



# Dateline Federation

NEWSLETTER OF THE HEMOPHILIA FEDERATION OF AMERICA

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47 Year Wait

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## HEMOPHILIA FEDERATION OF AMERICA STATEMENT ON SINGLE SOURCE PROVIDER CONTRACTS WITH MEDICAID

The Hemophilia Federation of America (HFA) adamantly opposes any state Medicaid program plan to implement a single source provider for anti-hemophilia factor concentrates. Single source programs threaten the efficacy and efficiency of treating bleeding episodes suffered by hemophilia patients. As such, single source programs will not realize any cost savings and will cause needlessly prolonged and aggravated hemophilia induced bleeding. The result is additional and costly medical intervention which could have been avoided had the patient received proper product at the onset of their bleeding episode.

### ABOUT THE HFA AND HEMOPHILIA

The Hemophilia Federation of America is a national nonprofit organization that assists and advocates for members of the blood clotting disorders community including persons with hemophilia and von Willebrand's Disease (vWD). HFA serves as a consumer advocate for safer blood products, affordable and obtainable health insurance coverage, and a better quality of life for all persons with bleeding disorders. HFA officers and staff work actively with the Food and Drug Administration (FDA), the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH) and Congress to remove all barriers to both choice of treatment and quality of life, to promote blood safety and availability and to address reimbursement methodologies, lifetime insurance cap reform and other important public policy issues

Hemophilia is a hereditary blood-clotting disorder that results in excessive bleeding which occurs either spontaneously or after injury. Hemophilia is treated with factor replacement therapies to compensate temporarily for the clotting factor the hemophilic patient is unable to produce. Clotting factor concentrates are available in plasma-based form (monoclonal factor) and a synthetic or recombinant analogue. The standard of care for patients with hemophilia is self-infusion clotting factor at the very outset of hemorrhaging, pursuant to a dosing schedule earlier prescribed by a physician. Therefore, the hemophilia patient or a family member may infuse the dose of clotting factor without costly and time consuming recourse to a hospital, emergency room or doctor's office. *Thus, self-infusion with clotting factor provides the fastest, medically efficient treatment at costs much lower than utilizing the services of medical treaters and hospital.*

Understandably, the Hemophilia Federation works to ensure that all hemophilia patients, in consultation with their doctors, have ready access to the

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## President's Patter

HFA is a national organization representing over 20 member chapter organizations across the nation. We exist to assist and advocate for the blood clotting disorders community.

We also welcome membership from individuals wishing to be part of our organization. Each and every person with an interest in blood clotting disorders should consider membership. The Federation is about people helping people. Our vision is to remove all barriers to both choice of treatment and quality of life. We must never lose sight of this vision.

We reach out to the local community through our programs which include helping hands, new families, feminine focus and dads in action. (Please see the outstanding report about our latest training program in this issue).

We are now facing very serious issues regarding reimbursement legislature which will have direct impact on the matter of choice and availability of

product and services. Our advocacy team along with our paid lobbyists in Washington DC are working diligently on your behalf to achieve acceptable outcomes.

We are very proud to introduce a new program to enable everyone to participate in the advocacy projects. Please visit our web site [www.hemophiliafed.org](http://www.hemophiliafed.org) and click on the picture of our nations capital. The Legislative Action Center allows you to discover what is happening on a local, state and national level. You will be able to communicate with government officials and express your opinion about these important matters. HFA is pleased to offer this tool now.

We believe in the importance of continuous education and the value of networking. We know that a hug may be just as important as a new technical document. Our biggest annual event is the spring educational symposium where you will shake hands and rub shoulders with all of your blood brothers and sisters. Be sure to mark your calendars for next April 1-3, 2005 in Nashville Tennessee. Gather your boots and your guitars and be ready to have a great time in the Music City. 🎸

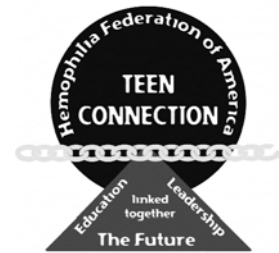


## HFA Teen Connection Wants YOU!!

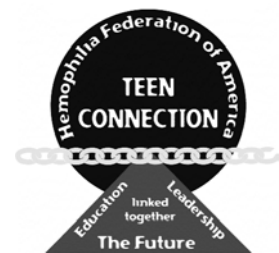
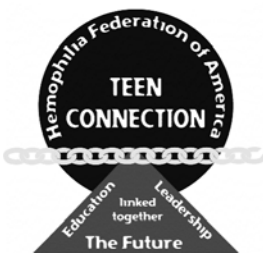


Are you between the ages of 13 and 18 and a member of the blood clotting disorders community? Do you want to connect with other teens from around the country that have interests and concerns just like you? If your answer is yes,

then you need to join HFA's Teen Connection! Last year in Vegas, over 30 teens met to share ideas and engage in discussions about real life issues that affect your generation. Attendees renewed old friendships and made new ones.



Plans are in the works for a fun and event-filled gathering in Nashville, but we need your input and suggestions for the types of events you would like to see offered. Email Teen Committee Chair Zuiho Taniguchi ([zuiho@lycos.com](mailto:zuiho@lycos.com)) or HFA staff with your ideas for ways to make our Nashville gathering rock!! 🎸





Jan Hamilton, Executive Director  
Hemophilia Federation of America

September 1, 2004

Dear Friends:

The last month has been a whirlwind for my family. My husband has been diagnosed with cancer of the esophagus and he is almost eighty years old. We have been going through a series of tests and evaluations to determine the best course of action. Regardless of the treatment protocol selected, it will be difficult at best to cope with the ramifications of the process.

The items at the top by my personal pyramid are God, family and HFA. Our family will certainly need both God and HFA support in order to get through the next few months. While there is no time that is good for something like this to happen, our 2004 successful symposium is behind us and we have moved into new offices across town that better fit our needs.

I have asked our Board for a leave of absence in order to cope with my family situation and they have been very generous. I will be on sabbatical until January. We are in the process of hiring an Associate Executive Director and/or Business Manager who will assist in leading activities at the office while I am away. Needless to say, each member of the Board of Directors has offered to also step forward and assume more of a leadership role in the affairs of HFA.

Your regular e-mails and correspondence to me will be directed to the appropriate person handling that phase of my job. In addition, for those of you who would have personal correspondence or conversation with me, my personal contact information is listed below:

909 Beaujolais Parkway, Lafayette, Louisiana 70503  
337-344-7382 (cell)      337-984-7982 (H)      [jan.hamilton@cox.net](mailto:jan.hamilton@cox.net)

I may be able to see you from time to time on special occasions during the next few months if Chuck's health permits. One of those times may be the NHF meeting in Dallas. If I am not visible at various events, please know that you are in my heart and I will hope that we are in your prayers.

HFA will be strong in my absence with the support system that we have set in place. Thank you for understanding. 🙏

Sincerely,

Jan Hamilton



# Chapter Chat

## **HFA Welcomes our Newest Member Organization and Their New Executive Director**

The Hemophilia Foundation of Illinois is pleased to announce the promotion of Kathleen M. Drayton to the position of Executive Director. Kathleen takes on this role with over twenty years of Executive level management and development experience with nonprofit organizations, mainly YMCA, Girl Scout Council Hospitals and charitable federations. She has been the Director of Development for HFI since August of 2003. She will continue her role of overseeing the development opportunities for HFI in addition to that of the Executive Director. ♀



## **More *IS* Better**

By Susan Soleil  
Executive Director of the UHF

For over 25 years, the Utah Hemophilia Foundation has hosted a week-long camp for boys with bleeding disorders. But the last four years have brought tremendous growth to our camp. That's when Camp Valor was finally opened up to girls with bleeding disorders, carriers, kids of affected parents and a limited number of siblings. Their inclusion at camp has facilitated changes at all levels and all for the better!

A heartfelt "thank you" to the amazing staffs of the other summer camps for kids with bleeding disorders around the country – your ideas, camp materials and support made our growth possible. ♀



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## **3rd Annual NACCHO - Save the Date**

We are pleased to report that Wyeth is continuing its sponsorship of NACCHO. The 3rd Annual NACCHO Conference will be held February 11 - 13, 2005, in Arizona. Registration forms and complete conference details will be available in the fall. If the 2005 meeting of the North American Camping Conference of Hemophilia Organizations (NACCHO) promises again to be the premier opportunity to meet with colleagues, and camping professionals, in order to share and learn new information and techniques that will enhance your camping program.

One item if you don't mind:

1. Please let me know if you have interest in helping to plan any of next year's sessions.

Thanks, and good luck with camp this summer. If you have any questions regarding next year's NACCHO, please feel free to contact me. ♀

Michael Rosenthal  
Executive Director  
Hemophilia Association, Inc.  
4001 N. 24th Street  
Phoenix, AZ 85016  
phone 602-955-3947  
fax 602-955-1962

## Plasma Protein Therapeutics Association Announces New Executive Director North America

I am happy to inform you that as of October 1, 2004 Julie Birkofer will assume the position of Executive Director North America. She has been working as Deputy Executive Director for more than a year and has demonstrated that she is ready for this important position. In her new position Julie will report to me.

The time between now and October 1 is a transition period where Julie will take over the responsibilities from Christopher P. Healey and be further briefed about the different activities. Julie Birkofer will continue to focus heavily on the Federal and State legislative agenda, stakeholder relations and Board liaison. During the transition period Julie Birkofer

will be the acting Executive Director and as such have increased exposure to all stakeholders.

Chris Healey has fulfilled a double role since last year with responsibilities for both the North America and Source Division. In the new structure, Chris Healey will focus 100% on the activities of the Source Division.

I would like to thank Chris Healey for his hard work for the North America Division. 🙏

Best regards,

Jan M. Bult  
President

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## Industry News

**Wyeth Pharmaceuticals Receives Food and Drug Administration Approval for New Delivery System for ReFacto® Antihemophilic Factor (Recombinant) ReFacto R2 Kit to Provide Additional Convenience to Hemophilia Community**

Collegeville, Pa., September 13, 2004 – Wyeth Pharmaceuticals, a division of Wyeth (NYSE:WYE), announced today that it has received approval from the U.S. Food and Drug Administration (FDA) for the ReFacto® Antihemophilic Factor (Recombinant) R2 Kit, the first needle-less reconstitution device with a prefilled diluent syringe for hemophilia. ReFacto is a recombinant factor VIII product formulated without human serum albumin in its final formulation. 🙏

For more information please contact:  
Christopher Garland  
Tel.: 484-865-6323

To see the whole article please go to  
<http://www.hemophiliavillage.com>

**Bayer Biological Products Launches Initiative to Aid Kogenate® FS Patients**  
*Multi-faceted patient assistance initiative developed in response to community needs*

**RESEARCH TRIANGLE PARK, N.C. (August 4, 2004)** — Bayer Biological Products (BP) has launched a patient assistance initiative in the United States for eligible patients receiving treatment with Kogenate® FS (**Antihemophilic Factor [Recombinant], Formulated with Sucrose**). The Bayer Kogenate® FS Assure Program (BKAP) is comprised of four components — a coupon-based program, patient assistance program, insurance support program, and HELPline, (800) 288-8374, a service that will answer questions about BKAP, eligibility, enrollment, and general reimbursement issues. 🙏

For more information please contact:  
Tricia McKernan  
Tel.: 919-316-6316, Fax: 919-316-6673  
E-mail: [tricia.mckernan.b@bayer.com](mailto:tricia.mckernan.b@bayer.com)

# Dads In Action

## Committee Update

### Dads In Action Training 2004

The second Hemophilia Federation of America Dads in Action training held July 23-25, 2004 was a great success! Dads from all over the country gathered together in Lafayette, Louisiana to learn more about the Dads in Action program. Their training included role-playing, several informational sessions, and the opportunity to question an expert panel. They also participated in a scavenger hunt.



Newest Dads Meet in Lafayette

Actions speak louder than words and many of the participants are moving forward with implementing a Dads in Action Program in their communities. Whether they have started by formally introducing the program to their local chapters or by having an informal round table discussion over breakfast with some other dads, actions to get these programs going are being put in place. Participating dads are also in the process of forming an online network for sharing ideas and information.

When asked how they felt about the training, some of the dads were quoted as saying:

*I was very impressed with the training and found it very rewarding.* – James Whitmire, SC

*The training was very worthwhile. It was time and money well spent.* – Rick Wells, CA

*I loved the training and there were plenty of ideas given to use for the future.* – Stanford Murray, TN



## Texas Central Hemophilia Association

Robert Champagne's

Chapter President Acceptance Speech  
(This is an excerpt from his letter)

I am addressing you today because I have a vision that dads of children with bleeding disorders get involved in the community and become advocates for their children. One of my goals as president will be to increase the involvement of dads within the chapter.

In order to meet that goal, we have started a Dads In Action Program, sponsored by the Hemophilia Federation of America. This worthwhile program involves a network of dads created to encourage, educate and support each other and their families.

I assume most of you think that I am here because my son has hemophilia, but that is only half of the reason. The other half has

nothing to do with hemophilia at all. It's because I am a simply "a dad". All dads can have fun together and learn parenting skills from one another. Hemophilia or not, dads must be involved in their children's lives.

Two years ago, my then 8-month-old son was diagnosed with severe hemophilia after spending nine hours in the emergency room. After the tears dried from my cheek, I realized the challenge ahead of me and made a pledge to myself that I would always let my son know how much I love him and that I would help make the community better for him. That's what dads do: we try to make things better.

Time has passed since that day, and letting my son know how much I love him is pretty easy at this point. He is now almost 3-years old. It's when he gets older that I am afraid it will become more difficult and his hemophilia makes it more of a challenge. I figure that I have not stopped living my life since he was diagnosed, so why should he. I am determined that he will know how much I love him by what I let him experience in life. I will let my son play baseball, basketball, and other sports. Yes, he will get bruises, The bruises will fade, but the experiences will last his lifetime. He will take pride in those bruises, knowing that I loved him so much that I was willing to let him encounter life. I am putting my child first and hemophilia second.

I have realized I cannot provide my son a better community by myself. Making the community a better place takes a vision, time and a promise by me and by all of us dads. The Dads In Action vision is that our families develop into educated, involved and supportive members of the blood clotting disorder community. Dads, we have to envision a better community for our children. Without foresight, we cannot change, we cannot progress and we cannot succeed. Fathers should set a vision for their children. It will not be perfect. It will not be accomplished as perfectly as we want it to be. But we have to

try, in our own way, to succeed and we have to leave a positive impact on our children. Dads, we are the next generation of the hemophilia community. We must lead with a vision: a vision of change to strengthen the bleeding disorders community and our involvement in it.

We had our first Dads In Action meeting in March. It was a great success. We met for two hours and played Whirley Ball. I know Whirley Ball sounds weird, but what a blast it was. The goal of the meeting was just to have fun with other dad's in the community. I would like to set another game up in September, but we need your participation in order to do that.

We must never forget the challenges and trials of the past. The hardship that has been experienced and lived by some has and will always affect us. However, this is a remarkable moment in the history of the bleeding disorder community. Never has the promise of a better tomorrow been so vivid. Dads, our opportunities are too great and our lives too short to waste this moment. Let us seize this moment of greatness together, for our children and our community. I challenge each dad with a hope, dream and vision for their child to join me and become part of Dads In Action. I look forward to the years ahead helping all of us to have a better tomorrow.

In closing I would like to quote President Ronald Regan who stated "We will preserve for our children the best hope of man on earth. If we fail, at least our children and our children's children will say of us that we justified our brief moment here. We did all that could be done." I look forward to the years ahead helping all of us to have a better tomorrow. 🐾



## THE HEMOPHILIA FEDERATION OF AMERICA IS FIGHTING TO CLOSE THIS CHAPTER OF THE RICKY RAY FUND THE RIGHT WAY



By James Romano & Dale Dirks



Since The Health and Medicine Counsel of Washington began its professional services for the Hemophilia Federation of America, one of the paramount issues facing the hemophilia community was completing the payments of the Ricky Ray Fund in a fair and just manner. A number of community members received only half of the \$100,000 compassionate payment due them. These community members were single parents who cared for their infected sons and, ultimately, lost their child. The other parent was absent from their child's life. These parents never knew their children and did not file for their half of the compassionate payment of which they were legally entitled. In 2002, the Ricky Ray Fund issued an addendum to its rules, which allowed for caregiver parents who only received the half payment to file paper work to claim the rest. It was fitting justice for those we lost that their caregiver parent receive the full amount and not have the half payment forfeited.

The Hemophilia Federation of America spearheaded this project to assist these families at the behest of the administrators of the Ricky Ray Fund. HFA worked with our congressional allies in the offices of Senator Mike DeWine (R-OH) and Senator Bob Graham (D-FL), the original Senate sponsors of the Ricky Ray Act. HFA was successful in convincing Congress to include recommendations in the 2004 appropriations omnibus legislation (Public Law 108-199) in which Congress called on the Health Resources and Services Administration (HRSA), where the Ricky Ray Fund was housed, to assist these families in completing the payments and to report to Congress on the progress.

The Ricky Ray Fund closed on November 12, 2004. However, after that legislatively mandated closing date, the fund continued to pay 13 half payments after the closing date. Because of HFA's congressional presence and pressure to assist these families, the Ricky Ray Fund staff persevered and

continued to issue the payments. During the early months of 2004, a bureaucratic tug of war began between the Office of Management and Budget (OMB) and HRSA over the validity of the payments issued after the closing date. HRSA stopped issuing payments until further clarification on congressional intent was obtained.

During the fiscal year 2005 appropriations process, HFA was again able to work with Members of Congress to include recommendation in the Labor, Health and Human Services Appropriations bill. This language is subject to final passage this year. HFA has led the struggle to complete what our community started over 10 years ago.

The Hemophilia Federation of America is one step closer in completing the historic process begun many years ago to provide compassionate payments to those individuals with hemophilia and their family members who were infected with HIV/AIDS.

If you have any questions please email James at [Romano@hmcw.org](mailto:Romano@hmcw.org).

### *Our Deepest Sympathies*

Valentino Chaivielo, M.D.,  
son of Rosemary Chaivielo,  
passed away July 7, 2004.

#### **Memorials**

Please call our office if you would like to make a special memorial donation in the name of a loved one.



(Continued from page 1)

choice of clotting product, the choice of treatment regimen, and the choice of provider to ensure the most effective and efficient treatment of hemophilia induced bleeding and attendant conditions. *Our collective experience shows that access to the proper medications, including choice of the precise clotting factor that best treats a particular patient's condition, is not only the best treatment but also is the most cost effective as well. This is because the best treatment—treatment geared to the particular needs of each individual with hemophilia—stops hemophiliacs' bleeding in the shortest amount of time, with the lowest possibility of re-bleeding, side effects, damage to immune systems and other factors that lead to additional, expensive medical interventions.* Nonetheless, too often over the last 25 years, the hemophilia community has suffered because its right to choose the best health regimen for each individual patient has been challenged by industry and government officials who see only the very short term cost savings rather than the needless suffering and resulting additional medical care the costs of which quickly dwarf any short-term savings.

#### **WHY SINGLE SOURCE PROVIDER CONTRACTS ARE DETRIMENTAL FOR THE HEMOPHILIA COMMUNITY.**

As earlier noted, hemophilia patients treat their internal hemorrhaging and other bleeding episodes by self-infusing clotting factor. Intravenous infusions of blood clotting products replace the missing or deficient proteins needed for the blood to clot. Infusions must be given as soon as possible after the start of a bleeding episode to minimize damage from the bleeding. Clearly, the longer bleeding lasts, the greater the amount of clotting factor will be required to stop the hemorrhaging and more hemorrhagic damage will result, likely resulting in additional medical costs for physical therapy, orthopedic treatment, weakened immune systems, pain killers and the like.

Alternately, due to their very frequent bleeding, some patients are prescribed doses of factor at regular intervals as preventative prophylaxis treatment. In addition, many patients develop antibodies known as “inhibitors,” rendering substantially ineffective the

very factor therapies that formerly prevented or stopped their bleeding episodes.

It is vital to note that there are different types of clotting factors because some types or forms of clotting factors may be significantly less effective than others in stopping a particular patient's bleeding. Likewise, some forms are more appropriate for patients with weakened immune systems. Along similar lines, patients coping with inhibitors will need increased amounts of factor concentrates as well as different brands. They must have access to different types of factor concentrates than those patients with the same type of hemophilia who have not developed inhibitors. *In sum, sound, cost effective medicine has proven that a single type of factor cannot fit all hemophilic patients.*

Understandably, each patient's expert medical treaters, such as his hematologist, will prescribe the type and quantity of clotting factor best suited to stop bleeding as quickly and completely as possible, taking into account the overall medical condition of the given patient. Therefore, a single source provider strategy threatens the efficacy and efficiency — including economic efficiency — of medical treatment for the entire hemophilia community. Thus, a single source provider of anti-hemophilia concentrates could have a negative safety impact because:

- Single source providers are not subject to any standards of care for product distribution. Medicaid patients can be limited by the providers as to what type of product to take and how many days a week a product will be covered, regardless of the treating physician's best medical opinion. Currently in South Carolina, Medicaid will not reimburse for recombinant analogue product for patients who are not newborns. Plasma-based anti-hemophilia factor concentrates are not the standard of care for patients. If state Medicaid departments adopt that policy, patient care will be set back two decades.
- Plasma based medicines can be dangerous for many in the hemophilia community coping with the effects of HIV/AIDS, Hepatitis C (HCV), and other infectious diseases because blood products contain extraneous materials that cause further complications of immune systems. This could lead

(Continued on next page)

to hospitalization stays and increased costs for extra medications to treat the effects of these deadly diseases.

- The emergence of infectious diseases poses a continued threat to the hemophilia community. Only recently the community was decimated by infection with HIV/AIDS and the Hepatitis C virus (HCV) which, at the beginning, industry and government officials reassured the community was not a significant threat. Scientists have yet to determine if many of these more prevalent infectious diseases of our time are blood based pathogens such as new variant Creutzfeldt-Jakob Disease (nvCJD), West Nile Virus, and Severe Acute Respiratory Syndrome (SARS) as well as other emerging pathogens. By limiting choice of product to a single source and single type of product, the state could be creating a potential safety nightmare in the future. This would result in a repeat performance to a community still carrying scars from the first.

The adoption and implementation of single source providers by States will be far from the economic cost-savers they are reputed to be for one clear reason: in a surprisingly short time, costs to the State and medical institutions resulting from the infirmities of single-source treatment will greatly overwhelm any very short-term merger saving. There are very serious economic as well as health impacts to observe:

- The hemophilia community is in a unique position to be able to receive its vital medical treatments in a home setting. A single source provider of anti-hemophilia concentrates will diminish competition of hemophilia home care providers thereby endangering access to product. If home care providers leave the market; hemophilia patients could be forced to receive their treatment in an emergency room or doctor's office setting. HFA has collected anecdotal but consistent and reliable evidence that too often emergency room settings provide poor hemophilia treatment. The standard of care as a response to trauma is to infuse with factor as soon as possible otherwise patients' health and lives are placed at risk. Moreover, even if properly done, ER care is much more expensive and slower than home infusion of clotting factor. There is no economic or medical rationale to channel hemophilia patients into ERs.

- Single source providers are not only bad from a patient's health viewpoint but it can lead to increased costs because of the need for extra doses of medication, more numerous medications, more doctors, increased hospitalization times, more emergency room treatments, and greater loss of productivity. Any immediate savings would quickly be eclipsed by extraordinary and needless additional costs not only in terms of pain and suffering but also in terms of dollars for treatment.

A one-size fits all approach does not work for the hemophilia community. Access to the proper type of clotting factor is smart medicine, the efficiencies of which should not to be threatened by a single source supplier's exclusive contract with Medicaid. Because the solicitation and implementation of single source provider contracts by state Medicaid departments threatens continued access to care for the hemophilia patient community throughout the United States. **The Hemophilia Federation of America emphatically urges the complete rejection of single-source funding and similar schemes.** ♀

***HFA attempts to include all news items in Dateline in a timely fashion. Please keep an eye on our web site to stay in touch with items that may not make it into this issue.***  
***[www.hemophiliafed.org](http://www.hemophiliafed.org)***



**MUSIC CITY INFUSION**  
**NASHVILLE 2005**

By Donnie Akers

The HFA 2005 Symposium will be held April 1-3, 2005 at the Sheraton Music City Hotel, Nashville, Tennessee. Donnie Akers and Star Tyree, Co-Chair persons of the 2005 Symposium, have been working with members of HFA Board and Staff to insure that the 2005 meeting will “focus on the community and family” aspect of those who suffer from blood clotting disorders. The choice of the Sheraton Music City was made because the hotel is ideal for “family style” meeting that HFA plans to host next year.

The hotel is designed in the style and heritage of a “southern manor” and sits atop many acres of beautiful landscaping. The lobby and public areas are intimate and inviting. It is furnished in comfortable

period furniture which will provide community members, families and members of industry a place to visit and to forge the bonds that are always made at HFA’s symposium. Meeting and exhibit space are ideally designed for close proximity and ease of access for both the community and industry. The hotel was chosen with the members of the community in mind. It has received awards for being among the best meeting and convention facilities in the industry.

HFA plans to present sessions dealing with Advocacy and Reimbursement Issues along with updates on Medical and Technical Issues pertinent to the community. HFA also plans to present valuable sessions specifically designed for the “individuals” who make up the blood clotting disorders family. Ideas in the works include topics and presentations dealing with “techniques for better living,” “life change and transitions,” and other areas in keeping with HFA’s mission to remove barriers to choice and to enhance our quality of life.

Make plans to attend the HFA 2005 symposium in Nashville and look for further information and details in upcoming issues of Dateline and at HFA’s website at [www.hemophiliafed.org](http://www.hemophiliafed.org). 📍



As a non-profit organization, Factor Foundation of America (FFOA) is committed to raising the standards of care and well-being of people with hemophilia and other bleeding disorders.

As such, Factor Foundation has created **FactorFirst™**, a grassroots program dedicated to changing the manner in which hospital emergency rooms and emergency personnel treat hemophiliacs and others with bleeding disorders. The one key element that is needed to fuel this program is membership.

Members of FFOA play a key part in “carrying the torch” towards improving the lives of people within the bleeding disorder community. Although FREE,

membership is quite valuable. Anyone can become a member both within the bleeding disorder community and the general public.

There are three levels of Membership:

- Basic/Individual
- Organization
- Professional

Membership supports FFOA’s program, “**FactorFirst.**” It is the goal of Factor Foundation to create the groundswell to address Emergency Room guidelines around the country. Please visit our website [www1.factorfoundation.org](http://www1.factorfoundation.org) to sign up today. 📍

## HFA KIDS "BEAR WITH IT"

By Judy Igelman

The "HFA Kids Program" at symposium is a unique four station learning opportunity providing children with their own meeting while their parents attend the HFA symposium. The kid's program is wonderfully created and directed by HFA board members Joyce Donlan from Nebraska and Judy Igelman from North Carolina.

"Imagination Station," "Granny Good Food's Station," "Make It and Take It Station" and "Bear Clinic Station" create a safe, kid-friendly and hands-on area where the children can make decisions about what they want to do. Here they can meet others dealing with clotting disorders, learn coping skills in a playful way as well as bond with each other through song, movement, yoga and dress up play.

This year's Bear Clinic took on an added dimension. Each child was given the opportunity to give life to their own bear, which they later took to "Ted E. Bear Hospital". The bears were lovingly sewn by Mona Constantini, a new HFA volunteer from Connecticut. Mona is not only an art therapist but also a candidate for a Doctor of Ministry degree who adores sharing her bear's healing hugs. Mona is busy making new bears for the HFA 2005 Symposium in Nashville.

The bears are brought to Bear Clinic un-stuffed and made from fabric hand selected with a pattern fitting the theme of the symposium. For Las Vegas, the "star theme" was chosen as every child was considered a star. The bears were then hand stuffed by the children who selected not only their bear's own design but also "charms" that represent the character traits, talents and other attributes they desire for their special bear friend. These charms were sewn into the bears as they stuffed them making it as unique as each child. The bear characters ranged from biker bears to ballerina bears. Each bear was filled with a marvelous ability to love and be loved.

As the children stuff their special "gene" charms for hemophilia or VonWillebrands they feel free to talk about their own issues in a protected and personal way since everyone at Bear Clinic understood these



conditions. The fellowship of other children who share the same condition is so special to the children. It helps them realize they are not different and that there are many children with hemophilia and VonWillebrands on earth.

One very young boy glued his hemophilia gene on the top portion of his bear's paw believing that hemophilia was the spot where he received his infusions. He wanted his bear to match him! A little girl said, "I want to sew a heart on my bear's hand so she can throw love to the whole world"

After the bear comes to life the child takes it to Ted E. Bear Hospital. It is there where real medical supplies are provided and the children become the doctors for their bears. In this area an adult with hemophilia and a visit from a medical doctor is available. The children are encouraged to ask questions and learn through practice on their bears how to do home infusion, elevate the leg, use ice packs and the importance of rest.

### "HFA Goes Bearing Down the Road"

From this touching symposium experience Mona and Judy decided to take "Bear Clinic" on the road. Mona made bears for children at Victory Junction Gang Camp, a Hole in the Wall Gang Camp in NC . The fabric choice this time was racing cars reflecting the theme of the camp. At this camp something new was added. Each bear received a birth certificate with a new born picture (taken by the child) and name tag. It was exciting to see the how many children were learning to sew for the first time. The bright smiles on their faces glowed with empowerment.

(Continued on next page)

There is love, learning, healing and nurturing in the HFA Kid's Bear Clinic and Children's Program along with a multitude of great big hugs! We can "bearly" wait for you to join us in Nashville April 1-3, 2005 at the HFA Symposium 2005 to be held at the Sheraton Music City Hotel, Nashville, Tennessee. 🐻

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## 47 Year Wait

By Barbara Forss

I'm a healthy, 52-year-old woman with a bleeding disorder, but life wasn't always this way! For 47 years, I was misdiagnosed and treated as if my severe bleeding was something that just "happened" to some women. My health was precarious; my career was jeopardized due to loss of workdays; and several times I almost died. All these things needn't have happened if just one doctor had performed a simple blood test.

From 1951 through 1998, I'd had over 50 hospitalizations and surgeries and over 250 blood transfusions, most related to bleeding episodes that appeared to have no known cause. In many of my hospital charts and records, it was noted that I bled "like a hemophiliac", but that as a female, I couldn't possibly have hemophilia. Then I had a routine dental exam that changed my life.

At my checkup, my dentist noted that I had yet another subconjunctival hemorrhage of my eye. This had occurred frequently, (five times in 18 months), but it had been medically termed "a nuisance". For those who are unaware, a subconjunctival eye hemorrhage is where the sclera (the white part) turns blood red, often in seconds. I had experienced many of these in my lifetime, but I had always been told that this was probably due to my having coughed or sneezed, thus causing the hemorrhage. Even though I knew I hadn't coughed or sneezed, the doctors that I was referred to (my PCP and an ophthalmologist), assured me that this was the only explanation for why my eye would hemorrhage so severely and so often.

According to my dentist's records, I'd had another subconjunctival eye hemorrhage at my previous appointment, just six months earlier. He also noted that every time I came in for either a routine exam or cleaning, my gums bled profusely "just on touch" and "with absence of any periodontal disease." I also had many mouth and tongue lesions that showed signs of bleeding.

This dentist then suggested that I IMMEDIATELY be seen by my primary care physician, based on a belief that I might have a "bleeding disorder", something my dentist had recently read about on the Internet. I raised concerns that my PCP would just shrug his shoulders if I once again presented with a "nuisance eye hemorrhage", so my dentist personally made the call to my doctor and requested that he run a prothrombin time test. The test results indicated that I needed to be seen by a hematologist and ultimately led to my diagnosis of F-VII Deficiency.

This is a rare hereditary bleeding disorder that had been missed for 47 years, causing me to undergo countless unnecessary surgeries and other traumatic procedures, much unnecessary pain both physically and psychologically, including a total abdominal hysterectomy at age 31, following four miscarriages and fourteen abdominal procedures to stop my severe menorrhagia. I was hospitalized 18 days for a routine tonsillectomy, 11 days for removal of wisdom teeth and once spent close to four months in and out of the hospital following an ankle surgery (synovectomy) that became gangrenous and bled inward. The antibiotics given for gangrene caused me to develop a bleeding colon, which I still suffer from. One of the complications people with bleeding disorders experience is wounds that do not heal and sometimes begin bleeding again post-surgery.

My mother, a nurse at the hospital I frequented most often, was told by the ER doctor there that had she not have been a colleague, he might have suspected that I was an abused child, with all of the bruises and bumps that I always presented with. These were explained away by my being a serious "tomboy" who frequently played as rough and tumble as my brothers did.

My father, grandmother and an aunt all died of head bleeds at ages 47, 23 and 6, respectively. It can be presumed that they were also F-VII Deficient, with what is now known about my condition, family history and genetics. 🐻

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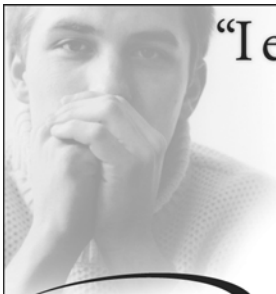
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