



Dateline Federation

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HFA REMEMBERS AND UNITES AT 2003 HOUSTON SYMPOSIUM

By: Donald Akers, Jr., Co-Chair

The HFA Annual Symposium, HOUSTON 2003 MISSION CONTROL, blasted off March 28 at the Bush Intercontinental Airport Marriott Hotel and landed March 30 after a Saturday Night Blast from the Past. Yes, Elvis was in the house that night!

This year's symposium was significant in numerous ways. The events began with the honoring and remembrance of members of the community, America's armed forces, the victims of the 9/11 tragedies and the lost Columbia Space Shuttle Crew.

For the first time, HFA and the community welcomed to symposium members of the pharmaceutical and manufacturing industry. With their presence, every segment of the clotting disorders family was represented including patients, families, caregivers, home health providers, manufacturers, medical experts and others. Despite suffering some growing pains, HFA and the community witnessed the unity and common purpose of all in attendance to help make symposium a monumental success.

A truly holistic theme was evident throughout our events. Symposium provided a wide range of topics and events for young and old, for patient and caregiver and for everyone involved with the community. In addition to the coverage of important medical and financial issues, symposium dealt with topics such as struggles in dealing with chronic illness, nutrition, women's issues, family issues, communication skills, yoga, art therapy and many more.

HFA is also pleased and believes it is the first national organization for the bleeding disorders community to provide simultaneous Spanish translation services to the Hispanic members of our community at a national meeting. This service allowed attendance, participation and inclusion where such an opportunity had not been provided before.

Once again, HFA's symposium was the premiere national event for the community designed solely with the people of the community in mind. Our thanks go out to all that helped to make our 2003 symposium a success. Symposium provided the opportunity for all to come together for the singular purpose of service and advocacy to the hemophilia and clotting disorders community.

We look forward to our 2004 symposium and invite all to make plans to help HFA celebrate its 10th anniversary in March 2004.



My Thoughts About the Houston Symposium

By: Barbara Chang, Co-Chair

As the long planned anticipated day to start the 2003 HFA symposium drew closer, my heart raced as we faced new issues that were impossible to predict. The war in Iraq and increased homeland security issues brought questions of safety, potential flight cancellations and possible disruption of the symposium. Personal involvement of family members serving our country at wartime, brought suggestions of the need for us to continue with our plans to have the best symposium possible in spite of the uncertainties.

As everyone knows, we proceeded in stride and carried on with everything on schedule. Once we arrived in Houston, everything started to fall into place. The board of directors meeting was a welcome gathering of friends and newcomers. We had a productive and fun time. The local chapter (Lone Star) hospitality and assistance was outstanding. The HERB meeting was helpful.

When I reflect upon the entire eventful days in Houston, I concluded all of the major goals and objectives were accomplished. The speakers were compelling and appropriate, the attendance was good (considering world events), and the wide variety of breakouts and events for children, teens, adults and Spanish speaking attendees was excellent. The entertainment and food was yummy with our Elvis impersonator getting us all singing and dancing. But what made the event so special?

The passion, compassion, sharing, warmth, embracing, family atmosphere among all attendees made everything worthwhile. Truly, there was something for everyone. I did not expect to see a friend of mine crying in the lobby when sharing stories about caring for a child with hemophilia; I did not expect to hear from an "older Mom" that she learned something new about bleeding disorders. I did not expect the welcome mixture of persons throughout our community to blend so well together. We were so happy to have the manufacturers join us, the Spanish speaking communities join us and new friends join us such as Miss California.

In conclusion, I am proud to say, "I was there" and proud to have been a part of putting the pieces together to produce a memorable event. Many thanks to everyone who worked long and hard to bring the symposium together, and many thanks to everyone who took the time to come. See you next 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, 102-B Westmark Blvd., Lafayette, LA 70506.

Mission Statement

Hemophilia Federation of America is a national nonprofit advocacy organization established for and directed by persons with hemophilia and other coagulation disorders and their families of origin and/or families of choice. The Federation exists for the sole purpose of serving its constituents as a patient advocate for, but not limited to, product safety, treatment, insurance and quality of life issues in a positive and proactive manner. Its mission is to serve the needs of all families with coagulation disorders and complications of treatment, such as HIV.

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HFA Welcomes the New Member Organizations



“Hello!” from Hemophilia Foundation of Northern California

Hello, my name is Michelle Gilmore and I am the VP of Development for the Hemophilia Foundation of Northern California, (HFNC). I am honored to join the Board of Directors of the Hemophilia Federation of America representing our local organization. As a long time member chapter of NHF, HFNC is pleased to become a member organization of Hemophilia Federation of America. Having access to the benefits and expertise of two national organizations will strengthen our ability to serve our local community.



The Hemophilia Foundation of Northern California was established more than 40 years ago and is dedicated to improving the lives of families and individuals coping with bleeding disorders through community outreach, education, advocacy and service programs. Serving 26 counties in northern California, HFNC provides networking opportunities for both families and healthcare professionals. The Chapter is supported by its own fundraising activities, individual memberships and generous donations of our friends in both private and business sectors.

HFNC's services include several annual programs, including **Summer Camp**, which has one of the most experienced staffs in the country. Each year, in the beautiful foothills of the Sierra Nevada, we provide an extensive program for more than 150 children with hemophilia and other bleeding disorders.

Family camp began more than 10 years ago and provides an informal way for families to meet and share experiences while spending a relaxing time (usually Mother's Day weekend) in a natural environment. This very popular program has grown over the years to accommodate more than 150 individuals. Each year HFNC sponsors an **Annual Educational**

Symposium, inviting leading physicians and scientists to present the latest advances in treatment of hemophilia, hepatitis, and other related issues. HFNC also works closely with our local Hemophilia Treatment Centers to include comprehensive services to the bleeding disorders community.

As an important resource for the community in Northern California, in addition to our annual program HFNC, provides outreach, educational scholarships and Legislative Advocacy. Working with HFA will provide additional resources and expertise on a national level that we know will enhance our offers to persons with hemophilia and other bleeding disorders. We are looking forward to a long and positive relationship.

The officers of HFNC include, Val Bias, President, Michelle Gilmore, VP – Development, Jay Russo, Treasurer and Beth Connolly, Secretary. For more information please visit our website at www.hfnconline.org, or call us at **1 888 749 4362**.

Hemophilia Outreach of El Paso Joins HFA

Founded 1993 El Paso Texas

The support group meets the needs of 60 plus families with bleeding disorders in El Paso and the surrounding communities of Western Texas. Throughout the year the group holds Health Fairs, Picnics, Bowl-A-Thon's and Christmas Party with "Presents" for the entire family and an occasional Free Flea Market for the families.

The President Rosa Maria Coles brings 22 years of teaching experience to the support group. Her untiring efforts in the Greater El Paso School District have led to several nominations as Teacher of the Year. She also has translated several English to Spanish Hemophilia Articles for the Hemophilia Industry. Carnell Chappelle, the Youth Development Coordinator (acting E.D.) started the groups Youth Employment work program. It has been a great success working with the School Districts and local industry and the local Mayors in getting kids employed.

This year the group continues to expand its outreach to the local community by holding Health Fairs and bringing in nationally known speakers and offering CEU's for the Medical Community.

For any information you may need, the groups phone number is **915.751.3942** or you can reach Carnell at **505.259.2424**, or contact us by email, Rosa's email at cdk425@yahoo.com or Carnell's email at chappyusn@yahoo.com.

The group is truly blessed and we open and close all meetings with a prayer. The slogan we have adopted speaks of the Board's commitment to the Bleeding Disorder Community:

*Whatever you do,
Do all to the,
Glory of God
1 Corinthians 10v31*

Thank You

Carnell Chappelle



Undiagnosed Bleeding Disorders Affecting Women

By: Jamie Siegel, MD

Inherited bleeding disorders are thought of principally as affecting men. Certainly, Hemophilia A and B, which are X-chromosome linked disorders, manifest severely in men. However, greater attention is being given now to women who also have symptoms of inherited bleeding disorders. Although these symptoms may be milder and are first detected with trauma or surgery, they have gone undetected in the monthly menstrual cycle. To get a true bleeding history, questions regarding extensive bruising, excessive bleeding with dental work, and how often a woman needs to change her pad or tampon need to be asked. Patients frequently have recall of important bleeding events only after they have left their doctor's office and return with more information on the second visit.

Inherited bleeding disorders usually have had lifelong symptoms. Typically there is another family member with bleeding symptoms. The symptoms can range from mild to severe. The questions asked include outcomes of surgery, dental work, and unanticipated need for a blood transfusion as well as bruising and menorrhagia (excessive menstrual bleeding). Routine laboratory work drawn in a primary care physician's office may not identify the bleeding abnormality. If there is any doubt then testing should be done through the office of a hematologist, knowledgeable in bleeding disorders, and preferably by a special coagulation laboratory.

How does a woman know if she has excessive bleeding with her menstrual cycle? An accepted definition is greater than 80 ml of blood loss over the cycle. There are visual assessment aids under development to make approximate measure of a woman's blood loss. Until these pictorial blood assessment charts are further modified and validated the need to change the

menstrual pad within a 2 to 3 hour time span may be an indicator of an underlying bleeding disorder.

Table 1: Bleeding Disorders Affecting Women

von Willebrand Disease
Carriers of the Hemophilia A and B gene
Factor XI deficiency
Platelet function defects
Factor V, VII and fibrinogen abnormalities

Studies have shown that in women with objective criteria of menorrhagia there is a 13%-20% incidence of undetected von Willebrand Disease and up to 4% incidence of undetected Factor XI deficiency.

More recent studies are indicating that mild platelet function defects may be associated with up to 50% of unexplained menorrhagia in women.

Carriers of the Hemophilia A and B genes may also have the bleeding symptoms described above.

The ACOG (American College of Obstetricians and Gynecologists) Guidelines from 2001 recommend von Willebrand testing for adolescents presenting with severe menorrhagia before hormonal therapy is begun and for adult women with menorrhagia without other cause. The hope and expectation is that alternative treatments may be offered or, at least, a patient with a bleeding disorder will be identified before having surgery. Then treatment intervention for that bleeding disorder can be given, bleeding complications minimized, and possible avoidance of surgical intervention achieved.

INDEPENDENT SECTOR Commends Senate for Passing the CARE Act of 2003

Statement by Diana Aviv, President and CEO, INDEPENDENT SECTOR

(Washington, DC April 9, 2003)—On behalf of INDEPENDENT SECTOR and its hundreds of members, representing thousands of charities across this nation and millions of donors and volunteers, we congratulate the Senate on this historic vote to fortify the vital partnership between government and the nonprofit organizations that serve and strengthen our communities.



The CARE Act has been a major focus for INDEPENDENT SECTOR for more than two decades. The tax incentives for charitable giving this bill provides will bring additional support to the thousands of nonprofit organizations that are struggling to help people of all ages and walks of life during a time of war and economic uncertainty.

The CARE Act sends a strong message that our government thinks it is important that we all do more to give back to our communities and to reach out to those in need. It will recognize and encourage the charitable contributions of taxpayers who don't itemize their tax deductions. It will free older Americans who want to make contributions to charity from their Individual Retirement Accounts to do so without having to worry about adverse tax consequences. It provides additional incentives for corporations to contribute food and all of our charitable gifts matter.

We commend the Senate for its action on the many other provisions this bill contains that will strengthen the ability of nonprofit organizations to serve and that are important to so many of our members, including the sunshine requirements that will strengthen accountability, lobbying simplification rules, and funding for the Social Services Block Grant.

This legislation comes at a critical time when state and local governments are struggling under the most severe budget crisis in decades. We must act now to ensure that the network of services will be there for people and communities in need. This partnership between government and private aid is imperative.

The CARE Act is a real tribute to how much we can accomplish when we set aside our differences and focus on the common goal we all share - making sure that the charities that are serving our most vulnerable people have the resources they need to provide services.

We all owe thanks to Senator Santorum and Senator Lieberman for their tireless efforts to address and resolve the concerns of their colleagues and move the CARE Act forward. We thank Senator Grassley and Senator Baucus for their leadership on behalf of this bill in the Senate Finance Committee. And we thank Senator Frist and Senator Daschle for bringing this bill to the Senate floor.

This is a real victory for these leaders and for the entire Senate. Most important, it is a real victory for all of us who care about the nonprofit organizations serving our communities and the people who depend upon those organizations for help.

The House of Representatives is now key to ensuring that these critical tax incentives move forward. We urge the House to act quickly to send a bill to President Bush. Our nation's charitable organizations – and the people they serve – are counting on the Congress to deliver this much-needed support.

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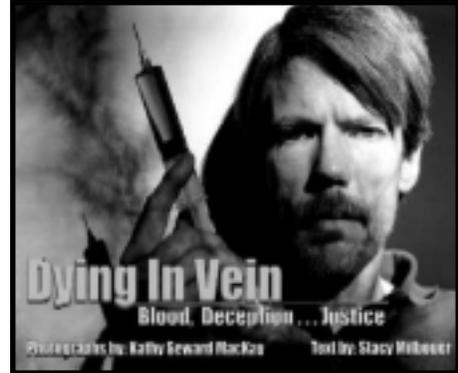
Jamie E. Siegel, MD

DYING IN VEIN: BLOOD, DECEPTION ... JUSTICE

Photos by Kathy Seward MacKay

Text by Stacy Milbouer

After reading this book no one will be able to think of the nation's blood supply in the same way again. Kathy Seward MacKay is an award-winning photographer and the widow of a hemophiliac husband who died at age 33 of hepatitis C. He left behind his grieving family including two young sons and devastated friends - among them, writer Stacy Milbouer. Not long after her husband, David's, death, MacKay, camera in hand, set out to document the vanishing world of hemophiliacs infected with the HIV and the hepatitis viruses: Those who suffered. Those who perished. Those who have survived the deaths of hemophiliac loved ones. And those warriors who are fighting for justice every day.



Book Cover- Rick Nagler



Millie Gonzales

She and Milbouer were determined to create a book of photography that would chronicle this hemophilia tragedy as well as record the images and voices of those who were affected either directly or those who had to cradle their loved ones as they died. And of course there are the faces who live on - the children of hemophiliacs who are creating a new future and a new generation of hemophiliacs who will hopefully escape the fate of so many of their family members.

Yes this is a book about devastation and pain. But it's also a book about justice and hope. You will never forget the faces you see in "Dying in Vein" and hopefully no one else will either. "Dying in Vein" will be available late summer 2003 through Hollis Publishing Company. You may order by *phone: 1-800-635-6302, fax: 1-603-889-6551 or email: books@hollispublishing.com.* (Paperback) \$ 19.95 (shipping & handling is additional)



Peggy McGilton



Our Deepest Sympathies

Michele Paper-Molia
passed away
March 2, 2003 of
complications from
Hepatitis C. Sister of
Renee Paper.

Billy Joe Little, son of
Deborah Best, past away
in March of this year.

Our thoughts and
prayers are with
both families in their
time of need.

WORLD FEDERATION OF HEMOPHILIA



WFH Executive Director Appointment

Release from Brian O'Mahony, President, WFH

As was previously announced, Line Robillard, WFH Executive Director for the past nine years, will be leaving at the end of April. Line Robillard has played an instrumental role in bringing the WFH to where it is today, and it was not an easy task to find someone who could fill her shoes.

I am very pleased to announce that Miklos Fulop has been appointed to replace her, starting on April 1, 2003. Miklos Fulop was the unanimous choice of a Search Committee which I chaired and which included WFH Vice-Presidents Paul Giangrande, Ken Poyser, David Page and Bruce Evatt as well as Peter Levine, who headed the Search Committee in 1994, and WFH patron Jan Willem André de la Porte.

Miklos Fulop holds a degree in Commerce and a Masters in Sociology from McGill University, and has worked in the non-profit sector in Canada for thirty years. For the past nine years, he has been the Executive Director for the Quebec Multiple Sclerosis Society. During this time he transformed this organization into one of the province's most successful not-for-profits. His contribution was recognized in 2000 when he was named Executive Director of the Year by the Professional Association of Charitable Organization Managers.

Miklos Fulop's background in health care, along with his experience in fundraising, advocacy, education and strategic planning will be of great benefit to the WFH, as we build on the success achieved over the last nine years. I am confident that Miklos Fulop has the talent and energy to maintain the pace of rapid growth and increase our success in improving care of people with hemophilia worldwide.

Brian O'Mahony
President, WFH



FYI CORNER

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High-Dose Interferon Effective in Patients Coinfected With Hepatitis C

A researcher in Japan has found that interferon (IFN) treatment may be effective for both HIV and hepatitis C virus (HCV) infection. Hideji Hanabusa, working at Ogikubo Hospital in Tokyo, assessed the efficacy of high-dose IFN therapy in coinfecting hemophiliacs. He reported that IFN-treated patients showed significant reductions in levels of both viral pathogens.

Thirty patients — 15 coinfecting with HIV and HCV, and 15 age-matched patients with HCV alone — took high-dose IFN-alpha-2a therapy for 24 weeks. The report states that HIV viral loads dropped from roughly 7,410 copies/mL to 320 copies/mL after two weeks. Data showed that HCV RNA was undetectable in four of 12 evaluable HIV-positive patients, and in six of 15 HCV-alone patients after 24 weeks. Three HIV-positive patients had to discontinue treatment because of IFN-related toxicity.

“Induction therapy and the dose of IFN should be evaluated in combination therapy with IFN and ribavirin,” Hanabusa concluded. The full report, “Efficacy of Induction Therapy with High-Dose Interferon for Patients with Hemophilia and Human Immunodeficiency Virus-Hepatitis C Coinfection,” was published in *Clinical Infectious Diseases* (2002;35(12):1527-1533).

Drug Week 01.24.03; Michael Greer

Chapter Development Workshop Expands

By: Jan Hamilton, HFA Executive Director

Last year at our Cleveland symposium, HFA offered a noon breakout session on Chapter Development topics. It was very well received but there just wasn't enough time to devote to even the two topics we had selected. In planning the agenda for our 2003 symposium in Houston, we decided to utilize time on Friday morning and offer a half-day workshop.

The agenda for the workshop included:



- **Board Development** by Jan Hamilton, HFA Executive Director

- **Fund Raising and Finance** by Star Tyree, HFA Board member and former Executive Director of Hemophilia of Indiana



- **Conflict of Interest and Board Evaluation** by Rich Vogel, Past President of HFA and board member of Hemophilia of New Jersey

- **Communications (including Newsletters)** by Lauren Kelley of Kelley Communications



The workshop was well attended by one or more representatives of close to twenty organizations and there was a lot of interaction on all levels. We have already received requests to cover other topics next year. If you have a topic you would like to see covered in our 2004 workshop, just send an email to me at j.hamilton@cox-internet.com or call me at **1-800-230-9797**. We would love to hear from you.

See you next year!

2003 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

Coalition for Hemophilia B
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HFA KIDS

We want to thank all the families that shared their children with us during the HFA symposium. It was a joy to get to know them and to meet you. We planned a "mini symposium" for the children covering some of the same topics that were being provided for the adults and adding some other projects that would be especially fun and age appropriate for them. We also built in some activities that reflected the great Lone Star State of Texas as our Lone Star Chapter played host to the symposium.

The infants were provided with loving attention to their special needs as well as lots of snuggles and hugs from a corps of great volunteers.

The toddlers had fun with a program, which remained in the hotel and included as many of the following activities as were appropriate for their age.

Children ages 5 through 12 enjoyed activities divided into four areas:

·Arts and Crafts—where they designed their own neon colored baseball caps & bandanas by painting on designs with glitter paint and stamping stencils, (The caps were invaluable as identification on our field trips). In addition, these children created beautiful ceramic tiles using glass paint and they strung together wooden, colored beads to create their own name bracelets and necklaces.

·Relaxation Station—in this area we played relaxing background music (yes, it did have a positive effect on the noise and activity level). We then worked on a "create a dad" project where they talked about what things a dad needed or should have, and drew those things for our "dad" puppet and put some of those ideas in a mural.

·Teddy Bear Hospital—here each child received their own teddy bear they used in medical play and a Teddy Bear Hospital activity book. On a mural in that area they were encouraged to draw pictures about going to the hospital or what they would do if they were the doctors.

·Food and Nutrition— "granny good-food" (Joyce Donlan) with the help of the children, created a watermelon whale with a celery stalk waterspout after which they snacked on the watermelon and cantaloupe. Other activities included creating cheese and carrot daisies and Rice Krispie star-shaped lollipop cookies. Some of the children gave "granny good-food" their own recipes for some of their favorite foods (written down in exactly their own words) and they also drew their favorite foods on a mural in that area.

The children ages 5 - 12 also got to participate in some special activities on the topics of golfing with the help of professional golfer Perry Parker who has hemophilia and yoga provided by Lana Bienvenu, the speaker for the adult breakout on Yoga and hemophilia.

On Saturday morning the younger children went on a field trip to Old Mc Donald's farm, an outdoor petting zoo where they also had lunch. The older group went to Mountasia where they had the opportunity to play all kinds of games and miniature golf as well as eat lunch. Thanks to all the great volunteers who helped and gave the kids time on the bus for getting better acquainted, singing and other fun.

The children presented a review of our activities to the adults during the Sunday morning general session. Two great tumbling kids led the parade and the rest came in carrying their murals, art, teddy bears and wearing their hats and bandanas. For our finale, we sang our own version of "Deep in the Heart of Texas" with the audience joining in each rousing chorus.

Joyce Donlan (granny good-food) &
Judy Igelman (yellow duckie)



HFA KIDS

Some of the children would like to share their favorite recipes:

Anthony's Flapjacks (age 11)

Mix eggs and milk. Then you put it on a pan and flip it.



Caydin's Oatmeal (age 4)

Oatmeal with raisins. Put it in the microwave for a minute.



Florina's Rice (age 10)

Buy a package of rice. Wash the rice in a basket. Put all the washed rice in a big pan and mix it. Cut up vegetables (carrots & tomatoes) in little pieces and put that in the pan. Cook it good on high for half an hour. Let it rest for 1 hour. When the rice is totally ready, make a sauce with green pepper so it will be hot and eat it with the rice.



Christina's Waffles (age 10)

To make, put batter mix in the waffle iron. Then put syrup, powdered sugar and pecans on top.



Aaron's Chocolate Pecan Cake (age 10)

Ingredients: cake mix, chocolate and water.

Mix and pour into cake pan and put into oven @ 250 degrees.

Bake for three hours.

Frosting: Melt some chocolate and put it on the cake and then sprinkle pecans on top.



Rachel's Dessert Sandwich (age 8)

(This is her own made up recipe)

2 slices of any bread

melted chocolate, melted marshmallows.

Mix those together (like S'mores) and spread both slices of bread.

Put your favorite candy, cut up, and put on top of one slice with whipped cream on top.

Put other slice of bread on top with whipped cream and decorate with a cherry.



Michael's Ramen Noodles (age 6)

They taste good. They're kind of like spaghetti. They come in a square. It has a package of spicy stuff that you put on the noodles.



We asked some of our consumers who attended this year's symposium to give us some of their opinions and experiences:

As a parent who has been very involved in the community for the past 13 years and attended many meetings and seminars during such time, I can honestly say that I have not attended a meeting that was so consumer driven in quite some time. As a consumer I felt that many of the programs and speakers spoke to me and not at me.

The information was presented in a way that the layperson can understand. I thought the sessions were well thought out and planned and the staff of HFA and the sponsoring chapter did an excellent job of answering questions. As a matter of fact, when I returned from Houston, I contacted several families that have attended the national meeting with me over the years to suggest that they mark their calendars for the HFA meeting next year.

I have recommended to the Board of Directors of Hemophilia of Indiana Incorporated, (HII) that we become a member of HFA and we plan to do so as soon as we have adequate funding to do so. Again, thank you for a great experience, I am looking forward to next year's event.

Michelle Rice
Assistant Director (& Parent)
Hemophilia of Indiana, Inc.

I had just been told before coming to the symposium that I had adult onset diabetes. I attended the session on Diabetes & Hemophilia. The presenter covered some information outlining what diabetes is & how insulin & glucose work in the normal human body & in the body of an individual with diabetes. She then opened it up for discussion & questions. There were several of us there with diabetes &/or the symptoms or with family members that had diabetes. I was able to describe the tests that had been done to determine that I "had diabetes". She explained a couple of other tests that were much more conclusive, which I had done when I returned from the symposium with the end result of finding out that I do not have diabetes. I will have to follow a diet & exercise regime to be sure that I do not develop diabetes & to lower my tri-glycerides and reduce my risk of heart attack & stroke. I definitely considered that a benefit. I appreciated the fact that this session as well as several others did not deal exclusively with hemophilia, since we have all the problems common to man with the added stress of having a bleeding disorder.

I feel that HFA symposium dealt with us as individuals not as a group. Keep up the good work.

Thanks!
Charles Music
Lexington, KY

Just wanted to write and let you know how wonderful the Symposium was. We loved the small sessions, it gave us the opportunity to be more involved. Nicholas & Douglas really enjoyed the youth program, they couldn't wait to get home to tell everyone how much fun they had and what they did. We have been spreading the word on how much we got out of the symposium. At our next auxiliary meeting which is May 15th, George & I will be talking to the whole group, about our trip to Houston. Letting them know about the wonderful Symposium you and your staff put together. Keep up the good work!!!

Thank You,
Cheryl, George, Nicholas & Douglas Motquin
Green Bay, WI

As a mother of a 2 year-old son with severe hemophilia A, I often felt like I was losing control of his disorder. We have faced many challenges along the way. We have had disagreements with doctors and nurses, insurance companies, the government on social security issues, even with family members. But we have always made it through these bad times. After some thinking and some praying, my husband and I decided that it was time that we take control of Jesse's hemophilia.

In March of this year, I had the great pleasure of attending the Hemophilia Federation of America symposium. What an experience I will never forget. While I was there, I talked with many wonderful people who, should I say, pushed me in the right direction that I needed to go. My goal into going to the meeting was to learn how to do my first "stick". In my own mind, I still thought that Jesse was too young for me to infuse him; more so, I was scared to death of hurting my child. Needless to say, I was on a mission.

On the final night of the meeting, I was asked if I wanted to infuse someone. With some hesitation, I decided that I would go for it. What better place to learn how to infuse than at a hemophilia meeting. With support and guidance from some friends, I successfully did my first "stick" with no problems. What a feeling that was. I went from being absolutely terrified to crying happy tears. To make a long story short, I am very proud to say that I am no longer that scared mother that I used to be. I have been successfully infusing Jesse for about a month now. Infusing him at home has given us the freedom and the control that we were looking for.

On a final note, I would just like to say that you can do whatever your heart and mind is telling you to do. All you need is some good support in your corner. And to everyone at HFA, and to Carl, Stat, and Pam, thank you all so much for being there for me when I needed you. I couldn't have made it this far without each and everyone of you.

Tabby Mayhan
Mother of Jesse-2 year old with severe hemophilia A

TEEN CONNECTION

Houston was the place for teens associated with the bleeding disorders community from around the country to get connected. The group had a weekend jam-packed with educational activities and lots of fun and made memories and friendships to last a lifetime.

"We are very excited with this group of teens," said HFA Program Director, Mary Beth Carrier.

"I am hoping they will stay in close contact with each other throughout the year and understand they would like to have another face-to-face meeting here in Lafayette this fall."



The focus of HFA's Teen Connection is to develop leadership skills in the community members who fall in this age group. Carrier also explained the need for this group by saying, "The teenage population is our next generation of leaders and it is extremely important to the bleeding disorders population to develop skills in these young people that will enable them to lead us into the next generation."

Speakers from across the country including a teen favorite from the past, Donna Aucoin, PhD worked with the group throughout the weekend. The weekends' topics covered everything from psychosocial issues to leadership training and beyond and the information was well received by all those in attendance. One highlight of the weekend was the groups' work with playwright and person with hemophilia, Dan Noonan. Dan and his wife made wonderful use out of a very small amount of time to help the teens to begin the development of an educational film to be used in schools where there are students with hemophilia. "We hope the group is able to work with Dan again soon so we are able to get the video produced and in the school systems," explained HFA Executive Director, Jan Hamilton. "This is something we hoped could happen for quite some time and we're excited that Dan has agreed to lend his talent and leadership to the teens."



Houston Symposium Art Contest Winners

Adult- Greg Collins-1st Place

Teens- Neal Collins-1st Place
Katie Pennington-2nd Place

Child - Gabriel Forbes-1st Place
Raphael Forbes-2nd Place

This was a close one!!! Gabriel won by only two votes.

"Other"-Joyce Donlan-1st in category for her quilt doll.

Elvis Was Here!



**Jamie Aaron Kelley
and the TCB Dancers
performed
"The Essence of Elvis"**



Elvis was in the building! Jamie Aaron Kelley, a.k.a. Elvis, put on a wonderful show, taking the audience through the 50's, the 60's, and the 70's of Elvis' professional career, a level of accuracy higher than ANY other Elvis tribute show EVER- something that's been noted with high acclaim by Elvis fans from all over! Jamie has performed since the age of three with his Dad, who leads his band and is a retired impersonator himself.

Jamie has played all around the country, reminding fans of what Elvis has meant to them. He brought the "The Essence of Elvis" to this stage, along with The TCB Dancers, who travel with him and add an authentic "Hollywood" feel to the movie portion of the show. Everyone really enjoyed themselves!



THANK YOU, THANK YOU VERY MUCH!

Highlights of the weekend:



Elvis Highlights
Women's Tea
Signing the Banner
Registration
Booth
Hemo Hunks
Art Contest
Infusion Session



Thank you to everyone who attended, see you next year!

Hemophilia Federation of America is proud to announce the awards that were presented on Saturday night at the Awards banquet.

- **Michael Davon Community Service Award** was presented to Patrick Collins and Meredith Levenson
In appreciation for and recognition of their outstanding work on behalf of the coagulation disorders community. Both Patrick and Meredith have worked tirelessly for the community both in their current positions and their previous positions. They have both been involved in tracking reimbursement issues and working toward better solutions in addition to Ricky Ray and other issues on Capitol Hill.



- **The Ron Niederman Humanitarian Award** was given to Chris Walsh, MD, a member of our HERB (medical advisory board). Dr. Walsh has been very helpful in guiding HFA on medical issues and speaking at our symposia.



- **The Volunteer of the Year award** was given to HFA's Office Manager, Susan Swindle, for her untiring efforts and extra volunteer hours in supporting HFA's programs and goals.



- **HFA's President's Award** goes to someone who has been very faithful to the goals of HFA and has given 110% effort toward whatever project he undertakes. This year's recipient is Alan Converse, an independent board member from upstate New York.



Thank you & Congratulations

HFA Adds Creative Arts Scholarship Award

In addition to the three educational scholarships we awarded at symposium this year, we added a Creative Arts Scholarship. This award goes to Dan Noonan, a person with hemophilia, HIV and Hepatitis C from the Chicago, Illinois area. Dan is a 35-year old award winning playwright who has written a play about living with hemophilia and HIV. It is a very inspirational piece and will be performed in a workshop setting in Chicago.



Dan came to symposium and he and his wife (who teaches drama) worked with our Teen Connection group to develop a video to be shown in schools attended by persons with coagulation disorders. They are a great team and were a big help with the Teen program.

HFA Announces the 2003 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 year's winners. After many hours of reviewing and ranking the applicants, the committee has chosen the following individuals as the winners:

Edgar S. Martinez
Oviedo, Florida

Edgar will be attending
Orlando Culinary Academy.



Daniel G. McDonald
Wauwatosa, Wisconsin

Daniel will be attending
University of Wisconsin-Madison.



Matthew S. Schmitt
Houston, Texas
Matthew will be attending
Texas Christian University.



Thank you to all of you who took the time to apply for our 2003 Scholarship Program. I know our scholarship committee's task of choosing three recipients out of an amazing field of candidates was daunting and they feel these applicants stood out.

I encourage you to apply for our 2004 program. Applications will be sent in January of 2004. Please send your name, address, and phone number to: mb.carrier@cox-internet.com to be put on our 2004 mailing list. Good luck to all of you!

Mary Beth Carrier
Program Director

Question and Answer on FDA Guidance Entitled "Recommendations for the Assessment of Donor Suitability and Blood and Blood Product Safety in Cases of Suspected and Probable Severe Acute Respiratory Syndrome (SARS) or Exposure to SARS"

Guidance for Industry: Recommendations for the Assessment of Donor Suitability and Blood and Blood Product Safety in Cases of Suspected and Probable Severe Acute Respiratory Syndrome (SARS) or Exposure to SARS

Are there alternative procedures to inclusion of specific questions on SARS in the donor questionnaire that would meet the intent of the guidance?

Section III.A. of the above guidance provides examples of questions that may be used to ask donors (either orally or in writing) about history of SARS, suspected SARS or treatment for SARS within the previous 28 days; close contact within the previous 14 days with persons with SARS or suspected SARS; and travel or residence in areas affected by SARS within the previous 14 days. The guidance also recommends that blood establishments show donors a list of affected areas as updated by CDC.

FDA recognizes that the rapid introduction of several new questions to the donor questionnaire instrument introduces practical challenges to blood establishments seeking to follow these recommendations. The key elements that the guidance recommends are that the donor receive written or oral questions to address the information defined in Section III.A. The administration of questions and the donor responses must be documented in accordance with 21 CFR 606.100 and 606.165.

Although introduction of new questions into the donor questionnaire instrument is the standard mechanism for implementation of donor deferral criteria based on donor history, FDA believes that, during this transition period, alternative interim measures can satisfy the applicable statutes and regulations in this circumstance.

For example, it has been suggested that a blood establishment could provide to every donor a printed information sheet that contains a description of SARS risk factors and the three questions described in our SARS guidance document. The information sheet would instruct a potential donor who responds "Yes" (either in writing, or orally to the donor screener, in accordance with donor screener procedures) to any of the questions to self-defer for the time period indicated in the guidance. A single question would be added to the donor history questionnaire: "Have you read the SARS information and answered "No" to all questions?" A donor who responded affirmatively would not be deferred for SARS or SARS exposure. A donor who said "No" or needed clarification would be asked the three questions orally and deferred for the time(s) specified in the guidance, if appropriate.

We believe that blood collection facilities may implement this procedure, provided that blood collection facilities document the donor's responses to these questions. We also remind blood establishments that they will need to update the information sheet to reflect updates by the Centers for Disease Control and Prevention. Each blood establishment should have a process in place to ensure that only the most current version is available at all donation sites, include bloodmobiles.

We further note that licensed blood establishments should report implementation of these procedures to FDA in their Annual Report under 21 CFR 601.12(d). Additionally, licensed blood establishments should report the date that the specific donor questions related to SARS were fully incorporated and implemented as part of the donor history questionnaire in their Annual Report. Unlicensed blood establishments are not required to report this change to FDA.

Unlicensed blood establishments may either incorporate the questions described in our SARS guidance document directly into the donor history questionnaire, or may use the procedures described above. In addition, if an unlicensed blood establishment wishes to use a mechanism different from those described in our SARS guidance document or in this document, we encourage them to discuss the plan with FDA.

FDA recommendations may be modified as appropriate depending upon progress of the SARS epidemic or the availability of new scientific information.

Last Updated: 4/25/2003

Source: <http://www.fda.gov/cber/cberac.htm>

HFA'S BOARD ANNOUNCES THE CREATION OF THE CHARLES STANLEY HAMILTON LEGACY AWARD

At its annual meeting at the HFA Symposium in Houston this past March, the HFA Board, in special session, enacted the following resolution. Stay tuned to future issues of Dateline regarding this special award named for Charles Stanley Hamilton and to be given to his parents, Dr. Charles Hamilton and HFA Executive-Director, Jan Hamilton. Those who attended the Saturday Night Event at Symposium witnessed the emotion surrounding the successful accomplishment of the surprise announcement of the award and the naming of the Hamiltons as the first honorees and recipients.



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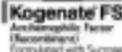
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Community Calendar 2003

JUNE

From the 11th-13th, **PPTA Plasma Forum** will be held in Reston, Virginia at the Hyatt Regency Reston at the Reston Town Center. For more information, visit www.plasmatherapeutics.org.

BPAC (Blood Product Advisory Committee) holds their meeting June 19 & 20. To get more information, call 1-800-741-8138.

The Immune Deficiency **Foundation National Conference** will be held in Baltimore, Maryland on the 19th-21st. For registration information, call them at 1-800-296-4433.

Gateway Hemophilia Association hosts "**Family Education Weekend**" on June 20 to 21. For more information, contact the Chapter at 1-314-652-9133.

JULY

New England Hemophilia Association (NEHA) will hold their **Family Camp** from July 23-26 in Geneva Point Center, Center Harbor, NH.

AUGUST

BSAC (Blood Safety Advisory Committee) will hold their meeting August 21 & 22. For more information and location, call 1-202-690-5560.

SEPTEMBER

BPAC meeting has been scheduled for September 18-19. Location to be announced. To receive information about this meeting, call 1-202-690-5560.

Hemophilia Federation of America's 2nd Annual Board Retreat to be held in September in Lafayette. Board members, contact HFA office for details. Dates announced in next Dateline.

OCTOBER

The Lone Star Chapter of the **National Hemophilia Foundation** honors Loras J. Goedken in "A Night at the Cotton Club", October 17th in Houston, Texas. All proceeds benefit the Lone Star Chapter. For more information on this benefit, call 1-281-861-6644. Everyone is invited to attend.

NOVEMBER

The **American Association of Blood Banks** is holding their Annual Meeting in San Diego on November 1-4. Email meeting@aabb.org for more information.

November 6-8, The **National Hemophilia Foundation** hosts their 55th Annual Meeting in Salt Lake City, Utah. Call 800-424-2634 or visit www.hemophilia.org.

DECEMBER

The **American Society of Hematology** Annual Meeting will be held in San Diego, California from December 5-9. For more information, visit www.hematology.org.

BPAC holds a meeting on December 11-12. More information to come.

"The glory of friendship is not the outstretched hand, nor the kindly smile, nor the joy of companionship; it's the spiritual inspiration that comes to one when he discovers that someone else believes in him and is willing to trust him with his friendship."

- Ralph Waldo Emerson

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