

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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Blood Brotherhood Comedy Night

The HFMD has been a part of the Hemophilia Federation of America’s Blood Brotherhood program since July 2010. Through the BB program, the HFMD organizes a number of events for our adult men living with bleeding disorders ranging from chat sessions via teleconference to Twins baseball and Wild hockey games. Each event is designed to offer a night out to reconnect with one another and to stay involved and active in our community. Through educational pieces and most importantly, a good time, Blood Brothers are able to share their experiences, offer ideas on how to cope, and always unite with a good laugh! Thanks to a little planning group of Blood Brothers, our latest event was filled with improv and a lot of laughter!

On Friday, November 4th, our Blood Brothers met out in Chanhassen for dinner, a financial speaker, and Stevie Ray’s Comedy Cabaret Show at the Chanhassen Dinner Theater. Everyone arrived at 7:00PM, happy to reconvene and get our dinner on. With signage directing us through to our private seating area, the guys quickly caught up with one another and settled in as our server took our dinner orders - choosing between hearty portions of steak, chicken, and fish plates. As requested, the guys partook in a short, but informative piece from Beverly Cory, AAMS, Edward Jones, on personal financial management. During our meal, we learned about budgeting, investment basics, and hammered out questions about social security. After dinner we hurried down the ramp, into Stevie Ray’s comedy room where we were seated at the front tables, ready for some roasting. Stevie Ray’s Comedy Troupe performed a comedy variety show of improve, sketches, and music. Our group really seemed to be having a great time. Several of our guys even participated with witty suggestions for some of the comedy sketches and even got on stage for their comedy debut. Our dear friend, Tom Dudinsky, who recently passed away, was the life of the show! He really got a kick out of giving the poor comedians a hard time, which made it even funnier for the rest of us. The comedians were hilarious and judging from the smiles as you looked around, you knew everyone was having a great time. After a great night of bonding, learning, and enjoyment, we packed everybody up and headed off.



If you or someone you know would like more information about our Blood Brotherhood program, please contact the HFMD or visit: www.hfmd.org and click on the Blood Brotherhood link.

By Carrie Kissoon
Event Coordinator

TRIBUTE TO THOMAS DUDINSKY

The HFMD lost a Blood Brother on Sunday December 11th, 2011. Tom Dudinsky will be dearly missed by this organization, the bleeding disorders community, friends, and family. Tom was an original HFMD Blood Brother who attended nearly all of our events for adult men with bleeding disorders. When we had an upcoming event, guys would often ask; is Tom going to be there? As someone who was easy to like, Tom was friends with many other guys who also have hemophilia. Tom was involved with the HFMD for many years as a volunteer and advocate for the bleeding disorders community. Our thoughts and prayers are with the Dudinsky family.



Tom Dudinsky pictured (right) with friends Chris Maddix (left) and David Frelix (middle) at TCF Bank Stadium.

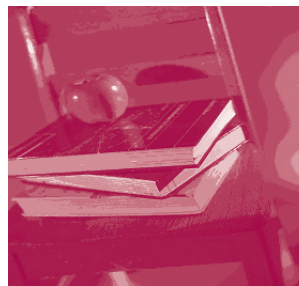
KATHY KIRKEBY

After six years of caring for patients and organizing community events in North Dakota, Kathy Kirkeby is leaving the Sanford Hemophilia Treatment Center in Fargo. Kathy was promoted to Lieutenant Colonel in the Air National Guard where she now has a fulltime commitment.

Kathy will be missed by her patients, staff, and Dr. Nathan Kobrinski who she worked with side by side as his Physician's Assistant. Kathy will also be missed by the HFMD who worked closely with Kathy during this time in planning numerous education events throughout the year. Kathy made a big impact on seeing that there were more opportunities for patient/family community events in the Fargo area. She even led a few in Bismarck. Part of her success in this area was being so persuasive in getting families to turnout for the events. It was hard for anyone to say no to Kathy when she extended a personal invitation with a phone call.

In addition to all of her medical related work at the clinic, she found time to help bring the community together for fun and festive occasions. With a positive attitude and great sense of humor, Kathy always made the events fun and relaxed. The HFMD would like to salute Kathy on her military promotion and thank her for all of the good work she did for our North Dakota patients and families.

2012 HFMD Scholarship Applications



Knowing that education is usually necessary for people to attain the kind of work they dream of, the Hemophilia Foundation will again be accepting scholarship applications for post-secondary education beginning January 30, 2012. Forms will be available, at that time, by calling the HFMD office at 651-406-8655 or 1-800-994-4363, or on line at 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 being a patient of one of the Hemophilia Treatment Centers in these states, and be a participant in HFMD programs and services, and (3) be accepted into a post-secondary educational program.



HFMD's 12th Annual
Hearts of Hope Gala



“DIAMONDS TO DENIM”

Saturday, February 11, 2012
Minneapolis Airport Marriott
Bloomington, MN

Cocktails & Silent Auction at 5:30 p.m.

Wine Wall with a Cork Drawing

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ND FAMILY EDUCATION DAY

The ND Family Education Day was held this year on October 15, 2011 in Fargo, ND to honor Dr. Nathan Kobrinsky's 20 years as director of the North Dakota Hemophilia Center. There were about 100 attendees including patients, family members, staff, and industry.

The program included a great presentation from Dr. Kobrinsky, his former nurse who helped start the HTC, Dottie Stegman, and lifelong patient, Robert Stone. The program also included a great presentation from Cazandra MacDonald, sponsored by Walgreens Infusion Services. She too shared her experiences with having two sons with hemophilia.

Many of the families took the opportunity to express their gratitude, as well as share personal stories about how Dr Kobrinsky had affected their lives over the past 20 years. With many of these heartfelt stories came tears not only from families but from all who were present. It was truly evident that Dr Kobrinsky has touched many lives and that he will continue his commitment to the treatment of hemophilia.

A plaque sponsored by HFMD for Dr Kobrinsky's 20 years as director to the ND HTC was presented to him by Robert Stone.

Following the presentations, "Minute To Win It" challenge took place. We had teams of 5 with 5 challenges. One team was successful at getting all 5 challenges in less than a minute. That team was Chelsea and Stephen Strand, Sam Friedrich, Miranda and Andrew Solem. We also had a team who were all of over the age of 70 who did a great job missing only one. The 1st place team each received a gift card from Walmart.

3 door prizes sponsored by HFMD were also given away. An assortment of games to Rob and Nicole McIvor family, cookbook and cooking basket to Jan Titus, and a movie night basket to Adam Bohrer.

We would like to thank our sponsors Baxter BioScience and Sanford Health. The following exhibitors

also supported the event and shared information about their products and services without guests: Accredo HHS, ARJ Infusion Services, AxelaCare, Baxter BioScience, Bayer, CSL Behring, Grifols USA, Kedrion BioPharma, Inc., Octapharma Plasma, Pfizer, and Walgreens Infusion Services.

Despite all the trials and tribulations that HFMD went through to make this a success, the facilities turned out to be great with plenty of room, Ramada staff were quite helpful that day and the food was great. HFMD also provided a bonded daycare team from Minneapolis to watch the younger children during the day. A picture slide show was presented during the evening meal by Mark Wiener, CSL Behring. The pictures dated back from 1995 to 2011 including pictures taken at the event which made it complete. A special thanks for all you who came out to honor Dr Kobrinski.

By Kathy Kirkeby, Nurse Coordinator, Sanford Health HTC, Fargo

2011 Board Retreat

Each year the HFMD board holds an all day meeting to review organizational programs, services, and financial statements. Board officers are nominated and elected in the process. Dan Tinklenberg was reelected as Board President, Steph Miller was reelected as Treasurer, and Liz Myers remains as Board Secretary. Aaron Reeves was nominated and elected as the new Board Vice President.

Steph Miller reported on 2011 financial statements which were very close to what had been budgeted. There were good discussions on the state of the HFMD. Our first annual Walk, "Step Out for Bleeding Disorders" was a big success, and we had a record turnout of 250 attendees at the Annual Meeting back in April. These are just some of the highlights from 2011. It was another good year for the Foundation and we look forward to an exciting year with our members in 2012.

“Bad Blood” Movie Screening

On Sat. Nov. 5th, 2011 the documentary “Bad Blood: A Cautionary Tale” was viewed by a group of families, teens and medical staff at Children’s Hospitals and Clinics of Minnesota in Minneapolis.

“Bad Blood” tells the story of the 1980’s HIV/AIDS crisis from the “hemophilia perspective” by interviewing families, medical staff and government workers who were involved and deeply affected, as so many were.

The day started with Dr. Margaret Heisel Kurth giving an introduction and brief presentation on the history of HIV and AIDS in the world, in the United States and more specifically in Minnesota. After Dr. Heisel Kurth’s presentation the group watched the full-length documentary.

When the film was over Dr. Heisel Kurth again took the stage for discussion and questions. The group had a great discussion with many thought-provoking questions, including several from the teens in attendance. Everyone was grateful to Dr. Heisel Kurth for leading the discussion and answering the questions in an honest and open way. She emphasized the importance of open communication and talking about what happened so it doesn’t get forgotten, and so that families and patients that are new to the bleeding disorders community are aware of the tragedy, the lessons learned and what has happened since to greatly improve the safety of blood and factor products.

If you would like to know more, there was a great article in the “Parent Empowerment Newsletter” by LA Kelley Communications, Inc. in the November 2010 Issue. Google “Bad Blood, Good Movie? PEN article November 2010” to find the article and more information about the movie.

Thanks to the staff at HFMD for organizing the event and providing lunch! Thanks to the staff of Children’s Hospitals and Clinics of Minnesota and the University of Minnesota Center for Bleeding and Clotting Disorders for attending and participating in this important discussion, especially Dr. Heisel Kurth and Dr. Mark Reding. Also thanks to Vicki Neis, Children’s Child Life Specialist and Children’s Volunteer Services for providing education and child care to the kids!

Mark your calendars, on Sat. March 10th we will be viewing another film, “Thicker than Water” which is a documentary of a family from Minnesota dealing with sports choices and hemophilia. This will be at the same location – the Education Center at Children’s Hospital in Minneapolis starting at 10am. Hope to see you there!

By Angie Boyd, Hemophilia Treatment Center Coordinator, Children’s Hospitals & Clinics

CARRIE KISSOON

HFMD hired intern Carrie Kissoon as the part-time Event Coordinator. After successfully completing a one year internship at the Foundation, demonstrating strong skills in event planning, fundraising, and community organizing, Carrie earned a part-time position.

During her internship, Carrie played a key role in planning and executing HFMD 1st Annual Walk fundraiser. She was an effective Site Coordinator for our Blood Brotherhood program and will continue in that role to help plan and lead events for adult men with hemophilia. Carrie has proven her skills in getting items donated for our Gala and has shown leadership during committee meetings. The HFMD is pleased to welcome Carrie aboard for 2012.



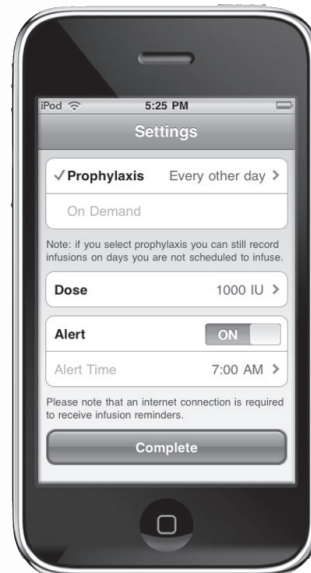
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of Minnesota/Dakotas
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Coming Soon!

HFMD's 2012 Annual Meeting "Anything is Possible"

Come join us for Programs, Activities for all ages,
and featuring your favorite
Friday Night 'State Fair' Carnival!

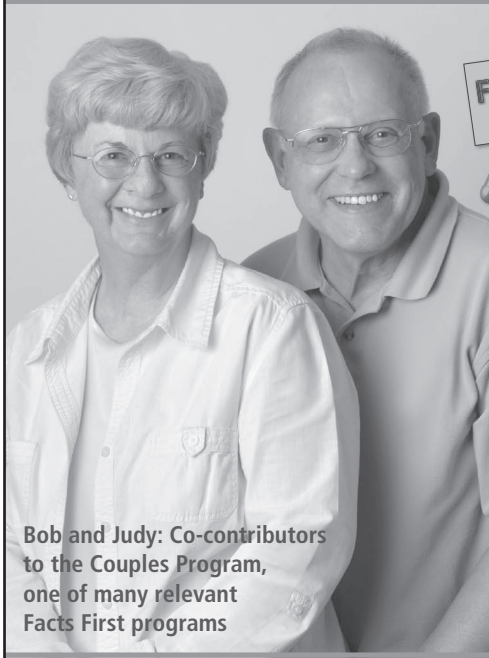
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April 20 & 21, 2012

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Contact your Baxter representative to learn more
about attending a Facts First program:

Stacie Cowen
(612) 701-5880
stacie_cowen@baxter.com

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Baxter's Commitment to
the Hemophilia Community

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Join us for a viewing of the Movie: **Thicker Than Water**

The film is about Tony, an 11-year-old who “absolutely, positively” loves hockey, and is about to play his last game. He is also a hemophiliac. The frequent scratches and bruises that mark the childhoods of active kids seem harmless to the healthy, but these same small injuries can be debilitating or fatal to a hemophiliac. Undeterred by a family history of chronic illness and loss, Tony’s parents continue to support and encourage his ambitions. *Thicker Than Water* is a documentary about dealing with chronic illness, living life to the fullest, and playing your last game as well as you can.



“I am absolutely amazed by this film. It addresses so many of the family issues of bleeding disorders.”

*Margaret Heisel Kurth, MD - Director Children's Hospitals and Clinics of Minnesota,
Hemophilia and Thrombosis Center*

Join Us:

We will be viewing the “Thicker Than Water”
Movie with time for comments and questions
with Dr. Margaret Heisel Kurth.

Room: Main Hospital 2nd Floor in the **Education
Center** – across from the 2nd Floor
Welcome Desk.

RSVP: By March 5th to the HFMD: (651) 406-8655
or email hemophiliafound@visi.com

What: Movie and Q & A

When: Saturday, March 10, 2012

Where: Children's Hospital of MN
Minneapolis Campus
2525 Chicago Avenue S.
Minneapolis, MN 55404

Time: 10:00 a.m.

Other: Child care and Lunch will be provided.

Baxter Announces Approval of ADVATE for Prophylaxis and Longer-Acting rFVIII Trial

Baxter International, Inc., announced in December 2011 that the U.S. Food and Drug Administration (FDA) has approved ADVATE, one of the company's recombinant factor VIII products, for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children (0-16 years) with hemophilia A.

The approval is based on a Phase IV, Baxter-sponsored study demonstrating that ADVATE for routine prophylaxis significantly reduced median annual bleed rates in hemophilia A patients from 44 to 1, compared to an on-demand regimen. In the study, 42% of patients had no bleeds during one year on prophylaxis.

“Emerging data provide important information to help physicians optimize care for hemophilia patients of all ages by preventing unexpected bleeding events that can have a detrimental impact on the lives of patients,” said Leonard Valentino, MD, Director, Rush Hemophilia and Thrombophilia Center and Section of Pediatric Hematology/Oncology, Rush University Medical Center, Chicago, and lead investigator of this study. “These data confirm the important clinical benefits of ADVATE when used as a prophylactic therapy to reduce bleeding episodes.”

ADVATE is also indicated for the control and prevention of bleeding episodes in adults and children (0-16 years) with hemophilia A, and perioperative management in adults and children (0-16 years) with hemophilia A.

Baxter also announced the dosing of the first patients in a Phase I clinical trial of its lead investigational candidate, BAX 855, a longer-acting (PEGylated) form of a full-length recombinant factor VIII (rFVIII) protein therapy. The manufacturing process for BAX 855, which uses rFVIII molecules and is free of plasma or albumin, is the same as that for ADVATE.

The Phase I trial is a prospective, open-label study that will assess the safety, tolerability and pharmacokinetics of BAX 855 in previously treated patients 12 years or older with severe hemophilia A. When used for prophylaxis, Baxter's ADVATE requires patients to infuse every two to three days to reduce the occurrence of bleeding episodes. This phase I trial is the first step in assessing whether BAX 855 can be infused less frequently.

“This trial is designed to provide new insights about our investigational longer-acting FVIII molecule, BAX 855, with the ultimate goal of improving care for patients living with hemophilia A,” said Hartmut J. Ehrlich, MD, vice president of global research and development in Baxter's BioScience business. “The Phase I results will serve as the foundation for advancing this important program through clinical development and determining whether BAX 855 can offer a treatment regimen requiring fewer infusions than ADVATE.”

Source: Baxter International, Inc.

FDA Approves Pfizer's BeneFIX® 3,000 IU Dosage

Pfizer Hemophilia recently announced that the U.S. Food and Drug Administration approved the 3,000 IU dosage strength of BeneFIX®, a recombinant factor IX product indicated for the control, prevention and peri-operative management of bleeding episodes in adult and pediatric patients with hemophilia B.

According to Pfizer, the new dosage option will be available to patients in the coming months. Pfizer Hemophilia is the first to offer this new dosage strength for hemophilia B patients, providing reconstitution convenience for those taking 3,000 IU or higher dosage strengths.

Source: Pfizer

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NEWSLETTER OF
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2012 Calendar of Events

- February 11.Hearts of Hope Gala
Minneapolis Airport Marriott
Bloomington, MN
- February 24-26. Mayo Family Retreat
Metropolis Resort
Eau Claire, WI
- February 25. Advocacy Workshop, 6:00 p.m.
Timber Lodge Steakhouse
Bloomington, MN
- March 10..... Movie Viewing "Thicker Than Water," 10:00 a.m.
Children's Hospital of MN
Minneapolis, MN
- March 23..... Blood Brotherhood Event, 6:00 p.m.
Nutritional Program and Dinner
Mall of America
- April 20-21..... HFMD Annual Meeting
Minneapolis Airport Marriott
Bloomington, MN
- July 22..... HFMD 2nd Annual Walk
Como Park Pavilion
St. Paul, MN
- August 5-10..... HFMD Summer Camp
Camp Courage, Maple Lake, MN
- October 26-28..... Minnesota Family Retreat
Arrowwood Resort & Conference Center
Alexandria, MN

****The HFMD Board of Directors meets quarterly on the fourth Tuesday at 7:00 p.m.****

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

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