

HFMD MISSION

We dedicate ourselves to advancing the quality of life of individuals and families affected by hemophilia or other bleeding disorders by providing a broad range of services and programs.

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HFMD Walk 2015 “Step Out for Bleeding Disorders” Saturday October 3rd

Dear HFMD Members, Friends, and Supporters,

We have kicked off our 5th Annual Walk fundraiser online and family teams are up and running now on our Walk website at www.firstgiving.com/hfmd. We ask you to join the fun and form your Team today, or register as an individual. HFMD Walk teams can be families, couples, individuals or groups, and you can take the lead by becoming your Team Captain.

Forming a Team on our Walk Website is fun and easy to set up. You can name your Team, post pictures on your page, and begin reaching out to family & friends to join your Team and donate. Everyone can participate even if they can't attend the walk on October 3rd. The HFMD Walk is an important source of funding for this organization to carry out the programs and services we provide for our

bleeding disorders community. Our annual Walk has been so successful thanks to all of the Teams who have raised donations and are currently doing so on our site at:



www.firstgiving.com/hfmd



Please support the HFMD by creating your Walk Team today!!!





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2015 HFMD Annual Meeting



Everyone you know is fighting a battle you know nothing about. Exhilarating. Change. Joy. Fear. Abrupt. Just a few words that at one time or another can describe a life situation for anyone, at any given time. No matter who you are or what you're dealing with, we can all agree - "Our World is a Rollercoaster" – the theme of the 2015 HFMD Annual Meeting. On April 10th and 11th members of the HFMD, HTC staff, and a record turnout of 18 exhibitors came together to support and learn from one another at the Crowne Plaza in Bloomington, MN. As the long registration line finally came to an end, attendees hurried to finish their dinner to be the first to jump on the HFMD shuttle.

In addition to our record turnout of exhibitors, we are proud to announce our record turnout of children – 44 kids! We have one small guess as to where the hype from our kids came from – the HFMD shuttle ride to Nickelodeon Universe at the Mall of America! The shuttle went back and forth from our hotel to

MoA every 30 minutes, driving attendees to and from as needed until 10 o'clock at night. The group spent the night twisting, turning, jumping, and spinning in Minnesota's largest indoor theme park. With 7-acres of rides and attractions, park-goers were able to leave any possible worry behind and fly through wild and unpredictable changes...on *real* rollercoasters!

Saturday morning the group met up for time with exhibitors, in some very close quarters until breakfast was served. After HFMD's opening address and updates, parents brought their children to the magnificent HFMD childcare team lead by Vicki Neis, CCLS. This year's child programming theme was, "Bugs and Spring Creatures Explorers". Children were introduced and reacquainted to one another and got down to fun and education, complete with a fieldtrip to the Minnesota Wild Life Refuge Center. Meanwhile, our teens had a great time with Bio Rx's "Clot Shots" team. Teens broke up into groups and learned "hands on" lessons in commercial, high-def film production techniques, including writing, filing, acting, lighting, editing, and directing.

Back in the main ballroom, adults rejoined to listen to this year's keynote speaker, Mark Reding, MD from the University of Minnesota's Center for Bleeding & Clotting Disorders. Dr. Reding touched on topics such as new treatments coming down the pipeline. Thank you, Dr. Reding for spending time with our members! After the keynote address and more time with exhibitors, attendees broke for morning breakout sessions. This year's breakouts included: Biogen Idec's, "Managing Chaos" – a program chosen to help deal with our life's rollercoasters, a Carriers/Woman's Session and a Young Family Mentoring session where parents of young children with a bleeding disorder networked with parents that have had more practice working with bleeding disorders.



continued on page 11

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Miriam
Caregiver, Miami, FL

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June 2015 USBS/MG1/15-0381

BLOOD BROTHERHOOD - TWINS GAME



On Sunday, May 17th, 2015 our Blood Brothers gathered at the beautiful Target Field for a MN Twins game against the Tampa Bay, Rays. The afternoon later turned into rain, but that didn't matter for our Blood Brothers as they were tucked away in a swanky MN Twins Premier Suite. The event began with an interactive presentation on nutrition, "Good Fats and Protein", by Joni Osip, NP from the UoMN's Center for Bleeding and Clotting Disorders. Thank you, Joni, for making the educational piece so engaging and fun! And a special thanks for the healthy

treats that you brought! Our guest services team then brought in the food, and lots of it! The Blood Brothers enjoyed kettle chips and dip, popcorn, a snack basket, caesar salad, grilled quesadillas, hot dogs, chicken tenders, sliders, and cookies and brownies! Everyone had a great time catching up with one another and discussing plans for the next Blood Brotherhood event. Please watch for the next BB event flyer! The HFMD would like to thank the Hemophilia Federation of America and Baxalta (formerly Baxter BioScience) for sponsoring this event!

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 Tap into it!
 COAGULATION

Summer Fitness Event at **BUNKER BEACH**



The Hemophilia Foundation of Minnesota/Dakotas hit the ground running this summer with our Summer Fitness Event that took place at Minnesota's largest outdoor water park, Bunker Beach. We had a great turn out this year with 65 people and plenty to eat! Though the skies looked ominous early in the day, they cleared up in time for our event and it turned out to be a beautiful sunny day.

Bunker Beach is loaded with fun activities for the entire family. There is a 900-foot lazy river, a wave pool that generates 3-foot

waves, several slides, a sand box, volleyball court, and so much more. Our group gathered in the south beach pavilion where they could put their things down and go straight to the water park.

After about an hour of swimming fun, we all met under the pavilion for some entertainment and lunch. The families had an option of hot dogs, burgers, corndogs, and a choice of chips with a drink. The food went fast, but many had the opportunity to have seconds! Our education for the day was Dr. Heisel. She brought up topics that each of our families could relate to and at the end of her presentation, we had a very successful question and answer session. Members could ask Dr. Heisel anything and we even had a younger member ask a question!

Once Dr. Heisel finished presenting, the families finished up eating and headed straight to the water. Dr. Heisel and Angie Boyd, HTC Coordinator at Children's Hospital and Clinics of Minnesota, stuck around to talk with the families about any concerns or topics they had on their mind. It was a lovely day for our families to enjoy the water park and enjoy each other's company. Families had plenty of free time to mingle and listen to each other's stories. Be sure to keep an eye out for our next Fitness Event, it is a great way to get to know other families in the HFMD community!



By Ketrin Vinokur

NHF Leadership Conference 2015



This annual conference hosted by the National Hemophilia Foundation is designed to educate and inform affiliated chapter staff and Board members with information pertaining to the operations of a non-profit agency and issues related to bleeding disorders.

Joined by HFMD Board President, John Scott Schulte, we arrived in Tempe AZ for this four-day conference on May 11th. The opening session that day featured some ice-breakers and a presentation on chapters of excellence. NHF is making a concerted effort to encourage all of their affiliated chapters to have a standard base of programs and services for their members. Chapters are required to meet these standards in order to remain an NHF chapter.

The second and third day included presentations running from 8:00 a.m. – 5:00 p.m. While all of the speakers shared some good information, there were several that stood out to me. For example, an attorney from North Carolina presented on a wide range of liability issues that non-profit managers should be aware of, well prepared for, and a completely insured organization.

Another interesting presentation focused on potential risks that volunteers can bring to a non-profit agency. First, many smaller organizations like HFMD with just a few staff depend on volunteers to help host our events and we have been very fortunate to have such great volunteers who have not created any problems for us. But, there are certainly other organizations that have had negative experiences with a very small number of volunteers. The presentation suggested requiring a formal volunteer application and conducting background checks on volunteers you may want to bring aboard. To make it easier for volunteers to understand what is expected of them, there should also be a clear description of their tasks.

These NHF conferences are an excellent opportunity for catching up with other chapter staff to find out what new programs and events they are doing for their members. It is also helpful to share fundraising strategies and organizational policies.

NHF staff did a terrific job in hosting this conference! The conference was generously sponsored by Baxalta (formerly Baxter), Bayer Healthcare, Biogen, CSL Behring, Grifols, Hemophilia Alliance, Novo Nordisk, and Pfizer. On behalf of the HFMD, I thank NHF and event sponsors for hosting such an informative conference.

By James Paist



BeneFix
Coagulation Factor IX (Recombinant)
Room Temperature Storage

**I LIKE TO STAY ACTIVE.
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BeneFix is the most prescribed recombinant factor IX treatment FDA approved for hemophilia B.*

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IMPORTANT SAFETY INFORMATION FOR BENEFIX

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash or hives.
- Your body can make antibodies, called "inhibitors," which may interfere with the effectiveness of BeneFix.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

- Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

WHAT IS BENEFIX?

BeneFix® Coagulation Factor IX (Recombinant) is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

Please see brief summary of full Prescribing Information on next page.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

*BeneFix was approved February 11, 1997.

†IMS National Prescription data October 2013.



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R_x only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-934-5556.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal remedies.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take.

Your doctor may need to test your blood from time to time.

BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing
difficulty breathing
chest tightness
turning blue (look at lips and gums)
fast heartbeat
swelling of the face
faintness
rash
hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE BeneFix. BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Store the diluent syringe at 36° to 86°F (2° to 30°C). Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

Different storage conditions are described below.

Product labeled for Room Temperature Storage Store at 2° to 30°C (36° to 86°F).

If you have the product kit labeled for room temperature storage, it can be stored at room temperature (below 30°C or 86°F) or in the refrigerator (2° to 8°C or 36° to 46°F).

Product labeled for Refrigerator Storage Continuous refrigeration

[2° to 8°C (36° to 46°F)]

If you have the product labeled for storage in the refrigerator (2° to 8°C or 36° to 46°F) and you have not taken the kit out of the refrigerator, then the expiration date printed on the package still applies. You can store the product at room temperature (below 30°C or 86°F) for up to 6 months or until it has reached its expiration date, whichever comes first.

If you have taken the product kit labeled for storage in the refrigerator out of the refrigerator and stored it at room temperature (below 30°C or 86°F), then use the product within 6 months from the time you took the product out of the refrigerator or until it has reached its expiration date, whichever comes first. If you cannot remember when you took it out of the refrigerator, then subtract one year (12 months) from the date that is printed on the end flap of the carton package. The date you get is your new expiration date. Throw away any product that has gone over the new expiration date.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use BeneFix for a condition for which it was not prescribed. Do not share BeneFix with other people, even if they have the same symptoms that you have.

If you would like more information, talk to your doctor. You can ask your doctor for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® Coagulation Factor IX (Recombinant) Prescribing Information LAB-0464-8.0, revised November 2011.

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HTC=Hemophilia Treatment Center; pdFVIII=plasma-derived factor VIII

Indications

ALPHANATE® (antihemophilic factor/von Willebrand factor complex [human]) is indicated for:

- Control and prevention of bleeding in patients with hemophilia A
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Important Safety Information

ALPHANATE is contraindicated in patients who have manifested life-threatening immediate hypersensitivity reactions, including anaphylaxis, to the product or its components.

Anaphylaxis and severe hypersensitivity reactions are possible. Should symptoms occur, treatment with ALPHANATE should be discontinued, and emergency treatment should be sought.

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Plasma products carry a risk of transmitting infectious agents, such as viruses, and theoretically, the Creutzfeldt-Jakob disease (CJD) agent, despite steps designed to reduce this risk.

The most frequent adverse events reported with ALPHANATE in >5% of patients are respiratory distress, pruritus, rash, urticaria, face edema, paresthesia, pain, fever, chills, joint pain, and fatigue.

Please see brief summary of ALPHANATE full Prescribing Information on adjacent page.

You are encouraged to report negative side effects of prescription drugs to the FDA.
Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.



For more information: **Grifols Biologicals Inc.**
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GRIFOLS

...continued from page 3



After lunch, children and teens rejoined their assigned groups, while adults broke for afternoon breakouts. Afternoon breakouts included: Baxter BioScience's, "Navigating Health Insurance", which can be the Kingda Ka of all rollercoasters, a Blood Brotherhood session lead by Mark Weisberg, Ph.D., ABPP, titled, "Integrative Medicine Approaches". Dr. Weisberg reviewed the relationship between stress, bleeding, and pain and led a group discussion on techniques for reducing stress and

managing bleeding pain episodes. And last, but certainly not least, the always acclaimed, "Ask the Doctors" session with Margaret Heisel-Kurth, MD, Mark Reding, MD, and Susan Kearney, MD. Due to the level of popularity of this session, plan for next year's Annual Meeting to host the, "Ask the Doctors" as a keynote address.

A huge thank you to our Annual Meeting Planning Committee: Co-Chairs: Amy Eckerman & Jim Paist and the committee: Angie Boyd, Carrie Kissoon, David Moss, Nancy Golden, Vicki Neis, and Vicky Hannemann.

The HFMD would like to extend a special thank you to our event sponsors: Baxalta (formerly Baxter BioScience), Children's Hospitals and Clinics of Minnesota, Mayo Clinic, and U of MN Medical Center, Fairview. We would also like to give our thanks to our exhibitors: Accredo Health, ARJ Infusion Service, Axelacare, Baxalta, Bayer HealthCare, Biogen, Bio RX, CSL Behring, CVS Caremark, Emergent, Grifols, Kedrion Biopharma, Mid-West Cornerstone Healthcare, Novo Nordisk, Octapharma, Pfizer, Superior Biologics and Option Care (formerly known as Walgreens Infusion Services).

Please save the date for the 2016 HFMD Annual Meeting on April 22nd and 23rd, 2016 at the Hilton Airport/MoA in Bloomington, MN! We look forward to seeing you there for more networking, education, and FUN!

By Carrie Kisson, HFMD Event Coordinator



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Hemophilia
stop you from
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Jen's son, Donovan, lives with hemophilia A with inhibitors.



Jasmine lives with Glanzmann's thrombasthenia.

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Board & Staff News

We have recently welcomed community members Vidar Romerheim and Bob Newman to the HFMD Board. With a background in engineering, Vidar brings a unique skill set to our Board. He, his wife Kari and the Romerheim family have also been our 1st place Walk Team the past two years demonstrating effective fundraising skills. Bob Newman is a talented artist, a former President of the HFMD Board, and recipient of our Lifetime Achievement Award. At age 86 he brings decades of experience to the table. Also newly elected to the HFMD Board by our Industry Relations Committee are Troy Gleason (Novo Nordisk) and Jessica Hutchison (Accredo). While they are both non-voting members, our Board values the perspective of our Industry Relations Committee Representatives.

HFMD is also happy to welcome back our summer intern, Ketrin Vinokur.

THE VEINLINE IS MOVING TOWARD *PAPERLESS!!!*

If you would like to receive future issues of the Veinline via email instead of hard copy, please email us at info@hfmd.org and let us know the email address(es) where you would like to receive future newsletters?

Organizational Contributors:

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Deano's Collision and Mechanical
National Coatings & Supplies/Norton Abrasives

Up to \$499

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United Health Group

\$1,000 and Up

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Frank Kurth & Margaret Heisel-Kurth
Jai & Carrie Kissoon
Patrick McNamee
Pat & Amy O'Malley
Carol Tucker (2014 omission)

\$500 - \$999

Susan Bickmore
Chris Collins
Tim & Diane Boonstra
Dusty & Bethany Diekman
Pat & Julie Dorsey
Jonathan & Aimee Grant
Jeff & Char Kandt
Randy & Laura Halter
Andrew Lawrence
Roxanne Makepeace
Jim & Stephanie Miller
Larry & Maria Patterson
Tom & Karen Pettyes
Scott Rappa
Aaron Reeves
Dr. Kearney & Dr. Rothaar
Theresa Schneider
Jennifer Paist & Tom Tiegen
Tom & Cheryl Wistrom

\$200 - \$499

Jon & Beth Andersen
Ken & Alix Behm
Karen Bohrer
In memory of Martha Richter
Jennifer Breitinger
Perry & Stacie Cowen
Jason & Helen Dohm
Greg & Rhonda Gilmer
In memory of Paul Gilmer
Alfred & Vicky Hanneman
Deon & Kathy Kissoon
Larry Kruse
Sarah Langhout
Annie Ly
Joel & Kris Manns
Tim & Patti O'Brien
James Paist
Mike & Shirley Propp
Mike Ragan
Bob & Jill Riley
Jon Schlosser

Sandra Schlosser
Jeff Schmidt
Jon Schulte
Bob Tinklenberg
Estate of Margaret (Peg)
Vogelgesang
In memory of Paul Gilmer
Mike Wheeler

\$100 - \$199

Angela Boyd
Nathan Bremer
Christina Chan
Phil & Sue Curoe
John & Amy Eckerman
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David Singer
Paul Skoog
Monte Smith
Dan Tinklenberg
Elwen & Terry Tinklenberg
Barry & Heather Vaughan
Brian Zeuli

\$50 - \$99

Brenda Adamson
Stacie Bernhoft
Eva Breitinger
Dave Diederichs
Larry & Patty Gavin
Dayna Hansen
Mark & Rebecca Hunter
Jessica Hutchison
Jason Kalenborn

Aran Kissoon
Rich Lantz
Jessica Libby
on behalf of Nathan Kvittum
Lois Nyman
Dawn Olive
Kathi Reeves
Simon & Abbey Stark Lowes Up to \$49

Patricia Alver
John Bahnemann
Nick & Jodi Buche
Paul Crooks
John Fenwick
David & Kari Franklin
Rosie Gutteridge
Michael Johnson
Kathy Leese
Kim Makela
Zach Schaeffer
David Schlosser
Tessah Schmidt
Mark Simpson
Stephen Strouder
Ericka Webb

In Memory of Dr. J. Roger Edson
Margaret Beauvais
Cheryl Ellefson
Jody Hargrove
Elizabeth Merchant
Jeanne Mugge
Stewart Rosoff
James & Bonnie Schmidt
U of M Physicians, Faculty & Staff
Dept of Laboratory Medicine & Pathology

The HFMD gratefully acknowledges our donors who have given so generously. Below are donations received from January 1, 2015 through JUNE 30, 2015. If you have made a donation and your name is not listed, please contact HFMD.

Post-Secondary Scholarships 2015

This year a number of wonderful candidates applied for the HFMD Post-Secondary Scholarship Award. In total eleven scholarship recipients were awarded \$900 each to assist with tuition expenses of the 2015-2016 school year at the college or vocational school they attend.

Following is a note HFMD received from one of the recipients:

Dear HFMD,

"I would like to take this opportunity to give you my many thanks for having received the HFMD scholarship. I truly cannot express how much this award will help me in my pursuit of a career in Physical Therapy. In short, this award is very much appreciated by myself and my family. Thank you so much. I will remember your generosity all throughout college."

Editor Notes

The HFMD deeply regrets the unintentional omission of the Mayo Clinic Factor Program in the Donor Section in our Spring 2015 issue of the Vein-line. We are grateful for their very generous donation of \$25,000 to this organization in 2015!!!

In Memory of Paul Hanson



Hanson, Paul A. age 58, of Apple Valley, passed away on June 21, 2015. He was a US Navy veteran from 1976-1980. Preceded in death by mother, Elleonore and sister, Silvia. Survived by son, Nicholas; father, Kenneth; siblings, Robin, Dolores, Diane; and many friends. Copied from Star Tribune June 25th.

Our deepest sympathies from the HFMD go out to his son Nicholas and the entire Hanson family. Paul was such a loyal and generous member of this organization. It was always fun to see Paul at our events with his energy and quick wit. He will truly be missed by many friends at the HFMD. Paul and Nicholas pictured center below at our group fitness basketball clinic in 2007.

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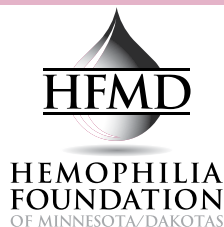
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Donations can be made by sending them to the HFMD office or on our website www.hfmd.org using the PayPal donate button.



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2015 Calendar of Events

- July 12-17, 2015..... Camp Courage North (True Friends)
- August 13 - 15, 2015.....NHF's 67th Annual Meeting
Dallas, TX
- October 3, 2015.....Step Out for Bleeding Disorders Walk
Como Park, St. Paul
- February 20, 2016..... 2016 Hearts of Hope Gala
Radisson Blu, Mall of America
- April 22 - 23, 2016..... HFMD's Annual Meeting
Hilton Minneapolis/St. Paul Airport Mall of America

Visit our web site at www.hfmd.org for exciting news and updates!