

## HFMD Fitness in Action

On Saturday, June 29th, the HFMD Fitness program featured canoeing at Lake Calhoun in south Minneapolis. The weather was perfect and the waters were calm before we launched our boats and began paddling through the chain of lakes. Our captain for the day, Kerry Hansen, RN, shared a brief education session prior to leading our fleet of five canoes on a course which included going through Lake of the Isles and Brownie Lake before returning to the site of our launch at Lake Calhoun.



Kids and adults got a terrific cardiovascular workout paddling for just over one hour before we docked the boats. HFMD board member, John Schulte found a comfortable grassy area where we tossed footballs and Frisbees around for a while before lunch. Fitness Committee Chair, Dan Tinklenberg coordinated the submarine sandwiches, which have become a staple of our fitness program. Seventeen people participated in this summer fitness event which we plan to repeat next year because it was so much fun! For a personal account of this event and more pictures, see page 3 to read about the exciting time one of our young paddlers had.

### 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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# HFMD'S 8TH ANNUAL HEARTS OF HOPE GALA & CASINO NIGHT

The Hemophilia Foundation of Minnesota/Dakotas invites you to join us for an exciting evening of fine dining, auctions, and casino games. We are pleased to announce the return of Joe Schmit as our Master of Ceremonies.



Saturday, January 26th, 2008  
Hilton, Minneapolis (1001 Marquette Ave)  
Cocktails & Silent Auction 6:00 p.m.  
Dinner Served at 7:30 p.m.

*Honorary Co-Chairs*

*Dr. Margaret Heisel-Kurth & Dr. Mark Reding*

*Gala Planning Committee*

*Co-Chairs: Lisa Kallberg & Jim Paist.*

*Beth Andersen, Pam Cella, Nancy Golden, Alicia Lee,  
Deb Melhado, Liz Kallberg, Aaron Reeves, & Peggy Wier*

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(651) 406-8655 (\$100 per ticket)

*Donated New  
Items are  
Welcome!*



## My Canoe Trip

By Nick Hanson

One Saturday, I went on a canoe trip with the HFMD. at Lake Calhoun. I had a great time. Let me tell you about it.

Ok. First, we thought about bringing our dog, "Darby". He is a very nice poodle. He is very nice to people but, he has never been in a boat before. I have been in a canoe before so, I am a good paddler but, it is tiring. I sat in the front and, my mom sat in the back. I like to sit in the front because I do not like to steer. When we got in the canoe, Darby was having some trouble getting in. So, I helped him get in the canoe. After that, Darby was smiling because he was happy. I told him to sit while we were in the canoe so we would not fall overboard.

It was very pretty on the lake. There was an island just for birds and, I saw a lot of lily pads. Now, I am starting to think big. So, in the middle of the lake, our dog jumped out of the canoe, and tried to swim. I guess that Darby wanted to take a dip. Then, I knew that he was going to drown so, I reached way over, and grabbed him by the collar. Next, I hauled Darby to the canoe and pulled him in. Next, Darby licked me all over. He was shaking the water all over us and, I got very wet. He loved me so much. Now, we learned a very good lesson to NOT bring a dog except if your dog is a good swimmer.



Front: Carolyn & Nick Hanson with Darby  
Back: John & Cole Schulte

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†Butler R, Larson P, Mannix S, et al. *J Outcomes Res.* 2004;8:63-78.

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*Fitness Program Continued...*

## Gettin' in the Game

In spite of an unusually cold and wet day in August, we held a CSL Behring Gettin in the Game event in St. Paul with the Minnesota Thunder. Some of our youth attendees came early and kicked balls around the field in the rain before our soccer clinic started. Fortunately a tent had been set up, so there was some shelter for cover.



Pete Dyson speaking to HFMD group

Thunder players Sasha Gotsmanov, Craig Mallace, and Ansu Toure joined our group onto the field and demonstrated proper dribbling technique. After some professional instruction and drills, our kids were given a chance to score on Thunder players in net. After the clinic, we moved into the tent to hear from collegiate athlete Peter Dyson, who spoke of his experience playing college baseball and how he managed his hemophilia as a player. His message was informative, upbeat and very inspirational.

Before settling in for the game, we were treated to a picnic dinner under the tent. Although some of our group left shortly after dinner due to the rain, the rest of us sat down in ponchos to watch the Minnesota Thunder versus the Rochester (NY) Rhinos. The Thunder ended up losing the game, but we had a great time with this HFMD family fitness event. We would like to extend a very special thanks to Mark Wiener, CSL Behring and the Minnesota Thunder for making it so much fun!

## Saturday December 1<sup>st</sup>, 2007 10 a.m. - 12

Hancock Recreation Center  
1610 Hubbard Avenue  
St Paul, MN 55104

### Basketball & Lunch with HFMD

*We invite patients, couples & families of all ages to join us*

### Lunch will be served at noon.

Please RSVP to HFMD at  
651-406-8655 by November 28<sup>th</sup>



# HFMD Capitol Day in St. Paul

Public Policy Advocacy Training  
Wednesday, February 20, 2008

With rising health care costs and ongoing institutional efforts to make cuts, this workshop will provide an opportunity for our community to learn how to become an effective citizen lobbyist, learn from each other, explore proven strategies in influencing related public policy, and how to mobilize our base. While it is never an easy task to change or protect existing laws, it is especially challenging for a community whose numbers are so few. The HFMD is urging its members to get involved by joining us on February 20<sup>th</sup>, 2008 at the Minnesota state Capitol in St. Paul from 9:00 a.m. – 3:30 p.m.



## Our Workshop will Feature:

- \* **Public Policy 101**
- \* **Speakers from the State Legislature**
- \* **HFMD Staff & Advocacy Committee Members**
- \* **Lunch Break**
- \* **Roundtable Discussions**
- \* **Telling Personal Stories**
- \* **Meetings with Lawmakers**

## YOU CAN MAKE A DIFFERENCE!!!

*RSVP to HFMD to reserve your spot:  
(651) 406-8655, or  
email to [hemophiliafound@visi.com](mailto:hemophiliafound@visi.com)*



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## The 2007 Dakota Family Retreat

*By Bob Stone, HFMD Board*

The 2007 Dakota Family Retreat was held on August 25-27 in Keystone, SD. One hundred and twenty-five community members and vendors gathered at the Travelodge Motel with a view of Mt. Rushmore from their rooms. A short walk, over an old wooden bridge, led to the rustic, open-air meeting hall where the education sessions were held and the meals were served.

Denise Cadwell, an HFMD Board member, opened the education session with a fascinating talk on bringing up her son who has Von Willebrand Type IIA as well as what she learned about advocacy at Washington Days. Then Dr. Margaret Heisel, from Fairview Hospital, mesmerized her audience with a talk about the transitions that people with bleeding disorders experience as they live through the stages of life. Next Jeff Kallberg, a physical therapist, had everyone up on their feet and performing Tae Kwon Do. He explained how Tae Kwon Do had improved his quality of life as an hemophiliac.



Saturday afternoon proved to be exhilarating for the community members who sped down the Alpine slide. Other people spent their afternoon, panning for gold while the majority of the attendees climbed aboard the 1880 train for a relaxing two-hour trip. The train chugged along a scenic route from Keystone to Hill City and back. The rest of the afternoon was spent enjoying the shops and sights of Keystone.

Following a dinner buffet, the conference goers drove to Mt. Rushmore where they experienced the lighting of the monument at dusk.

After eating breakfast and completing the conference evaluation forms, the exhausted, happy community members began the long drive home. They were already talking about the 2008 Retreat.



Mark August 1-3, 2008 on your calendars. On those dates the 2008 Dakota Retreat will be held at the Governors' Inn and Conference Center in Casselton, ND. The Inn has the only saltwater water park in North Dakota. Sea salt rather than chlorine keeps the pool clean. Bring your swimsuits! See you in Casselton!

## What A Nice Event This Was!

*By Liz Myers, HFMD Board*

Unfortunately Friday night we missed out on the fun of Pizza and Ice Cream Social. On Saturday, we had a very exciting and adventurous day. With a very interesting talk given by Denise Cadwell regarding her son and some of the obstacles they have been through, and the cost, as well as the emotional impact. Following this presentation we had another great informational talk given by Dr. Heisel regarding transitions. This really said it all and how it truly is. Transitions are a part of life and she did a great job going through it the way she did. After lunch Jeff Kallberg talked about his struggles with his bleeding disorder and how he grew up with a targeted bleed to his elbow and how it caused a disability to not only the elbow but the whole arm as well. He went on to tell about his experience in Tae Kwan Do and how that has benefited him. He and his wife demonstrated different moves and techniques involved in Tae Kwan Do. They had almost everyone there up and moving, kids and adults alike, including their own daughter. It was such fun. It seemed that everyone enjoyed participating.

The other item that was offered was for the kids to learn to stick themselves. This was especially welcomed by my daughter, who has wanted to learn self-infusion, but hasn't had the opportunity to do so. At camp she is on the list, but for whatever reason it just doesn't seem to work out for her, and this has been something she has requested to me to have at the meetings, (which I have not mentioned) so I am grateful that it was being offered at the retreat, she was able to work on this and hopefully soon, transition into that role of self-infusion. Actually I noticed quite a few people who were interested in this as well. In the afternoon we had our choice of activities:

Alpine Slide, Panning for Gold, or a Train Ride to Hill City. My family and I choose the Train Ride. We rode in a restored car, this car was open, there was no air-conditioning just the open air, and the weather was beautiful, it wasn't too hot, just nice and comfortable. As we traveled from Keystone to Hill City we were informed of the history of the train, and we also enjoyed the great scenery along the way. We seen a lot of rock formations, different types of trees, and some wildlife, restored homes, and the highest peak in South Dakota. This was about a two-hour ride.

After we got back we got to have a little down time before supper and after supper we were treated to visiting the four faces of Mount Rushmore. They had some technical difficulty with the sound system for the music that was to be played but outside of that just the opportunity to be there and to see this famous monument was very touching and very nice. On Sunday we met for breakfast and had a short meeting, then we were off for the road home. The one thing I really like is when you attend these retreats and even the annual meetings you get to know people who go through a lot of what we do, what we all do, you are able to relate to them and they to you in ways not many others do, and in that you meet many new people and they become your friends, so each time you attend these meetings you get the opportunity to see them again. What a great opportunity and what a wonderful organization the HFMD is! Thank you HFMD.

The HFMD gratefully acknowledges our donors who have given so generously. Below are donations received from January 1, 2007 through September 30, 2007.

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## \$15,000 of Post High School Scholarships Awarded to Ten Students

By Pam Cella

*"I am grateful to your organization for your continued support. I have been accepted into the Study Abroad Program and hope to study in Italy next year. Your scholarship will allow me to reduce the number of hours that I work during the school year as I try to earn money for the opportunity to study overseas," said one of our recipients.*



Knowing that a high school education is usually necessary for people to attain the kind of work they dream of, the Hemophilia Foundation was delighted to award post-secondary scholarships to ten students this year. During the month of July, \$15,000 of scholarship monies was awarded to those ten recipients.

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.

Congratulations and very best wishes to all of the scholarship award recipients!

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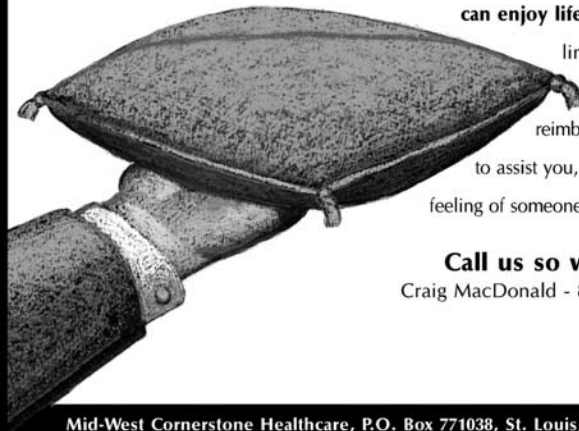
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## HFMD's 11<sup>th</sup> Annual Golf Tournament

On Monday, September 10<sup>th</sup>, we hosted our classic Golf Tournament scramble fundraiser at the Indian Hills Golf Course in Stillwater. Just over 80 golfers came to test their skills and to support the work of HFMD. The range balls opened at 11:30 for those who wanted to brush up on their drives and putts, and lunch was served just before noon.

The shotgun start sounded at 1:00 p.m. sharp as our foursomes found their starting holes. At 65 degrees and sunny, the weather was perfect for eighteen rounds of golf. This year we had a few youngsters golfing with us including Dominique Lyng, Brady and Cody Kunkel. Because it was so exciting last year, we offered another chance for one golfer to make a 60 foot putt. Andrew Makepeace's name was drawn, so he headed off to the green to take a swing for \$10,000. With several dozen onlookers watching in suspense, Andrew didn't waste any time in taking his shot. He hit the ball with good velocity as it was headed straight for the hole. A collective gasp was heard as the ball bounced right over the hole, as he came so very close to making it.

Afterwards, people settled in for dinner, a raffle, and live auction. Mark Plencner gave a heartfelt invocation before the meal was served. HFMD Executive Director, Jim Paist greeted everyone and said a few words about the organization's important programs and services for the bleeding disorders community. He also took a moment to thank and recognize longtime HFMD volunteer Dick Bone for his outstanding contributions to the golf tournament. Our Master of Ceremonies, Kert Severson opened up the raffle and shared some creative humor with our group. As no stranger to a microphone, Kert kept the evening moving as he rattled off raffle tickets winners and prizes. Golf Committee Chair, Jeff Kandt announced the winners of the longest drives, longest putts and best team scores. Mark Wiener did a nice job in leading the live auction. Everyone seemed to have a great time. The HFMD would like to thank our Golf Planning Committee: Jeff Kandt, Dick Bone, Kert Severson, Peggy Wier, Pam Cella & Jim Paist. We would also like to thank the many volunteers who helped the day of the event: Deb Melhado, Kirstin Schmidt, Lori Kunkel, Gail Kretman, Steve Oas, Jessica Hutchison, and Jessie Poundstone.



Kirstin Schmidt, Peggy Wier, Deb Melhado, Pam Cella

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## HTC News

### A Story of Hope

Jeff VanDamme, 47, is a husband and father of two, living in Duluth, Minnesota. He has had hemophilia (an inherited bleeding disorder) all of his life and has endured the problematic affects associated with it. Jeff was in stage IV liver disease with cirrhosis before his recent liver transplant.

In the early 80's, Jeff received many blood/clotting products due to severe bleeds that had not been properly tested for impurities. These blood products were what exposed Jeff to the hepatitis C virus. He has been managing the HCV for over 20 years through a variety of physically demanding treatments, prescriptions, and alternative therapies. In spite of various treatment methods, his liver continued to deteriorate, causing increased complications with other body functions, including portal hypertension, ascities, esophagel varicies, cephalic encephalopathy, muscle/joint pain and flu-like symptoms.

*(Above copied from Caringbridges website)*

*As some of you know, my cousin Jeff from Duluth has been battling very serious health issues. He's an incredibly kind man with an amazing wife and two great sons. While things looked pretty grim for a while now, I'm thrilled to report Jeff had a liver transplant at the University of Minnesota Medical Center Fairview on October 3 and everything appears to have gone perfectly!*

*What makes this story special (besides you can donate 60% of your liver and it grows back!) is the amazing kindness of the donor, a physicians assistant at SMDC named Jose -- who didn't really know Jeff or the family. While members of our family and many friends were tested and found not to be potential donors, the answer finally came when Jose's wife Cindy, who worked with my cousin's wife Sue at SMDC, asked Jose about it. The rest is history. Or should I say, the rest is the future!*

*It goes to show there are some amazing and generous people out there. Cheers to the power of our healthcare community and the great work they do each day to change lives -- and to the power of connections we may not even know we have in the people around us.*

Adam Suomala

### Return to Armenia

Our first clinic patient was a 17-year old young man who had been in the hospital for 1 month with an ilioposas hemorrhage. They initially thought he had von Willebrand disease but was re-diagnosed with factor IX when he did not respond to treatment. When we saw him in clinic he was carried in by his brother. He had a contracted psoas muscle and was unable to stand. We had little to offer him but referred him to the pediatric rehabilitation facility where he could stay for up to one month. We did not expect him to cry at this advice but he did. He had missed his home which was 250 kilometers away. It was September and his friends had just returned to school. He had led a pretty normal life up until his muscle hemorrhage.

So began our Comprehensive Clinic in Yerevan, Armenia. We returned to Armenia September 8<sup>th</sup> -16<sup>th</sup> to see how our "Twin" was managing in it's care of patients with bleeding disorders. We were a team of three: Dr. Margaret Kurth, Jan Vogt from the University of Minnesota Special Coag Lab and me.

We brought with us reagents for the laboratory, ankle supports, an assortment of educational material and approximately 40,000 units of factor concentrate. A member from the World Federation of Hemophilia brought an additional 80,000 units. It's sad, really, to know that their government is still not buying enough medication. Until they do, the patients with hemophilia will never be treated adequately for their hemorrhages. On a bright note, the Yerevan Hemophilia Center now has a director and psychologist and the coagulation laboratory is now regularly testing factor VIII and IX levels.

Did we accomplish our goals this visit? I thought we did. Jan from the Coagulation laboratory worked with the lab to help them get more accurate diagnoses. Margaret and I saw 30 patients with their director and psychologist. We spent a lot of time discussing complications like synovitis and inhibitors and Hepatitis C. We discussed ways to develop self-esteem and a sense of control. We plan on returning next fall to continue our education of providers throughout the country.

By Joni Osip, RN, Program Manager, University of MN/Fairview Hemophilia & Thrombosis Center

## Research & Industry News

### **Bayer Reports Potential Longer-Acting Recombinant Factor VIII with PEG**

*(Reprinted with consent from NHF)*

Bayer HealthCare recently reported on preclinical data suggesting that a pegylated form of recombinant factor VIII (rFVIII) could have longer-lasting therapeutic effects. The company presented three scientific abstracts at the 21st Congress of the International Society on Thrombosis and Haemostasis (ISTH) held July 6-12 in Geneva, Switzerland, highlighting promising results of Bayer-administered studies of the new formulation using mouse models.

A protein molecule, in this case human FVIII, is attached with polyethylene glycol (PEG), or pegylated, to prolong its presence inside the body. By using this process, Bayer plans to produce an enhanced hemophilia A therapy that offers extended protein activity and prevention from bleeding. Since pegylated proteins are less susceptible to antibodies, they are also not as likely to be neutralized by inhibitors.

"Developing a longer-acting FVIII product is high on Bayer's priority list, and the positive findings from our preclinical studies presented this week represent a major step forward," said Glenn Pierce, MD, PhD, vice president, Applied Research and U.S. Medical Affairs, Hematology/Cardiology, Bayer HealthCare Pharmaceuticals.

In preclinical studies using mouse models with hemophilia A, pegylated FVIII molecule (PEG-FVIII) showed prolonged bleeding protection compared to rFVIII alone. Mice injured 48 hours after treatment with PEG-FVIII exhibited less bleeding (30%) than those injured 24 hours after rFVIII treatment minus pegylation (77%). Pharmacokinetic studies showed approximately double the increase in half-life for the pegylated rFVIII versus rFVIII alone. In addition, PEG-FVIII demonstrated greater resistance to inhibitors than FVIII in four of the eight patient plasma samples tested.

The three Bayer HealthCare abstracts presented during the ISTH Congress were:

- "Site-Specific PEGylation of rFVIII Results in Prolonged in Vivo Efficacy"
- "Evaluation of PEG-FVIII Molecules with Prolonged Half-Lives in a Murine FVIII-Dependent Bleeding Model"
- "PEGylation Protects Factor VIII from the Inhibition of Antibody Inhibitors"

Source: PRNewswire, July 12, 2007

### **Baxter Study Shows Benefits of Prophylactic Use of Advate®**

*(Reprinted with consent from NHF)*

Baxter Healthcare Corporation reported findings from the "Analysis of Data from ADVATE® Prospective Trials" (ADAPT) study program database showing a statistically significant correlation between the amount of time that factor VIII (FVIII) blood levels are below one international unit per deciliter (1 IU/dL, 1% of normal factor VIII level) and an increase in the annual bleed rate in people with hemophilia A.

The ADAPT results were announced during the 21st Congress of the International Society on Thrombosis and Haemostasis, July 6-12, 2007, in Geneva, Switzerland. They appear to suggest that maintaining levels above 1 IU/dL with prophylactic therapy may decrease the number of bleeding episodes, especially in children. The findings were presented by Peter W. Collins, MD, FRCP, FRCPath, Department of Haematology, University Hospital of Wales, Cardiff, UK, one of the authors of the report.

"Until now there has been insufficient clinical evidence to demonstrate that factor VIII levels less than 1 IU/dL are associated with increased bleeding in patients receiving prophylaxis for the management of hemophilia A," said Collins.

Members of the ADAPT study group, all of whom had participated in Advate® clinical trials, included 48 children, ages one to six years old, and 100 adolescents and adults, ages 10 to 65 years old. All had severe hemophilia A, with factor VIII levels less than 1 IU/dL. The participants were initially evaluated in a 48-hour pharmacokinetic study to measure their rate of clearance of Advate® prior to beginning prophylactic therapy. The adolescent/adult group was on a fixed prophylaxis regimen, 3-4 times per week for 75 exposure days. The child group dosages were determined by the treating physician.

*To read the rest of the story, please see: [www.baxter.com](http://www.baxter.com)*

## Women's Education Weekend

(by Sue Curoe, RN, U of MN/Fairview HTC)

## *Women's Outreach*

The 2<sup>nd</sup> Women's Weekend was held September 29<sup>th</sup> & 30<sup>th</sup> at the Oakridge Conference in Chaska, Minnesota. This event was sponsored by a grant from CSL Behring, and hosted by the Hemophilia Centers at the University of Minnesota and Mayo Clinic.

This year we had Dr. Margaret Heisel Kurth, from the Hemophilia Center at Children's Minneapolis, talk about menorrhagia and its treatments. The women really appreciated her expertise in this area and her willingness to spend time with them to answer their questions. We also added sessions on weight lifting this year led by Kim Baumann, PT from the HTC at the University of Minnesota, and also had a session where the women could share their own stories.

Sue Curoe, RN and Skye Peltier, PA from the HTC at the University of Minnesota lead various educational sessions about bleeding disorders & treatments as well as how to get involved within the bleeding disorders community. We were excited that many of the participants were interested in joining the HFMD's women's outreach program.

Diane Rankin and Kim Walsh, two women with bleeding disorders who are on the CSL Behring speakers group, presented their personal stories and also shared how connecting with their local HTCs and foundations has changed their lives for the better.



Besides the great education sessions that were provided, the women also were able to enjoy chair massages, yoga, humorous skits performed by their providers, and fabulous food that the Oakridge had to offer.

I want to give Mark Wiener and CSL Behring a special thank you for making this great event possible! Not only did they financially support the event, Mark was instrumental in organizing many of details related to the weekend.

# Venline

NEWSLETTER OF  
THE HEMOPHILIA  
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THE DAKOTAS  
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**We're on the web!**  
[www.hfmd.org](http://www.hfmd.org)

## 2007-2008 Calendar

- Oct. 31 – Nov. 3, 2007.....59<sup>th</sup> Annual NHF Convention  
World Center Marriott  
Orlando, FL
- November & December.....Poinsettia Sales begin at HFMD
- January 18 – 20, 2008.....Minnesota Family Retreat  
Lodge at Brainerd Lakes
- January 26, 2008.....Hearts of Hope Gala  
Minneapolis Hilton  
Downtown Minneapolis
- February 20, 2008.....Capitol Day  
St. Paul, MN
- April 18 – 20, 2008.....HFMD Annual Meeting  
Sheraton Minneapolis West  
Minnetonka, MN
- August 1 – 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

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

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