



Dateline Federation

NEWSLETTER OF THE HEMOPHILIA FEDERATION OF AMERICA

Symposium 2004

Special Edition

In This Issue

Symposium Preview
By Jan Hamilton

Symposium Attractions
By Jan Hamilton

Bleeding Disorders
Affecting Women
By Jamie Siegel, MD

Important Information
About Symposium

Map of Hotel

Registration Forms

Session Selection Form

Agenda for Symposium

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!**



HEMOPHILIA FEDERATION OF AMERICA
102-B WESTMARK BOULEVARD
LAFAYETTE, LA 70506
WEB: WWW.HEMOPHILIAFED.ORG
TOLL FREE: (800) 230-9797
LOCAL: (337) 991-0067
FAX: (337) 991-0087

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.

Noon breakout session on Friday will feature an exciting excerpt from our recent Dads in Action training program with an update from those chapters that have already started the program. Come and hear how you can have a Dads in Action program in your chapter. Also on the noon Saturday agenda are an encore session on Pain Management by John Mulder, MD and the latest on the hemophilia research horizon from Christopher Walsh, MD.

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. 🐾

Bleeding Disorders Affecting Women

By: Jamie Siegel, MD



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.

REGISTRATION DEADLINE IS MARCH 10TH, 2004.

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 | |
|-------------------|-------------------|
| Grande Ballroom E | Exhibit Hall |
| Grande Ballroom F | General Sessions |
| Room 103 | Office |
| Rooms 104-110 | Breakout Sessions |

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.

| | | | |
|---|------------|---------------------|----------------|
| Child's last name | First name | Name (for name tag) | Age |
| Street address/P.O. Box | | City | State Zip Code |
| Father's full name | | Mother's full name | |
| 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? <input type="checkbox"/> Factor VIII <input type="checkbox"/> Factor IX <input type="checkbox"/> von Willebrand <input type="checkbox"/> Family member <input type="checkbox"/> Friend <input type="checkbox"/> Other _____ | | | |
| Please be aware that some activities planned for the youth and teen program may take place 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.

REGISTRATION

1:00 p.m. - 2:00 p.m.

Welcome Reception

2:00 p.m. - 5:30 p.m.

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

7:00 p.m.

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

5:00 p.m. - 6:30 p.m.

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.

Break

10:30 a.m. - 11:00 a.m.

HFA Kids Presentation

11:00 a.m. - 11:30 a.m.

Teen Highlights

11:30 a.m. - 12:00 Noon

Closing

the
A.C.C.E.S.S.
program

A service provided by Hemophilia Health Services, Inc.


Advocating for Chronic Conditions, Entitlements and Social Services

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



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**Riviera Hotel and Casino
2901 Las Vegas Boulevard South
Las Vegas, Nevada 89109**

**Dates
March 26-28, 2004**