



## HFMD 2008 ANNUAL MEETING



Stephanie, Luke, Jim & Nathan Miller

The HFMD held its 2008 Annual Meeting April 18th & 19th at the Sheraton Minneapolis West in Minnetonka. The theme of this year's meeting was a Story of Hope. Friday evening opened with a buffet dinner and a keynote speech from Pat "Big Dog" Torrey, sponsored by Wyeth Pharmaceuticals. Pat shared an uplifting message of hope and perseverance with some compelling personal stories woven in.

Saturday morning started with troubling news that our daycare company was cancelling one hour before they were scheduled to arrive. HFMD board members, HTC staff, and members of the community stepped up to volunteer, forming an impromptu daycare team. The hotel manager's daughter even came in to help.

As our attendees settled in for breakfast, HFMD executive director, Jim Paist welcomed everyone, shared some updates, and encouraged people to get involved with our events as participants and as volunteers. Jim also spoke of how people can make a difference in getting involved with public policy that affects our lives, and cited the amazing story of how our own Brenda Neubauer had recently inspired US Senator Byron Dorgan to introduce the Lifetime Health Insurance Cap Expansion Bill on behalf of the bleeding disorders community.

Our keynote presentation for the morning was a patient advocacy panel focused on health insurance and legislation on state and federal levels. Chris Fredericksen gave a riveting presentation on how to become a strong advocate for your families' health insurance. As someone with a perspective of working inside of the insurance industry, Chris shared valuable information on how to attain the best policy and coverage for you and your family. Mark Plencner, RPh. Meritcare Fargo HTC gave a great presentation on health insurance and the rising costs of health care. Jim Paist talked about public policy advocacy and the need for this community to become more involved.

Prior to the panel, attendees had some time to visit the exhibitors from the fifteen companies who supported the event. Attendees had breaks in the morning and afternoon to learn more about the quality life-saving medicines and services they offer. Two morning break out sessions included life-coach Martha Franke and physical therapy with Kim Baumann. Our youth ages 11-18 had the opportunity to participate in the Leading Edge program with Pat "Big Dog" Torrey who lead a 3 hour session on youth empowerment and building self-confidence.

Over lunch, awards were given to representatives from our event sponsors: Baxter BioScience, Novo Nordisk, Inc., and Wyeth Pharmaceuticals. It was also time for the raffle where

*continued on page 2*

### HFMD MISSION

To meet the needs and to enhance the quality of life for persons living with hemophilia, related inherited bleeding disorders and their complications.

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our exhibitors generously donated prizes which were given to the lucky winners. Afternoon breakout session featured a Women's Health program led by Sue Curoe and Kirstin Schmidt, a youth leadership meeting led by Nickolas Gamache and Pat Torrey, along with roundtable discussions on a variety of important topics. Photos from the event were taken by Paige Reeves. Our Annual Meeting was adjourned at 3:30 p.m., and the HFMD held its monthly board meeting at 4:00 p.m. We would like to extend a very special thanks to our annual meeting planning committee, our event sponsors and the companies who exhibited. *by Jim Paist*

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HFMD gave awards for outstanding community support to our event sponsors Baxter BioScience, Novo Nordisk, and Wyeth. (left to right) Jim Paist, Peggy Wier, Mark Hunter, Deb Melhado, Dan Tinklenberg.



**Grifols is pleased to announce the launching of**

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**GRIFOLS**

# Looking for Another Way to Give?

*by Mike Neubert*

*About Payroll Giving:*

## Did you know?

- The HFMD has **over 1000 members** across the three states!
- We rely on a few events each year to provide funding for our organization, this revenue allows us to provide
  - ☆ Summer Camp!
  - ☆ Annual Meetings & Retreats
  - ☆ Patient Assistance
  - ☆ Scholarships
  - ☆ And More!
- If each of our members set up an automatic donation plan through their employers the HFMD would be able to **significantly increase the services to the bleeding disorder community!**
- All donations are **tax deductible**
- Many employers will match charitable donations

## Here's How!

- Donating through work is EASY
  - ☆ Option #1 (CHCM): If your company provides the option to give to Community Health Charities of Minnesota (CHCM)
    - Just select the HFMD when you setup your automatic contribution plan!
  - ☆ Option #2 (United Way or Other): If your company gives through United Way or any other means
    - Just provide the information below to ensure your dollars go to the cause nearest to your heart.

Please remember us when your company's annual contribution plan enrollment comes around again. Your support is what enables us to continue to reach out to the bleeding disorder community with a voice of hope to share an array of useful information and bring the community together.

Thank You!!!

**Check out the new "Donate" button on our website too! [www.hfmd.org](http://www.hfmd.org)**

Hemophilia Foundation of Minnesota and the Dakotas, Inc.  
Is proud to announce its:

**Twelfth Annual Golf Tournament**  
*To benefit HFMD and its Community Programs*  
Monday, September 8, 2008  
1pm Shotgun starts  
4-Person Scramble Format  
Chance to be drawn for a \$10,000 putt

**Indian Hills Golf Club**

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Mark your calendars and watch your  
mail for additional information!

Call The Hemophilia Foundation at (651) 406-8655 with inquiries



**Tom Halden** - Weekend anchor and reporter for FOX 9 news. Please join us for a fun filled day of excitement with this year's celebrity golfer.



**DIRECTIONS:**  
I-694 to MN Hwy. 36  
East to Keats Ave.  
Left (North) on Keats  
to 6667

The Hemophilia Foundation  
of  
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Wyeth Pharmaceuticals

Par Level  
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Names (List All) \_\_\_\_\_

Address \_\_\_\_\_

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#Attending Dinner \_\_\_\_\_

Fee \$175.00 x # of Persons on Registration \_\_\_\_\_ Full Foursome: \$700.00 \_\_\_\_\_  
\$35.00 Dinner only - No golf

This year, the total players fee of \$175.00 will also include the longest drive and the marshmallow contest. Each player will receive one mulligan, which is non-transferable, plus an extra raffle ticket.

Total Enclosed \$ \_\_\_\_\_

Make check payable to: **HMFD**

Hemophilia Foundation of Minnesota and the Dakotas  
750 South Plaza Drive, Suite 207, Mendota Heights, MN 55120



## Unique Scholarship Opportunity

James H. Maguire Scholarship –Applications are encouraged from students studying chemistry or biochemistry at the University of Minnesota Duluth (UMD). The late Dr. James Maguire received his B.A. in Chemistry from UMD in 1970. In 1992, his wife, Dr. Louise Ball, gave a generous gift in his memory to establish this endowment in the Department of Chemistry at UMD. In addition, other family members also contribute to the scholarship. The endowment creates an award to benefit academically gifted students who are conducting scientific research, specifically in chemistry or biochemistry with preference for students with haemophilia or other substantial physical disabilities.



This announcement was reprinted with consent from the College of Science and Engineering at the University of Minnesota Duluth. The HFMD would like to thank the Maguire family for their generosity in creating this scholarship opportunity. Please contact the HFMD if you are interested in submitting an application.

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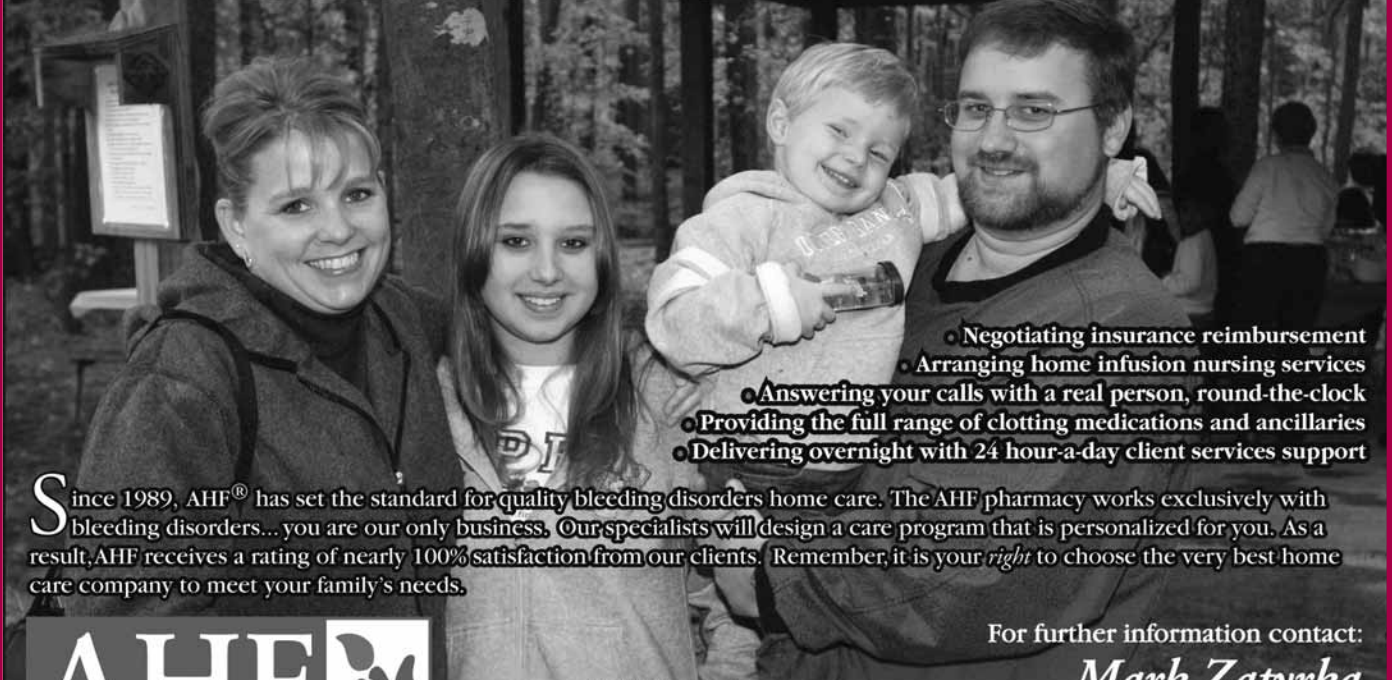
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## Bayer Launches Electronic Data Device

On April 21, 2008, Bayer HealthCare announced the launch of EZ-Log Web Client, a new online tool for hemophilia patients and healthcare providers to record and track their treatment infusions on the EZ-Log Web site.

“With EZ-Log’s Web Client application, our clinic can use one program to manage treatment and monitor compliance for all our hemophilia patients, regardless of their treatment needs,” said Katie Westover, patient services coordinator, Milwaukee Comprehensive Center for Bleeding Disorders. “This tool gives us the ability to connect directly with individual patients electronically and allows patients to easily update their own records from anywhere.”

“We are pleased with the added convenience that Bayer’s new EX-Log Web Client will provide for both patients and healthcare professionals,” said Terry Tenbrunsel, Vice President, Sales and Marketing, Bayer HealthCare. “We’re committed to continue providing more choices for those living with hemophilia while working with healthcare professionals to find new ways to help improve compliance.” Another option for capturing and transmitting hemophilia patient data is Bayer’s EZ-Log PDA, (personal digital assistant, a type of a handheld computer). Bayer’s PDA records a patient’s treatment data by real-time scanning of the barcodes on treatment packaging. *(reprinted with consent from NHF website)*

## FDA Approves New Recombinant FVIIa Formulation

The U.S. Food and Drug Administration approved a new formulation for NovoSeven RT, Novo Nordisk's recombinant factor VIIa product. NovoSeven RT, manufactured with sucrose and L-Methionine, can be stored at room temperature--up to 77 degrees Fahrenheit for up to two years.

“Approval of this product for room temperature storage creates greater flexibility in disease management for both patients and physicians,” said Jesse L. Goodman, MD, MPH, director of the FDA's Center for Biologics Evaluation and Research. “As with all FDA-approved products, the agency will monitor NovoSeven RT throughout its life cycle.” The new formulation will primarily help healthcare facilities with limited refrigerated storage space.

NovoSeven RT has the same indications as its predecessor, NovoSeven®, including the treatment of bleeding and the prevention of surgical bleeding in patients with hemophilia A or B and an inhibitor. In addition, it can be used for the treatment of bleeding and the prevention of surgical bleeding in patients with congenital factor VII deficiency and the prevention of surgical bleeding in patients with acquired hemophilia.

Side effects of NovoSeven RT include fever, bleeding, local reaction at the injection site, joint discomfort and headache. Some older patients experienced an increased risk of arterial clotting when the product was used outside of its approved indications.

Source: FDA news release dated May 9, 2008 (*reprinted with consent from NHF website*)

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Minneapolis, MN 55404  
612-813-5940  
margaret.heisel@childrensmn.org

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St. Paul, MN 55102  
651-220-6732  
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Cheryl Hansen, PT  
Lorri Thompson, PT  
Cindy Jarosch, PT  
Terry Hammink, MSW  
Jennifer Roggenbuck, Genetics Counselor  
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Sioux Falls, SD 57117  
605-333-7171

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Erin Tobin, RN  
LeAnn Schneider, PT  
Carrie Kindopp, CCLS  
Quinn Stein, Genetics Counselor  
Jan Grogan, MSW  
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**Center for Bleeding and Clotting Disorders  
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B549 Mayo Building  
Minneapolis, MN 55455  
612-626-6455  
htc@fairview.org

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**Mayo Comprehensive Hemophilia Center**  
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eckerman.amy@mayo.edu

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Fargo, ND 58122  
701-234-7544

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Sandeep Batra, MD  
Kathy Wussow, PA-C  
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## A Fresh New NHF?

### HFMD's Review of the 2008 NHF Leadership Weekend

*Written by: Denise Cadwell (Member, HFMD Board of Directors)*

The National Hemophilia Foundation (NHF) organizes, facilitates and sponsors a "NHF Leadership Weekend" event on an annual basis. The NHF Leadership Weekend is typically attended by Chapter Representatives which include, Chapter Staff, Board of Director Members or Chapter (recommended) Members. NHF's purpose for the Leadership Weekend is to gather these key Chapter Representatives from all over the Country and converse about the year in review, as well as, discuss collaborative objectives and joint aspirations between NHF and the local Chapters. NHF focuses on providing Chapter education, encouraging two way communication and sharing their mutual support on the challenges we all face within the Bleeding Disorders Community.

On June 13 and 14th, Brenda Neubauer and I attended the 2008 NHF Leadership Weekend, which was held in Fort Lee, New Jersey (right across the river from Manhattan, New York City). I was honored to represent our HFMD Chapter on a national level. I was also privileged to attend this event with my Co-Board of Director Member, Brenda Neubauer. With Brenda's notoriety in being our Chapters' "Advocacy Leader", I felt confident that HFMD had strong Chapter Representation at the event.

The NHF Leadership Weekend started with a Welcome and Introduction by Val Bias, NHF's new CEO. Val spoke to the Chapter Leaders and was very passionate about getting the word out that the NHF is committed to "**protecting our Nations blood supply.**" He does not want to be shy about what NHF and the nations Chapters have accomplished and endured. NHF intends to let the World know about our history and about our

continued efforts to protect our blood supply, not only for the Bleeding Disorder Community, but for everyone!

NHF's new Vision was also introduced:

**To support a strong national organization, part of a coordinated and unified system within the bleeding disorders community, in order to realize our common vision:**

*By the year 2012, people living with bleeding disorders will receive the services they need to lead full productive lives, regardless of where they live. The ultimate goal remains to find better treatments and one day a cure for bleeding disorders. And until that day, to ensure that every person living with a bleeding disorder has every opportunity to reach their full potential.*

*And if we don't move in this direction, we can all agree "**there will be a systematic breakdown in people's ability to access treatment centers and the full range of products.**"*

After Val's introduction we viewed a 15 minute news documentary called, "*Bad Blood: A Cautionary Tale*" by Marilyn Ness. Wow, this was an excellent documentary that discussed the tainted blood supply in the 1980s. The film was excellent, informative and had quite the lasting impact.

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Other topics covered during the NHF Leadership Weekend included:

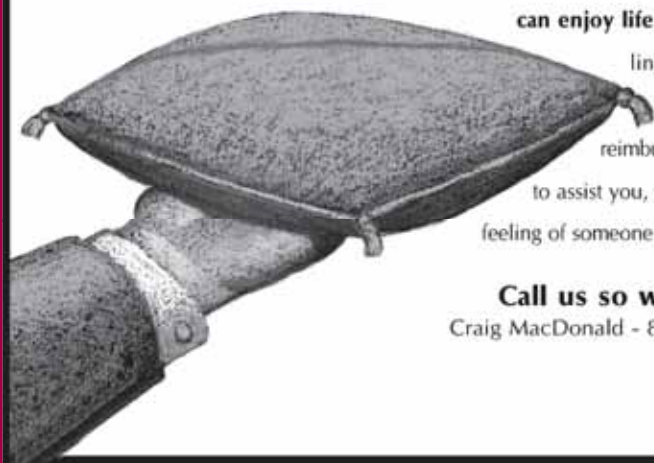
- Open discussions with NHF Staff on how we can work collaboratively to build stronger Member organizations.
- Learning how to get your message out by using the Media to raise awareness of Bleeding Disorders, as well as raising awareness to our advocacy efforts locally..
- An open discussion with the NHF Public Policy Staff on how NHF can help the local Chapters with their State Advocacy needs.
- How Board Governance Policies can assist individual Chapter Boards.
- Introduction to NHF's new "Chapter Services" Department which will focus on improving Chapter Relations through "Chapter Advisory" participation.
- Learning how NHF recruits their NHF Board Members. This session was facilitated by our very own (Past HFMD President), Eileen Bostwick. Eileen is NHF's Secretary of the Board.

The Leadership Sessions came to an end late Saturday afternoon. Many of the Leadership Participants attended the closing night event which was held at Madame Tussauds Wax Museum in the heart of New York City's Times Square. This was a good opportunity to relax, tour the Wax Museum and mingle with other Chapter Representatives. This is exactly what I did!

I would like to thank HFMD, the HFMD Board of Directors, the HFMD Chapter Members and NHF for supporting my Board involvement and my volunteer endeavors on my continued effort to bring awareness of all aspects of our Bleeding Disorders Community on a Local and National platform!



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## 2008 Calendar

- July 26, 2008.....Junior Nationals – Getting” In The Game  
Muskego Lakes Country Club  
Muskego, WI
- August 2, 2008.....Family Fitness Day – Bicycling & Canoeing Event  
Cannon Valley Trail  
Cannon Falls, MN
- August 2 – 3, 2008.....Dakotas Family Retreat  
The Governor’s Inn & Conference Center  
Casselton, ND
- September 8, 2008.....HFMD Golf Tournament  
Indian Hills Golf Club  
Stillwater, MN
- October 4 - 5, 2008.....Women’s Education Day  
Oakridge Conference Center  
Chaska, MN
- November 13 – 15, 2008.....NHF’s 60th Annual Meeting  
Denver, CO

\*\*The HFMD Board of Directors meets every month on the third  
Tuesday at 7:00 p.m.\*\*

Visit our web site, [hfmd.org](http://hfmd.org), for exciting news and updates!