

Come On In.....

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Partner with LHF*

Enclosed in this newsletter are: camp interest forms, zoo snooze, crawfish boil, and annual meeting sign-up forms.

To conserve resources(time, postage, paper, etc.) we are mailing all required forms at one time. Please use the envelope provided to return your forms

If you would like to attend any of these events, please take the time "now" to complete these forms and return them in the envelope provided.

President's Perennials

I want to thank all of you who continue to lend your assistance, guidance and good will to help fulfill the mission of LHF. This community is one blessed with people who come from all walks of life and who bring with them such a variety of experiences and wealth of knowledge. Much of the knowledge is what has been learned from dealing with hemophilia or other bleeding disorders in your daily life and embracing the fact that active participation is what keeps you on top of your health care needs.

I cannot express to you enough the gratitude I feel when I have the fortunate opportunity to meet our members and hear their stories and life experiences. You are the reason why we need to continue advocating for assistance, support research, and encouraging our community to band with us to continue our work for a cure.

Additionally, I want to send a warm thank you to all of the supportive staff at our local Hemophilia Treatment Center in New Orleans for joining us in several collaborative events being held this year and in future years.

I look forward to our Annual Meeting and hope you have the ability to join us in Baton Rouge for this event. We plan to have some stimulating presentations, opportunities to network with others, and many fun events at the meeting.

I also ask each of you to embrace the fact that we can all learn from each other and need to reach out and become one voice for a higher need. Each one of us has a unique personality and special talents that combined together can help us to achieve wonderful things.

Thank you for sharing and caring.

Edgar Guedry

Edgar Guedry

March 2011							April 2011							May 2011							
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June 2011							July 2011							August 2011						
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September 2011							October 2011							November 2011						
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December 2011							January 2012							February 2012						
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18	19	20	21	22	23	24	22	23	24	25	26	27	28	19	20	21	22	23	24	25
25	26	27	28	29	30	31	29	30	31					26	27	28				

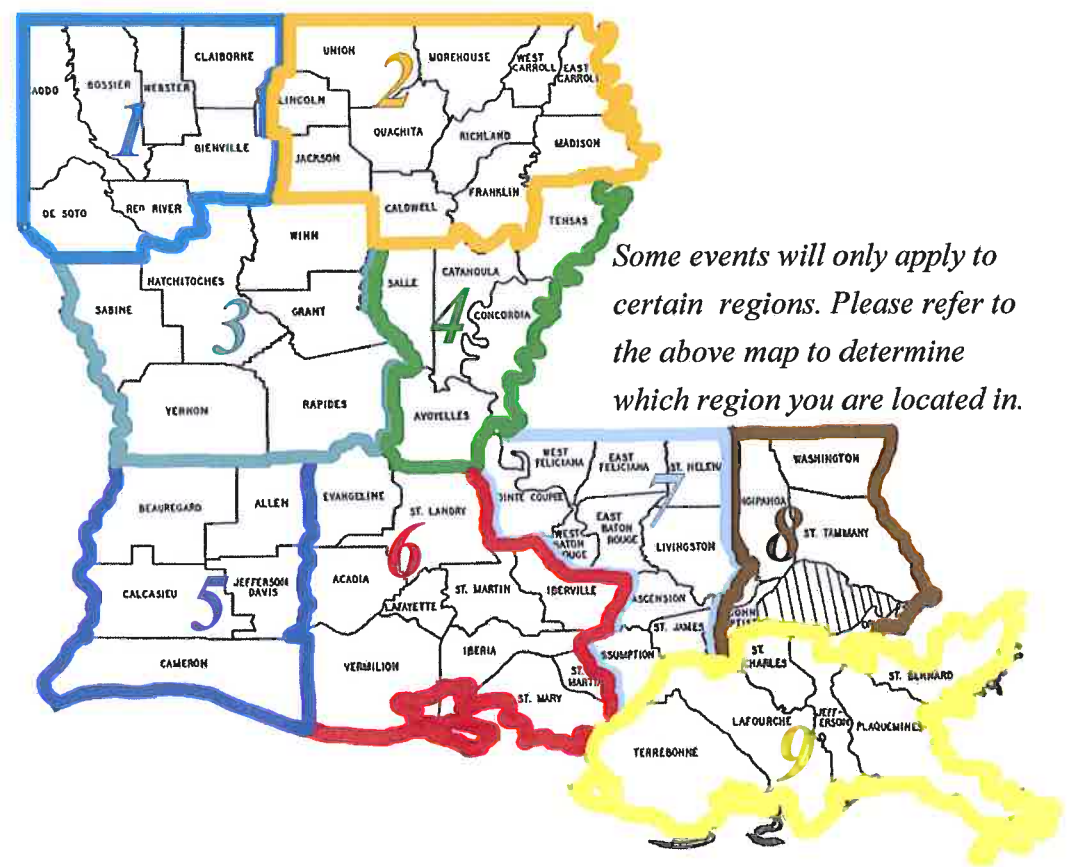
Notes

- March 12- LHF Annual Skeet Shoot
- April 2- LHF Board Meeting
paid members may attend - must RSVP
- April 14-16 HFA Educational Symposium
- April 15 Dinner Presentation (Metairie)
Region: 7, 8, 9 invitations will be mailed
- May 7- Zoo Snooze
(form enclosed)
- May 14- LHF Annual Crawfish Boil
(form enclosed)
- June 10-12 LHF
Annual Meeting/Educational Symposium
(form enclosed)
- July 10-15 Camp Wounded Knee
(interest form enclosed)
- October 24- LHF Annual Golf Tournament
- November 10-12 NHF
63rd Annual Meeting in Chicago
"Inspiration in a Windy City"
- December 10- LHF Christmas Luncheon

Save the Dates 2011 - 2012

LHF Regions

-  REGION 1
-  REGION 2
-  REGION 3
-  REGION 4
-  REGION 5
-  REGION 6
-  REGION 7
-  REGION 8
-  REGION 9



Washington Days

"A Louisiana Family Speaks Out"



The Major Family
with Mayor Landrieu's aide.

Advocacy: the act or process of advocating or supporting a cause or proposal. Each year the National Hemophilia Foundation hosts Washington Days in Washington, D.C. The purpose of this event is to empower individuals in the bleeding disorders community to affect the legislative process. The Hemophilia community has a strong track record of affecting public policy on both the State and National level. This event allows community members to become better informed on legislative issues that may affect quality access to care, meet face to face with law makers, and learn grass root level advocacy techniques.

This year I had the opportunity to bring my wife and kids to D.C. and share our experiences and stories with our lawmakers. Soon after arriving we were briefed by NHF lobbyists regarding what was going on Capitol Hill. This year congress was very focused on the national budget and health care reform. Even though health care reform was passed last year and many aspects of the reform have already started to become implemented, challenges continue. Several states have filed lawsuits against the federal government and the House of Representatives voted to repeal the plan. The senate has protected the plan up to this point but it is essential to keep a close watch on political maneuvering as things can change quickly. Some of the aspects of health care reform that directly impact the

hemophilia community are as follows: Insurance companies are barred from denying coverage to children, under the age of 19, who have pre-existing medical conditions, insurance companies have to provide coverage for dependent children up to the age of 26, Insurance plans are prohibited from imposing lifetime caps on coverage and Annual limits are being phased out. For plan years that began September 23, 2010 and later, the annual limit cannot be below \$750,000. The minimum limit will be raised to \$1.25 million in September 2011, and \$2 million in September 2012.

My family and I had the opportunity to meet with the offices of Senator Mary Landrieu, Senator David Vitter and Congressman Bill Cassidy. Our discussions centered around several issues. One issue was to inform the members about federal hemophilia programs and how they are funded. There are two federal programs that provide funding to the HTC's: one at the Maternal and Child Health Bureau, which funds coordination of care services that are critical to managing the high costs of the disease. The other program is at the CDC; it funds prevention and blood safety programs. We asked the Member to oppose cuts to the Maternal and Child Health programs and the CDC in 2011 and asked that funding be maintained in 2012! We were not asking for an increase, but only to maintain the funding. Secondly, we asked their support to maintain the private insurance reforms included in the Affordable Care Act, which allow individuals with high-cost conditions, such as hemophilia, access to adequate and affordable coverage.

The boys really enjoyed the experience and have taken an interest in advocacy by sharing a report with their classes and teachers. Walking the long halls of the capitol can be exciting as well as exhausting. Our last appointment of the day with Congressman Bill Cassidy proved to be just too much for our little Madden, as he fell asleep on the Congressman's couch. After leaving Madden looked up at Morgan and I with hope in his eyes and said, "one day I want to work in D.C. so I can help all of the people with hemophilia." Morgan looked at him and proudly responded by saying, "Madden, by coming here you already have."

To get involved with the Advocacy committee please contact the office so your voice can be heard!

Sincerely,
Tres Major
Louisiana Hemophilia Foundation
Advocacy Chair

Each year LHF sponsors people to attend this program



The Major Family
at Capitol Hill.

Families from all across our nation came to participate in the Washington Days program. For more information, visit NHF website at www.hemophilia.org.



ALL AGES
ALL RACES
ONE BLOOD



2011 EVENT SPONSOR



Skeet Shoot "Shoot for a Cure"

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Industrial
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Contractors



Hydro Electric
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- Atlantic Scaffolding
- ~Owen's Collision

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Research Update

Red Cross Bans Blood Donations

from CFS Patients

The American Red Cross (ARC) announced on its website December 3, 2010, that it won't accept blood donations from individuals with chronic fatigue syndrome (CFS). It maintains that donor deferrals are necessary in light of a possible, though yet to be established, link between CFS and xenotropic murine leukemia virus-related virus (XMRV).

According to the Centers for Disease Control and Prevention, XMRV is thought to infect many types of human cells, including some types of blood cells. If it is transmissible through blood donations, it could possibly present a threat to blood safety. In addition, a potential link between XMRV and CFS in humans was not reported by researchers in a 2009 study published in *Science*. The report showed that XMRV was found in approximately two-thirds of CFS patients. However, other studies showed an absence of XMRV in individuals with CFS.

The National Heart, Lung and Blood Institute Task Force is conducting research to determine the frequency of the virus in the donor population, whether it is transmitted via blood transfusion, and if recipients can become infected and develop the disease. Further, the AABB (*formerly the American Association of Blood Banks*) Interorganizational Task Force is reviewing data, assessing the risk of transfusion-induced infection by XMRV and providing information to the public. In addition, AABB is recommending that blood-collecting organizations use donor education materials to discourage CFS patients from donating.

In the meantime, ARC is erring on the side of caution. "At present, there are no specific federal recommendations regarding deferral of individuals with CFS or other diseases that have been diagnosed with CFS," read part of the statement. Currently there is no cure for CFS and there are no drugs to treat it.



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Sources: (article provided by NHF) Bloomberg news (online), December 4, 2010 and ARC press release dated December 3, 2010

Research News

DNA Affects VWD Testing in African Americans

Researchers from the Medical College of Wisconsin (MCW) in Milwaukee and several other institutions published a study in the July issue of *Blood*, the journal of the American Society of Hematology, suggesting a DNA-based explanation for discrepancies found in certain lab tests that help diagnose von Willebrand disease (VWD) in African Americans.

The lead author of the study was Veronica Flood, MD, pediatric hematologist/oncologist and assistant professor, Division of Hematology/Oncology, Department of Pediatrics, MCW. Flood's research was funded, in part, through a Career Development Award from the National Hemophilia Foundation.

VWD and its subtypes are characterized by either quantitative defects (decreased amount) or qualitative defects (abnormal structure or function) in von Willebrand factor (VWF). Bleeding symptoms can be mild, moderate, or severe, depending on the type. Types I and III

result from quantitative defects—either partial VWF production or a lack of it while type II and its subtypes result from dysfunctional VWF. A patient history of bleeding symptoms, plus the presence of measuring VWF quantity and function can confirm the diagnosis.

VWF ristocetin cofactor activity (VWF:RCo) is a relatively simple lab test in which blood cells are separated from a patient's plasma (liquid component of blood). Ristocetin, an antibiotic that prompts the binding of VWF and platelets, is then added to the plasma. Blood with viable VWF will clot, blood without it will not. Researchers have found in this and prior studies that African Americans often exhibit a poorer ristocetin-induced platelet aggregation, while showing higher levels of VWF, measure by the VWF antigen (VWF:Ag) test, which indicates the quantity of VWF in the blood.

Investigators used data from the TS Zimmerman Program for the Molecular and Clinical Biology of VWD (ZPMCB-VWD), a large multicenter study on patients



with VWD. Citing the ZPMCB-VWD data, the authors explain that this discrepancy in the VWF:RCo/VWF:Ag ratio, which is sequence known as single nucleotide polymorphisms (SNP). The SNP in this instance is triggered by an amino acid substitution in the "D1472H" location in the DNA sequence.

These contradictory results could cause problems for patients. "Reliance on this ristocetin cofactor activity assay, however, may be a source of diagnostic error in certain patients, especially those possessing SNPs that directly affect ristocetin's interactions with VWF. In addition, the presence of D1472H may affect ristocetin-induced platelet aggregation and could be a source of diagnostic error in platelet function testing. It is important to consider each patient's bleeding history, taking into account historical challenges and family history, as indiscriminate VWF testing may result in erroneous diagnosis and treatment," concluded the authors.



Source: Article provided by NHF, The Study, "Common VWF Exon 28 Polymorphisms in African Americans Affecting the VWF Activity Assay by Ristocetin Cofactor," was published in the July 2010 issue of *Blood*



You cannot become a great person unless you are also a good person.

Great people respond generously to their instincts to do good.

Scholarships & Recipients

The *Huey and Angelina Wilson Foundation* along with the *Louisiana Hemophilia Foundation* and The *Scott G. Fisackerly Memorial Scholarship*, offers to extend a helping hand to those with bleeding disorders who seek to further their education.

Traditional Scholarship

~ Huey and Angelina Wilson Foundation (HAWF)
 ~ \$1000 awarded twice a year
 ~ *Requirements: attend a four year college in Louisiana, Louisiana residents only, be a student TOPS qualified, and have a bleeding disorder.*

Traditional Scholarship

~ Scott G. Fisackerly Memorial Scholarship (SGFMS)
 ~ Louisiana Hemophilia Foundation (LHF)
 ~ \$500 awarded twice a year
 ~ *Requirements: attend a technical school, community or 4 year college in or out of state, Louisiana residents only, be student of any age and have a bleeding disorder*

Non-Traditional Scholarship

~ Huey and Angelina Wilson Foundation (HAWF)
 ~ \$1000 awarded twice a year
 ~ *Requirements: attend a four year college in Louisiana, Louisiana residents only, be over 21, have a bleeding disorder or be the parent of a person with a bleeding disorder*

LHF sincerely hopes that all who are eligible will take advantage of these exceptional opportunities. Education opens the door to increased options for living life to the fullest in the 21st century. Please let us help you open these doors by awarding these scholarships to you. The funds are waiting for **YOU** to use them to learn and acquire additional skills. For a complete listing of available scholarships not only for the person with the bleeding disorder but also for immediate family members visit www.hemophilia.org. The list below shows our current scholarship recipients.

NAME	AGE	ISSUER	TYPE	HOMETOWN	FIELD	SCHOOL
<i>Aaron Yates</i>	26	<i>HAWF</i>	<i>Non-Traditional</i>	<i>Denham Springs</i>	<i>Toxicology</i>	<i>University of Louisiana at Monroe</i>
<i>Adam Haydel</i>	28	<i>SGFMS</i>	<i>Traditional</i>	<i>Plain Dealing</i>	<i>Biblical Studies</i>	<i>Oval Bible College</i>
<i>Adam Mier</i>	20	<i>HAWF</i>	<i>Traditional</i>	<i>Lafayette</i>	<i>Biological Science</i>	<i>Louisiana State University</i>
<i>Brandon Vining</i>	21	<i>LHF</i>	<i>Traditional</i>	<i>Morgan City</i>	<i>Drafting</i>	<i>La Technical College</i>
<i>Brennon Russell</i>	20	<i>HAWF</i>	<i>Traditional</i>	<i>Oscar</i>	<i>Business</i>	<i>Louisiana College</i>
<i>Christopher Boyer</i>	23	<i>HAWF</i>	<i>Traditional</i>	<i>Belle Chasse</i>	<i>Mechanical Engineer</i>	<i>University of New Orleans</i>
<i>Jacob Allen</i>	22	<i>HAWF</i>	<i>Traditional</i>	<i>Houma</i>	<i>Chemical Engineer</i>	<i>Louisiana State University</i>
<i>Jared Dier</i>	22	<i>HAWF</i>	<i>Traditional</i>	<i>Franklinton</i>	<i>Kinesiology</i>	<i>Louisiana State University</i>
<i>Kimberly Dupre</i>	22	<i>LHF</i>	<i>Traditional</i>	<i>Gray</i>	<i>Nursing (RN)</i>	<i>Fletcher Technical</i>
<i>Tyler Brown</i>	21	<i>HAWF</i>	<i>Traditional</i>	<i>Denham Springs</i>	<i>Physical Therapy</i>	<i>University of Louisiana at Monroe</i>

**Each recipient receives a complementary LHF membership.*

*** All scholarship programs require 8 service hours after being awarded scholarship in order to reapply.*

Arrangements must be made with the Executive Director in advance , who will schedule service hours conveniently.



One Step Further... Addressing the 21st Century

The 36th Annual Meeting and Educational Symposium is being held at the Embassy Suites Hotel in Baton Rouge. Check in is Friday, June 10th, the sessions are Saturday, June 11, and check-out is Sunday, June 12th.

We took your comments and suggestions from the 2010 survey very seriously. Therefore, we incorporated the suggested changes into the 2011 schedule. For example, instead of five general speakers before the late afternoon break-out sessions we will only have four. Two will speak in the morning, followed by lunch, and two will speak the afternoon. Next we'll pull for door prizes and then head over to break-out sessions and afternoon refreshments.

In the meantime the 6 to 12 year olds will be away at a movie and pizza day and the teens will be on a special field trip for the day. Of course, the little ones will be safe and sound with the day care staff at the hotel.

Hotel rooms for 2 nights, all of the meals, and the youth and teen programs are **PROVIDED AT NOT COST TO YOU**. Your only cost to attend the weekend meeting is the registration fee. **Please save the dates on your calendar and sign up today.**

Upcoming Events... Sign Up Today!

Zoo Snooze

Sponsored by Hemophilia Preferred Care on Saturday, May 7th at the Baton Rouge Zoo. Only 20 children can attend, so be sure to reserve your child's spot today by completing and sending the sign-up form in this newsletter.

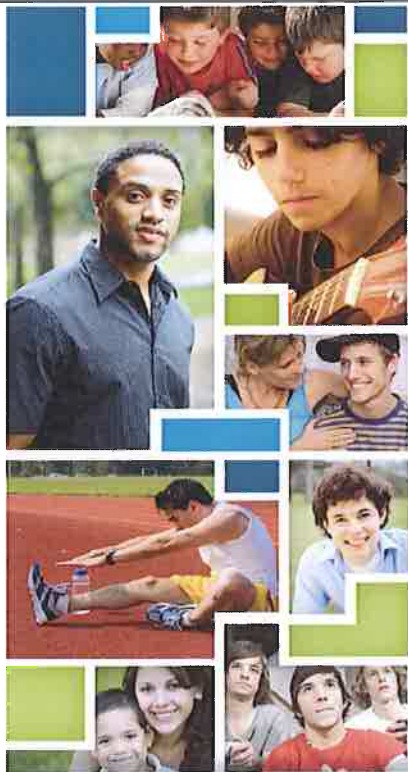
Crawfish Boil

Sponsored by AxelaCare and Bayer on Saturday, May 14th at the Baton Rouge Zoo. Like last year, all attendees will receive entry into the zoo for the day. After the crawfish boil has ended you are free to tour at your own leisure.

Summer Camp

Camp is being held in Monroe, LA and begins Sunday, July 10 and ends Friday, July 15. All transportation is provided and there is no charge for camp to the families of the attendees. If your child has a bleeding disorder, is between the age of 6 and 16, and wants to attend, please fill out the camp interest form. Send it back in the envelope we have provided in this newsletter. Once this form is received, the actual camp application and forms will be sent to you.

Please save the dates on your calendar and sign up today.



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Through Therapies

Over the years, Baxter has introduced a variety of innovative therapies in response to your search for hemophilia treatment options. Unique therapies such as ADVATE [Antihemophilic Factor(Recombinant), Plasma/Albumin-Free Method], the first factor VIII therapy free of blood-based additives, Highlight our commitment to choice. They also illuminate our investment in research and development.

Through Participation

In listening to your request for education programs, we've developed a range of initiatives for patients, families, physicians, and nurses. Baxter is also committed to supporting local and national organizations, community events, and volunteering.

Please see following page for Brief Summary.

Through Progress

Looking to the future, Baxter is dedicated to improving current therapies, including simplifying infusions and improving packaging for easier handling and traveling. We will continue to invest in research to offer new and better ways to manage hemophilia A- innovations inspired by listening to you.

ADVATE is indicated in hemophilia A (classical hemophilia) for the prevention and control of bleeding episodes. ADVATE is also indicated in the perioperative management of patients with hemophilia A. ADVATE is not indicated for the treatment of von Willebrand's disease.

Important Safety Information

There is a possibility that you can have an allergic reaction to ADVATE. Symptoms of an allergic reaction may include rash, hives, itching, tightness in throat or chest, difficulty breathing, or feeling dizzy, light-headed or weak pulse. If you experience any of these symptoms, stop the infusion immediately and promptly contact your doctor. Let your doctor know if you have had any previous allergic reactions to other factor VIII products or mouse or hamster proteins. The most common related Adverse Reactions observed during the ADVATE clinical studies include: strange taste in mouth, headache, dizziness, and flushing. The formation of inhibitors has been observed with all Factor VIII products including ADVATE. Contact your doctor if you are not able to prevent or control bleeding episodes with your regular doses of prescribed Factor VIII therapy.



COMMUNITY PROGRAMS

Patient & Community Educational Programs
Facts First, Camp Superfly, Knights' Crossing, Careers, Education & Opportunities (CEO) and more.



INSURANCE & ADVOCACY

Assistance, Support, & Information
Factor Award, grants for advocacy, training and advocacy projects, and a toll free assistance hotline 1 888 BAXTER9



CLINICAL INITIATIVES

Support of Medical Education & Clinical Training Programs
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"Regret nothing, but learn from everything."

~ Jason P. Duronslet

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In Loving Memory

~ let us so live that when we come to die, even the undertaker will be sorry. ~

Mark Twain

by: Garland & Bernell Cade
In Memory of
Tom Dutsch

by: Sharen Haddad
In Memory of
Brad Cross

by: Sharen Haddad
In Memory of
Paul Stewart

by: Darrell D. Jones
Deborah Mack
In Memory of
Janice Raybourn

Merry Christmas
Edgar Guedry
Donations by:
Sydney Guedry, Linda Guedry,
Jaunita Guedry,
Richard & Judy Dudenhefer,
Dr. Sydney J. Guedry Jr.

* Edgar asked for his Christmas gifts be donations to LHF

In Memory of
Marrietta Ware
Huey Wilson
Patricia Ricou
Charlene Rhodes

Donations by:
Leo Dixon
Brady & Jennifer Purpera
Trust Altruism
Hospice Associates
of New Orleans

Phil Blomquist of
Lone Star Chapter of NHF, Houston, Tx.

SYMPOSIUM



Register Online at www.hemophiliafed.org or call 1.800.230.9797.

A warm welcome awaits you this spring in Louisville, Kentucky – host city of the Hemophilia Federation of America's 2011 Educational Symposium. HFA cordially invites you to join us at Symposium – the community-centered program that annually brings together more than 400 community members, 100+ exhibitors, as well as speakers, staff and volunteers from nearly every state in the country. This year, HFA will award at least 100 scholarships to first time attendees. Visit the HFA website at www.hemophiliafed.org to apply today!

Hemophilia Federation of America (HFA) would like to announce their 2011 annual Symposium. This year's theme is entitled "Racing Ahead: A Community United" and is being held in Louisville, Kentucky from April 14 - 16.

LHF encourages first time attendees to apply to HFA for one of the 100 scholarships to attend.





Louisiana Hemophilia Foundation

ESTABLISHED IN
1976

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Web: www.lahemo.org



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Be an LHF partner by joining! Together we can strengthen our community.

The Louisiana Hemophilia Foundation was established in 1976 to help Louisiana residents with hemophilia, von Willebrand disease and other bleeding disorders lead normal and productive lives. While we support research for a cure to bleeding disorders and look forward to the cure, our families continue to need the services that we offer to increase the quality of their lives. Our programs are designed to meet the needs of the community.

Our mission is to improve the quality of life and assist persons affected by inherited bleeding disorders by providing education, advocacy, support services and by promoting research.

Member Level (check all that apply)

- \$10 Individual \$20 Family \$25 Supporting Member
- \$50 Supporting Family \$100 Century Club \$200 President's Club
- \$500 Benefactor Other \$ _____ Donation \$ _____

**Membership can also be done online over our secure network visit www.lahemo.org and click on the "Donations/Join" tab*

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**Payments are to be made out to The Louisiana Hemophilia Foundation or LHF*



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