

HEADLINE NEWS

Focused on Today's Care, Tomorrow's Cure

Vol. XXXVII, No. 1 Winter, 2007

2006: A YEAR IN REVIEW

By Kathleen Roach

It is with great pride that Great Lakes Hemophilia Foundation (GLHF) looks back at 2006. This past year, GLHF stayed true to its strategic planning goals and focused on:

- 1) providing needed programs,
- 2) fund-raising efforts,
- 3) public relations in a number of venues,
- 4) advocacy on behalf of the bleeding disorder community and
- 5) assessing the expansion of the population we currently serve.

The year was busy with a number of exciting programs that GLHF and the WI Hemophilia Treatment Centers collaborated on including a program for newly diagnosed patients, a program for the Amish Community, a fitness and nutrition program and a program on joints and treatment. GLHF also continued to provide quality ongoing services and programs with the patient financial assistance program and educational scholarships, camperships and the annual Family ACCESS Weekend.

HELPING FAMILIES: Hemophilia is one of the most expensive chronic illnesses. Treatment can cost over \$200,000/year. In 2006, GLHF provided over \$42,000 in Patient Financial Assistance to cover uncovered medical bills, assist with health insurance premiums and meet basic living expenses of fifty-one families.

HELPING YOUTH: One of the most valuable programs for our youth is summer camp. It gives youth the opportunity to meet others facing similar challenges and

helps them learn important self-care skills, including self-infusion. In 2006, we sponsored 25 young people to attend camp.

INVESTING IN THE FUTURE: GLHF sponsors important programs to help individuals and families invest in their future. One such program, the Education and Training Scholarship program, strives to improve the quality of life for individuals with bleeding disorders through career advancement and improved vocational opportunities. In 2006, GLHF provided \$7,000 in scholarships to seven individuals.



Save the Date

Family Fun and Education Weekend
(formerly ACCESS)

June 23—24, 2007

Regency Suites and KI Convention Center
Green Bay, WI

Walk with the Animals

September 29, 2007

Milwaukee County Zoo

Sponsored by the Great Lakes Hemophilia Foundation
Registration required—watch your mail for
registration forms.

For more information call (414) 257-0200
or (888) 797-4543.

ENSURING ACCESS AND APPROPRIATE

TREATMENT: The Woman-to- Woman Project. GLHF continues to commit resources to this award winning program which focuses on women reaching out to other women informing them about bleeding disorders and how it can affect their lives. January through September 2006, Woman-to-Woman volunteers attended 22 health fairs and gave eight presentations to various groups to reach over 5,700 people.

REGIONAL CORE CENTER FOR REGION V-

WEST: During 2006, GLHF continued its commitment to the Federal Hemophilia program. GLHF serves as the region core center coordinating comprehensive services in five states-Wisconsin, Illinois, Minnesota, North and South Dakota. Through the program, the Foundation provides funds for 15 hemophilia treatment centers assuring the availability of comprehensive, coordinated state-of-the-art care and prevention services to individuals with bleeding disorders.

PROVIDING INFORMATION:

GLHF is dedicated to supporting the bleeding disorder community through updated information. The Foundation takes a leadership role in providing education and support programs for families affected by bleeding disorders. The 2006 ACCESS Conference held in Madison, WI attracted 28 families and over 120 individuals. GLHF also publishes quarterly the newsletter Headline News which is distributed to a readership of nearly 2,000 households.

As we look back, the success of our work could only happen with the dedicated volunteers that have generously given their time and resources throughout the year. As we look forward to 2007, we hope to build on these important programs and introduce new programs to improve the quality of life and health of the Wisconsin bleeding disorder community. GLHF will continue to improve Today's Care, while seeking Tomorrow's Cure.

Together, we can make a difference.

**Bleeding Disorders
Treatment Centers in
Wisconsin Provide
the Best Care for You and
Your Family**

Green Bay

Hemophilia Outreach Centre
1794 East Allouez Avenue
Green Bay, WI 54311
920-965-0606
800-992-6026

La Crosse

Gunderson Clinic
1836 South Avenue
La Crosse, WI 54601
608-782-7300 ext. 2905

Madison

University of Wisconsin Hospital and Clinics
(UWHC)
Comprehensive Program for Bleeding Disorders
2704 Marshall Court
Madison, WI 53705
608-890-9493

Milwaukee

Comprehensive Center for Bleeding Disorders
8739 Watertown Plank Road, P.O. Box 2178
Milwaukee, WI 53201-2178
414-257-2424
800-312-2223

REMEMBER

The Great Lakes Hemophilia Foundation is a benefiting agency of the **WE CARE** program through Pick 'n Save. When you sign-up for your 2006 Advantage Card, please remember to include GLHF's six-digit identification number – 293550. Every penny helps!

Learning to Recognize a Head Bleed

By Mary Anne Schall

Adapted from the article [Uncommon Bleeds](#), Hemalog, 7-99.

In all age groups, head bleeds accounts for the majority of deaths among persons with hemophilia. While a joint bleed is unmistakable, often beginning as an area of warmth and tingling and then moving on to swelling and discoloration, head bleeds can be more difficult to detect. Their symptoms may seem fairly ordinary - perhaps a headache, or sleepiness and irritability. Yet these seemingly mundane situations can signal a bleed that is dangerous and sometime life threatening.

What are the signs of a head bleed?

Early identification and treatment of a head bleed is critical. Left untreated, a head or intracranial bleed can cause a build-up of blood that may lead to brain damage or even death. While some of the warning signals, such as seizure or loss of consciousness are unmistakable, obvious indicators are not always present. Sometimes the signals are mild and can be confused with symptoms of flu or gastrointestinal upset – a persistent headache that does not respond to analgesics, confusion and difficulty concentrating, drowsiness, dizziness, or stiff neck. More alarming are changes in behavior, lethargy, strange gait, slurred speech, visual problems (e.g., double vision) or sudden, forceful vomiting. Every symptom of bleeding in the head must be taken seriously, even if you do not remember whether an injury has taken place. A head bleed can also occur without trauma. Any head bleed is life threatening, so even the suspicion of one is urgent: infuse immediately, notify your treatment center, and get to your treatment center physician or an emergency room.

Rapid treatment is critical

Parents will want to make sure that their child's school personnel know to alert them should the child take a fall or blow to the head (even a seemingly insignificant one). If your child tells you of a fall, or you see one happen, treat it seriously. One HTC Medical Director recalls a young patient who had a mild head trauma, but soon started to complain of headaches. Fortunately, his parents infused him with factor right away and then

made the long trip – they lived in another state – to the treatment center. “These symptoms were in fact from an intracranial bleed,” the physician recalls, “but, because it was treated so quickly, the child has had no resulting neurological problems. What was important was the rapidity with which everything was done.”

In the event of suspected head trauma

What to watch for:

- Sleepiness, irritability, or confusion
- Headache, nausea, or vomiting
- Weakness on one side of body or face
- Vision changes or unusual response of pupils to light
- Seizure activity

What to do:

- Treat immediately with a dose sufficient to correct the factor level to 100%
- Call your treatment center physician
- Get evaluated by the HTC, a physician recommended by the HTC, or at an emergency room.

Say Hello to GLHF's Newest Staff Member!



Great Lakes Hemophilia

Foundation welcomes a new Director of Resource Development, Maripat Monahan. Maripat brings ten years of experience in nonprofit fund development and has previously served in that role for the YMCA of Metropolitan Milwaukee, the American Red Cross Greater Milwaukee Chapter, and the AIDS Resource Center of Wisconsin. She will be responsible for conducting and overseeing all fundraising activities for GLHF, and will be involved in GLHF's community relations efforts as well. When she's not pouring over data, writing grants, or inviting individual support, she enjoys attending live theater productions and travel. She recently visited New York City with her one child, Magdelyn (Maggi), to take in a few Broadway shows. Maripat is thrilled to join Great Lakes Hemophilia Foundation, and looks forward to meeting the volunteers, donors and clients who make GLHF such a great organization.

GLHF'S Patient Financial Assistance (PFA) Program Pays \$42,035 In Fiscal Year 2006 to Help Patients Statewide

By David Linney

For Fiscal Year (FY) 2006 (from October 2005 through September 2006), GLHF's Patient Financial Assistance (PFA) Program spent \$42,035 to help 51 needy Wisconsin individuals with bleeding disorders pay for:

- **Health Insurance Premiums- \$22,439**
- **Medical Bills for Bleeding Disorders and Complications- \$6,083**
- **Basic Living Expenses- \$13,513**

A summary of numbers of recipients and dollars spent by area follow:

Area	No. Recipients	Dollars Spent
Green Bay	8	\$ 6,093
Madison	14	\$12,536
Milwaukee	27	\$22,631
Unaffiliated	2	\$ 775

Information about GLHF's Patient Financial Assistance Program

GLHF's Patient Financial Assistance (PFA) Program provides benefits to needy Wisconsin individuals with bleeding disorders who are registered with GLHF. Eligibility is based on need and individuals meeting Program requirements. Benefits are only paid after insurance and other resources have been utilized. Individuals with hemophilia and severe von Willebrand disease are eligible for a higher level of benefits because these conditions are so very expensive.

Overall financial assistance is limited to dollars budgeted by the GLHF Board of Directors. Specific PFA requests are dependent upon available funding.

For more information about the GLHF Patient Financial Assistance Program, contact GLHF's Financial Projects Coordinator, David Linney at (414) 257-0200 or toll-free at (888) 797-4543.

Consumer Report from the NHF Annual Meeting

In October, our family had the opportunity to go to the NHF annual meeting in Philadelphia due to the generosity of a GLHF travel grant. We had a great time. The sessions were informative (as always). The speakers proved to be very motivating whether the topic was patient advocacy, parenting or women's health. I walked away with a new sense of confidence in my ability to speak up to professionals on behalf of my children. The rap session for women with bleeding disorders opened my eyes to the struggles that women face who have hemophilia. The bleeding disorders community has come a long way in recognizing the needs of those with von Willebrand Disease but those with hemophilia still have a long way to go in order to receive adequate treatment. I met many wonderful women who face their problems with positive attitudes.

My sons, Jozef (15) and Sam (13), enjoyed the trip as well. They reconnected with friends from camp and made new friends as well. They had fun sightseeing in downtown Philadelphia. Coming from a farm in the country to a BIG city made quite an impression on them. It had been several years since they went to the annual meeting and had forgotten how big the bleeding disorder community really is. We were reminded of the past treatment of hemophilia by the physical frailty of many of the older men, while at the same time appreciated the advances made in current treatments as showcased in the vendor hall.

The best part for all of us was the Rocky Run and Walk. It combined fitness with awareness. We walked almost 4 miles round trip! A very large group of us walked to the Philadelphia Art Museum and ran up the stairs (okay, some of us didn't exactly run) just as Sylvester Stallone did in "Rocky." It was through the historical section of the city which provided great sightseeing as well as fresh air and exercise.

We all thank GLHF for the opportunity. Remember next year to apply for the travel grant so your family can reap the benefits of a trip to the annual meeting!

Darcy Zwier (and Jozef & Sam)



2007-2008 Scholarship List

1. GLHF Education Scholarship

Wisconsin residents or attending Wisconsin HTC

Award: Various scholarships from \$500 to \$2,000

Deadline: May 1, 2007

Terms: This scholarship not only targets the traditional college and vocational students, but also looks at re-training adults with bleeding disorders who are finding it difficult to function in their chosen field because of health complications. It also targets parents of children with bleeding disorders who through career advancement can better meet the financial needs of caring for their child.

Contact: Great Lakes Hemophilia Foundation
Tammy Molter 414-257-0200 or 888-797-4543

2. GLHF Individual Class Scholarship

Wisconsin residents or attending Wisconsin HTC

Award: up to \$500 per class (maximum award \$500)

Terms: This scholarship provides funding assistance for tuition and enrollment fees relevant to continuing education in a non-traditional or non-degree format for members of the Wisconsin bleeding disorder community. It is intended to enable people affected by bleeding disorders or their immediate family members to enhance career advancement. This program not only targets individuals with bleeding disorders, but also parents of young children and spouses of individuals with bleeding disorders.

Contact: Same as #1 (Cannot apply for both.)

3. The Hemophilia Health Services Memorial Scholarship Program

Award: One-year scholarships from \$1,500 and up

Deadline: May 1, 2007 notified by July 2007

Terms: Individuals with hemophilia (factor VIII or IX), von Willebrand disease (type 1, type 2, 2A, 2B, 2M, 2N, or type 3), factor I (fibrinogen), factor II (prothrombin),

factor V (proaccelerin), factor VII (proconvertin), factor X, factor XI or factor XIII who are U.S. citizens going to school in the U.S. or Puerto Rico.

Contact: Hemophilia Health Services
Application www.scholarshipadministrators.net
(access key – hemo)
Questions 800-800-6606 ext. 5175 or
Email scholarship@hemophiliahealth.com

4. Scott Tarbell Scholarship

Award: One-year scholarship from \$1,500 and up

Deadline: May 1, 2007 notified by July 2007

Terms: Individuals with hemophilia A or B severe, only. Must be majoring or seeking degree or certification in computer science and/or math.

Contact: Same as #2 (Can apply for either or both.)

5. Mike Hylton and Ron Niederman Memorial Scholarship

Award: Five \$1,000 scholarships

Deadline: April 30, 2007 notified by July 1, 2007
(Applications completed with essay and references post-marked by April 30, 2007.)

Terms: Men with hemophilia or von Willebrand disease or their immediate family members

Contact: Factor Support Network Pharmacy
www.FactorSupport.com

6. Millie Gonzalez Memorial Scholarship

Award: Two \$1,000 scholarships

Deadline: April 30, 2007 notified by July 1, 2007
(Applications completed with essay and references post-marked by April 30, 2007.)

Terms: Women with hemophilia or von Willebrand disease

Contact: Same as #4

7. The Kevin Child Scholarship

Award: \$1,000 scholarship

Deadline: Information available January 2007
Call for more details and application.

Terms: Individuals with hemophilia or von Willebrand disease

Contact: National Hemophilia Foundation
800-42-HANDI or www.hemophilia.org

8. Project Red Flag Scholarship for Women with Bleeding Disorders

Award: Two \$2,500 scholarships

Deadline: mid May 2007
Call for more details and application.

Terms: Women diagnosed with von Willebrand disease, hemophilia or other clotting factor deficiency or carrier status who are US citizens

Contact: Same as # 6

9. The Eric Delson Memorial Scholarship

Award: Three \$2,500 scholarships - renewal for up to three years
One \$1,500 scholarship for student attending private school, grades 7-12

Deadline: July 1, 2007

Terms: Individuals with bleeding disorders

Contact: The Eric Delson Memorial Scholarship
866-792-2731

10. Hemophilia Federation of America

Award: One \$1,500 artistic encouragement grant

Two \$1,500 parent continuing education grants
Three \$1,500 sibling continuing education grants
Four \$1,500 educational scholarships

Deadline: April 1, 2007

Terms: Individuals with bleeding disorder attending any accredited two or four year college, university or vocation/technical school in U.S.
Also available to parent or sibling as listed above.

Contact: Hemophilia Federation of America
800-230-9797 or sandy.a@cox-internet.com
Updated information on website www.hemophiliafed.org

11. Bill McAdam Scholarship

Award: One \$2,000 scholarship

Deadline: May 15, 2007

Terms: Individuals with hemophilia, von Willebrand disease or other hereditary bleeding disorders. Also available to spouse, partner, child or sibling.

Contact: Bill McAdam Scholarship Fund
313-563-1412 or
Email mcmcadam@comcast.net or
Send a self addressed stamped envelop to:
McAdam Scholarship Fund
22226 Doxtator
Deerborn, MI 48128

12. NuFactor's Eric Dostie Scholarship Program

Award: Ten \$1,000 scholarships

Deadline: Apply by March 1, 2007

Terms: Individuals with hemophilia or related bleeding disorder or family member enrolled in a two or four-year accredited college.

Contact: NuFactor
800-323-6832 ext. 1300 or www.nufactor.com and go to Consumer Section

13. Soozie Courter “Sharing a Brighter Tomorrow” Hemophilia Scholarship

Award: Sixteen \$5,000 undergraduate scholarships
Two \$7,500 graduate scholarships
Two \$2,500 vocational scholarships

Deadline: April 17, 2007

Terms: Individuals with hemophilia A or B

Contact: www.hemophiliavillage.com
888-999-2349

14. Colburn-Keenan Beth Carew Memorial Scholarship Program

Award: Five \$2,000 scholarships

Deadline: Applications will be accepted with postmarks of February 1, 2007 through April 4, 2007.

Terms: Individuals, high school seniors or full-time registered undergraduate students, who have hemophilia, von Willebrand or another related inherited bleeding disorder.

Contact: Colburn-Keenan Foundation
800-966-2431 or www.colburn-keenanfoundation.org

15. Lawrence Madeiros Memorial Scholarship

Award: Various scholarships from \$1000

Deadline: June 16, 2007

Terms: Individuals, graduating high school seniors (in 2007), living with a chronic disorder and continuing their education at an accredited college or university.

Contact: Positudes
518-661-6005 or www.adirondackspintacular.com

16. Coagulife Educational Scholarship

Award: Up to \$5000 per scholarship

Deadline: May 15, 2007
November 15, 2007

Terms: Individuals with hemophilia, von Willebrand disease or other inherited bleeding disorder

Contact: Coagulife
866-858-9200 or www.coagulife.com

17. Professor Ulla Hedner Scholarship

Award: Various scholarships from \$2000

Deadline: April 30, 2007

Terms: Individuals under the age of 23 with hemophilia complicated by inhibitors

Contact: Seven SECURE
877-NOVO-777

18. Seven SECURE Scholarships

Award: Up to \$2500 per scholarship

Deadline: Year-round

Terms: Individuals over the age of 23 with hemophilia complicated by inhibitors who are seeking to improve or transition to a new career.

Contact: Seven SECURE
877-NOVO-777

Santa Spreads Holiday Cheer Again

GLHF would like to send an enthusiastic “**Thank you**” to the staff at GE Medical Systems and Leo Reisinger, “Santa.” Every year, GE Medical Systems shares their holiday spirit by providing toys and gifts to be distributed at several Wisconsin treatment centers. These gifts bring many bright smiles on Christmas morning. Thank you for your generosity!

Medical News

From NHF eNews

Drug Regimen May Lead to Improved Treatment in Hemophilia Patients

Adapted from NHF eNews September 2006

Source: Hematology Week, August 28, 2006

A recently published research paper suggests that a treatment regimen that includes both plasma-derived, activated prothrombin complex concentrates (aPCCs) and recombinant activated factor VII (rFVIIa) could potentially control bleeding in hemophilia patients who normally do not respond to either of the drugs alone. Geoffrey Allen, MD, is lead author of the study. He is the director of the Comprehensive Hemophilia & Thrombosis Program at Children's Memorial Hospital in Chicago.

Hepatitis C Study Looks for Genetic Links Among Siblings with Hemophilia

Adapted from NHF eNews September 2006

Researchers from the University of North Carolina at Chapel Hill recently completed a study to determine the significance of genetics as a contributing factor to viral clearance among hemophilia patients infected with the hepatitis C virus (HCV). Patients are considered to be "cleared" of the virus when molecular tests (assays) show no detectable levels of HCV in the bloodstream.

The investigators, led by Michael W. Fried, MD, examined 257 pairs of siblings who had hemophilia and evidence of HCV infection but who were HIV-negative. They looked for genetic patterns that could contribute to either spontaneous and treatment induced clearance of HCV or progression of liver disease.

When HCV disease characteristics typically found in randomly paired, unrelated hemophilia patients were compared with those of the siblings, authors reported some noteworthy, if not dramatic, findings.

Matching disease characteristics (concordance) for spontaneous clearance was twice as high (8.8% vs. 4.3%) in siblings with HCV and hemophilia as in the randomly paired individuals. Concordance for treatment generated

HCV clearance among the sibling pairs was more than double that of the random pairs. Concordance for advanced liver disease was higher among siblings (4.0% vs. 2.3%). Overall, the researchers concluded that these and other results were not statistically significant. They were therefore reluctant to overstate the study's implications.

Hemophilia Prevention Data Appear in Leading Public Health Journal

Adapted from NHF eNews September 2006

The results of a national survey conducted by the National Hemophilia Foundation (NHF) and the Centers for Disease Control and Prevention (CDC) appeared in the September 2006 issue of the American Journal of Public Health. The survey, "Knowledge, Attitudes, and Behaviors of Youths in the U.S. Hemophilia Population: Results of a National Survey," focused on prevention in the U.S. hemophilia population.

The survey was conducted using a random sample of 459 patients taken from 20 hemophilia treatment centers and eight hemophilia associations. Of those respondents, 110 (24%) were 13-21 years old. The phone surveys measured knowledge, behaviors and barriers to prevention.

There were several significant findings among the younger respondents. Results showed that 36% believed that joint disease is not preventable and 60% avoided physical activity. Only 31% treated bleeding episodes within one hour. In addition, 78% of respondents were unaware of the transmission routes for hepatitis C, while 67% were not aware of the transmission routes for hepatitis B.

The authors concluded that young people with chronic disorders need targeted prevention messages about steps they can take to prevent complications associated with their bleeding disorder. Survey results helped NHF and CDC develop "Do the 5!," a series of prevention tips that are part of NHF's National Prevention Program (NPP).

Gene Therapy Research Focuses on Nonviral Delivery

Adapted from NHF eNews October 2006
 Source: Ascribe Newswire, October 5, 2006

Researchers from the U.S. and Switzerland recently reported on the potential for nonviral gene therapy using a transposon known as piggyback. A transposon, or jumping gene, is a sequence of DNA that can move to different positions within the genome of a single cell. Much of gene therapy research has focused on different viral modes of gene delivery. While viruses seem well suited to deliver therapeutic genetic material, they are also effective at entering host organism's DNA. A significant drawback in using this therapy has been that it can trigger immune reactions or activate cancer-causing genes. The theoretical advantage of using a piggyback, in contrast, is that the gene can be delivered safely to a specific location in the genome, where it can achieve the desired therapeutic response. Scientists believe that this type of gene therapy could have multiple applications, including the correction of single gene disorders such as muscular dystrophy and hemophilia.

Two Pharmaceutical Companies to Develop a Recombinant Factor FVIIa Product

Adapted from NHF eNews October 2006
 Source: America's Blood Centers Newsletter, October 6, 2006

GTC Biotherapeutics, Inc., of Farmington, MA, and Paris-based LFB-Biotechnologies will collaborate on the development of therapeutic products using recombinant plasma proteins and monoclonal antibodies (identical antibodies used in the production of pharmaceuticals). Their first collaborative product is a recombinant human factor VIIa (rhFVIIa) therapy. The rhVIIa will be developed from the milk of GTC's transgenic rabbits. Transgenic animals, such as cows and rabbits, are produced using externally introduced genes that are designed to trigger the production of specific human proteins in their milk. These proteins are then purified for other therapeutic uses, such as the treatment of patients with bleeding disorders.

Canadians Improve Tool to Measure Quality of Life

Adapted from NHF eNews October 2006

A recently published paper by Canadian researchers demonstrates the validity and reliability of a quality of life (QoL) measurement tool customized for boys with hemophilia. Development of the Canadian Haemophilia Outcomes-Kids' Life Assessment Tool (CHO-KLAT), which began in 1999, was a cooperative effort involving staff from multiple Canadian hemophilia clinics, patients and family members.

In all, 52 children with moderate or severe hemophilia ages 4-18 years and their parents were given a questionnaire with 79 items, a version of CHO-KLAT. Questions were designed to measure the following QoL areas: physical and social functioning, emotional well-being, satisfaction of treatment and overall care, impairments and health care needs and perceived health.

Although the authors concluded that providers should not base actual treatment decisions on these kinds of measurements, they did report that supplemental information drawn from CHO-KLAT may complement established clinical management practices.

Research Update: Less is More with Synthetic Inhibitors for Activated Protein C

Adapted from NHF eNews October 2006

Millions of units of factor VIII (FVIII) and factor IX (FIX) are used annually to save the lives of people living with hemophilia. Recently, a group of scientists from the University of Vermont and Cleveland State University discovered a technique that may significantly decrease the amount of FVIII and FIX needed to manage the symptoms of hemophilia by inhibiting the activity of a substance called *activated protein C (APC)*. APC is a chemical naturally found in the blood that stops blood from clotting once a significant blood clot is formed. It can down-regulate blood coagulation by inactivating factors in the blood that play a role in forming clots.

Professional Medical Organizations Collaborate on Menstruation Report

Adapted from NHF eNews November 2006
 Source: American Academy of Pediatric news release dated November 6, 2006.

The American Academy of Pediatrics (AAP) and the

American College of Obstetricians and Gynecologists (ACOG) published a clinical report to help providers educate adolescents and their parents on menstruation. The report emphasizes the need for girls, their parents and doctors to be able to recognize what constitutes a “normal” menstrual cycle and what should be considered irregular or excessive bleeding. Proper evaluation, asserted the study authors, will allow doctors to better assess the health status of patients and make the necessary clinical decisions.

The report also discusses the association between acute menorrhagia – heavy bleeding and prolonged periods – with von Willebrand disease and other bleeding disorders.

College in Wisconsin Receives a Federal Grant for VWD Research

Adapted from NHF eNews November 2006
 Source: Medical College of Wisconsin news release dated October 27, 2006.

The Medical College of Wisconsin in Milwaukee recently received a five-year, \$9.7 million Program Project Grant from the National Heart, Lung and Blood Institute to study the genetics of von Willebrand disease (VWD). Using blood samples from patients at multiple hemophilia treatment centers (HTCs) across the U.S., investigators will examine clinical and genetic aspects of VWD.

VWD patients will be recruited from HTCs in Atlanta, Detroit, Iowa City, Indianapolis, Houston, New Orleans, Pittsburgh and elsewhere. Their blood samples will be tested at the BloodCenter’s Hemostasis Laboratory.

NHF and Community News

From NHF eNews

Opening New Doors at NHF’s Annual Meeting

Adapted from NHF eNews October 2006

The National Hemophilia Foundation (NHF) hosted its 58th Annual Meeting at the Philadelphia Marriott Downtown. More than 2,200 attendees gathered in the “City of Brotherly Love” for this year’s conference -“Opening New Doors” – eager to open new doors of information,

education, advocacy and networking. The conference continues to bring together diverse groups of people, from consumers and families of newly diagnosed children to health care providers and industry representatives, for the three-day event.

Mark your calendar for the 59th Annual Meeting in Orlando, FL from November 1-3, 2007.

Youth Lead by Example at NHF’s Annual Meeting

Adapted from NHF eNews October 2006

The National Hemophilia Foundation (NHF) held its third National Youth Leadership Institute at the 58th Annual Meeting in Philadelphia. Youth leaders from around the country honed their leadership skills and used them with the younger kids.

“On Saturday, our Youth Leaders got practical experience by providing peer-to-peer education to kids and teens,” said NHF Education Manager Lauren Daitch. “Educational games were customized to each age group.” The curriculum focused on leadership, team building and self-empowerment.

Congratulations!

Shelly Mattson, GLHF Board member and National Youth Leadership Institute member and chair of the Youth Leadership Council, received the Meritorious Service Award in honor of Ryan White at the NHF Annual Meeting in Philadelphia. The award is presented to a young person who has helped educate others both within the bleeding disorders community and among the general population by increasing awareness and understanding. Shelly is an invaluable volunteer to both GLHF and NHF and an inspiration to all.

Upcoming Programs and Events Sponsored by Great Lakes Hemophilia Foundation

Fun and Educational

February 17, Saturday, from 11:00am - 12:00pm

Betty Brinn Children's Museum, Milwaukee

Children, ages 2-10, explore the museum while parent's attend Facts First Program sponsored by Baxter

March

Men's Discussion Group *

Date, place and topic TBD.

May 19, Saturday, from 12:00pm - 4:00pm

Women's Wellness and Pampering Day *

Ladies, ages 16 and up, come and be pampered.

Sheraton Milwaukee Brookfield

June 23-24, Saturday and Sunday

Family Fun and Education Weekend (formerly ACCESS) *

KI Convention Center and Regency Suites, Green Bay

August 18, Saturday

Couples Get Together *

Place and specifics TBD

September 29, Saturday

Walk with the Animals at the Milwaukee County Zoo *

Walk through the zoo and learn ways to live a healthy lifestyle. Specific details to follow.

*** You must register for these programs. To register for programs or for more information, please call 414-257-0200 or 888-797-4543.**

Fun and Fund Raising

March 31, Saturday

Gala 2007 – Monte Carlo

Milwaukee Hilton's Crystal Ballroom

May 21, Monday

Golf Outing – Teeing Up for Charity

The BOG, Saukville - Presented by Harley's the Store for Men

Please call Jessica for details at 414-937-6780.

Woman-to-Woman Training

A Woman-to-Woman training program was held October 21-22 in Milwaukee. Nine women from throughout the state were trained on the program. These volunteers will now staff health fairs, conduct the Girl Scout Highway to Health badge program and speak to groups about women and bleeding disorders in their local communities.

If you would like to learn more about the Woman-to-Woman program or have a volunteer come and speak to your group or present the Junior badge program to your Girl Scout troop, please call Tammy at the Foundation at 414-257-0200 or 888-797-4543.



Exercise and Nutrition Program

GLHF in partnership with Baxter sponsored a Facts First program on November 4 at the Wisconsin Athletic Club. Twelve people from the bleeding disorders community in Wisconsin attended the program and listened to speakers on the topics of Joint Health, Nutrition and Exercise. They also had the opportunity to try out the exercise equipment with the guidance of a personal trainer from the club.

The Wisconsin Athletic Club is offering a one week free trial membership for GLHF families. Please call Eric Gresham, 414-443-5000, at the athletic club for more details and mention that you are a GLHF family. There are several programs at five locations available.



Poinsettias and Wreaths Fly Out the Door

Once again our annual Poinsettia and Wreath sale was an abounding success! Even a blizzard couldn't stop this dedicated group of "Poinsettia Believers." True red and green volunteers from the years past and a few new faces joined the crew....

Debbie Straus, Pam Behling, Ed Behling, Russ Wade, Dick, Cheryl, Jeff, Terri, Michael, and Christopher Wade, Jay, Claire Zellner, Bob Ward, Johannes DeGraaf, Kathleen Roach, Barb Eder, Dorothy Smith, Elaine and Brianna Alred, Leann and Sarah Scheder, and students from Milwaukee High School of the Arts.

We appreciate the outstanding job the volunteers did preparing orders and delivering them throughout town. We also salute the work of **Mileager's** where our gorgeous poinsettias came from and **Minor's** the home of the beautiful wreaths. Thank you to **Assurant Health** for printing our brochures this year and **MPTV Friends** for allowing us to use their auction facility as central control.

One last thank you goes to all the businesses and individuals who continue to order from us each and every year. We would like to specially recognize the top donors:

Direct Supply, Inc.; Marcus Theatres, Benefits, Inc.; Jenny Hillis; WDJT CBS 58; Lois Richter; Miller Brewing Company; Quarles & Brady; Dawn Schweder; Milwaukee Yacht Club; Shorewest Realtors; CG Schmidt, Inc.; and Strattec Security Corporation



A Night to Remember in Monte Carlo

Date: March 31, 2007
 Location: Milwaukee Hilton's Crystal Ballroom

With the help of an outstanding committee and our Title sponsor **ZLB Behring** plans for this year's Gala are in full swing, and the excitement of Monte Carlo is catching on. This year our guest of honor is **David Linney** in recognition of his thirty years of service with GLHF. While the night of March 31st will be filled with music, high stakes gambling, and bidding you can wet your appetite on **March 1st**- when the bidding begins at our online auction and you can get a sneak peak of our Voice Auction packages. Also a new feature this year is online registration. Check out our website for the most up to date news concerning "A Night to Remember in Monte Carlo." If you would like to experience the gala for yourself, have questions, want to donate items to the auction, or would like to volunteer for the night's excitement call Jessica at 414-257-0200 or go online at www.glhf.org. Hope to see you soon in Monte Carlo!

Table Prices: \$1500 table of 8
 \$1800 table of 10
 Individuals: \$100 per person

During the period September 2, 2006 through December 7, 2006 the following donors provided financial support for which no goods or services were received in exchange. On behalf of people with bleeding disorders and their families, we thank these donors for their commitment, generosity and vision.

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**GLHF thanks the
following for their
sponsorship in 2006:**

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Anonymous

Jacob Mueller
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Cliff Roach
Mary Roach

Mission Statement

We dedicate ourselves to advancing the quality of life of individuals and families affected by hemophilia or other blood disorders by providing a broad range of services and programs while supporting research to improve care and to find a cure.

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The material provided in Headline News is for your general information only. GLHF does not give medical advice or engage in the practice of medicine. GLHF 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.

Have you remembered GLHF in your will?



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