



Dateline Federation

NEWSLETTER OF THE HEMOPHILIA FEDERATION OF AMERICA

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THE POWER OF THE HFA SYMPOSIUM

I am an attorney who has practiced law for the past 22 years in Louisiana and serve as a member of the Board of Directors of HFA and Co-Chair of the 2003 HFA Houston Symposium. Many of you are unaware that I do not have hemophilia or any of its related illnesses and never had any connection to Hemophilia before my involvement with the Federation. How is it that I became so involved with HFA? The HFA 2000 Symposium in Atlanta is largely responsible.

Prior to my involvement with HFA and by some divine providence, I had the pleasure of being introduced to Jan Hamilton, HFA's Executive Director, at the law offices of a colleague next to the HFA offices nearly four years ago. For some unexplained reason I remembered that I had met a Charles Hamilton in a college class some 20 years before and that he happened to have hemophilia. When I asked Jan whether she knew Charles Hamilton, she indicated that he was her son. I asked what Charles was doing and sadly, and to my chagrin, learned that he was deceased.

Those of you who have met and know Jan are acutely aware that no person or thing is off limits when it comes to helping the hemophilia community or the HFA cause. Jan needed legal advice for a community member on a number of occasions and began to call on me regarding issues pertinent to my practice. One thing led to another and not only did I become a volunteer legal advisor to HFA, but I was convinced (or coerced) by Jan to attend the 2000 Atlanta HFA Symposium to provide general legal information for attendees regarding issues such as disability, insurance questions, and the like.

I reluctantly agreed to attend due to her insistence (the word "no" is not in Jan's vocabulary) but feared meeting "those people who not only had hemophilia but also HIV, hepatitis C and various other scary conditions." I had not been exposed to any of this and frankly was quite concerned. Jan was also concerned about my response and cautiously awaited my reaction to the community in Atlanta.

My reaction was monumental, but not what I or anyone else would have predicted. Today, we laugh at how Jan's concern went from handling my fears to the exact opposite reaction of my connecting with many newly made friends in the community. Long before the end of the symposium I was embracing those whom I met. We now refer to my Atlanta HFA Symposium experience as my "HFA conception" and the place where I "developed" my hemophilia.

While at the Atlanta Symposium, I attended a number of breakout sessions. At the Couples Communication session presented by Dana and Jan Kuhn, I was especially moved when I saw the emotional response of a brother who was not allowed to be with his niece and godchild because of the ignorance of his brother-in-law. I saw the difficulties and issues of persons who struggled in their interpersonal relationships because of the diseases and perceptions of others about their conditions.

• Continued on page 17 •

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Contact Shannon Pennington
at spennington@rock-grove.k12.ok.us
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questions. Artwork can be picked up at the
end of symposium.

HFA Recognizes William Schumacher, MD



At our Cleveland Symposium last April, HFA bestowed the first annual Ron Niederman Humanitarian Award to William Schumacher, MD. Dr. Schumacher was unable to be present in Cleveland, so it was physically presented to him on September 20 during a dinner for our Board of Directors. This dinner was held in conjunction with our Board Retreat in Lafayette, Louisiana.

Dr. Charles Hamilton made the presentation on behalf of the board in recognition of Dr. Schumacher's efforts to improve Emergency Room triage for persons with hemophilia. As you may remember from an article in Dateline Federation dated Fall, 2001, Dr. Schumacher wrote an article that was published in the October, 2001 issue of Emergency Physicians Monthly calling attention to the lack of proper triage for patients with hemophilia when visiting their hospital emergency rooms. He also sent a letter at his expense to every hospital emergency room in the U.S. asking for better triage practices and referring those hospitals to HFA for guidance in triage.

The moving and emotional presentation was made by Dr. Hamilton, husband of HFA Executive Director Jan Hamilton. Dr. Hamilton recounted stories of Dr. Schumacher's youth and journey through medical school of which he was acutely aware. When Kip Schumacher was a little boy, his pediatrician was Dr. Hamilton.

At the close of the evening, an invitation was extended to Dr. Schumacher to join HERB (HFA's medical advisory board) and he graciously accepted the invitation. We are pleased to have him work with us.

Golf Anyone?



If you are a golfer, know someone who is or would just like to help HFA – here's an offer too good to pass up.

Thanks to one of our new HERB members, Jon Hendry, DDS, we have a wonderful fund raising opportunity. Dr. Hendry is the chair of the Louisiana Open (a stop on the PGA tour). In conjunction with the Open each year they offer a fabulous prize to be raffled off. This year it is a trip to Pebble Beach and some great second and third place prizes. In actuality, it is a \$5,000 travel package so that if whoever wins is not a golfer they can still have a very nice prize.

The tickets sell for \$10 each and we get to keep all of the money we raise with the tickets except for \$500. These tickets should be super easy to sell.

If you would like to purchase one or more tickets or sell some for us, just call our office and we will get them to you. It's also a good way to get excited about HFA's very own golf tournament on May 8 at Pelican Point – another first for us, thanks to chair Gary Cross, a former member of our board and his lovely wife Karen.

Good to the Last Drop!

Wastage Potential of Small Volume Factor Concentrates

as I see it: by Ruth Andrea Seeler, MD

Are you throwing away up to 25% of your factor? This is the risk of using what I call “super concentrated factor concentrates”—those with volumes of only 2.5 and 4.0 ml. You know them by the names ReFacto®, BeneFIX®, Kogenate® FS, and Helixate® FS.

Most members of the hemophilia community are used to infusing with 10cc diluent per bottle of factor; and using BD “scalp” (butterfly) needles and tubing. When you infuse, do you leave a little something in the tubing and bottle? If this extra is only about 1 ml, you’ve wasted only about 10% of your total volume of factor. However, if you use the smaller volumes (2.5 or 4.0 ml) found in the “super concentrated” factor concentrates, the same volume wastage will mean a profound percentage loss—25% to 40%!

I first became concerned about factor wastage when the smaller volume factor concentrates were in development or new to the market. As a hemophilia camp “Doc” for 27 years, I’ve had the opportunity to observe first-hand how many teenagers and adult counselors do their own infusions. These “experienced infusers” were trained by numerous hemophilia treatment centers. What concerned me was how much wasn’t being injected! Why were we wasting so much?

First, if a vein is blown, the infusion set is typically tossed and another set is used. If you use the BD infusion set, there is a tubing volume of 0.25 to 0.3 ml. If you use the Terumo® winged infusion set, there is a volume of 0.4 ml. When you throw away the infusion set, you may throw away between 0.3 and 0.4 ml of factor. If you use a second set to complete the infusion, this is also eventually tossed. Using two infusion sets results in a combined factor concentrate loss of 0.6 to 0.8 ml!

Second, consider the factor concentrate left behind in the bottle. Using TB syringes, I measured the residual volume in discarded factor bottles at camp. The residual volumes ranged from 0.2 to 0.5 ml, with most between 0.3 and 0.35 ml. This means a total loss of 0.9 to 1.0 ccs. This wastage wasn’t due to any particular style of infusing; I observed at least 20 different campers, and all left factor behind in the discarded bottle.¹

In response to this concern, some manufacturers have revised their package inserts to recommend use of the infusion set provided with the factor, which has a smaller volume of 0.15 ml. However, variations in tubing length, syringe adapter, needle size and needle grasper (the “butterfly”) lead some with hemophilia to prefer the BD infusion sets to those supplied by the manufacturer. How can we stop wasting expensive and valuable factor concentrate? Well, it’s easy to correct part of this wastage. First, use the infusion sets provided with the 2.5 or 4.0 ml concentrates.² Second, be sure to get all of the factor out of the bottle by having the tip of the withdrawal needle just at the top of rubber stopper (not a millimeter or so higher!).

Third, a little air (0.5 cc) in the infusion syringe would allow the factor to be infused to the “last drop” at the end of the needle. Factor is expensive. Its cost has an impact on your insurance; sometimes on your wallet; and on insurance premiums of all Americans. Let’s do our part to prevent waste of this life-giving medicine. Let’s remember that every drop is good, and can be used.

1) I did not measure residual amounts in any bottles reconstituted and infused by experienced RNs and MDs.

2) Baxter BioScience does not currently include infusion sets with its products. The new BAXJECT® device is designed to eliminate residual factor loss in the bottle.

Aventis Behring Foundation Awards Second Round of Grants to Benefit Bleeding Disorders Community

Aventis Behring commits \$1 million more in incremental funding to the Foundation for grant cycles beginning in January 2003.

King of Prussia, PA- November 25, 2002- The *Aventis Behring Foundation for Research and Advancement of Patient Health* announced today that it has selected a second round of 2002 grant recipients. In total for 2002, the *Foundation* awarded \$1 million to fund a variety of educational and outreach initiatives designed to benefit the bleeding disorders community.

Governed by an independent Advisory Council that has the sole authority to award grants, the *Aventis Behring Foundation* is a non-profit organization dedicated exclusively to charitable, scientific and educational purposes that advance the standard of care for persons affected by bleeding disorders. In response to two grant cycles initiated in 2002m the *Foundation* received over 100 grant applications from hemophilia treatment centers (HTCs), non-profit organizations such as hemophilia chapters, foundations and associations, and healthcare professionals dedicated to the treatment of people with bleeding disorders.

"Given the high quality of the applications and the merit of the proposed projects, the Advisory Council found the selection process for this recent grant cycle to be particularly challenging," explained Val Bias, Advisory Council Chair. "After much consideration, we selected the applicants who most clearly demonstrated the positive impact of their proposed work in the bleeding disorder community, with special consideration given to projects that would help to fill currently unmet needs."

The Advisory Council selected 9 applicants from the second grant cycle to receive funding. This is the second disbursement of the initial \$1 million in incremental funding provided to the *Foundation* upon its inception by Aventis Behring. Continuing its commitment to the *Foundation*, Aventis Behring has allocated an additional \$1 million in incremental funding for 2003, with the initiation of the next grant cycle in January.

"We have already begun to see the positive impact that the *Aventis Behring Foundation* is making in the community. We are pleased to continue to support the *Foundation's* mission in 2003," said Michael Sumner, MD, and Executive Director of the *Foundation*.

Founded in 2001 as an independent, non-profit corporation, the *Aventis Behring Foundation for Research and Advancement of Patient Health* is the only corporate foundation dedicated exclusively to charitable, scientific and educational purposes designed to advance the standard of care of persons affected by bleeding disorders. The *Foundation* is governed by a seven

member Advisory Council consisting of healthcare professionals and advocates who are known for their dedication to the bleeding disorder community. The Advisory Council has the sole authority to award all grants.

The following are the 9 recipients with a brief description of the projects that receive funding:

- **Hemophilia Outreach Centre** (Green Bay, WI): Design and launch of a web site dedicated to providing nutritional information, education and counseling geared toward the special needs of the bleeding disorder community.
- **Utah Hemophilia Foundation** (Salt Lake City, UT): Community educational and outreach campaign to raise general awareness of von Willebrand disease (vWD) and drive testing and diagnosis.
- **Bleeding Disorder Foundation of Washington/Hemophilia Treatment Center at Puget Sound Blood Center** (Seattle, WA): Develop and implement Annual Outreach Meeting and Educational Symposium to reach the underserved populations of eastern Washington.
- **Gateway Hemophilia Association** (St. Louis, MO): Implementation of Rural Outreach Program, in partnership with local county health departments, healthcare providers, hospitals, physicians and clinics to identify underserved populations in rural areas of southeastern Missouri and southern Illinois and enhance access to services.
- **Hemophilia Foundation of Minnesota/Dakotas, Inc.** (Mendota Heights, MN): Winter retreat for adolescents and young adults aged 13-25 to encourage networking and build leadership and transitional skills.
- **Mount Sinai Regional Comprehensive Hemophilia Treatment Center** (New York, NY): Community educational and outreach project to increase access to comprehensive care for low-income minorities and underserved populations with bleeding disorders.
- **Comprehensive Hemophilia Treatment Center/Newark Beth Israel Medical Center** (Newark, NJ): Develop and implement annual program, "The Sports Connection: Sports and Hemophilia-Learning the Connection," to promote exercise for children with bleeding disorders by educating children and their families on how to exercise safely.
- **Michigan State University** (Lansing, MI): Utilize computerized animation to develop three multimedia training programs targeted to laboratory technicians, medical students and residents, and physicians. Titles of programs include: *Why Does Blood Clot?: Laboratory Diagnosis of Coagulation Disorders*; and *von Willebrand Disease*.
- **Alta Bates Summit Foundation on behalf of the Alta Bates Hemophilia Treatment Center** (Berkeley, CA): Develop documentary video on bleeding disorders to inspire feelings of courage, hope and perseverance in the stimulate new medical providers to pursue a specialization in the treatment of bleeding disorders.

Wyeth Pharmaceuticals Introduces the First 2000 IU Vial of ReFacto® for Hemophilia Treatment

St. Davids, Pa. (October 11, 2002) – Wyeth Pharmaceuticals, a division of Wyeth (NYSE:WYE), announced today the introduction of a 2000 IU vial for ReFacto® Antihemophilic Factor (Recombinant), the company's recombinant factor VIII product for the treatment of Hemophilia A.

With the introduction of the 2000 IU (International Units) vial, Wyeth becomes the first manufacturer to introduce product in this vial size. The new vial contains more ReFacto with the same small volume (4mL) of reconstitution.

“Since the introduction of ReFacto, we’ve received requests from the community for a larger vial size. The availability of the new vial size should translate to greater dosing convenience for individuals using ReFacto,” says Victoria Kusiak, Vice President, Global Medical Affairs and North American Medical Director, Wyeth Pharmaceuticals.

Currently, ReFacto is available in four vial sizes: 250 IU, 500 IU, 1000 IU and now, 2000 IU. Many individuals require infusions of greater than 2000 IU per dose, which necessitates that they use a variety to create their dosage. With the availability of a larger size, these patients will be able to use fewer vials, allowing for easier, faster administration. In addition, the larger vial size is expected to be useful in the surgical setting, which often requires higher doses of Antihemophilic factor.

Hemophilia is a rare, inherited blood clotting disorder for which there currently is no cure. People with hemophilia are deficient in the key proteins that are vital in the clotting cascade to prevent bleeding- factor VIII (Hemophilia A) or factor IX (Hemophilia B). Both forms of hemophilia are characterized by spontaneous hemorrhages or prolonged bleeding, typically into joints and soft tissue. In the U.S., nearly 4,000 people have Hemophilia B and between 15,000 and 17,000 people have Hemophilia A.

ReFacto is a recombinant factor VIII product formulated without the addition of human serum albumin in its final formulation. ReFacto is indicated for the control and prevention of hemorrhagic episodes and for surgical prophylaxis in hemophilia A patients and for short-term routine prophylaxis to reduce the frequency of spontaneous bleeding episodes. The effect of regular routine prophylaxis on long-term morbidity and mortality is unknown. As with the intravenous administration of any protein product, adverse reactions may include headache, fever, chills, flushing, nausea, vomiting, lethargy or manifestations of allergic reactions. The remote possibility exists for hypersensitivity to non-human mammalian proteins. The Chinese hamster ovary cell line used to produce ReFacto is grown in culture medium that contains human serum albumin; no albumin concentration is below the detection limit of the assay.

Wyeth Pharmaceuticals, a division of Wyeth, has leading products in the areas of women’s health care, cardiovascular disease, central nervous system, inflammation, hemophilia, oncology and vaccines. For more information, call the Hemophilia Hotline at **1-888-999-2349** or visit **www.hemophillavillage.com**.

The following individuals are scholarship recipients for the 2002-2003 academic year from Wyeth:

- Barham Bratton (Swarte, LA.)- Louisiana Tech University
- Tom Budescu (Champaign, Illinois)- University of North Carolina, Chapel Hill
- Yuri Chumak (Toronto, Ontario)- University of Western Ontario
- Mark Guest (St. Louis, Missouri)- Washington University
- Bryon Jasper (Houma, Louisiana)- TBD
- Daniel Jenson (Decatur, Illinois)- Bradley University
- Joshua Lunior (Accord, New York)- Ulster County Community College
- Geoffrey Merl (Dayton, Ohio)- Ohio State University
- Christopher Paige (Portsmouth, Virginia)- TBD
- Richard Strodtman (Glasgow, Missouri)- University of Missouri, Columbia*
- Vladisav Vilenchik (Chicago, Illinois)- Illinois Institute of Technology
- Craig Wright (Franklin, Tennessee)- Lipscomb University*

Graduate

- Caesar Pascual (Carson, California)- TBD
- Beau Ward (Llano, Texas)- Trinity University*

Vocational

- Israel Ambriz (Wastonville, California)- Heald College
- Willie Brasley (Hopskins, South Carolina)- Midlands Technical College

To receive an application for the *Soozie Courter Sharing a Brighter Tomorrow Hemophilia Scholarship Program 2003-2004* academic year, please call 888-322-6010. To be eligible for the scholarships, students must have either Hemophilia A or B, and be either a high school senior or have a graduate equivalency diploma (GED) or currently be enrolled in an accredited junior college, college (either undergraduate or graduate), or vocational school.

* Indicates a repeat scholarship winner.

Baxter Celebrates 10 Year Anniversary of Flagship Hemophilia Treatment

~RECOMBINATE rAHF Reaches Milestone with Proven Efficacy, Safety and Supply~

Deerfield, Ill October 29, 2002- Baxter's RECOMBINATE Antihemophilic Factor (Recombinant) (rAHF) celebrates the 10-year anniversary of its availability this month as it continues to remain the leader in hemophilia treatment. RECOMBINATE rAHF is the only recombinant factor VIII replacement therapy to consistently meet the demands of efficacy, safety and supply.

In the early 1980s, the hemophilia community was devastated to learn that viruses could be contracted with the use of hemophilia therapeutics because of tainted blood donations. This led to the development and discovery of safer treatments, including the first monoclonal antibody purified solvent detergent treated factor VIII concentrate, introduced by Baxter in 1988. But desiring to take safety one step further, in 1992 Baxter introduced RECOMBINATE rAHF, which was a major advancement in the quest for a new level of hemophilia therapeutic safety.

"It was a revolution in hemophilia treatment and has brought peace of mind to patients and caregivers alike," said Dr. Leonard A. Valentino, Associate Professor of Pediatrics and Director of the Rush University Hemophilia & Thrombophilia Center, Rush-Presbyterian St. Luke's Medical Center. "Thanks to RECOMBINATE rAHF, an entire generation of people with hemophilia has had access to treatment that is highly effective and very safe."

RECOMBINATE rAHF also has a proven supply record. In fact, since 1995 the global demand for hemophilia therapy has doubled, and Baxter is the only supplier to have increased supply every year since its introduction.

"We are dedicated to providing novel treatments and services to the hemophilia community. This 10-year milestone for RECOMBINATE rAHF reinforces our commitment to developing innovative, safe and effective therapies for patients and providing consistent supply," said Peter O'Malley, President, Baxter BioScience North America.

Baxter's goal is to have the production capacity to provide more than two billion units of recombinant factor VIII therapy by 2005. The company is currently building a fourth processing suite at its Thousand Oaks, California facility and anticipates regulatory approval in 2004. Additionally, Baxter is investing in a state-of-the-art, multi-purpose facility in Neuchâtel, Switzerland for the processing of recombinant therapies.

Another First from Baxter

Baxter continues to research and develop innovative therapies to treat hemophilia. Antihemophilic Factor (Recombinant), Plasma/Albumin Free Method (rAHF-PFM) is Baxter's latest technological advancement and is the first factor VIII recombinant therapy to be clinically developed and prepared without the addition of any human- or animal-derived raw materials in the cell culture process, purification or final formulation.

In June, the Company submitted a Biologics License Application (BLA) to the U.S. Food and Drug Administration (FDA) for rAHF-PFM, and in September, submitted a Marketing Authorization Application (MAA) to the European Medicines Evaluation Agency: Committee for Proprietary Medicinal Products for rAHF-PFM through the European Union (EU) Centralized Procedure.

(Baxter and RECOMBINATE are trademarks of Baxter International Inc. Baxter is registered in the U.S. Patent and Trademark Office.)

**Come and join the
Hemophilia Federation of
America for the
1st Annual Golf Tournament
to be held at Pelican Point
in Gonzales, Louisiana
May 8th, 2003.
Everyone is invited
to attend.**

**For more information about the tournament,
contact Gary & Karen Cross at 225-673-3660
or the Hemophilia Federation at 800-230-9797.**

FYI CORNER



Making a Health Plan for Your Child

"Information sharing between parents and school personnel is one of the most important factors affecting a child's educational success," says Dr. Barbara Spencer, director of Elementary Education at Tuscaloosa County Schools in Alabama. "When such information concerns a bleeding disorder, which could place the child in a life-or-death situation and the school system in a legally liable one, this exchange becomes critical."

The message here: GET ORGANIZED! With the help of your physician, HTC and school, develop an *individualized health plan* (IHP) for your child that details vital information. Maier explains what's generally included in IHPs.

- Parent/guardian's name, address and home/work phone numbers
- Child's name, date of birth, school and physician's name and phone numbers.
- Child's health history, including a description of the type of hemophilia the child has, his blood type and the treatment he receives.
- Specific procedures for bleeding episodes, including whom to contact and where the child should be treated, if necessary.
- People trained to conduct procedures
- An emergency plan for life-threatening injuries.

(Source: *The Baxter Factor News Brief*)

Filtering Blood for Transplant Donation



When kidney patients receive a new kidney, their bodies often reject the new organ and complications ensue. Through a method that filters the kidney patient's blood of antibodies that are instrumental in rejecting foreign bodies, transplantation becomes more successful, no matter the blood type of both donor and recipient. Nearly 52,000 people are on the national waiting list for a kidney (according to the United Network for Organ Sharing) and this therapy could help reduce that number. Historically, people awaiting a kidney transplant had to find someone who shared their blood type for a donation, but this obstacle has been lifted thanks to blood filtering. During the process of blood filtering, the plasma is removed and replaced with other fluids, thus making cross donations between blood types possible.

Transplantation surgeries using the blood-filtering methods performed at Johns Hopkins University Medical Center on 29 patients have been very successful, with 27 of them having no signs of rejection. Medication to suppress rejection must still be taken daily after the operation.

This procedure has the potential of increasing the number of living donor transplant operations by one third to one half. Living donor transplants are preferable to kidneys obtained from cadavers, as live kidneys last twice as long, work right away and result in shorter hospital stays.

(Source: *Johns Hopkins Medical Institutions press release*)

Bleeding Disorders Related to Women

Symptomatic carriers of hemophilia and women with von Willebrand disease or other bleeding disorders have special gynecologic and reproductive concerns. These include excessive menstrual bleeding and excessive bleeding after childbirth or miscarriage. Longer and heavier menstrual flows often lead to low iron levels. Therefore, it is recommended that women with bleeding disorders routinely be tested for anemia. To help control menstrual bleeding, doctors may prescribe birth control pills or Stimate® nasal spray. These will boost factor VIII and von Willebrand factor levels. Decisions about what path to pursue should be based on personal preference, family planning goals, and severity of bleeding problems, and discussed by a woman and her doctor.



During pregnancy, levels of factor VIII and von Willebrand factor usually increase in women with bleeding disorders. For women with vWD, postpartum bleeding may be treated with desmopressin acetate or a von Willebrand factor-containing concentrate. A woman who becomes pregnant should see an obstetrician as soon as possible. This will ensure that the doctor can work with the local hemophilia treatment center to provide pre-and postnatal care for the woman and her fetus and testing of the baby.

Miscarriages and abortions, even early in the course of pregnancy, can result in excessive bleeding. Women who know or think they are miscarrying, or who are choosing to end a pregnancy, should promptly seek medical care.

(Source: www.shemophilia.org/women)



March 28 – 30, 2003
Marriott Houston
Intercontinental Airport
(on the airport property adjacent
to C Terminal)

Important Information about Symposium 2003

TRAVEL:

It is important to make your flight arrangements for **Intercontinental Airport**. Houston Hobby Airport is an hour away and shuttle service is expensive. Houston is a hub for Continental Airlines. If you need to use a travel agency, Travel Machine is our designated agency. Kay Simmons is the account representative. Their telephone number is 1-800-683-9882.

If you plan to drive, the airport is conveniently located between Interstate 45 and Interstate 59 just south of Texas Farm Road 1960 (a 6 lane highway) and right on Beltway 8.

HOTEL:

Make reservations **DIRECTLY** with the Marriott Houston Intercontinental Airport Hotel in the **Hemophilia Federation of America** block. The telephone numbers are: Direct to the hotel 281-443-2310, Reservations number is 1-800-228-9290. Check out the hotel property online. Go to www.Marriott.com, type in Houston, Texas and go down to the listing for our hotel.

REGISTRATION:

To register for the symposium, complete a Family registration form AND a Sessions form for each adult and a separate Youth and Teen form for each person 18 and younger. There is no charge for child care or youth and teen functions. A \$40 family registration covers parents and children living in the same household.

REGISTRATION DEADLINE IS MARCH 12, 2003.

SCHOLARSHIP:

If you need information on scholarship availability, call our office at 1-800-230-9797 and ask for Susan Swindle. Priority will be given to first time attendees.

CHAPTER DEVELOPMENT WORKSHOP:

A new feature this year will be our **FRIDAY MORNING** chapter development workshop. It will be from 9:00 a.m. until noon. There will be three components: Board Organization, Development and Planning, Budgets and Fund Raising, and Communications featuring newsletters and web sites. There is no additional charge for this workshop. Chapter staff and leaders are encouraged to attend.

REMINDERS:

1. **Flights should be planned for Houston Intercontinental Airport.**
2. **Hotel reservations should be made directly with the Marriott Hotel Houston Intercontinental Airport unless you are on scholarship.**
3. **If you plan to attend the Chapter Development Workshop you will need to arrive on Thursday.**
4. **On site registration will be available for early arrivals on Thursday.**
5. **A separate registration form must be completed for EACH person attending.**



HFA's 6th Annual Meeting and Symposium • March 28-30 2003
Houston Airport Marriott • Houston, Texas

Registration Deadline is March 12, 2003

Mail: Completed form(s) with payment to:

Hemophilia Federation of America, 102B Westmark Blvd., Lafayette LA 70506

Fax: Completed form(s) to 337-991-0087

For more information call 800-230-9797 or 337-991-0067

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

First Name	Last Name	Spouse's First & Last Name	
Street Address or P.O. Box	City	State	Zip Code
Home Phone	Office Phone	Fax	E-mail

Relation to Hemophilia: (Circle One)

Patient Spouse Carrier Family Member Other _____

Complete the following if registering as a family.

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

Do you authorize the use of any photographs or videos taken for the Federation's use only? ___ Yes ___ No
Scholarship information can be obtained by contacting Susan Swindle at 800-230-9797.

Hemophilia Federation of America Youth and Teen Program Registration Form



Sixth Annual Meeting and Symposium
 March 28-30, 2003
 Houston Airport Marriott
 Houston, Texas

To register: (Registration deadline is March 12th, 2003).

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 Blvd., 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? <input type="checkbox"/> yes <input type="checkbox"/> no			
What is the child's relationship to hemophilia? <input type="checkbox"/> Factor VIII <input type="checkbox"/> Factor IX <input type="checkbox"/> von Willebrand <input type="checkbox"/> Family member <input type="checkbox"/> Friend <input type="checkbox"/> Other _____			
Please be aware that some activities planned for the youth and teen program may take place off site. Do you grant permission for your child to go on a field trip without your supervision? <input type="checkbox"/> yes <input type="checkbox"/> 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 2003 Symposium in Houston, Texas. 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."

Session Selection Form

There will be 3 times when breakout sessions are offered: Friday afternoon, Saturday noon, and Saturday afternoon. For the sessions on Friday afternoon and Saturday noon, you may only select one to attend. On Saturday afternoon we will run all sessions twice, so you may select 2. We will assign whether you attend the first or the second group.

Name of 1st applicant (First and Last) (Complete One Form Per Person)

Friday Afternoon: (Select One) Spouses Parents Patients Siblings
 Hispanic Pain Management Women

Saturday Noon: (Select One) Kathleen Hill, PhD, City of Hope
 Dads in Action Reimbursement Issues How Do Mutations Arise?
 How Can They Be Bypassed?

Saturday Afternoon: (Select Two)

<input type="checkbox"/> Stress Management Through Yoga	<input type="checkbox"/> Sports, Fitness and Hemophilia
<input type="checkbox"/> Express Yourself through Art Therapy	<input type="checkbox"/> Diabetes and Hemophilia
<input type="checkbox"/> Dental Essentials for young patients	<input type="checkbox"/> Fundamentals of Hemophilia Care
<input type="checkbox"/> How and Why of Home Infusion	<input type="checkbox"/> Dr. Robert Keller
<input type="checkbox"/> Couples Communication	<input type="checkbox"/> Gene Therapy

Name of 2nd applicant (First and Last) (Complete One Form Per Person)

Friday Afternoon: (Select One) Spouses Parents Patients Siblings
 Hispanic Pain Management Women

Saturday Noon: (Select One) Kathleen Hill, PhD, City of Hope
 Dads in Action Reimbursement Issues How Do Mutations Arise?
How Can They Be Bypassed?

Saturday Afternoon: (Select Two)

<input type="checkbox"/> Stress Management Through Yoga	<input type="checkbox"/> Sports, Fitness and Hemophilia
<input type="checkbox"/> Express Yourself through Art Therapy	<input type="checkbox"/> Diabetes and Hemophilia
<input type="checkbox"/> Dental Essentials for young patients	<input type="checkbox"/> Fundamentals of Hemophilia Care
<input type="checkbox"/> How and Why of Home Infusion	<input type="checkbox"/> Dr. Robert Keller
<input type="checkbox"/> Couples Communication	<input type="checkbox"/> Gene Therapy

2003 HFA Symposium Agenda

March 28 – 30 • Houston Airport Marriott at Intercontinental

Thursday, March 27

4:00 – 7:00 p.m. Exhibitor registration and set up

Friday, March 28

9:00 a.m. – 12 Noon

Chapter Development Workshop

- Board Organization & Development Jan Hamilton
- Fund Raising and Finance Star Tyree
- Conflict of Interest & Self Evaluation Rich Vogel
- Communications (Newsletters, etc.) Laurie Kelly

11:00 a.m. – 5:00 p.m.

REGISTRATION

1:00 p.m. – 2:00 p.m.

Welcome reception

2:00 p.m. – 4:30 p.m.

General Session

Welcome and Introductions

- Conquering Your Chronic Illness John Valusek, PhD
- Nutrition and Hemophilia Lynda Schaumberg, RDA
- Effects of a Blood Disease in Women

4:30 p.m. – 4:45 p.m.

BREAK

4:45 p.m. – 5:45 p.m.

Break Out Sessions

- Patients • Parents • Spouses • Siblings • Hispanics
- Women • Pain Management

6:30 p.m.

DINNER AND ENTERTAINMENT

Saturday, March 29, 2003

8:00 a.m. – 9:00 a.m.

Continental Breakfast in Exhibit Hall

9:00 a.m. – 12:00 Noon

GENERAL SESSION

- Hepatitis C – Hari Conjeevarum, M.D.
- Government Relations – Patrick Collins & Jan Hamilton
- Lifetime Caps – Don Colburn
- Winning the E.R. Game – William Schumacher, M.D.

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
- Session 2 – Reimbursement Issues
- Session 3 – How Do Mutation Arise?/How Can They Be Bypassed? -- Kathleen Hill, PhD

12:15 p.m. – 1:45 p.m.

HERB meeting

1:45 p.m. – 2:00 p.m.

BREAK

2:00 p.m. – 3:15 p.m.

Break Out Sessions – Panel One

- Yoga for Hemophilia
- Art Therapy
- Dental Care for young hemophiliacs
- Home Infusion Techniques
- Couples Communication
- Sports and Hemophilia
- Diabetes and Hemophilia
- Introduction to Hemophilia
- Dr. Robert Keller
- Gene Therapy

3:15 p.m. – 3:45 p.m.

BREAK

3:45 p.m. – 5:00 p.m.

Break Out Sessions -- Panel Two

(Repeat of the first Panel)

5:00 p.m. – 6:00 p.m.

Women's Tea

6:30 p.m.

Dinner and Entertainment

Sunday, March 30, 2003

8:00 a.m. – 9:00 a.m.

BREAKFAST

9:00 a.m. – 9:45 a.m.

Inspirational Speaker – Ray Hollister

9:45 a.m. – 10:15 a.m.

TBA

10:15 a.m. – 10:30 a.m.

BREAK

10:30 a.m. – 11:00 a.m.

HFA Kids Shine

11:00 a.m. – 11:30 a.m.

Teen Connection Highlights

11:30 a.m. – 12:00 Noon

Closing

Express Yourself: Using Art Therapy to Explore Living with Hemophilia

By: Carole G. Lancon, Med, MAAT, Lafayette, LA

Art therapist Carole G. Lancon will be back at this year's HFA Symposium to guide breakout session participants in simple, non-threatening, and pleasurable activities that individuals and families can use to gain insight into ways they can cope with chronic disease. Diagnosis of a chronic condition affects a person's whole being: physical, mental, emotional, and spiritual. Research suggests that persons living with chronic disease are at greater risk of developing depressive disorders and symptoms. Chronic disease also affects the patient's family or caregivers. The daily burden of care and its social, economic, and emotional consequences place the physical health and emotional well-being of the entire family at risk (AIFS, 1996). Family members often deal with their own feelings of survivor guilt, unexpressed frustration and anger over unfulfilled expectations, hopes and dreams, and mental and emotional fatigue from the day-to-day care of a physically-handicapped person. Carriers of the hemophilia gene must deal with the emotional consequences of passing the hemophilia gene on to their child/children.

Physical benefits of creative experiences are enhanced brain functioning and structure. Brain scans show increased blood flow to the brain during periods of creative thought and any creative activity that is enjoyable can result in increased serotonin levels and alpha wave patterns typical of the restful alertness found in meditation (Chopra, 1993). The C.E. Koop Center (1998) found that art-making in hospitals provided stress reduction, increased communications of feelings about symptoms, and improved heart rate, blood pressure, and respiration.

Art Therapy can assist individuals and families affected by hemophilia in exploring their inner and outer worlds through images and words. Art therapy uses imagery and the creative process as powerful tools that help people express uncomfortable, and sometimes unconscious, beliefs and feelings. Art-making is a simple and efficient way of translating sensations and emotions into symbolic images. Because imagery is the bridge between the mind and body, art-making enables people to transfer feelings into concrete forms that can be less threatening than words and bring about conscious understanding, synthesis, and healing.

References: AIFS (1996). [On-line] Children and families and chronic illness. www.aifs.org.au/institute/afrcpapers/martin.html.
C.Everett Koop Center (1998) [Online] ArtCare Program. www.koop.dartmouth.edu/programs_arts_5.html/.
Chopra, D. (1993). *Ageless body, Timeless Mind*. New York: Harmony Books.

Resources on the Internet: American Art Therapy Association (AATA). (847)949-6064
1202 Allanson Road, Mundelein, Illinois 60060 www.arttherapy.org
National Coalition of Arts Therapies Associations (NCATA). (202) 678-6787
2117 L Street, N.W. #274, Washington, D.C. 20037
Arts And Healing Network. (415)771-3696. PMB 612, 3450 Sacramento St. Box 616, San Francisco, CA 94118
www.artheals.org
Art As a Healing Force Web. www.artashealing.org
National Family Caregivers Association (NFCA) www.nfcacares.org



How Yoga Helps

By: Lana Bienvenu, R.Y.T.

Whether you are living with a chronic medical condition or acting as a caregiver, yoga can be a valuable aid to healing and to managing your life.

Yoga can be practiced by anyone with any level of mobility. There are even practices designed for patients who are bedridden. All that is required on the part of the student is patience and self-acceptance.

Although many feel beneficial effects from the start, initial yoga sessions may bring areas of physical tension and emotional pain more deeply into your awareness. You might feel that it is impossible to quiet your mind and that you simply cannot relax.

Be persistent. Know that “to heal it, you must first feel it.” Then you can let go and let the blessings flow.

These are just a few benefits you can expect to receive from your yoga practice:

- **Relaxation** is achieved through techniques such as breath control, guided imagery, and positive affirmation.
- **Concentration** and control of mental activity are gained through meditative practice, leaving you with a refreshed and recharged mind.
- **Strength and Flexibility** are achieved with practice of the physical postures (asanas).
- **Good Internal Health** is maintained with yogic techniques which improve, for example: circulation, endocrine function, digestive function and the immune system.
- **Emotional Well-being** is enhanced through yogic philosophy which promotes joy and acceptance and through simply being with others in a supportive atmosphere.

Come and be a part of our gentle yoga for beginners group. Come and discover why yoga, the oldest self-improvement program known to man, is still so widely popular today. You will be embarking on a life-changing journey.

• Note: Lana Bienvenu is a Registered Yoga Teacher and Teacher of Integrative Yoga Therapy in Little Rock, Arkansas. She is eagerly looking forward to once again sharing healing energy with you at the HFA Symposium, March 28-30, 2003 in Houston, Texas.

FDA STATEMENT ON BLOOD INDUSTRY'S VOLUNTARY MARKET WITHDRAWAL OF CERTAIN FROZEN BLOOD PRODUCTS TO REDUCE RISK OF WEST NILE VIRUS TRANSMISSION FROM TRANSFUSION

December 12, 2002- The Food and Drug Administration (FDA) has been working with the Centers for Disease Control and Prevention (CDC) and the blood banking community to assess and manage the potential risk of West Nile Virus transmission from blood and blood products.

A small number of cases of West Nile Virus infection have been linked to the receipt of blood products that carried the virus. The estimated risk to recipients of blood and blood products is thought to be low; but it varies by region and time period of the epidemic.

In October 2002, FDA issued a final guidance document that provided recommendations for the assessment of donor suitability and blood and blood product safety in cases of known or suspected West Nile Virus infection (www.fda.gov/cber/gdlns/wnvguid.htm).

Although the risk from an individual unit of blood or plasma collected and frozen during the epidemic is likely to be low, FDA believes that the voluntary withdrawal of certain frozen products is a rational response to the risk at this time.

FDA will continue to review its recommendations as we learn more about the epidemic. As in many situations involving potential risks from blood products, it is important to weigh the public health benefits of possible interventions to ensure that an adequate supply of blood products is available. FDA is pledged to working with CDC and the blood banking community to help ensure that safe products will be available wherever they are needed.

FDA will provide updates to this situation as new information becomes available.

HFA Office Hosts Guest

On Monday evening, January 13 and Tuesday, January 14, the HFA office staff and some of our board members welcomed a visitor to our midst. This visitor was Mr. Dick Hellner, new Executive Director of NHF.

This was a wonderful opportunity for Mr. Hellner to learn about HFA – who we are and what we do. We entertained him at dinner Monday evening with three of our board members (Donnie Akers, Joey Privat and Randy Ratcliff) plus our Executive Director, Jan Hamilton. It was an informal occasion where we learned a little about him and he a little about us.

On Tuesday morning, he came to our office for some Cajun hospitality and more information about HFA's structure and function. He had the opportunity to meet each of our staff members and learn of their roles in the organization. On our way to return him to the airport, we had lunch at a local restaurant where the chef is the father of a young adult with Factor 9 deficiency. The chef came to the table and visited with us.

HFA says, "Thank you!" to Dick Hellner for his visit and we hope it will open doors toward opportunities to work toward the common goal of a better life for persons with hemophilia and their families.

At symposium, I witnessed the difficulties of members of the community in dealing with the everyday hardships of living with hemophilia and its related conditions. I saw myself as one of the ignorant public who needed education and eye opening. I saw community members respond and react to each other in positive and sharing ways. Ultimately, I saw, I experienced and I felt at symposium. Symposium converted me. I was completely won over. I had to be a part of this community's great work.

Since Atlanta, I have been inspired and have worked hard for the community and the causes of HFA. I was honored and humbled to be asked to serve on the Board of Directors as an independent member and to serve on many committees. I have gone from being the invited guest at the Atlanta Symposium to working with the 2002 HFA Cleveland Symposium Committee and now serving as the Co-Chair of the Houston 2003 Symposium along with my friend, Barbara Chang of California.

HFA Symposium is a gathering of the community and serves as a large support group and meeting for those with hemophilia and its related conditions as well as for their caregivers, families and the medical and health care professionals who work within the community. HFA Symposium is truly the one significant event "of the community, by the community and for the community" where all come together for the single cause of the community. HFA Symposium is about information, camaraderie, fellowship and sharing. HFA Symposium is about taking time for and caring for one's self and communing with others who are uniquely the only others who share the same trials, tribulations, joys and experiences without great introduction or need for explanation.

Because of symposium, HFA is a large part of my life now and provides me with more satisfaction and reward than anything that I have been able achieve in more than 22 years of practicing law. Working with HFA, its Board and its community members allows one to work to effect positive change and to help in making life better for all of us.

Attendance at HFA's 2003 Houston Symposium March 28-30 just might change your life. I know it will make your life much better as it did mine. I strongly recommend that you come and enjoy the experience and all that symposium has to offer.

HHS Announces Approval of New Rapid HIV Test

HHS Secretary Tommy G. Thompson announced an important step in America's war against HIV/AIDS: the FDA approved of a remarkable new rapid HIV test. The OraQuick Rapid HIV-1 Antibody Test, manufactured by OraSure Technologies, is a marked improvement over previous HIV tests, which required a vial of blood and a wait of several weeks for results. The new test uses only one drop of blood, and in just 20 minutes it can detect HIV antibodies with 99.6 percent accuracy.

"This is a wonderful advance that will save countless lives. Extraordinary cooperation between HHS and the manufacturer helped expedite getting this OraQuick test to market. The FDA deserves high marks for the unprecedented speed and diligence with which they reviewed the OraQuick application," Secretary Thompson said.

The Centers for Disease Control and Prevention estimates that one-fourth of the up to 950,000 HIV-infected people in the U.S. are not aware that they are infected. That means that more than 225,000 Americans don't know that they have this life-threatening viral infection - an infection that they may unwittingly pass on to others.

Each year, 8,000 HIV-infected people who take an HIV test do not return one or two weeks later to get their test results. The OraQuick test will help reduce that number by giving a result in less than 30 minutes.

This test will also be a great help in identifying HIV-positive women during labor who were not tested during pregnancy. It will mean that they and their newborns can quickly receive the drugs necessary to help prevent the newborns from becoming infected.

This approval is the product of departmental cooperation, including the FDA, CDC, and CMS. The Centers for Disease Control and Prevention is actively working with public health officials, and the Centers for Medicare & Medicaid Services is offering technical assistance and training to testing personnel and laboratories interested in providing this test.

The Bush Administration is committed to doing everything possible to stop the spread of HIV and AIDS. Overall HIV/AIDS spending by the U.S. government has increased from \$14.2 billion in fiscal year 2001 to more than \$16 billion for fiscal year 2003. That includes a doubling in international HIV/AIDS funding over the same period. The Administration is devoted to finding a cure and an effective vaccine. That's why it has allocated unprecedented resources to the National Institutes of Health. The NIH budget request for fiscal year 2003 includes \$2.8 billion for HIV research - a more than \$500 million increase over 2001.



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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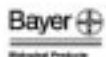
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Community Calendar 2003

FEBRUARY

The **American's Blood Centers** Annual Meeting will be held in Washington, D.C. February 22-26. Contact 202-393-5725. This meeting will be open for members only.

MARCH

On March 1, 2003, The **Hemophilia Association of San Diego** will hold their County Annual Meeting at Salk Institute in La Jolla, CA. For more information, visit their website at www.hasdc.org.

Hemophilia Federation of America holds its **Annual Symposium** in Houston, Texas on March 28-30. For more information call us at 337-991-0067.

MARCH/APRIL

At the end of March, The **International Pharmaceutical Industry Congress 2003** will be held in New York, New York from March 31st to April 2nd. For more information on how to attend, visit their web site www.pharacongress.net.

MAY

HFA hosts their first annual golf tournament May 8th at Pelican Point in Gonzales, LA. More details to come.

JUNE

The **9th Annual Non-profit Workout** will held on June 2nd and 3rd at the Hyatt Regency Cambridge and sponsored by **Third Sector New England**. Registration opens January 13th.

On the 4th to the 6th, **Advances in Transfusion Safety**. The meeting will provide overview of the "state of the art" for transfusion safety. Visit www.iabs.org/page110 for more information.

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.

The Immune Deficiency **Foundation National Conference** is being held in Baltimore, Maryland on the 19th-21st. For information, contact 800-296-4433.

JULY

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

NOVEMBER

The **American Association of Blood Banks** is hold 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.

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and Who loves,
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