



Spring

2008

Washington Days 2008 Lifetime Insurance Cap Expansion Bill Introduced!

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.

It is an exciting time for our bleeding disorder community. There is nothing more exciting than to know that change will happen. We must remember whether it be today, next month, or next year it will happen because we will make it happen. This message was sent loud and clear at the annual NHF's Washington Days 2008.

Over 250 participants from 38 states attended this year's events. Our foundation was able to send a number of participants. Attendees included from North Dakota my son, Jacob and I, Sherri and Carson Ouellette, and Shawna Delzer, and from Minnesota, Eileen Bostwick, Denise Cadwell and her son Nick Gamache. There were three core issues this year: Lifetime Insurance Caps; Medigap Expansion; and Additional Funding for HTC's.

As many have already heard the story, during a meeting in Bismarck this past November between Jim Paist, myself, and Senator Byron Dorgan to discuss Medigap, Senator Dorgan left us both speechless when he unexpectedly announced that it was time to tackle insurance caps. Senator Dorgan had listened to my story year after year. He understood not only the emotional and physical impact of dealing with a bleeding disorder, but also the devastating financial impact, especially when dealing with lifetime caps.

A man of action, Senator Byron Dorgan (D-ND) introduced Senate Bill 2706, the Health Insurance Protection Act. The Senate Bill as introduced will increase the limitation on lifetime aggregate limits to \$5 million dollars for the first two years after the effective date of the legislation, and \$10 million for the third and fourth year, with the amount thereafter adjusted by consumer price index.

I was given the honor of presenting Senator Dorgan with NHF's advocacy award. During his address Senator Dorgan spoke of his commitment to healthcare, to our community, and his own personal experiences dealing with the loss of his daughter. It was apparent to all that Senator Dorgan is truly a "Senator for the people" and a champion for our community. His staff is just as compassionate and motivated in their efforts.

Our congressional visits were just as productive and provided an opportunity for all to relay their personal stories. It was most moving when the young men in our group talked about how living with a bleeding disorder impacts their daily life. As always, by the end of the day we were tired and ready to rest our feet.



Brenda Neubauer, Senator Byron Dorgan and Ray Standhope, NHF Board President.

The next morning we attended a training session to learn what was happening in other states. Discussion was had regarding high risk pools in North Carolina, and standards of care legislation in California, New Jersey, and Minnesota. Alabama was recently dealing with sole provider issues. Training such as this gives up valuable information and resources to use in our tri-state advocacy efforts.

At this point, we are still in the process of obtaining co-sponsors on Senator Dorgan's lifetime cap bill. Certainly if anyone has any contacts or ideas, please contact either myself or Jim Paist. It's also encouraging that several representatives are interested in introducing companion legislation on the House side. The Medigap bill, HR 1282, has five new co-sponsors and still needs a Senator to introduce a bill in the Senate. Last, a Senate letter of support is being circulated for increased funding for HTC's. On the House letter, at my last count there were 36 co-signers.

continued on page 5

Inside this issue:

MN Retreat	2
Treatment Centers	3
Hearts of Hope Gala	4-5
Scholarships	5
Washington Days	6-7
Contributions	8
Fitness	9
Research/ Industry News	10
Board News	11
Calendar	12

9th Annual Minnesota Family Education Retreat

The 2008 Minnesota family retreat was held on January 18th - 20th near Brainerd, MN, hometown to Paul Bunyan and Babe the Blue Ox. Hearty community members braved the frigid 50 below zero wind chill to gather at the “Lodge at Brainerd Lakes” in Baxter. The Lodge was a great place for the education retreat with it’s rustic “up north” atmosphere, fireplaces and warm hot tub for people to re-ignite friendships and make new ones.

Dan Tinklenberg, interim President of HFMD welcomed everyone to the 9th annual family retreat during Friday evening’s dinner, and everyone had the opportunity to introduce themselves. After dinner on Friday and Saturday, families were able to visit with each other, relax and play at the indoor water park and arcade.

Dianne Horbacz with Hemophilia Health Services kicked off Karing for Kids Saturday morning, an education program for children. The program was specially tailored to meet the needs of the youth and their parents ages 4 - 11. Dianne first met with the adults, discussing the interactive stations that the kids will be doing. The kids were brought in and excitedly interacted at the many stations and learned about clotting and bleeding disorders.

Saturday afternoon provided the community members the opportunity to voice their personal and community questions about all bleeding disorders during the Ask the Experts panel discussion. Many health issues were discussed, along with many health insurance questions.



A special thanks to our sponsors:
U of MN Fairview HTC
Baxter BioScience
Bayer HealthCare



Following “Ask The Experts”, the attendees were able to choose between attending a session about Physical Therapy or one which they could share their story.

The teens had their own breakout session with Dan Tinklenberg during the afternoon where they discussed teen issues. The youth got to spend time together talking about current issues regarding their bleeding disorders, and issues that are important to them.

Our family looks forward to this retreat each year to reconnect with those we know well in the bleeding disorders community, and to make friends with new members. We feel very fortunate for the opportunity for us and for our children to connect with other people like ourselves and for the bonds and friendships that happen because of the programming provided and the time we get to spend together.

A special thanks to all who organized, facilitated, and financially supported the MN family retreat. You make it possible for us to continue to learn from you, from each other, and to gather and share our experience, strength and hope with each other in the bleeding disorders community.

By Beth & Jon Anderson

Send Us Your Email Address We like to stay in touch with our readers to share announcements of upcoming events and activities. We would also be happy to send you the Veinline electronically. Please send your email address (and name) to hemophiliafound@visi.com

Center for Bleeding and Clotting Disorders
University of Minnesota Medical Center, Fairview
 420 Delaware Street SE - MMC 713
 B549 Mayo Building
 Minneapolis, MN 55455
 612-626-6455
 htc@fairview.org

Mark Reding, MD
 Skye Peltier, PA-C
 Joni Osip, RN, MS
 Vicky Hannemann, RN, BSN
 Susan Curoe, RN, MS
 Kerry Hansen, RN, BS
 Kim Baumann, MPT
 Terry Hammink, MSW
 Melissa Truelson, Genetics Counselor
 Shannon Fabick, Admin. Secretary

South Dakota Center for Blood Disorders
 1305 West 18th Street
 Sioux Falls, SD 57117
 605-333-7171

Linda Stout, MD
 Michael Sprehe, MD
 Erin Tobin, RN
 LeAnn Schneider, PT
 Carrie Kindopp, CCLS
 Quinn Stein, Genetics Counselor
 Jan Grogan, MSW
 Kay Schroeder, RD

Hemophilia Treatment Centers (Tri-State Area)

Hemophilia and Thrombosis Center
Children's Hospital
and Clinics of Minnesota (CHCMN)
 2525 Chicago Avenue, Suite 4150
 Minneapolis, MN 55404
 612-813-5940
 margaret.heisel@childrensmn.org

345 North Smith Avenue
 St. Paul, MN 55102
 651-220-6732
 kimberly.jacobson@childrensmn.org

Margaret Heisel Kurth, MD
 David Slomiany, MD
 Sue Purdie, RN, BSN
 Jocelyn Gorlin, RN, CPNP
 Jane Hennessy, RN, CPNP
 Kristen Appert, RN, CPNP
 Nicole Leonard, RN, BS
 Kim Jacobson, RN, CPNP
 Linda Litecky, RN
 Lorri Thompson, PT
 Cindy Jarosch, PT
 Terry Hammink, MSW

Mayo Comprehensive Hemophilia Center
Mayo Clinic
 Hilton 106
 200 First Street SW
 Rochester, MN 55905
 507-284-8634 or 1-800-344-7726
 schmidt.kirstin@mayo.edu
 eckerman.amy@mayo.edu

Rajiv Pruthi, MD
 Vilmarie Rodriguez, MD
 Kirstin Schmidt, RN
 Amy Eckerman, RN
 Jim Langworthy, MS, LICSW
 Shannon Klavetter, Admin. Assistant

North Dakota Hemophilia/Thrombosis
Treatment Center
MeritCare Hospital
 820 Fourth Street North
 Fargo, ND 58122
 701-234-7544

Nathan Kobrinsky, MD
 Sandeep Batra, MD
 Kathy Wussow, PA-C
 Kristin Swenson, LCSW
 Courtenay Misheski, RN
 Linda Thorseth, PT
 Diane Sjolander, CCRP
 Mark Plencner, RPh

Families Trust AHF!

- Negotiating insurance reimbursement
- Arranging home infusion nursing services
- Answering your calls with a real person, round-the-clock
- Providing the full range of clotting medications and ancillaries
- Delivering overnight with 24 hour-a-day client services support

Since 1989, AHF® has set the standard for quality bleeding disorders home care. The AHF pharmacy works exclusively with bleeding disorders... you are our only business. Our specialists will design a care program that is personalized for you. As a result, AHF receives a rating of nearly 100% satisfaction from our clients. Remember, it is your *right* to choose the very best home care company to meet your family's needs.

AHF
 INCORPORATED

The Bleeding Disorders Homecare Company

www.AHFInfo.com

Setting the Standard of Homecare for the
 Bleeding Disorders Community

For further information contact:

Mark Zatyryka
 800-243-4621

31 Moody Road, P.O. Box 985, Enfield, CT 06083 • 800-243-4621 • AHF@AHFInfo.com

Hearts of Hope Gala

The HFMD held its 8th Annual Hearts of Hope Gala on Saturday January 26th at the Hilton Hotel in downtown Minneapolis. This year we decided to try a Casino Night for entertainment afterwards, and it turned out to be a big hit. The event was hosted for a third consecutive year by former Channel 5 (KSTP) Sportscaster and news Anchor Joe Schmit. Once again, Joe did a terrific job charming our guests with his quick wit and personal support for our cause.



L to R Peggy Wier, Mark Hunter, Deb Melhado, Mark Weiner, Nancy Golden, receive outstanding sponsorship awards from HFMD Board President Aaron Reeves.

Our silent auction was elegantly displayed by our creative team of volunteers. It featured a wide range of over 100 exciting items from wine baskets, to weekend getaways, to a reclining chair, to dinner with an astronaut. The live-auction was led by auctioneer Tony Elfeldt and Joe Schmit who made a great team. They paused during the live-auction for our patient assistance pledge. HFMD volunteer and RN from the Mayo Clinic, Kirstin Schmidt read a heartfelt statement from a 2007 recipient of our patient assistance program. The pledge alone raised \$10,000!

It turned out to be a thrilling evening of fine-dining, auctions, and casino games to raise money for the HFMD. So many people contributed their time and effort to make this a success. We also had a number of generous sponsors, and companies who donated auction items to support our work. We would like to extend a very special thanks to the gala planning committee and event volunteers.

Gala Planning Committee: *Co-chairs* Jim Paist & Pam Cella. *Committee Members*: Nancy Golden, Liz Kallberg, Alicia Lee, Deb Melhado, Stacy Pike, Aaron Reeves & Peggy Wier. *Volunteers*: Carol Bistodeau, Donna Bistodeau, Jim Brown, Denise Cadwell, Sue Curoe, Shannon Fabick, Vicky Hanne-
mann, Holly Haskel, Jessica and Jason Hutchison, Jim Langworthy, Lindsey Lynch, Muriel Lynch, Craig Looney, Kris & Joel Manns, Steph Miller, Steve Oas, Mary Ollhoff, Joni Osip, Skye Peltier, Jessie Poundstone, Aaron & Paige Reeves, Ron & Kathi Reeves, Erica Scofield, Caleb Sellers, Deb Starling, Mark Wiener, Bill & Kathy Wussow.



The HFMD deeply appreciates the generous support of our Gala sponsors.

Gala Sponsors

Diamond Level \$10,000

Baxter BioScience
Novo Nordisk, Inc.
Wyeth

Platinum Level \$5,000

Bayer HealthCare

Gold Level \$3,000

CSL Behring

Silver Level \$1,200

Critical Care Systems
CVS Caremark
Grifols
Hemophilia Health Services
Maguire Agency
Talecris
Walgreens - Option Care

Patron Level \$500 & Up

Frank & Jane Hennessy
Frank & Dr. Margaret Kurth
John & Barby Schulte
Western Bank
Supporter \$300
JBL Companies
Luther Nissan/Kia



When you need us,
Baxter will be there.

Through Therapies

Providing innovative recombinant factor, plasma-derived, and inhibitor management therapies highlights our commitment to choice and illuminates our investment in research and development.

Through Participation

Offering initiatives for patients, families, physicians, and nurses and supporting local and national organizations and community events, in addition to volunteering.

Through Progress

Improving current therapies and developing new and better ways to manage hemophilia A—innovations inspired by listening to you.

For more information on Baxter programs and services, visit www.thereforyou.com.

There when you need us

Baxter

Baxter, Adtec, C1 and Factor VIII Factor ADMM, and www.thereforyou.com are trademarks of Baxter International Inc.
©Copyright 11/06/07, Baxter Healthcare Corporation. All rights reserved. HY12852

continued from page 1



Sherrri Ouellette, Carson Ouellette, Shawna Delzer, Jake and Brenda Neubauer

We all need to be involved in advocacy. Each one of us can make a difference by contacting our state and federal legislators, open the lines of communication with our insurance companies, by forming coalition organizations with other serious disorders, and by telling our stories to anyone who will listen. We may be a small community but we are strong.

Brenda A. Neubauer

member of
**Community
Health Charities**
M i n n e s o t a

HFMD Post-Secondary Scholarship Applications are due June 2, 2008



Last year, the Hemophilia Foundation of Minnesota/Dakotas (HFMD) was delighted to award post-secondary scholarships to ten qualified recipients. The scholarship amount per student in recent years has ranged from \$1,000 - \$2,000. This year, the

HFMD will again be accepting 2008 post-secondary scholarship applications and these applications are due in our office no later than June 2, 2008. For those students interested in applying, please contact the HFMD office for an application or visit our web site, www.hfmd.org.

Scholarship eligibility requirements for applicants include (1) having an inherited bleeding disorder, (2) being a resident of Minnesota, North Dakota or South Dakota, or be a patient of one of the Hemophilia Treatment Centers in these states, and be a participant in HFMD programs and services, and (3) and being accepted into a post-secondary educational program.

NHF'S "WASHINGTON DAYS" WAS A BLAST! (A TEENS PERSPECTIVE OF HIS "WASHINGTON DAYS" TRIP)

By Nickolas Gamache

Mom and I left our home early on Wednesday March 5th, 2008. My mother and I gathered with our fellow Bleeding Disorder Community Members from around the United States that day. We were one unified group, gathered at our Nations Capitol for one goal, ...to inform, vocalize and be the voices for our Bleeding Disorders Community.

We all had appointments with our Legislators on Thursday, right there, in Capitol Square, with our own House of Representative Legislators and even our State Senators! We all shared our personal stories with them and we shared facts, figures and the reality of what is really happening out there in the Bleeding Disorders Community. Here are the three interests we needed their support on for our Bleeding Disorders Community:

We were asking them to increase in the minimum lifetime medical insurance caps, approve an increase of their funding to go to the Centers for Disease Control (CDC) for our Hemophilia Treatment Centers (HTCs) and to "open up" or increase availability to their existing Medical Insurance Program called Medigap.

A "Big Wig" from the Senate showed up to give us a little pep talk and to let everyone know that he is so supportive of our Bleeding Disorder Community that he had agreed to introduce a Bill to all of the other Senators of the United States. This "Big Wig" was our very own Senator Byron Dorgan from North Dakota! This was a **HUGE** triumph of support for all of us in the Bleeding Disorders Community! Even our own HFMD Chapter Mom and Board Member, Brenda Neubauer got up for a minute and spoke to everyone who was there supporting our Community from around the United States! Hey.... She was totally responsible for this victorious milestone because she was the one who has been having meetings with Senator Dorgan for many, many years and she never gave up! Well, Senator Dorgan finally agreed to help her by helping all of us in the Bleeding Disorders Community.

For those of you who don't know, the issues that we tackled out in Washington DC are **VERY** important to the Bleeding Disorder Community, as well as to us young adults, teens and little bleeders too. Why? Because this is our future!

These issues are important to us in several different ways. Let me explain more;

Efforts to increase **Lifetime Medical Insurance Caps** are essential because this lifetime limit cap issue has not been addressed or changed in the Insurance Industry since the 1970s. The last time it was addressed the minimum lifetime cap was set at 1 million dollars, which at today's rate of inflation, with higher medical costs, would be equal to about 10.1 million dollars. However, most Medical Insurance Policies given to Employees (under private medical insurance plans) still only average about 2-3 million dollars of a lifetime maximum. This means that when a family, or even one family member, has reached that lifetime maximum limit amount (because of medical services and sometimes factor or prescription costs) that their medical insurance company can (and will) no longer cover any more of their medical costs!

The second issue we were pressing for was the need for **additional funding to go to the CDC** so that the CDC can help our 140 HTCs (in the United States) with more financial assistance.

Finally, the **Medigap** topic. Currently the only people eligible to get this Medical Insurance option are the elderly folks over 65 years old who already have Medicare. But if you are really lucky and are under the age of 65 and disabled (well, that is not lucky) and you happen to live in 1 of the 24 States you do the option to apply for Medigap Insurance coverage already. However, you are not so lucky if you live in 1 of those other 26 States.

But the problem our Bleeding Disorder Community is facing is that even if they do qualify for Medicare Insurance coverage, Medicare will only pay for 80% of their medical costs. This means 20% of this charge has to come out of their own pockets!

Think about this for a minute, I had a nose bleed with complications for 6 weeks and between medical care costs and my vWD Factor costs and Home Care treatment I used up nearly \$900,000 of our families'

lifetime maximum limit. But if I had to for 20% of this bleeding episode out of my pocket, I would be paying \$180,000.00!! **FOR ONE BLEED!** (I better start planning for College now.)

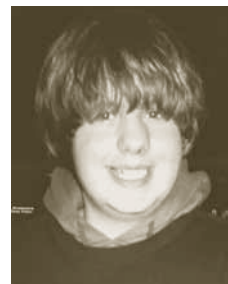
We were out in Washington DC to ask for the support of our Legislators. We asked for current changes in Medigap Insurance availability in order to:

- Allow all Medicare Disabled folks under the age of 65, the opportunity to get Medigap Insurance coverage in all 50 States (not just 24).
- Make Medigap Insurance more accessible to our Bleeding Disorder Community (and other chronically disabled folks that qualify) by mandating open enrollment periods, available to everyone on Medicare.

In short, Washington DC was a lot of fun. But it was more than just fun...we were there to get something accomplished for the future of our Bleeding Disorder Community, and we can only hope that we did.*

See you all soon!

~ Nick G.



Nickolas Gamache is 16 years old and is a sophomore at Hastings High School, in Hastings Minnesota. He has a strong interest in pursuing a career in Political Science, Medicine and Law. Nickolas has von Willebrands Disease (Type 2A) and has a secondary Platelet Disorder. Nickolas applied last summer to NHF to be a Youth Member for NYLI (National Youth Leadership Institute), but was encouraged to get more "Bleeding Disorder Community" experience under his belt and then reapply this summer. Since that time, Nickolas has attended our HFMD Capitol Days event, attended the Washington DC event and has attended a weekend youth retreat in Texas, given by NYLI!

Biotherapies for Life™ CSL Behring

He can be just
one of the guys

Helixate^{FS}
Antihemophilic Factor (Recombinant)
Formulated with Sucrose
Take Life On™

The HFMD gratefully acknowledges our donors who have given so generously. Below are donations received from January 1, 2008 through March 31, 2008.

Organizational Contributors:

\$40,000 and Up

Fairview Foundation
MeritCare

\$20,000 - \$39,999

Baxter BioScience

\$9,000 - \$19,999

Bayer HealthCare
Novo Nordisk, Inc.
Wyeth Pharmaceuticals

\$3,000 - \$8,999

American Homecare Federation, Inc.
Community Health Charities-MN
CSL Behring
Mid-West Cornerstone Healthcare

\$1,000 - \$2,999

Critical Care Systems
Factor Health Management
Grifols
Maguire Agency
NuFactor
Talecris Biotherapeutics
Walgreens-OptionCare
Western Bank

Up to \$999

Baxter International Foundation
JBL Companies
Luther/Nissan KIA
United Way

Individual Contributors:

\$1,000 +

Frank and Dr. Margaret Kurth
Dick & Tracy Noble
Tom Teigen & Jennifer Paist
Barry & Heather Vaughan

\$500 - \$999

Abe & Kirsten Appert
Steven & Marty Chamberlain
Karin Erickson

Alfred & Vicky Hannemann
Frank & Jane Hennessy
Holly Haskell
Jeff & Char Kandt
Jon Lindfors & Kate Bryant
Mary Jo Moening
Mike & Heidi Neubert
Steve Nielsen & Nancy Starr
David & Erin Norris
Jean O'Connell
Carol Osip
Aaron & Paige Reeves
Linda Swanson
Dr. Blair & Joanne Woolsey

\$200 - \$499

Jason & Angela Alvig
Jon & Beth Andersen
Anonymous
Jim and Barbara Brown
John & Becky Fredericksen
Larry & Patricia Gavin
Dr. Jed & Jocelyn Gorlin
Dr. Robert & Kristi Gorman
James & Barbara Griffin
Terry & Pat Hammink
Mark & Tracii Hunter
Jason & Jessica Hutchison
William & Elizabeth Kallberg
James Langworthy
Sumner & Dr. Nancy McAllister
David & Deborah Melhado
Yoav Messinger, MD
James & Stephanie Miller
Arthur & Nancy MosBrucker
Steve Nelson, MD
Joni Osip
Jim Paist
Michael & Shirley Propp
Ron & Kathi Reeves
Joe and Laura Schmit
Clark Smith, MD
Dan and Deb Starling
Patrick & Peggy Wier
Steven & Jan Zitnick

\$100 - \$199

Susan Bickmore
Timothy & Diann Boonstra
John & Angela Boyd
Mr. & Mrs. M. K. Braff
Sylvia Jean Cook
Milton & Yvonne Datta
Ron & Lori Duchesneau
David & Sharold Friedrich
Gregory & Rhonda Gilmer
Steve and Deirdre Gollinger
Bridget Hanson

Paul & Carolyn Hanson
Beth Hessburg
Kent & Julie Krabbenhoft
Joe & Lori Kunkel
Andrew Lawrence
Linda Litecky
Muriel Lynch
Joel & Kris Manns
Craig & Kathie Neville
Steve & Paulette Oas
David & Vicki Oberkrom
Tim & Patti O'Brien
Stacy Pike
Richard & Clare Pilon
Mark & Stacy Plencner
Lavonne Propp
Rajiv Pruthi, MD
Mitchell & Barbara Rucks
Steve & Terry Schatz
Barbara Schaumburg
Gary & Lauri Schultzetzenberg
Robert & Karla Tinklenberg
Steve & Dawn Witcraft

Up to \$99

Andersen Log Homes, Inc.
Harold & Donna Bistodeau
Eileen Bostwick
Charles & Denise Cadwell
Dr. Joseph & Pam Cella
Mrs. Joseph Daly
Jean Krauss
Karen Evenson
John and Nancy Golden
Mary Helebrant
Joel & Ellen Janski
Andy & Pam Joe
Jean Kandt
Irene Kelly
Marsha Kohler
Connie Kretsch
Adrienne Lenling
Marilyn Lindquist
Bruce & LaDonne Loehrke
Craig Looney
Terry & Nick Mace
Michael Maguire
Margaret Moffit
Robert & Gayle Newman
Mary Ollhoff
Stephen O'Neil
Skye Peltier
Janice Rossbach
Neil & Nancy Sand
Marie Storhaug
Catherine Treichel
Bill & Kathy Wussow
Orville & Joan Zemke

Fitness Event in Fargo

Medical staff from our HTC in Fargo (MeritCare/Roger Maris Hospital) held a family bowling event on Saturday February 2nd. Activities opened with 30 minute stretching instruction by Physical Therapist, Linda Thorseth. PA Kathy Wussow and RN Cortenay Misheski bowled with a group of 38 community members. High scores for the day went to Sherri Ouellette and Courtney Misheski who each bowled over a 170 game! The event concluded with pizza and soda for all.



NEW 2000 IU
Kogenate[®] FS with
BIO-SET[®]

NEW Small
Grab & Go
Package

For more information, please contact your local Bayer HealthCare Account Executive, Nancy Golden, at (612) 810-1186, or by e-mail at nancy.golden@bayer.com.

Kogenate FS
Antihemophilic Factor (Recombinant)
Formulated with Sucrose
with BIO-SET[®]
Needleless Reconstitution System



BAYER, the Bayer Cross, and Kogenate are registered trademarks of Bayer. BIO-SET is a trademark of Biodome SAS.

©2007 Bayer HealthCare LLC. All rights reserved. Printed in USA 8/07 09147Y

Wyeth's XYNTHA Approved by FDA for Treatment of Hemophilia A

XYNTHA represents important improvements in product purification technology Collegeville, Pa., February 21, 2008* — Wyeth Pharmaceuticals, a division of Wyeth (NYSE:WYE), announced today that it has received approval from the U.S. Food and Drug Administration for XYNTHA™ (Antihemophilic Factor [Recombinant], Plasma/Albumin-Free), a recombinant factor VIII product, for patients with hemophilia A for both the control and prevention of bleeding episodes and surgical prophylaxis. XYNTHA (pronounced "ZIN-tha") is manufactured using a completely albumin-free process and state-of-the-art nanofiltration purification technology. In addition, XYNTHA is the only recombinant factor VIII product to utilize an entirely synthetic (non-human and non-animal based) purification process in its manufacture.

Please see XYNTHA full Prescribing Information available at www.wyeth.com. Wyeth Pharmaceuticals (484) 865-6671 (973) 660-5340

Promising New Recombinant Factor IX Drug Receives FDA Approval for Clinical Studies

Biovitrum AB and Syntonix Pharmaceuticals received U.S. Food and Drug Administration approval to begin phase I/IIa clinical studies to measure the safety, tolerability and pharmacokinetics of their recombinant factor IX (FIXFc) drug in previously treated patients with hemophilia B. The pharmacokinetic portion of the studies will focus largely on the product's half-life. Extending the half-life of the product could allow for less frequent infusions for individuals with hemophilia B, whether they are treating prophylactically or episodically, as bleeds occur.

Syntonix's technologies employ therapeutic proteins, peptides and antibodies to help create longer-acting biopharmaceutical therapies to treat chronic disorders such as anemia, multiple sclerosis and autoimmune disorders. Biovitrum develops and manufactures protein-based therapies for common diseases and those affecting smaller populations.

"Hemophilia is a prioritized therapeutic and business area within Biovitrum," said Martin Nicklasson, CEO of Biovitrum. "We are excited to develop FIXFc with Syntonix because we believe that the company's SynFusion™ technology has resulted in a very promising, long-acting recombinant Factor IX product opportunity that has the potential to reduce the frequency of infusions required for hemophilia B patients to manage their disease."

Biovitrum has headquarters in Sweden and the United Kingdom. Syntonix, a wholly-owned subsidiary of Biogen Idec, is based in Waltham, MA. The two companies first entered into a co-development and commercialization alliance to develop FIXFc in January 2006.

The only recombinant factor IX product currently available in the U.S. is Wyeth Pharmaceutical's BeneFIX®.

Source: Biovitrum press release dated March 4, 2008

***Hemophilia Foundation
of Minnesota/Dakotas
Board of Directors
2008-2009***

Dan Tinklenberg, Interim President
St. Louis Park, MN

Bob Stone, Vice President
Fargo, ND

Elizabeth Meyers, Secretary
Mellette, SD

Steph Miller, Interim Treasurer
Savage, MN

Beth Andersen
Walker, MN

Jim Brown
Lincoln, NE

Denise Cadwell
Hastings, MN

Jim Langworthy
Rochester, MN

Brenda Neubauer
Bismarck, ND

John Schulte
Woodbury, MN

Peggy Wier
Eagan, MN

Kathy Wussow
Fargo, ND

Staff:
Jim Paist
Executive Director

Pam Cella
Office Manager

Grifols is pleased to announce the launching of

Alphanate®
Antihemophilic Factor/von Willebrand Factor Complex (Human)

GRIFOLS

Grifols USA, Inc. 10000 Woodloch Forest Drive, Suite 100, Dallas, TX 75244
Customer Service: 800-225-8776 FAX: 214-347-4022 www.grifols.com

HFMD Board News

In February, HFMD Board President Aaron Reeves decided to step down from the board because he is starting a new position as the City Administrator of Cannon Falls, Minnesota. Aaron served six years as Board President demonstrating strong leadership throughout his term. He also volunteered on a number of committees. The HFMD would like to thank Aaron for his countless hours of time volunteered and for leading the organization so successfully.

We would also like to extend a very special thanks to Bill Kallberg. Bill had served on the HFMD board for the past two years and has been a very active volunteer with this organization for nearly forty years. He has been a big part of HFMD's success with outstanding work on our fundraising events, community programs, and public policy advocacy.

Venline

NEWSLETTER OF
THE HEMOPHILIA
FOUNDATION OF
MINNESOTA AND
THE DAKOTAS

HFMD
750 South Plaza Drive
Suite 207
Mendota Heights, MN 55120

Phone: 651.406.8655
Fax: 651.406.8656
1-800-994-4363
Email: hemophiliafound@visi.com

We're on the web!
www.hfmd.org

Prsrt Std
U S Postage
PAID
Lone Oak
Mailing Services

2008 Calendar

July 13 – 19, 2008.....Summer Camp, Courage North
Lake George, 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

November 13 – 15, 2008.....NHF's 60th Annual Meeting
Denver, CO

**Summer Group Fitness Events To Be Announced
**The HFMD Board of Directors meets every month on the third
Tuesday at 7:00 p.m.**

Visit our website: hfmd.org for exciting news and updates!

