAS the cost of care for bleeding disorders can be as high as \$8,000 per month per adult beneficiary which far exceeds even the highest paid Social Security benefits;

WHEREAS supplemental coverage may not be obtainable or affordable for disabled qualified Medicare beneficiaries;

WHEREAS the committee is aware that the substantial cost of patient co-pay results in reduced access to quality care, impact on *choice* of product, provider and physician and significant personal financial and social consequences;

WHEREAS Medicare policy decisions are followed closely by third party payors;

The Advisory Committee on Blood Safety and Availability urges the Secretary of Health and Human Services to support any proposed policy and/or legislation to address the extraordinary financial burden for these patients.

- The Committee finds that current reimbursement schedules for plasma derived products and their recombinant analogues for treatment of chronic conditions are not adequate to support optimal care of individual patients. Additionally, shortages in supply of these needed therapeutics has impacted the healthcare of these lifelong disorders. The Committee therefore recommends that the Secretary take steps to augment reimbursement of plasma derived products and recombinant analogues.

The Committee endorses the following principles to guide such efforts:

- Plasma derived products and their recombinant analogues should be reimbursed at rates consistent with their true costs, including costs of distribution and administration
- Reimbursement should be sufficient to ensure an adequate supply of these therapies
- Individual products within product classes should be recognized as therapeutically unique
- Equivalent reimbursement should be provided in different care settings
- The lifelong cost of treatment to the individual patient should be addressed in any pricing structure, including the extraordinary impact of co-payments

HFA Advocacy Team Visits 109th Congress

On Thursday, January 27, HFA's President Barbara Chang; Director of Advocacy, Jan Hamilton; and Board Members Lew Collins and Paul Brayshaw met several key members of Congress from Louisiana, California and Virginia to outline HFA's legislative priorities for the coming year. Much of the discussion focused on eliminating the burden of the 20% co-pay for clotting factor for Medicare beneficiaries and the problems associated with competitive bidding in the Medicare program and "sole source" providers in the Medicaid program.

Congress Passes Ricky Ray Amendment Pending Half Cases To Be Finalized

By Dale Dirks and Gavin Lindberg; HFA Washington Representatives

The Hemophilia Federation of America (HFA) has been working throughout the last year and a half to convince Congress and the Bush Administration to allow residual funding from the Ricky Ray Hemophilia Relief Program to finish paying off as many as 30 pending cases in which the sole caregiver has received only one-half of the compassionate payment offered by the fund. This effort was complicated by the termination (by law) of the Ricky Ray fund on November 12, 2003.

During consideration of its fiscal year 2005 funding measure, the Senate Appropriations Committee recognized this critical issue and recommended that the Department of Health and Human Services' (HHS) Health Resources and Services Administration (HRSA), which administers the fund, make provisions in anticipation of additional payments, in spite of the closing of the Ricky Ray program. Later in the fall, in the continuing appropriations resolution, Congress followed up on these recommendations with statutory language which would allow HRSA to utilize the residual funding to finish paying off the pending "half-cases." A January 2005 ruling by the HHS Office of General Counsel reaffirmed the statutory language, completing the final hurdle in this legislative effort.

According to the Ricky Ray Hemophilia Relief Fund program administrator, Paul Clark, HRSA is moving immediately to provide payment to four (4) cases that have submitted all of the appropriate paperwork. He estimates that there are roughly twenty (20) more cases pending that may be eligible to receive the second half of payments. Those cases are pending, and the outcome depends on the submission and approval of the appropriate paperwork and documentation.

HFA's Jan Hamilton led this marathon effort, by meeting with scores of senators and congresspersons over the last year and a half. She also kept in close contact with HRSA representatives, who helped advise the HFA on the pending cases, while maintaining the confidentiality of the individuals seeking payments. Although the odds were against a successful resolution to this challenge, and the relative amount of funding to finish off these half cases was modest by federal spending standards, HFA President Barbara Chang commented that "Those individuals who provided the compassionate care deserve to receive every penny to which they are entitled. It is gratifying that HFA could play a role in finishing off these cases."

Several key legislators played a role in securing the amendment that will allow for the half cases to be finalized. Senators Arlen Specter (R-PA), Tom Harkin (D-IA), Mike Dewine (R-OH), and Mary Landrieu (D-LA); all members of the Senate Appropriations Committee, led this bipartisan effort, with the support and concurrence from the House Appropriations Committee members: Congressmen Ralph Regula (R-OH) and David Obey (D-WI) and former Congressmen Porter Goss (R-FL) and Chris John (D-LA).

Medicare Reimbursement for Clotting Factor Concentrates Set

The Medicare Modernization Act of 2003 (Public Law, 108-199) placed into effect a methodology transition for the reimbursement of clotting factor concentrates will be reimbursed at ASP + 6% + a dispensing add on fee, which the Center for Medicare and Medicaid Services (CMS) has set at 14 cents per unit. The law allows for the dispensing fee not to exceed 37 cents. This fee was initially set at 5 cents per unit and HFA joined other members of the patient and home care community to reject this recommendation for a number of reasons, the most important of which is the loss of access to care. This combined effort resulted in the increase to the 14 cents per unit add on dispensing fee. HFA will continue to monitor the implementation of reimbursement rates for clotting factor. ♣

Our Deepest Sympathies



The Hamilton Family would like to thank you for your prayers and support during the illness and passing of their beloved husband, father and grandfather, Dr. Charles Hamilton. Dr. Hamilton passed away October 22, 2004.

HFA REMEMBRANCE WALL PROJECT

Our Glenn Falls, N.Y. Board Member, Alan Converse has a vision. He would like to create a portable REMBRANCE WALL honoring all the men and women that have died from blood clotting disorders, including HIV/AIDS and Hepatitis C. This wall will be on display at all HFA functions and on Capitol Hill.

Please submit family member names and year of their death to HFA at info@hemophiliafed.org. They will not only be remembered but will serve as an inspiration to future generations for their contribution in the fight to improve quality of life. ♣



Important Information Regarding Symposium 2005

REGISTRATION

To register for the symposium, complete a Family registration form AND a Session Form for each adult and a separate Youth and Teen Form for each person 18 and younger.

A \$50 family registration covers parents and children living in the same household. Childcare will be provided for infants and toddlers and a structured program is offered to all other HFA Kids and Teens.

REGISTRATION DEADLINE IS MARCH 15TH, 2005.

SCHOLARSHIP

HFA will provide a limited number of travel or accommodation scholarships to first time attendees.

Scholarship applications are available online, at www.hemophiliafed.org or call HFA for additional information at 1-800-230-9797.

HOTEL

Make reservations DIRECTLY with the Sheraton Music City Hotel at (800) 325-3535 or direct at (615) 885-2200. Please request the Hemophilia Federation of America block when making reservations to be eligible for the group rate. Check out the hotel property online at www.sheraton.com/musiccity. **The deadline for special group rates is March 10, 2005.**



LOCATION

The hotel is located at 777 McGavock Pike, at Century City, Nashville, Tennessee. An airport shuttle departs the Sheraton Music City Hotel at 15 minutes prior to the hour and 15 minutes after the hour. It arrives at the airport on the hour and the half-hour. This service is a complimentary service between the hours of 5:00AM and 12:00 Midnight.

Driving directions are provided for your convenience.

Hemophilia Federation of America Educational Symposium Preview 2005

Thursday, March 31, 2005

12:00 pm - 5:00 pm Building Strong Relationships for Men: Joe Caronna, Inalex Communications
2:00 pm - 5:00 pm Exhibitor Set Up and Registration
2:00 pm - 5:00 pm Early Attendee Registration
6:00 pm - 7:30 pm EXHIBITS OPEN

Friday, April 1, 2005

9:00 am - 12:30 pm EXHIBITS OPEN
9:30 am - 11:30 am Coalition for Hemophilia B Breakfast Meeting: Chris Walsh, MD Speaker
9:00 am - 1:00 pm REGISTRATION
12:00 pm - 1:00 pm Welcome Reception
1:00 pm - 1:30 pm Welcome & Introductions
1:00 pm - 5:00 pm Childcare 0 to 4 years - Kids - Teens

GENERAL SESSION

1:30 pm - 3:00 pm ADVOCACY PANEL: Moderator - Jan Hamilton
Jim Romano: Washington Perspective
Michael Bradley: Industry Perspective
Michelle Rice: Grassroots Perspective
Tony Garr: Coalition for all Bleeding Disorders
3:00 pm - 3:30 pm BREAK
3:30 pm - 4:30 pm Insurance Issues-Know Your Options : PSI - Dana Kuhn
4:30 pm - 5:00 pm Legislative Action Center
5:00 pm - 6:30 pm EXHIBITS OPEN
7:00 pm Dinner - Awards

Saturday April 2, 2005

GENERAL SESSION

9:00 am - 10:30 am
10:30 am - 11:30 am
10:30 am - 2:00 pm
TREATING THE WHOLE PATIENT
Resilience: Charles P. Gilbert II, ACSW, BCD
Medical Moderator: Jamie Siegel, MD
Physical Therapy: Jeffrey Kallberg, PT
Registered Nurse: Cherys Zimmerman, RN
Consumers: Sharen Haddad and Wayne Cook
EXHIBIT HOURS

NOON BREAKOUT SESSIONS

12:00 pm - 1:45pm
Dads In Action: Joey Privat & Tom Vaclavik
Women's Pampering Session: Feminine Focus Committee HFA
Alternate Therapies: Carole Lancon, Moderator
Yoga : Lana Bienvenu
Art: Mona Constantini
RAKI-Debra Couvillion

GENERAL SESSION

2:00 pm - 2:45 pm
2:45 pm - 3:30 pm
3:30 pm - 4:30 pm
4:30 pm - 5:00 pm
6:00 pm
INHIBITORS : Donna DiMichele, MD
Hemophilia 2005-What's New! : Chris Walsh, MD
An Unexpected Life : Brad Lewis, MD
Kids Presentation & Closing
Gibson Showcase: Dinner and Entertainment

Sunday, April 3, 2005

8:00 am - 9:30 am Breakfast



**Hemophilia Federation of America
 8th Annual Meeting and Symposium
 Sheraton Music City • Nashville, Tennessee
 April 1-3, 2005
 REGISTRATION FORM**

To register: (Registration Deadline - March 15th, 2005.)

Mail: Hemophilia Federation of America
 1405 W. Pinhook, Ste 101
 Lafayette, LA 70503
For more information call 1-800-230-9797 or 337-261-9787

Fax: (337) 261-1787

Please complete a **SEPARATE** Sessions form for **each** adult who will attend. To register children 18 and under, complete a **SEPARATE** youth and teen registration form for **each** child. Feel free to duplicate this form.

Payment must be received before we can process your registration.
***All Credit Card information requested below MUST be provided in order to process your payment.**
 Check the registration method: ___\$25 Individual ___\$50 Family (Parents & Children)

Payment Method: ___Check ___Money Order ___Credit Card *Card Type: (circle) Visa MC Discover AMEX

*Credit Card Number _____ *Exp. Date _____ *Security Code: 3 digits _____

*Name on Credit Card _____ *Signature _____

PRINT OR TYPE INFORMATION

 First Name Last Name Spouse's First & Last Name

 Street Address or P.O. Box City State Zip Code

 Home Phone Office Phone Fax E-mail

Relation to Hemophilia: (Circle One)
 Patient Spouse Carrier Family Member Other _____

Complete the following if registering as a family.

1. How many family members are you registering? _____
2. Please list the names of the children (first and last) you are registering. A **separate** form must be completed for **each** member you register. For children 18 and under use the youth and teen form.

Do you authorize the use of any photographs or videos taken for HFA's use only? ___Yes___No



Hemophilia Federation of America
8th Annual Meeting and Symposium
Sheraton Music City • Nashville, Tennessee
April 1-3, 2005
YOUTH AND TEEN REGISTRATION FORM

To register: (**Registration Deadline - March 15th, 2005.**)
 Complete form (duplicate if necessary) and mail or fax with adult registration form to:

Mail: Hemophilia Federation of America **Fax:** (337) 261-1787
 1405 W. Pinhook, Ste 101
 Lafayette, LA 70503

For more information call 1-800-230-9797 or 337-261-9787

Print or type all information. Complete a SEPARATE form for each child.

Child's last name	First name	Age	
Street address/P.O. Box	City	State	Zip Code
Father's full name		Mother's full name	
Parent/Legal guardian's address (city, state, and zip code) if different from above.			
Do you authorize the use of any photographs or videos taken for HFA's use only? <input type="checkbox"/> Yes <input type="checkbox"/> No			
What is the child's relationship to hemophilia? <input type="checkbox"/> Factor VIII <input type="checkbox"/> Factor IX <input type="checkbox"/> von Willebrand <input type="checkbox"/> Family member <input type="checkbox"/> Friend <input type="checkbox"/> Other _____			
Please be aware that some activities planned for the youth and teen program may take place offsite.			
Do you grant permission for your child to go on a field trip without your supervision? <input type="checkbox"/> yes <input type="checkbox"/> no			
All persons under the age of 18 MUST be accompanied by a responsible adult.			
Please indicate the responsible party who will be accompanying your child to symposium.			
Name _____		Relationship _____	
Cell phone number _____		Pager _____	
Please list ALL medical conditions, including ALL medications (including factor), as well as other pertinent information that we should be aware of during the course of the symposium to ensure your child's safety.			

"The undersigned parent/legal guardian hereby consents to their child _____, participating in the activities of the Hemophilia Federation of America's HFA Kids/Teen Connection at its 2005 Symposium in Nashville, Tennessee. The undersigned parent/legal guardian, does hereby release, hold harmless and agree to indemnify the Hemophilia Federation of America, from any and all liability resulting from the participation of their child in the activities sponsored and conducted by the Federation's Teen Connection."

Parent/Legal Guardian _____

Date _____

Revised 12/07/04

**HFA's 8th Annual Meeting and Symposium
Sheraton Music City • Nashville, Tennessee
April 1-3, 2005**

We will offer three noon breakout sessions on Saturday, April 2nd, please choose one for each adult attendee.

ADULT NOON BREAKOUT SESSION FORM

Name of Applicant: _____

Circle One:

DADS IN ACTION

FEMININE FOCUS – WOMEN'S PAMPERING SESSION

ALTERNATE THERAPIES

ADULT NOON BREAKOUT SESSION FORM

Name of Applicant: _____

Circle One:

DADS IN ACTION

FEMININE FOCUS – WOMEN'S PAMPERING SESSION

ALTERNATE THERAPIES

DIRECTIONS TO THE SHERATON MUSIC CITY HOTEL

FROM DOWNTOWN (2 nd Avenue, Broadway)	I-40 East. Turn left onto ramp. Follow I-40 toward Knoxville to Briley Parkway North, Exit 215-B. Go 1/2 mile to Elm Hill Pike, Exit #7, turn right. Go to 2 nd traffic light; turn right on McGavock Pike. Hotel is 2 Blocks on your left on top of the Hill.
FROM SOUTH (Birmingham, Brentwood, Franklin, I-440, Green Hills)	I-65 North to I-440 Memphis/ Knoxville, Exit #80. Follow I-440 East, Knoxville/Chattanooga. I-40 splits take I-40 East. Travel I-40 East to Exit 215-B, (Briley Parkway) Go 1/2 mile to Exit #7 Elm Hill Pike. Turn Right at 1 st light. Go to 2 nd Traffic light; Turn Right onto McGavock Pike. The Hotel is 2 Blocks, on Left at top of the Hill.
FROM NORTH (Louisville, KY, Hendersonville)	I-65 South to Briley Parkway/Opryland, Exit # 89. Go past Opryland Hotel/ Opry Mills. To Elm Hill Pike Exit # 7 Turn Left at Light onto Elm Hill Pike. Go down 3 traffic lights. Turn right onto McGavock Pike. The Hotel will be 2 blocks on the Left at top of the Hill.
FROM WEST (Memphis, Bellevue, Belle Meade)	Stay on I-40 East towards Knoxville. Continue in right lane on I-40 East to Briley Parkway / Opryland, Exit 215- B Go 1/2 mile to Exit # 7, Elm Hill Pike take Right, Follow to 2 nd traffic light, Take Right onto McGavock Pike. Follow McGavock Pike for 2 Blocks. The Hotel is on the Left on top of the Hill.
FROM EAST (Knoxville, Lebanon, Mt. Juliet, Hermitage)	Take I-40 West towards Nashville to Briley Parkway North Exit 215B Go 1/2 mile to Exit # 7, Elm Hill Pike. Turn right at ramp, go to 2 nd traffic light, (McGavock Pike) Turn right. The hotel is on left at top of the Hill.
FROM SOUTHWEST (Chattanooga, Murfreesboro, Atlanta)	Take I-24 West to I-40 East to Briley Parkway North, Follow Briley Parkway North to Exit # 7 (Elm Hill Pike) Turn right at the first light. Go to second traffic light and take right onto McGavock Pike. Follow McGavock Pike 2 blocks, The hotel is on the left on top of the Hill.
FROM AIRPORT	Take the Nashville Exit towards I- 40 West, Travel to Briley Parkway North. Go 1/2 mile to Exit # 7 (Elm Hill Pike) Turn right follow to 2 nd light Turn right onto McGavock Pike. Follow 2 blocks. The Hotel is on the left at top of the Hill.
FROM NORTHWEST (St. Louis, Clarksville Tn)	Take I-24 East to I- 40 West towards Knoxville. Take to Briley Parkway North, Follow Briley Parkway to Exit # 7 (Elm Hill Pike) and take a right Go down 2 Traffic Lights, and take a right onto McGavock Pike. Follow McGavock Pike 2 blocks. The hotel is on the left at top of the Hill.

777 McGavock Pike, Nashville, TN 37214

Phone: (615) 885-2200, Fax: (615) 231-1134



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Shuttle Service

The shuttle departs the Sheraton Music City Hotel at 15 minutes prior to the hour and 15 minutes after the hour. It arrives at the airport on the hour and the half-hour. This service is a complimentary service between the hours of 5:00 AM and 12:00 Midnight.

At 4:30 PM, the service changes to “on call”, which means that the shuttle will transport/pick-up guests to/from the airport as soon as notified.

The guest should go to the *Baggage Claim Area to retrieve luggage, then proceed to the Phone Bank, depress Button #46* to arrange for shuttle pick-up. The guest should then go *down one level to Airport Shuttle* pick-up to wait for the shuttle.

Sheraton Music City Hotel, 777 McGavock Pike, Nashville, TN 37214, Phone (615) 885-2200, Fax (615) 231-1136

Industry News

Bayer Signs Development Deal for Longer-Acting Kogenate®

Bayer BP has signed an exclusive, global technology license with Zilip-Pharma for the development and commercialization of a new, longer-acting Kogenate® product — a product with the potential to shift current treatment paradigms in hemophilia and simplify the lives of thousands of patients around the world. The deal between Bayer and Zilip-Pharma involves the application of patented liposome technology developed by Zilip-Pharma and its affiliated companies over several years. Clinical results obtained by Zilip-Pharma suggest that a prolonged interval between bleeding episodes — one week or more — occurs when factor VIII attached to liposomes is administered to individuals with hemophilia A.

Upon achievement of key milestones, including successful clinical development and regulatory approvals in key regions, upfront and milestone payments from Bayer to Zilip-Pharma would total \$100 million plus royalties from sales of the new product. The pilot clinical studies by the Zilip-Pharma group suggest that Kogenate® molecules attached to the surface of these liposomes can extend the interval between bleeding episodes requiring fewer treatments especially in prophylactic regimens.

Based on initial timelines for the project, Bayer and Zilip-Pharma hope that the next-generation Kogenate® could be launched in five years, pending continued positive clinical results, required regulatory reviews, and necessary license approvals. ♣



Chapter Chat

Hemophilia Outreach of El Paso and the Hemophilia Community

The Hemophilia Outreach of El Paso, Texas held their first Women's Tea on October 9, 2004. The Board of Directors of Hemophilia Outreach of El Paso hosted the event. There were twenty-six mothers and thirty daughters in attendance. They wore colorful hats, drank hot tea and ate sugar cookies. The Hemophilia Outreach of El Paso's board states that many new friendships were made and ideas were shared on spending quality time with their daughters. The women had such a great time that they have scheduled another meeting for February 12, 2005. Rosa Maria Coles, president of the chapter, opened and closed the gathering with prayer.

The group also participated in their fifth Health Fair for 2004 on October 14th. The Fair was held at the Western School of Medicine. Many medical/nursing students came by the table to pick up literature on

hemophilia and other bleeding disorders. Carnell Chappelle said, "Hemophilia Federation of America's Newsletter went like hot cakes."

The Hemophilia Outreach of El Paso hosted their first Dads in Action meeting. It was held on November 13, 2004 and was called, "Lets Get Together." Joaquin Lopez was the moderator for the meeting. The atmosphere was warm and friendly and the meeting lasted almost three hours. Twelve dads and seven sons attended. Fathers opened up and shared their feelings. The sons expressed their ideas and thoughts as well. Much like the Women's Tea, Dads in Action have asked to have another meeting. It will be held in January and will be followed by a Dads in Action Bowling Challenge for the dads and their sons.

Factor Foundation of America proudly sponsors the Hemophilia Federation of America's Dads in Action Program. ♣

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Website: ahfinfo.com E-mail: info@ahfinfo.com

John Reed RPh
Cliff Marshall RPh



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to help the hemophilia community"*



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