



Dateline Federation

NEWSLETTER OF THE HEMOPHILIA FEDERATION OF AMERICA

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The new office

We've Moooooved!

Can you believe it? We've been in Lafayette six years and we have just moved into our fourth new office! We spent three years at 102 B Westmark and enjoyed it, but when we started sharing desks and computers, we realized it was time to go.

The search began and we couldn't believe how much some of the landlords LOVE their property! We searched and searched, figured, cajoled, analyzed and finally arrived at a great location that is close to the university, medical centers, and downtown Lafayette.

We found an owner who appreciates our non-profit status and our need to stretch dollars. We will even have a small conference room and some storage. The best news is we were able to double our current space for the same dollars we have spent in our former location!!!

Many thanks go to all who assisted with the move including Desiree's daughters, members of the Comeaux High School Key Club, friends and neighbors. By the time you read this, we should be fully operational at our new location. Come see us!



President's Patter



It seems like the months have just flown by since our March Symposium and Board of Directors meeting held in Las Vegas. As the newly elected President, I have had the opportunity, on a daily basis, to observe and participate in the myriad of projects that interface with the mission and vision of our organization.

We are gaining strength in the areas of finance, new member organizations, committee functions and legislative/reimbursement issues. We have been interviewed, cited, mentioned and discussed in several publications which reach a broad audience. Our voice is being heard and folks are learning about the great works and vision of HFA. We want to be sure that we continue to represent the blood clotting disorder community so please continue to communicate with us. Tell us about the issues affecting your family. We must keep abreast of the local topics that may influence reimbursement or your CHOICE of medical treatment, care or supplier. We care about each and every individual affected by a blood clotting disorder whether it is you or a family member or friend. We have strength in our numbers and in our ability to network as one friend to another.

Our Executive Director, Jan Hamilton and her staff have located a new facility to house our national headquarters. This office will remain in centrally located Lafayette, Louisiana and will allow for increased efficiency due to the enlarged space and design. Please bear with us during the moving process as one can anticipate some minor disruptions during the transition. We extend an open invitation to anyone who wishes to stop by to visit, but be careful – we put everyone to work!

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, 1405 W. Pinhook, Ste 101, Lafayette, LA 70503.

Mission Statement

The Hemophilia Federation of America is a national nonprofit organization that assists and advocates for the blood clotting disorders community.

Vision Statement

The vision of the Hemophilia Federation of America is that the blood clotting disorders community has removed all barriers to both choice of treatment and quality of life.

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Kaissy Hammer, RN, M.Ed.

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Florida Chapter of NHF
Gateway Hemophilia Association
Hemophilia Association of the Capital Area
Hemophilia Foundation of Arkansas, Incorporated
Hemophilia Foundation of Idaho
Hemophilia Foundation of Illinois
Hemophilia Foundation of Maryland
Hemophilia Foundation of Nevada
Hemophilia Foundation of Northern California
Hemophilia Foundation of Southern California
Hemophilia of Indiana, Incorporated
Hemophilia of North Carolina
Hemophilia of South Carolina
Hemophilia Outreach of El Paso
Lone Star Chapter of the NHF
Nebraska Chapter of the NHF
Northern Ohio Hemophilia Foundation
Oklahoma Hemophilia Foundation
Tennessee Hemophilia & Bleeding Disorder Foundation
Texas Central Hemophilia Foundation
Utah Hemophilia Foundation

Genetic Alliance Press Release

The annual Genetic Alliance conference was held July 23-25, 2004, at the Key Bridge Marriott in Arlington, VA. Attendance surpassed previous records as advocates, genetics health professionals, pharmaceutical and biotechnology executives gathered for three full days. This year featured a number of day-long workshops. These included a meeting on epidemiology, registries and data collection presented by the Centers for Disease Control and Prevention; and a meeting for corporate advocates and liaisons, organized by patient advocates from Genzyme Corporation and Genomic Health. Over 20 workshops were offered, as well as a wonderful plenary presentation by author Steve Olson – “Stories from the Genome”. One participant articulated a common theme – declaring that she appreciated the *“incredible broadening of my experience and knowledge through presentations and discussions with similar organizations and the discovery of new pathways to achieve our mission.”*

Conference highlights included two meetings of advocates from a number of communities and organizations interested in outreach to diverse, underserved and underrepresented communities. Sponsored through a cooperative agreement with the Genetic Services Branch of the Maternal and Child Health Bureau, Health Resources and Services Administration, these meetings included a lively discussion about race in science and society, led by Dr. Harold Freeman, Director of the Center to Reduce Cancer Health Disparities, National Cancer Institute, NIH. Participants also discussed ways to improve access to culturally- and linguistically-appropriate genetics resources and services.

This year’s youth program was a special one. A grant from the Sylvia Bennett Trust funded instructors from TIGR and the opportunity to use the MDBio Lab – a portable hi tech lab – to solve a mystery using DNA technology. A young person involved in the program said *“I didn’t know science and genetics could be so much fun, I want to come back next year!”*

In the final session, passionate advocates shared stories of their effectiveness of advocates in overcoming obstacles with innovative efforts that have resulted in new paradigms. At the end of the conference, a participant commented, *“I am always amazed by the collective wisdom of this group and the selfless, transparent, way they share to help each others.”* This passion was celebrated in an original song led by Francis Collins, Director of the National Human Genome Research Institute. The next conference will be held July 29 – 31, 2005 in Rockville, MD.

The Genetic Alliance is an international coalition of over 600 genetic advocacy organizations, academic and industry professionals. Its mission is to increase capacity in genetic advocacy organizations to achieve their missions and to leverage the voices of the millions of individuals and families affected by genetic conditions.

P.S. from HFA board member, Maria Rubin:

I had the good fortune to attend the Genetic Alliance 2004 Annual Conference. As the title suggests, it is a true joint effort of the many advocacy groups that were represented at the conference to build on each other’s resources to be able to grow and to achieve their individual missions. There were many informational break out sessions and I attended as many as possible.

The Genetic Alliance Board recently took the challenge to redefine itself and grow to reach the next level. Heeding the words of Ghandi who said, “Be the change you want to see in the world”, they committed to a process of developing a powerful team dynamic that creates new levels of quality and to share their experience so that other groups may benefit. GA will develop a curriculum and training that will transfer the experience and knowledge to their member groups.

The Project Connect Network is a forum for all interested in genetics outreach. To join, visit the GA website at:

www.geneticalliance.org/outreach/projectconn.asp

Bike Washington DC

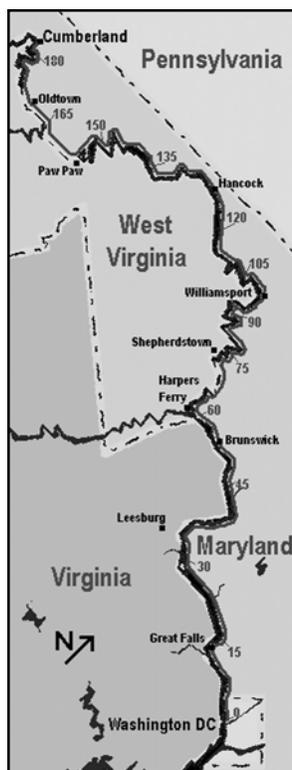
By: Paul Brayshaw

Over the last several years, my father and I have completed many multi-day bicycle rides. In planning for our next ride, I thought we were planning just another of these rides.

Our first ride along the Chesapeake and Ohio (C & O) Canal Towpath, 184.5 miles from Cumberland to Georgetown, was a great success. I arrived in Cumberland, MD Thursday night and spent the night at the Inn at Walnut Bottom. Cumberland provided a great staging point for the start of an amazing weekend along the towpath with family and friends in support of the Hemophilia Foundation of Maryland.



There were actually four committed riders, including: my father (Bill); my sister (Colleen); my friend (Andrew); and me. On subsequent days of the journey my other sister (Dana), wife (Frances) and mother (Susan) bicycled various distances.



The Friday segment took us from Cumberland, MD to Hancock, MD. The highlights of the day included head to toe coverage in mud, a walk through the 3,100 foot Paw Paw tunnel, and a hearty meal at Bill's Place in the town of Little Orleans.

When the ride was planned, we expected to cover approximately 60 miles per day, and sit on the saddle for 6 hours. Unfortunately, there were some serious miscalculations. On all three days the ride lasted more than 7 hours. Even with regular stops for history consumption, stretching and water replacement it was much longer than anyone expected. The conclusion of Friday alluded to the challenges ahead.

On Saturday, we departed Hancock and passed through Fort Frederick State Park. The Fort was used for various purposes between the French and Indian and the Civil Wars. We crossed the Antietam Creek Aqueduct, which is one of the best preserved aqueducts on the canal. The final portion of Saturday brought us to Harper's Ferry and a night at the Hilltop House Hotel. About one mile before we arrived in town, Andrew broke his chain. An unsuccessful attempt to fix the link caused us to use the towpath for an actual tow. The extra 180 pounds to complete Saturday and the walk up the hill to the hotel made for the most difficult day.

Sunday was the final day of the adventure and Father's Day made it extra special. The ride from Harper's Ferry to Georgetown provided the most excitement with people visiting Great Falls, boating or walking along this stretch. The added energy kept all of us focused and aware of wandering dogs and kids who presented as obstacles. Fortunately, there were no significant casualties and we arrived in Georgetown at 2 pm.

I would like to thank all of you who supported my efforts and assisted me in raising almost \$1900 for Hemophilia Foundation of Maryland. If you have not yet had the opportunity to contribute toward this event, you may still do so even though we have completed the actual ride. Just send donations to Hemophilia Foundation of Maryland, 8043 Kimberly Road, Baltimore, MD 21222. In future years I hope HFM can open this event to everyone who is interested in cycling. It would be a great opportunity for the Chapter to host an annual fundraiser that supports programs and services while promoting the importance of determination, commitment and a desire to improve the overall quality of life of individuals and for people with hemophilia.



Educational Presentations for ER Triage

This fall marks the launch of HFA's educational program for Emergency Room triage. The first presentation will be held in Lafayette, Louisiana at the University Medical Center in August.

Would you like to have one of these educational sessions in your area at one of your hospitals? We are looking for host facilities for these sessions as well as chapters, treatment centers, hospitals, home care or manufacturers to assist in the on site sponsorship and invitations.

Here is a list of the areas we have under consideration at this time, but feel free to add to the list if you are interest in being of assistance:

Tennessee, Missouri, Texas, California, Illinois, District of Columbia, Pennsylvania, New York, Oklahoma, Nebraska, Florida, Mississippi, Idaho, Utah, Indiana, Ohio, North Carolina, and South Carolina.

If you are interested in assisting with this project, call our office at 1-800-230-9797 and ask for Kaissy Hammer, RN, M.Ed. or Jan Hamilton, Executive Director.

HACA's Celebration Picnic



On June 6, Hemophilia of the Capital Area celebrated their 40th anniversary with a wonderful picnic which was held at Pohick Regional Park in Lorton, Virginia.

HFA Executive Director attended along with board members Lew Collins and Paul Brayshaw, and our Washington representative Jim Romano and his wife Carolee.

We were excited to see many old friends from symposia past and to join in wishing HACA many more successful years as advocates for the hemophilia Community.

(Here are Jim and Carolee getting everyone involved in the limbo – yes it is a hemophilia picnic!)



Dads in Action Training

A recipe for success: Take 14 dads from 13 states, add a heap of fellowship, a dash of fun and a barrel of strong desire to become better dads and the results were a rousing success for our second Dads in Action Training session July 23 – 25 in Lafayette.

Watch for Dads in Action groups starting in your neighborhood. We will have

complete coverage of the weekend in the fall issue of *Dateline Federation!* Also included will be a list of states who have already sent dads to an HFA Dads in Action training session.

If you would like to have an HFA Dads in Action group in your chapter call our office at 800-230-9797 to find out how to make it happen.

Colorado's 2004 AIDS Walk

Dear Generous Supporter,

Thirty percent of the 1 million individuals in America who have HIV have also been infected with hepatitis C. I was infected with both HIV and HCV twenty years ago by clotting factor I needed to take for hemophilia. Because of hepatitis C, liver failure is now one of the leading causes of death for people with HIV/AIDS.

I have beaten my hepatitis C with two years of intense medications and the support of my wife Jacque. Please help me as I continue my journey at Hep C Connection of helping others who have contracted HIV and hepatitis C.

Please help Hep C Connection raise needed funds for our Co-infection Program by giving generously to AIDS Walk Colorado 2004!

Seventy percent of all donations collected by "Team Hep C Connection" will go to support the important work I am doing in the HIV/HCV Co-infection Program

If you live in the Denver area, please consider becoming a part of our team and walking with us on Sunday August 22.

Thank you for your support,
Daniel Reilly
dreilly@hepc-connection.org
Co-infection Program Manager
Hep C Connection





Chapter Chat

You're Invited

The Hemophilia Foundation of Nevada cordially invites you to their 1st Annual Meeting & Family Information Day. Saturday October 9, 2004 at the UNLV Stan Fulton Building, 801 East Flamingo Avenue, Las Vegas, NV.

Home Health Care and Manufacture's are invited to exhibit their company's literature at the event. For more information contact HFNV at 702-564-4368 or email at hfnv@earthlink.net.



Health Fair in El Paso



Hemophilia Outreach of El Paso had their 4th Health Fair at the YMCA and it was a great success. The Health/Welfare Department has asked them to participate in two more Fairs, one in October and the other in November. Also the El Paso School District is having them present in September to the Senior Medical Students that are in the pipeline for careers in the Medical Field. They will also be coordinating two Hemophilia In Services for the School Nurses in the next several months.



FYI: Industry News Briefs

Managing Hemophilia Just Got Easier

Handheld electronic patient diary takes convenience to the next level

Technological advances continue to impact the health care arena in ways never thought possible. One such advance is now revolutionizing the management of hemophilia. EZ-Log is a handheld electronic diary that offers patients a new way to record and communicate accurate treatment and bleeding information. The system provides hemophilia patients with a higher level of convenience over the existing practice of using paper diaries or treatment logs.

EZ-Log, now available to the hemophilia community through Bayer Biological Products, the makers of Kogenate® FS (Antihemophilic Factor [Recombinant], Formulated with Sucrose), features a way to record home treatments and bleeding episodes, track product supply, and submit refill requests. Patients enter information using convenient features, such as user-friendly menus and bar code scanners. This information then can be transmitted securely over phone lines to a patient's hemophilia treatment center or personal physician, where his treaters and nurses can view the data over the Internet or possibly download it into an existing clinical database. The real-time transfer of information provides the treaters and nurses data needed to monitor and adjust treatment plans and, most importantly, improve patient care.

Patient confidentiality and data security are critical and therefore data communications are encrypted, including the collection of information through patient ID numbers rather than names. Access to the data is available only to the patient's hemophilia treatment center.

If you are a patient who is not using Kogenate FS® and would like to use the EZ-log software, you may access a web based version that will still transmit the data to your treater.

The Need to Improve Compliance

A study, titled "Barriers to compliance with prophylaxis therapy in haemophilia," published in *Haemophilia* in 2001, found the most significant barrier to compliance from the patient or parent point of view was the time-consuming nature of the treatment regimen. Further, the study said hemophilia patients must be provided with tools and support to minimize the challenges of adherence to this demanding regimen. The EZ-Log system not only minimizes the time it takes to enter information, it also makes the process easier and more convenient.

A study presented at the 2003 annual meeting of the American Society of Hematology (ASH) by researchers at McMaster University HTC, Hamilton, Ontario, Canada, reported the use of EZ-Log improved record-keeping compliance, quantity, and timeliness of data collected, as well as overall communication between patients and treaters.

Over the years, people living with hemophilia have expressed dissatisfaction with paper diaries because of the inconvenience associated with them. Attendees of the National Hemophilia Foundation's annual meeting in November 2003 responded positively to demonstrations of the revolutionary EZ-Log. Survey results following the demonstrations revealed the community's excitement about the product and its features, including a sense of empowerment among patients in gaining greater control over the management of their condition.

To obtain more information about EZ-Log, contact your local hemophilia treatment center.

HRA Merged with Accredo

In a letter received in mid June, HFA learned that Accredo, Inc., Parent Company of Hemophilia Health Services (HHS), and Hemophilia Resources of America (HRA) have agreed to merge operations. HHS and HRA both enjoy reputations of customer service excellence and have outstanding relationships with their insurance clients.

The merger will strengthen the ability of both companies to improve upon and enhance the level of service provided. It will enable us to continue the expansion of support programs for the hemophilia community, such as HRA's Karing for Kids™ program and HHS's Factor Care™ program, as well as allowing us to take better advantage of current and emerging technologies.

Company leadership has stated that, you can rest assured that the quality of service your members and/or patients have come to expect from HRA will not change. Your members/patients will continue to speak with the same HRA representatives that they have relied upon in the past and will continue to receive all of the products and services to which they are accustomed. Although HRA and Accredo have agreed to merge, they will continue to operate with no interruption of service to you or to your members/patients. Completion of the merger is expected in the middle of August.

If you have any questions, or would like additional information, please contact either Perry Bernocchi or Mark Scudieri at 800-549-2654.

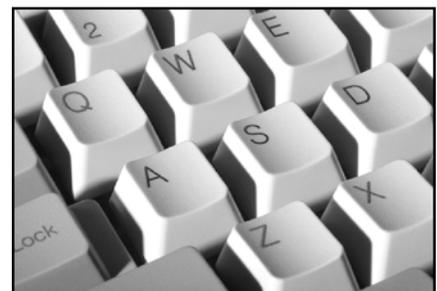


Information Station

Here are some websites you might want to list in your favorites for when you need an answer to a probing question:

Department of Health and Human Services (HHS)	www.hhs.gov
Food and Drug Administration	www.fda.gov
FDA Center for Biologics Evaluation & Research (CBER)	http://www.fda.gov/cber/
FDA Center for Drug Evaluation & Research (CDER)	http://www.fda.gov/cder/
Genetics Alliance	www.geneticalliance.org
Genetic & Rare Diseases Info Center	http://rarediseases.info.nih.gov/
HHS Advisory Committee on Blood Safety & Availability	http://www.hhs.gov/bloodsafety/
Hemophilia Federation of America	www.hemophiliafed.org
HIPAA Main Page	www.hcfa.gov/hipaa/hipaahm.htm
Medicare	www.medicare.gov
National Hemophilia Foundation	www.hemophilia.org
National Organization for Rare Disorders	www.rarediseases.org
Plasma Protein Therapeutics Association (PPTA)	www.plasmatherapeutics.org
Thomas Legislative Information on the Internet	www.thomas.loc.gov/
World Federation of Hemophilia	www.wfh.org

This is by no means a complete listing, but is a good start for contacts. You should also add your product manufacturer, home care company, HTC, and your Congressional contacts.



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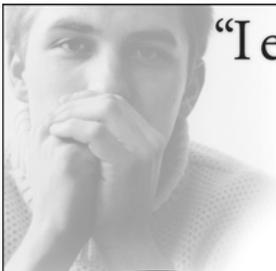
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Community Calendar 2004

August

26-27

Advisory Committee on Blood Safety and Availability at the Hyatt on Capitol Hill in Washington, DC

28

Hemophilia of Indiana's Annual Meeting at the Holiday Inn Select North in Indianapolis, Indiana

29

Hemophilia of Indiana is having their **Wheels for Winning** event at the Indianapolis Motor Speedway

September

10

Hemophilia of Idaho's **Annual Golf Tournament** at Purple Sage Golf Course

11

Adirondack Spintacular, a scenic, paved 6 or 12 mile challenging route for cyclists, runners, and walkers amidst the Adirondack Mountains and along the great Sacandaga Lake in Mayfield, New York. To benefit the Lawerence Madeiros Scholarship Fund. Event check-in is from 8:30 am to 9:30 pm, the race begins at 10:00 am, and a Barbeque at noon.

11-12

"Dads in Action" Father/child Camp-Out in Warren, Rhode Island for the New England Hemophilia Association

13

New England Hemophilia Association is having their **Annual Golf Tournament and Auction** at Shaker Hill Golf Club in Harvard, Massachusetts

13

Northern Ohio Hemophilia Foundation's **49th Annual Meeting** at Embassy Suites in Independence, Ohio

27

Gateway Hemophilia Association's **Golf Tourney** at Forest Park Golf Course in St Louis, Missouri

October

9

Hemophilia Foundation of Nevada is having their **1st Annual Meeting and Family Information Day** at the UNLV Stan Fulton Building in Las Vegas, Nevada

8-10

HFA Mid-Year Board Retreat will be held in Lafayette, Louisiana

November

4-6

National Hemophilia Foundation's **Annual Meeting** in Dallas, TX

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