

To:

### IMPORTANT INFORMATION:

The Louisiana Hemophilia Foundation  
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The material provided in Hemo-flo is for your general information only. LHF does not give medical advice or engage in the practice of medicine. LHF under no circumstances recommends particular treatment for specific individuals, and in all cases recommends that you consult your physician or treatment center before pursuing any course of treatment.

The paid advertisements in this publication are not endorsements of products or services by the Louisiana Hemophilia Foundation. These advertisers are NEVER provided with information about LHF members and or its patients.

### 2006 - 2007 SAVE THE DATES

- Christmas Luncheon, December 9, 2006
- 8th Annual "Shoot for a Cure" March 3, 2007
- Diva Day--(Women's Pampering Day) - Late March
- 3rd Annual "Ride for a Cure" - Early April 2007
- Annual Crawfish Boil- Mid April 2007
- Zephyr's Game Day- Mid-May 2007
- Annual Meeting, June 22-24, 2007- Location TBD
- Summer Camp, Sunday, July 22 - Friday, July 27, 2007

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Louisiana Hemophilia Foundation

Fall 2006

## NEWS

### State Factor Program Experiencing Changes

The State Factor Program is undergoing changes for the uninsured. The next meeting of the Advisory Board is in Mid-November. LHF Representatives will be in attendance and will provide more information as it is available. In the meantime, if you have questions or concerns, please call us at **1-800-749-1680** or contact the Hemophilia Treatment Center at **504-988-5433**

### LHF Receives National Award from NHF

LHF was recognized with a "Special Recognition" Award and \$1000 for its efforts in hurricane relief by the National Hemophilia Foundation at the 58th NHF Annual Meeting in Philadelphia, Pennsylvania. Many thanks to all that made this relief effort possible.

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



WE ARE A CAPITAL AREA  
UNITED WAY AGENCY

### LHF Celebrated 30 Years at the Annual Meeting

This year's Annual Meeting and Symposium was a blast from the past since we were celebrating 30 years of service to the community. The theme party went 70's.

*See page 8 & 9 to learn more*

### Camp Wounded Knee News

Camp Wounded Knee will be moving to Monroe in 2007. Camp will be held from Sunday, July 22 to Friday, July 27, 2007. More information to follow soon.

*See 2006 camp pictures page 10*

### It's time to reserve your Poinsettias

If you haven't bought poinsettias from LHF for Christmas, you are really missing out. We get our poinsettias from Broussards Nursery in Lafayette. They are big, beautiful and rich in color!

*See page 3 to learn more*



### Shonda Joshua What a Pleasant Surprise!

One day a woman came into the LHF office who we had never met before.

Shonda Joshua told us that her 4 year old son, Michael, had just been diagnosed with hemophilia.

To our pleasant surprise she asked what she could do to help the Louisiana Hemophilia Foundation.

She called to see what we needed help with and arrived, rolled her sleeves up and did what ever needed done.

Shonda is now on our Board as Secretary. She even suggested that we have an Outreach group to help newly diagnosed families. She now chairs the Outreach Group. Please contact LHF if you would like to join Shonda in this effort.

So who is Shonda and what makes her tick?

*See page 4 to learn more about Shonda and Michael.*

**Assistance Needed in Future:**  
We would like to begin an advocacy campaign to make the Medicaid program match the Medicare program for factor product while a patient is hospitalized. Please watch for details.



Back L to R:  
Clara Batiste; Diana Smith; Tres Major; Kim Yates; and Libby Fisackerly.

Middle L to R:  
Debra Parker; Donna LeBrun; and Lori Keels, Executive Director.

Front L to R:  
Susie Chiasson, Administrative Assistant and David Reynaud.

Not Pictured: Dan Jones, Shonda Joshua, Nathan Mouton, Millisa Shell, Polly Williams, Huey Wilson, and Karen Wulff.

**2006-07 BOARD OF DIRECTORS**  
**LOUISIANA HEMOPHILIA FOUNDATION**  
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 David Reynaud, Vice President Litcher  
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 Polly Williams, Lagniappe Ladies Baton Rouge  
 Huey Wilson, Co-Founder Baton Rouge  
 Karen Wulff, RN New Orleans

**LOUISIANA HEMOPHILIA FOUNDATION BOARD OF DIRECTORS**  
**2006-2007 MEETING SCHEDULE**

WBR Conf. Center	Saturday, December 9	9:00 AM
LHF Office	Saturday, February 24	9:00 AM
LHF Office	Saturday, April 21	9:00 AM
LHF Office	Saturday, June 23	9:00 AM

*Executive Board Conference Calls will be scheduled as needed.*  
**Please RSVP if you are a paid member and would like to attend the Full Board Meeting.**

**Medical Advisory #405: Novo Nordisk Issues Missing Product Alert**

May 30, 2006  
 Novo Nordisk was recently notified that a shipment of NovoSeven Coagulation Factor VIIa (Recombinant) 1.2-mg vials is missing from a storage facility that receives imported product. The missing material had not entered the Novo Nordisk Inc. warehousing and distribution network.

The Identification of the missing product is as follows:  
 Product: NovoSeven Coagulation Factor VIIa (Recombinant) 1.2-mg vials  
 NDC: 0169-7060-01  
 Lot Number: SU60608

There is no indication that this material entered any distribution channel, but we are alerting customers in the event that they receive this product from outside Novo Nordisk distribution channels.

Because this product was not processed through Novo Nordisk's distribution channels, we cannot guarantee that the material has been maintained at the proper storage conditions. When NovoSeven is not stored within the proper refrigerated temperatures (2-8C/36-46 F), there may be a loss of potency over time and the product should not be administered to patients.

Therefore, these vials should not be used or distributed by any patient, healthcare professional or distribution partner. If you are in possession of any of these vials, please contact Novo Nordisk immediately at (609) 987-5999.

Please note that we do not anticipate any interruption in the availability of NovoSeven.

**In Memory Donations:**

From Darrell D. Jones in memory of:  
 Sidney Lee Barber  
 Clara Broussard  
 Paul Masigale  
 Phillip Templett

From Agnes Henley in memory of:  
 Ann Frazier

From Deborah Mack in memory of:  
 Sid Barber

**Donations from:**  
 Lagniappe Ladies  
 Harley McKinney  
 Valero Energy

**Our Sincere Thanks To:**  
 All the people who have helped in this past year, in so many ways. Your help is vital to the success of LHF in carrying out its mission.

**Louisiana Hemophilia Foundation Membership/Donation Form**

\_\_\_\_\_  
 Name

\_\_\_\_\_  
 Mailing Address

\_\_\_\_\_  
 City, State, Zip

(\_\_\_\_) \_\_\_\_\_  
 Phone

\_\_\_\_\_  
 E-mail address

( ) Visa/Mastercard

\_\_\_\_\_  
 Credit Card Number

\_\_\_\_\_  
 Exp Date

- ( ) Individual Member \$10.00
- ( ) Family \$20.00
- ( ) Supporting Member \$25.00
- ( ) Supporting Family \$50.00
- ( ) Century Club \$100.00
- ( ) President's Club \$200.00
- ( ) Benefactor \$500.00
- ( ) Other \$\_\_\_\_\_
- ( ) Donation in honor of, for birthday, for graduation, or in memory of

Please make your check payable to:  
**Louisiana Hemophilia Foundation**  
 mail to LHF, or fax your form and credit card info to 225-291-1679



The 9th Annual "Swing For A Cure" Golf Tournament was held on October 30, 2006 at the Sherwood Forest Country Club in Baton Rouge. Once again this event was a great success due to Joe Major's leadership and the involvement and dedication of the volunteers on the committee and the day of the event. The annual golf tournament is critical in raising funding to support the programs and services that are provided to this community by LHF. Please plan to assist us at our 10th Annual tournament in October of 2007. If you would like to know more about the event or how you can help next time please call us at 1-800-749-1680.

Our 8th Annual "Shoot for a Cure" is being held on March 3, 2007 at Hunter's Run in Port Allen so round up your shot gun and your friends and head on out to have a good time, fine food and door prizes. If shooting skeet doesn't suit you don't worry you can ride your motorcycle, or get your friends to ride their motorcycles in the 3rd Annual "Ride for a Cure" in New Llano (and into Texas) in 2nd week of April 2007.

We work hard to provide opportunities for everyone to get involved with LHF and between the golf tournament, skeet shoot, motorcycle ride, and poinsettia sale I think we've got everyone covered.

### SevenSECURE

#### Medical Grants

If you are experiencing serious financial problem and/or your insurance does not cover all of the services you need, you may qualify for financial assistance to help pay for certain healthcare costs. SevenSecure provides support through PSI, which offers medical grants to assist with the following:

- Outpatient medical evaluation or treatment (clinic appointments, clinical trial evaluation, etc.)
- Travel costs
- Overnight accommodations
- Child Care
- Attendance at medical or support meetings
- Short term prescription assistance (non copayment)
- Noncovered expenses to see a doctor or dentist for evaluation
- Medical aids and devices

#### Edu-Grant and Scholarships

Edu-Grants are financial awards to help pay for tutors or learning assistance when students (K-12) miss a significant number of school days due to hemophilia. These awards help people with inhibitors who bleed frequently to stay on top of their studies.

SevenSECURE also provides scholarships for vocational school, college, or graduate school. The scholarships are named in honor of Professor Ulla Hedner of Denmark, who pioneered the development of NovoSeven. For adults who would like to further their studies, SevenSECURE offers nontraditional educational grant as well.

- Edu-Grants: up to \$500 per person per year
- Professor Ulla Hedner Scholarships: up to \$7000 per person per year
- Nontraditional Grants: up to \$500 per person



**For More Info: Contact NovoSeven at 1-877-NOVO-777**

## What's Kicking



Just think. Since January of 2006 we've held our 7th Annual "Shoot for a Cure" Skeet Shoot-- which was outstanding. In fact we doubled the number of teams and the net income of the event. Our 2nd Annual "Ride for a Cure" was held in New Llano in April of 2006 and it was fantastic. In June we held our 28th year of Camp Wounded Knee Summer Camp in Jackson, LA and our 30th Annual Meeting and Educational Symposium in Port Allen, LA. Both were very successful. Additionally we hosted many PALS Events which are regional events designed to bring families together for networking and educational opportunities. Events such as the Annual Crawfish Boil were sponsored by Baxter and Factor Health Management. A night with the Zephyr's was sponsored by Factor Health Management. A Family BBQ was sponsored by Wyeth and Hemophilia Health Services. Dinner at the Blue Dog Cafe in Lafayette and Dinner at Mike Anderson's was sponsored by Baxter.

Additionally, we have continued to provide all of our usual services: access to medical care including transportation, meals, gasoline reimbursement, and lodging; Medic Alert Bracelets to ensure that the emergency medical personnel understand the patients needs; sponsorship to national educational meetings; college scholarships; case by case financial assistance; educational materials; and we even threw in hurricane relief services and supplies to support people affected by hurricanes Katrina and Rita. If I could choose a few words to describe the foundation activities and events since our last newsletter I'd say grand, commanding, famed, celebrated, noted, elevated, superb and magnificent!



Just around the corner is our Annual Poinsettia Sale. We get our plants from Broussard's and they are just gorgeous. Every year someone will see us delivering them and ask if they can place an order as they had not realized that poinsettias could be so pretty. Please don't miss this opportunity to place your order for your businesses or family holiday celebration or family celebration. Please "talk it up" with your friends and neighbors as well. You can help them get ready for the holidays and help us raise funding for a good cause.

Speaking of the holidays. Our Annual Christmas luncheon will be held on Saturday, December 9, 2006 at the West Baton Rouge Conference Center in Port Allen, LA. and is sponsored by Novo Nordisk. As always Santa will be visiting the youngsters (through age 12) and his elves need to get started. Please complete your RSVP form that is included with the invitation in this newsletter and send it

## From The Director

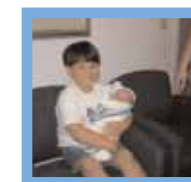
back immediately. Santa needs time to get ready for the kids.

Camp Wounded Knee will be moving to West Monroe in 2007. As always, the camp is provided free of charge including transportation to and from camp to anyone (male or female) with a bleeding disorder between the ages of 6 and 14. There will be much to do and see there and a great time to be had by all. The camp dates are set for Sunday, July 22 through Friday, July 27th so please save the date by marking your calendar now. More information about the location and specific activities will be provided in the next few months.

As you know all of the above events and programs take the dedication of volunteers and staff. I just want to be sure that you also remember that our Board of Directors is involved in managing our foundation on a regular basis as well. In fact, they meet every other month on a Saturday for several hours and participate in on committees and are involved in conference calls as needed. Some of them have a long drive and leave very early in the morning in order to participate. Next time you see one of our Board members be sure and take some time to thank them for their hard work. If not for Libby Fisackerly and Huey Wilson, thirty years ago, and a strong Board of Directors ever since LHF would not exist today to serve the bleeding disorder community.

Be sure and read up on our fundraising events on page 14. These events are critical to LHF as they enable us to provide the programs and services that are guided by our mission statement. A lot of people think they can not contribute because they don't know anything about golf, or skeet shooting or poinsettia sales. You'd be surprised at how much you can do and how satisfied you will feel because you took the time to help us make a difference. I look forward to working with you in the future and to seeing you at the fantastic events that are held through out the year.

I would be remiss to not mention the birth of a new baby. Colby Nathaniel was born on July 5, 2006 to Donna and Carl LeBrun and big brother Bailey. Donna is a Board member and active volunteer.





Well my son has Hemophilia. I look at it as something he will die with and not of, especially after being in the waiting area of St. Jude's affiliate office after we relocated to Louisiana. I have learned through whatever situation to look and depend only on God. He will place the right people on your path.

LHF has introduced me to resources that I may not have been afforded otherwise. I really appreciate LHF and the individuals involved.

I have learned that regardless of your background and what you may deem important, there are some things we cannot control.

So what do you do when you have done all that you can - You just stand! Worrying is only negative energy going towards a situation that you obviously cannot control. Guess what, if you could change it I promise that you would. To everything there is a season and when it is time for the lemons to fall from the tree of life, you take them and make lemonade (even though we are the ones being squeezed).

If I just continue to let go and let God while I bloom where He plants me, I will grow to my potential. My mother always said that as circumstances change, we change. As my responsibilities changed so have my priorities.

God gave me my son and I love him dearly. However, my assignment is to raise him in a manner which is pleasing to God. His bleeding disorder is what it is and nothing will change that, but as a mother I would like to help him to see that it is not a death sentence

as much as it is an opportunity to constantly live beating an odd.

Another thing my mother instilled in me was that nothing good comes easy. If it seems too good leave it alone because as a child of God trials and tribulations will come just like weapons may form, but rest assure they do not have to prosper.

### Welcome to LHF Shonda!

Shonda comes to us with great credentials. She has two degrees, but her focus is on Micheal and her family. While carrying Michael she had to be put on bed rest. She studied for finals in the hospital.

Michael was born on January 5, 2001 and Shonda got her Masters later that year, in November. She put her career on hold to become a stay at home mom. She has a:

Bachelor of Science in Chemistry  
Xavier University  
New Orleans, LA

Master in Business Administration  
Amberton College  
Dallas, Tx



*Shonda and her family at a recent event. Family is very important!*

## LAGINAPPE --- a little extra

### Feedback From The NHF Annual Meeting: New Outreach Committee Being Formed

#### Francie and Lane:

I would like to thank LHF for allowing Lane and I the opportunity to attend this years NHF meeting in Philadelphia on scholarship. We both enjoyed being able to learn more about Lane's hemophilia and also enjoyed meeting and talking with other families. I would strongly suggest that everyone attend an NHF meeting. We are already planning to attend the 2007 NHF meeting in Orlando, Florida.

#### Tres Major

Informative, thorough and well organized!


#### Debra Parker

I learned so much about women with bleeding disorders and gained an appreciation for their roles in the lives of their family. I will put my new found knowledge to work for LHF and the community by chairing a "Diva Day" program for Women in Spring of 2007. Many thanks to LHF and to NHF for this opportunity.

Shonda Joshua has agreed to chair a committee that will provide information about LHF and its services to local providers, including hospitals around the state. This information can then be provided to patients with bleeding disorders as they are seen at the facility.

Additionally, volunteers will be trained and provided with a packet of information that can be taken to the family while in the hospital (if they consent to the visit).

The idea is to let the families know that LHF and its families are here to assist them. As time goes on we hope that the family will continue to stay in touch with LHF and attend programs that we provide and utilize the services that we offer to the community. Volunteers are needed from all over the state to assist in this endeavor. The conference call system will be used in order to make getting together more convenient to all. If you would like to part of this outreach committee, or learn more about this committee please contact us at 800-749-1680.



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1-866-322-3461, extension 364

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To find out more about the new BAXJECT II, or about BAXJECT II preview events in your area, log on to [www.baxject2.com](http://www.baxject2.com). Or call 1-866-4BIOSCI.

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As easy as

1-2-3



## BAXJECT II

### Needle-less Transfer Device

Rx only. For safe and proper use of this device, please refer to the Instructions For Use.

Reference: 1. Debuson, R. (2005). Baxter Health Care Corporation. Baxter and BAXJECT are registered trademarks of Baxter International, Inc. © Copyright © Baxter Health Care Corporation. All rights reserved. Printed in the U.S.A.

**Baxter**

## Scholarship Corner

**So you're thinking about going to college? Need to get the 411 on where to get some money? Then keep reading. We may have some options for you to help finance your college career.**

Because the Louisiana Hemophilia Foundation is committed to improving the quality of life of its patients we offer two different types of scholarships. One is to a four year college in Louisiana and requires TOPS qualification. The other is to any other type of school such as trade or vocational or a four-year school but does not require TOPS.

### Huey and Angelina Wilson Scholarship

\$1000 per semester  
Requires TOPS qualification  
(you must also submit proof of TOPS Qualification with your application)  
Must be attending a Louisiana 4 year college

Mr. and Mrs. Wilson are the benefactors of the Wilson Scholarship program through LHF because they believe it is important for everyone to have access to education to improve their quality of life.

### Louisiana Hemophilia Foundation Scholarship

\$500 per semester  
TOPS not required  
This is available for any trade, or vo-tech, or college  
The student can be of college age or someone that is going back to school or changing careers

### What is TOPS?

TOPS stands for Tuition Opportunity Program for Students and is a comprehensive program of state scholarships available through the state of Louisiana. The purpose of this program is to defray the cost of college and application can be made by contacting the Louisiana Office of Student Financial Assistance (LOFSA) 1-800-259-5626 Ext 102 or by going to [www.osfa.state.la.us](http://www.osfa.state.la.us).

### How do I apply for a Wilson or LHF Scholarship?

**For either type of scholarship one must:**

- Complete the application by the deadline (usually December 31st and June 1st)
- Submit essay if you are a first-time applicant
- Provide LHF with a copy of your most recent grade report and TOPS qualification if applying for Wilson scholarship
- Have a bleeding disorder
- Be a Louisiana resident

**Applications are available on-line at**

[www.louisianahemophilia.org](http://www.louisianahemophilia.org) or by calling the LHF office.

If approved by LHF payment will be made directly to the student or to the student's designee, thus allowing the student to cover expenses other than the direct tuition bill such as living expenses or text books. Application must be made in order to reapply as stated above each semester.

### Are there other types of scholarships available?

Yes. Please see the LHF website under "Scholarships." We are posting scholarship packets and information as we receive information about them. A search of the internet may also produce information of interest to you.

### When should I apply for a scholarship?

Each scholarship has its own deadline. Please be sure and meet deadline requirements in order to allow appropriate processing time.

For more information about these or other scholarships call **800-749-1680** or visit our web site at: [www.LouisianaHemophilia.org/Scholarships.htm](http://www.LouisianaHemophilia.org/Scholarships.htm)

### Who are our recipients for 2006-2007?

Jerrard Bourque  
Thomas Cleveland  
Jarrod Galloway  
Joseph Gavin Jobe  
Jason Lousteau  
Justin Scott  
Aaron Yates

**Congratulations!**  
**Keep up the good work!**

**If you are interested in applying for a scholarship please contact the LHF office at 800-749-1680.**

**Get your applications in for Spring 2007 by December 31, 2006!**



## Minneapolis, Minnesota

More than 130 people gathered in Minneapolis, MN, on April 28-29, 2006 for the NHF On the Road Meeting. Families from the Minneapolis/St. Paul area, along

with participants from NHF Chapters and Associations, and Hemophilia Treatment Centers from the Northeast, Southeast and Midwest, participated in the following sessions:

A presentation by the Louisiana Hemophilia Foundation and Louisiana Comprehensive Hemophilia Care Center, sharing stories and experiences about dealing with bleeding disorders during Hurricane Katrina.

Exercises for participants were presented within the same geographical regions to begin preliminary emergency preparedness planning.

A presentation was made on understanding some of the psychosocial barriers to emergency preparedness prevention and the impact of post-traumatic stress.



L to R: Dr. Cindy Leissing, Louisiana Comprehensive Hemophilia Care Center; Jennifer Crawford, National Hemophilia Foundation Education Department, Lynn Russell, LHF Graphic Designer; and Debra Parker, LHF Trustee. Dr. Lessinger, Lynn and Debra all presented on "Stories from the Bayou and Beyond." Sue DuTreil, Also from Louisiana Comprehensive Hemophilia Care Center presented as well. It was our hope that we could help other people around the country be better prepared for emergencies.



The 58th Annual Meeting for the National Hemophilia Foundation was held from October 12th - 14th in Philadelphia, PA. This year over 2000 people were in attendance from all over the country. Every year LHF sponsors a family to attend. This year the Rodrigue family was

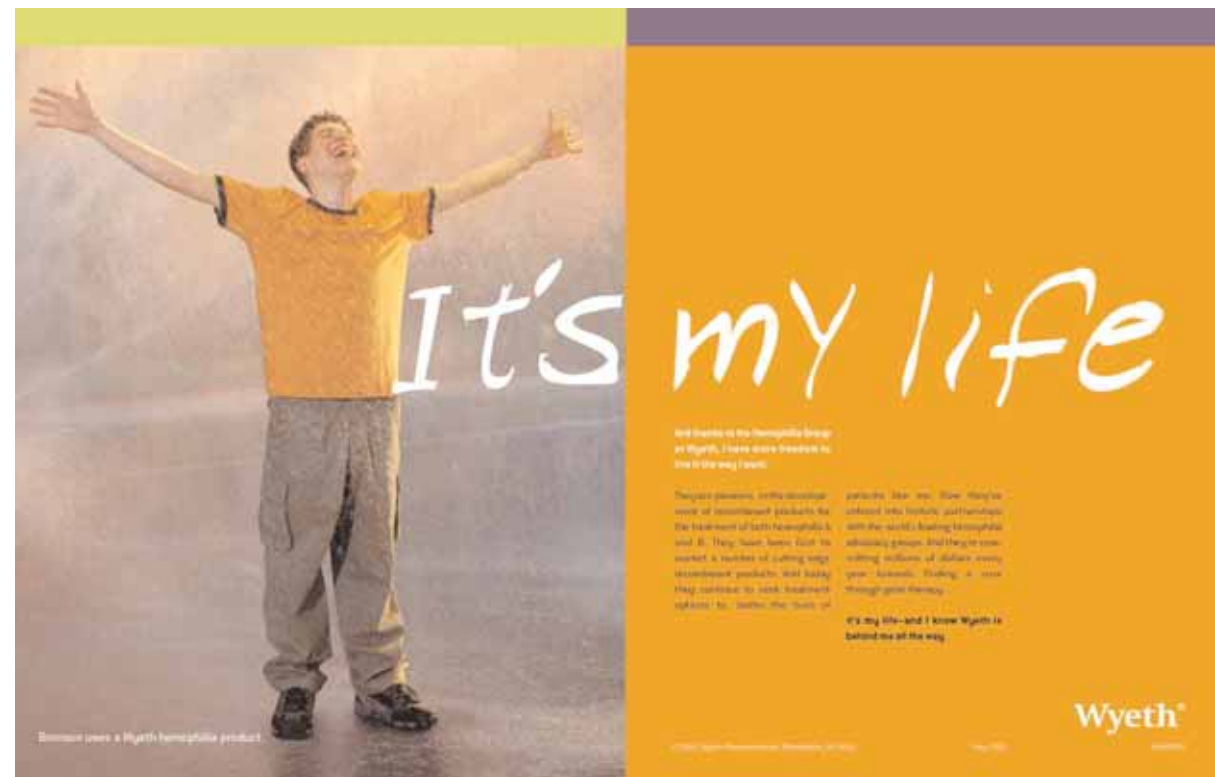
selected and attended. Also in attendance on behalf of LHF were Tres Major, Board President; Lori Keels, Executive Director; and Debra Parker, LHF Board Member and Volunteer for LHF. If you've never had the opportunity to attend a meeting of this caliber you really should think about attending the 59th Annual Meeting of NHF from Nov 1- Nov 3, 2007 in Orlando, Florida. LHF will sponsor a family so get your request into the office as soon as possible to the LHF Office.

As always these annual meetings give the attendees the opportunity to meet other families that have experienced similar issues and learn new information from professionals including medical doctors, social workers, physical therapists and many other specialties. There's something for everyone at these meetings. In fact, it's best to take a good look at the schedule before arriving at the meeting in order to plan your time to fit in all of the sessions that you really want to or need to attend. Just so you know, NHF uses the feedback it receives from the community to plan future meetings as well as the material presented at the meetings. So please continue to offer your ideas and feed back to them, or to us and we'll pass it on to NHF.

Now it's not all work and no play at the meetings. NHF along with the generous support of the meeting sponsors make it possible to enjoy a Friday night outing and a Saturday night gala with entertainment and food. The kids are having fun on both Friday and Saturday in the youth program which provides outings to neat places. This year the youth went to the Adventure Aquarium on Friday and the Academy of Natural Sciences on Saturday.

Many people and organizations were recognized for their work in the bleeding disorder community at the Awards Luncheon including LHF. To our surprise we were recognized for our work in offering relief to families during Katrina and Rita. Karen Wulff and Sue DuTreil were also recognized for their work during these times.

Many thanks go to the NHF Staff and the Chapter Staff Organization for once again offering a top notch meeting in a very nice city and to the Ann Rogers of the Delaware Valley Chapter for welcoming us to her city. We hope we left it as nice as we found it and that we didn't wear out our welcome.



Hosting Camp Wounded Knee is a labor of love and is expensive, yet the kids get so much out of it. A big thank you to everyone who helped make camp possible this year!

**Camp Sponsors:**

Baxter Healthcare  
Grifols  
Hemophilia Health Services  
Novo Nordisk  
Valero Energy

**Camp Co-Chairs:**

Donna LeBrun  
Penny Young



Carol Lizana- leading the way



**Camp Staff:**

Sue DuTreil- Social Worker  
Tally LaCasse- Transportation  
Marc Henderson- Camp Director  
Abbie Henderson- Assistant Director and Craft Director  
Allen Holliday- Lead Counselor  
Keith Riddle- Lead Counselor and "Techno Man"  
Tulane Medical Center- Residents program  
Harrietta Ware- Counselor  
Marrietta Ware- Counselor  
Karen Wulff- Nurse Coordinator

**Camp Volunteers:**

Rosa Carpenter- Transportation  
Anita Davies- Tulane Physical Therapist  
Terry Lamb- Horse Wrangler  
Donna LeBrun- Tie Dye Coordinator  
Carol Lizana- Director of Horse Program  
Anne Sibley - Transportation  
Markeith Wells- Transportation  
Betty Vidrine - Transportation  
Ellene Whitmore- Craft Assistant and Tie Dye Queen  
Counselors from Jesuit High, N.O.

**MEDIGAP ACCESS IMPROVEMENT ACT**

As you know the cost of medical treatment of bleeding disorders is very expensive. H.R. 6175, if passed, will ensure that Medicare insurance is available even if you are under the age of 65. We need your involvement to make sure this happens! A sample letter follows. Please use as your guide when contacting your representative. Feel free to tell your story and send pictures as well.

Sample Letter:

Dear \_\_\_\_\_:

The Medigap Access Improvement Act (H.R. 6175) recently introduced by Representatives Philip English (R-PA) and Bobby Rush (D- IL) would expand access to Medicare supplemental insurance, known as Medigap policies, for all Medicare beneficiaries with disabilities. As a constituent affected by a bleeding disorder, I am asking you to cosponsor this important legislation.

Many individuals with hemophilia and other bleeding disorders qualify for the important benefits Medicare provides because of

complications of their condition. However, the required treatments are very expensive, often costing \$100,000 a year and sometimes much more. Unfortunately, Medicare only covers 80% of these costs, leaving the rest for the patient to pay.

Currently, all Medicare recipients over the age of 65 can purchase Medigap policies during an open-enrollment period. However, only 24 states allow Medicare beneficiaries under the age of 65 with disabilities to access those policies. H.R. 6175 would correct this disparity by ensuring that the right to purchase Medigap supplemental insurance is provide to all people with disabilities on Medicare.

People with bleeding disorders and other chronic, high-cost conditions want and need this legislation. Please support us by cosponsoring H.R. 6175.

Sincerely,

To learn more about this initiative or how to locate contact information for your representative go to [www.hemophilia.org](http://www.hemophilia.org) or call LHF at 800-749-1680.



In your head, you want to protect him.



In your heart, you want him to go after his dreams.

We at Novo Nordisk are committed to supporting hemophilia patients with inhibitors and their families with cutting-edge research and recombinant treatments. Together, we'll let nothing inhibit their passion.

**For more information call**

**877-NOVO-777**



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# LHF Celebrated 30 Years of Service at Annual Meeting

## SPECIAL GUEST

Mr. Benjamin Shuldiner,  
New York City, NY  
Keynote Speaker

## SPECIAL PRESENTATIONS

By Tres Major, Board President and  
Lori Keels, Executive Director

Volunteer of the Year  
Carol Lizana

Excellence in Communications  
Lori Keels, Jr. Designer of the Year  
Brandy Landry  
Debra Parker  
Lynn Russell

Special Recognition  
Libby Fisackerly  
Huey Wilson

President's Awards  
David Reynaud  
Brooks Smith

## SPONSOR EXHIBITORS

### Pharmaceutical:

Baxter  
Stan Singley

Bayer  
Phil Despommier

Grifols  
Lesley LeMarie

Novo Nordisk  
Ellene Whitmore

Wyeth  
Dan Wolfe

ZLB Behring  
Hilary Meyer

### Home Health Agencies:

Coram  
Paul Wilson

Factor Health Management  
Joey Privat

Hemophilia Health Services  
Phyllis Wilkinson

New Life Homecare  
Annie Wade



Donna LeBrun, Susie Chiasson, Jina Dunnaway  
and Tres Major went back to the 70's for the  
Party! Where did they find that polyester?



Stan Singley, Baxter Healthcare

## SPEAKER SPONSORS

Baxter - Stan Singley  
Mary Kay Thrower

Factor Health Management - Joey Privat  
Eric Lowe

Hemophilia Health Services - Phyllis Wilkinson  
John Jarratt

Novo Nordisk - Ellene Whitmore  
Madeline Cantini



Joe Major, Morgan Major and Madden Major



Dance like  
it's 1976!



Ben Shuldiner, Keynote Speaker from New York

## SPECIAL SESSIONS

Teen Session  
Eric Lowe &  
Tom Cleveland

For Men Only  
John Jarratt

Inhibitors  
Madeline Cantini

Navigating the E.R.  
Mary Kay Thrower,  
Baxter Bioscience

Joint Health Care  
Mary Kay Thrower,  
Baxter Bioscience

## SPEAKERS

Madeline Cantini  
Thomas Cleveland  
John Jarratt  
Eric Lowe  
Debra Parker  
Lynn Russell  
Mary Kay Thrower

## INDIVIDUAL CONTRIBUTORS

Setting Goals - Teen Program  
Thomas Cleveland

Everyday Preparedness  
Debra Parker & Lynn Russell

Ben Shuldiner  
"Keynote Address"

## OTHER SUPPORT

ZLB Behring & Hilary Meyer  
"Photo Sponsor"