It’s a Federation Celebration
and YOU are invited!
Barbara Chang and Donnie Akers,
Symposium Co-Chairs

Are you ready to?.....

♣ Celebrate
♦ Enjoy a beautiful hotel
♥ Be excited by the glitz and glitter of Vegas
♠ Learn what is new in the hemophilia and blood clotting community
♣ Talk with the guest speakers
♦ Connect with your blood brothers and sisters
♥ Enjoy a class A convention facility
♠ Visit all of the exhibitors and representatives
♣ Get together with old friends and meet new ones
♦ Be inspired
♥ Have fun
♠ Share an experience unlike any other gathering

..... Pack your bags and come to the 10th anniversary Federation Celebration!

Remember the date:
March 26 – 28, 2004
Remember the place:
The Riviera Hotel,
Las Vegas!
2004 Symposium Speakers Address Key Community Needs

By: Jan Hamilton

Once again, HFA has invited speakers to address key community needs for all sessions at our 2004 symposium in Las Vegas on March 26 – 28, 2004 at the Riviera Hotel.

Beginning with Friday morning, March 26, Star Tyree and Jan Hamilton will present a workshop on Chapter Development issues. If you attended this workshop in 2003, you will find even more “pearls of wisdom” this year and expanded topics. The session will be from 9:00 a.m. until 1:30 p.m. and include lunch. Baby sitting will be available.

The general session speakers on Friday and Saturday will include: Hepatitis C Update by Jerry Powell, MD; The Washington Scene by Jim Romano and Dale Dirks of Health and Medicine Counsel of Washington; a sample presentation of our new Emergency Room Triage Education program; and a wonderfully inspirational message from Ray Hollister.

The popular Saturday afternoon breakout sessions will feature an encore presentation by Donna Aucoin, PhD on Family Communication, Alternative Therapies by Brad Lewis, MD, an informative presentation and open forum by Jamie Siegel, MD for Women with Bleeding Disorders; back by popular demand will be Infusion Techniques by Lew Collins, RN; Disabled Adventure Outfitters will have a session on their popular programs; Greg McClure, LSW will address Strategies for Family Finances and Mauricio Silva, MD will discuss important Orthopedic issues.

The always popular Teen Connection activities will be enhanced this year with speakers and activities for those 13 – 15 and for the 16 – 18 year olds led by Zuiho Tanaguchi and his committee. There are lots of exciting events planned so mark your calendars NOW!

Joyce Donlan and Judy Igelman will be back with their exciting HFA Kids program with activities for all ages infants to age 12. We will also bring in professional child care givers in addition to our always faithful volunteers.

We are also hoping to have a nationally known inspirational speaker to cap off the Sunday morning activities so be sure to plan to be on hand for Sunday morning.

2004 Symposium Extra Attractions

By: Jan Hamilton

Once again this year, we will have an Infusion Suite staffed by nurses and led by Lew Collins, RN. Renee Paper, RN and the Nevada chapter will also lend a hand in this area. If you find you need assistance with an infusion, stop by and there will be someone to help you.

The popular Women’s Tea and New Families Receptions will also be back this year.

The 2003 symposium in Houston was a trial run for offering simultaneous Spanish translation for all general sessions and most break out sessions. HFA will once again offer this service for our Hispanic population.

This year, HFA will again offer wheelchairs and scooters for use by those experiencing mobility impairment. Please let us know in advance if you will be needing this service to assist us in making sure there are enough to go around.

Another repeat offering will be video tapes of the speakers along with a documentary of the weekend. These tapes will again be given to all who attend symposium as soon as they are processed and available. There is no charge for this service.

And, of course, our Massage Program will be available to assist you in a more relaxed weekend.

A new feature this year will be the free evening on Saturday. Various companies will offer hospitality suites with a variety of activities and – if you choose to do so – you can visit other hotels and shows outside the hotel on Saturday evening.

Plan to come early and stay late – there is something for everyone including a wonderful opportunity to visit with old friends in the community and meet new ones.
We tend to think of Hemophilia when we talk about inherited bleeding disorders. Hemophilia, an X-linked disorder, is a life-long condition that impacts every aspect of an affected person’s existence. It is understood that a bleed can be life threatening. Bleeds can also cause significant pain. Younger children are protected by prophylaxis, prophylactic treatment with factor concentrates, but this requires intravenous injections two to three times a week. So, because of the prominence of this disorder affecting the lives of men, the influence of other bleeding disorders affecting women may have seemed trivial in comparison.

However, while not life-threatening to the same degree, bleeding disorders affecting women do significantly impact on their health and quality of life. Women with bleeding disorders suffer from excessive bleeding after surgery, dental work and with menstruation. These women may bruise excessively, bleed after delivery of a baby and occasionally may require blood transfusions. Often, women assume that their symptoms are “normal” because their family members have had the same symptoms or worse.

The bleeding disorders affecting women include von Willebrand disease, platelet function defects, factor deficiencies such as VII or XI, and fibrinogen abnormalities. In addition, women who are carriers for Hemophilia A (factor VIII deficiency) or Hemophilia B (factor IX deficiency) may have bleeding symptoms as well. All of these bleeding disorders are inherited conditions affecting the production of a particular protein in the blood that is necessary for the normal function of the coagulation system or for normal platelet function.

Von Willebrand disease, occurring in 1% of the population, is a disorder affecting the amount or function of the von Willebrand protein. This disorder is transmitted to both men and women but has variable levels of severity. Platelet function disorders may be the most common cause of mild bleeding abnormalities in women presenting with menorrhagia. It is unclear how much this platelet disorder impacts on other areas such as dental work and surgery, but if diagnosed then treatment intervention may minimize bleeding complications.

Women who are carriers of factor VIII or IX deficiency may have levels that vary considerably and may have variation in bleeding symptoms based on this. Some women carriers will describe severe menorrhagia, postpartum bleeding, bleeding with dental work or surgical procedures. Some women will have no symptoms. It may be prudent for a known carrier to have her level tested before an invasive procedure. This would allow for protective measures to be taken to prevent even “minor” bleeding if her level is low. If you have hemophilia you may want to suggest that your daughter, an obligate carrier, be tested before she proceeds with a surgical procedure.

Testing for all of these conditions requires specialized coagulation laboratories. These special laboratory results are critical for the diagnosis. It is important to know that for von Willebrand testing there is variation in the levels in the same patient over time. Repeat testing may be needed to make a diagnosis. An optimal time for testing for von Willebrand disease is during the first four days of the menstrual cycle when the levels are at their lowest. Platelet function testing should be done with both aggregation and release studies to optimize the diagnostic yield. Factor assays are subject to handling and processing artifact and are best performed in a specialized center.

Dr. Siegel is a member of HFA’s Medical Advisory Panel who will be presenting the Women with Bleeding Disorders Breakout Session at the 7th Annual Symposium in Las Vegas.
Important Information Regarding
Symposium 2004

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 $40 family registration covers parents and children living in the same household. Childcare will be provided for infants and toddlers and a structured program is designed for all other HFA Kids.


SCHOLARSHIP
HFA will provide a limited number of travel scholarships for first time attendees. If you need scholarship information, please contact Susan Swindle at 1-800-230-9797.

HOTEL
Make reservations DIRECTLY with the Riviera at (800) 634-6753 or direct at (702) 794-9412. 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.rivierahotel.com. The cut off for the reduced block rate is March 10th, 2004.

LOCATION
On the “strip,” three and a half miles from McCarran International Airport (Cab fare approximately $11). Three miles from Downtown, three blocks from the Las Vegas Convention Center.

ROOMS
Hotel Rooms - 2,075, including 177 Suites.
Meeting Rooms - 160,000 sq. ft. of state of the art expo and meeting facilities.
“Non-Smoking rooms available”

ENTERTAINMENT
Splash
An Evening at La Cage Riviera Comedy Club
Crazy Girls: Sensuality, Passion
Hail Hail Rock -n- Roll
Le Bistro Theatre - Live Entertainment Nightly
For show dates and time, please contact our Box Office at 1-800-634-3420 Ext.9433
### Map Key

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<th>Location</th>
<th>Description</th>
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<td>Grande Ballroom E</td>
<td>Exhibit Hall</td>
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<tr>
<td>Grande Ballroom F</td>
<td>General Sessions</td>
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<tr>
<td>Room 103</td>
<td>Office</td>
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<td>Rooms 104-110</td>
<td>Breakout Sessions</td>
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</table>
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.

Check the registration method:  
- ____ $25 for individual  
- ____ $40 for family (Parents & Children)  

Payment Method:  
- ____ Check  
- ____ Money Order  
- ____ Credit Card

Credit Card Number__________________________  Expiration Date________________

Name on Credit Card__________________________  Signature______________________

Print or Type all information

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<th>Spouse’s Name</th>
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<td>Fax</td>
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**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.

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Do you authorize the use of any photographs or videos taken for the Federation’s use only? **Yes** **No**

Scholarship information can be obtained by contacting Susan Swindle at 800-230-9797

**Dateline Federation • Symposium 2004**
Hemophilia Federation of America Youth and Teen Program Registration Form
Seventh Annual Meeting and Symposium
March 26-28, 2004
Riviera Hotel & Casino
Las Vegas, Nevada

To register:  (Registration deadline is March 10th, 2004.)
Mail: Photocopy this form (if necessary) and mail or fax it, along with completed adult registration form to:
Hemophilia Federation of America, 102 B Westmark, Lafayette, LA 70506
Fax: Fax completed form(s) to (337) 991-0087
For more information call 1-800-230-9797.

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

<table>
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<tr>
<th>Child’s last name</th>
<th>First name</th>
<th>Name (for name tag)</th>
<th>Age</th>
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<th>Father’s full name</th>
<th>Mother’s full name</th>
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Parent/Legal guardian’s address (including city, state, and zip code) if different from above.

Do you authorize the use of any photographs or videos taken for The Federation’s use only?  €yes  €no

What is the child’s relationship to hemophilia?
€Factor VIII  €Factor IX  €von Willebrand  €Family member  €Friend  €Other ___________

Please be aware that some activities planned for the youth and teen program may take place off site.

Do you grant permission for your child to go on a field trip without your supervision?  €yes  €no

In case of emergency, please indicate the responsible party who will be accompanying your child to the symposium.
All persons under the age of 18 MUST be accompanied by a responsible adult.

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 2004 Symposium in Las Vegas, Nevada. 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 __________________________
Session Selection Form

You have the opportunity to attend a Friday morning Chapter Development session, Saturday noon breakout and two rounds of sessions in the afternoon. If you plan to attend the Dads in Action noon session, sign up for one afternoon session only.

Name of 1st Applicant (First and Last)

Friday Morning:
□ Chapter Development Workshop

Saturday Noon: (Select One)
□ Dads in Action □ Pain Management □ Research Update

Saturday Afternoon: (Select one if attending Dads Session-Everyone else select two)
□ Family Communications □ Alternative Therapies
□ Women with Bleeding Disorders □ Home Infusion Techniques
□ Sports & Hemophilia □ Strategies for Family Finances
□ Orthopedics

Name of 2nd Applicant (First and Last)

Friday Morning:
□ Chapter Development Workshop

Saturday Noon: (Select One)
□ Dads in Action □ Pain Management □ Research Update

Saturday Afternoon:(Select one if attending Dads Session-Everyone else select two)
□ Family Communications □ Alternative Therapies
□ Women with Bleeding Disorders □ Home Infusion Techniques
□ Sports & Hemophilia □ Strategies for Family Finances
□ Orthopedics
2004 HFA SYMPOSIUM PREVIEW AGENDA
March 26 – 28
Riviera Hotel & Casino
Las Vegas, NV

Thursday, March 25
4:00 a.m. - 7:00 p.m.  Exhibitor registration and set up

Friday, March 26
9:00 a.m. - 1:00 p.m.  Chapter Development Workshop/Includes Lunch
( Babysitting available for attendees only)
10:00 a.m. - 4:00 p.m.
  1:00 p.m. - 2:00 p.m.
  2:00 p.m. - 5:30 p.m.
REGISTRATION
Welcome Reception
General Session
Welcome and Introductions
Inspirational Speaker-Ray Hollister
Government Relations-James Romano & Dale Dirks

5:30 p.m. - 6:30 p.m.
New Families Reception
Dinner & Celebration

Saturday, March 27
8:00 a.m. - 9:00 a.m.  Breakfast
9:00 a.m. - 12:00 p.m.
General Session
Hepatitis C – Jerry Powell, MD
ER Triage – Mock Road Show – Jan Hamilton & Chris Walsh, MD & Jamie Siegel, MD

12:00 p.m. - 12:15 p.m.  Break
12:15 p.m. - 1:45 p.m.
Lunch and Break Out Sessions
Session 1 - Dads In Action - Joey Privat
Session 2 - Pain Management – John Mulder, MD
Session 3 – Research Update – Chris Walsh, MD

1:45 p.m. - 2:00 p.m.
Break
2:00 p.m. - 3:15 p.m.
Break Out Sessions – Panel One
Family Communications – Donna Aucoin, PhD
Alternative Therapies – Brad Lewis, MD
Women with Bleeding Disorders – Jamie Siegel, MD
Home Infusion Techniques – Linda Collins, RN
Sports & Hemophilia – Disabled Adventure Outfitters
Strategies for Family Finances – Greg McClure, LSW
Orthopedics – Mauricio Silva, MD

3:15 p.m. - 3:45 p.m.
Break
3:45 p.m. - 4:30 p.m.
Breakout Sessions – Second Round
Repeat of First Round
Womens Tea

Sunday, March 28th
8:00 a.m. - 9:00 a.m.  Breakfast
9:00 a.m. - 10:15 a.m.
General Session
“What’s Your Excuse?” John P. Foppe

10:15 a.m. - 10:30 a.m.
10:30 a.m. - 11:00 a.m.
11:00 a.m. - 11:30 a.m.
11:30 a.m. - 12:00 Noon
Break
HFA Kids Presentation
Teen Highlights
Closing
Riviera Hotel and Casino
2901 Las Vegas Boulevard South
Las Vegas, Nevada 89109

Dates
March 26-28, 2004