



# Veinline

Newsletter of the Hemophilia Foundation of Minnesota and the Dakotas

Winter

2004

## Greetings from the Executive Director

Please allow me to introduce myself and tell you just how excited I am to be a part of the Hemophilia Foundation of Minnesota / Dakotas (HFMD). I am truly honored to be involved with the proud tradition of education, service and advocacy that this foundation has provided for over 35 years to the hemophilia community of the tri-state area. I would like to thank the HFMD board for hiring me and bringing me into this wonderful organization.

Previously, I worked for six years as the Executive Director of a not-for-profit organization focusing on affordable housing issues, fund development, community organizing and public policy advocacy. I enjoy the challenge of lobbying for a worthy cause and look forward to becoming actively involved with legislative policy issues related to hemophilia.

I began my work with HFMD at the end of August, and have already been greeted warmly by many people in the hemophilia community. Early on I noticed what an amazing network of support this foundation enjoys. Just weeks after I began, I had the opportunity to get to know our board members and their families, at our Medora Family Retreat. This event was made possible by the generosity of the Roger Maris Cancer Center of North Dakota (a division of MeritCare). The Medora retreat was a great opportunity for me to visit with families and to learn more about hemophilia and other inherited bleeding disorders from the medical experts of the North and South Dakota treatment centers. I had the pleasure of listening to fascinating presentations from the outstanding doctors, pharmacists, nurses, and physical therapists representing the Hemophilia Treatment Centers of North and South Dakota. The quality of their presentations was clearly a reflection of their passionate dedication to their treatment of patients with hemophilia.

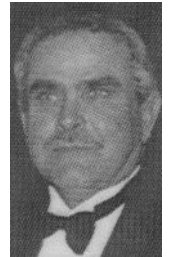
I also learned just how serious this chronic illness can be and why it is so important for this foundation to continue to advocate for patients with hemophilia and their families.

With a strong board of directors who are each committed to advancing the mission of this organization, I am looking forward to working toward common goals with everyone in our community.

Sincerely,

James Paist

## *In Memory of... Dennis John Klein*



Dennis was an easy going, helpful and kind man who always thought of other's needs before his own. He loved nature, whether he could actively enjoy it by hunting and fishing or just sitting and enjoying the outdoors. He was a devoted husband, father, son, brother and uncle. He left a legacy to our family that will live on forever. His life was enriched by the presence of friends and family. We would like to send a heartfelt thank you to the Hemophilia Foundation of MN/Dakotas board and staff, Mayo Comprehensive Hemophilia Center staff, Rochester Methodist Hospital staff and all the families who attended the North Dakota HFMD family retreat in Medora. Your words of comfort and support during this difficult time is appreciated very much. We sincerely thank you for all your generosity, kindness and concern.

*The family of Dennis Klein*

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## HFMD Preparing To Mobilize at the Capitol

In response to proposed legislation affecting persons and families with hemophilia introduced in the 2004 Minnesota session, **HFMD is urging all members and supporters to get involved** with this upcoming session in 2005 by calling and meeting with your state Senators and Representatives. Bills from last year could easily reappear in 2005. As you may recall, legislation was offered last March that could create a sole source provider of treatment and medicine for persons with hemophilia using state funded reimbursement programs in Minnesota. We are very concerned that this could ultimately affect both state and private insurance reimbursement programs, and could compromise the quality of care that persons with hemophilia receive. While we understand that this amendment was offered with good intentions to help contain costs, it is important for lawmakers to understand the impact of unintended consequences from this legislation on our hemophilia community. Specific medical treatments and comprehensive therapies prescribed by physician specialists are vital to the well-being of each hemophilia patient. In many cases, these are direct recommendations for a certain type of treatment and type of plasma or recombinant product ordered by a patient's doctor. Thus the issue of choice in prescription medicine (plasma/factor products), delivery of, and choice of care provider is essential to the quality of treatment for persons with hemophilia. The bill (HF1681) was offered and introduced by Representative Fran Bradley (Rochester) in March of the 2004 session. H.F. No. 1681, 5th Engrossment: 83rd Legislative Session (2003-2004) Posted on Apr 2, 2004, Art.2, Section 3, 5.27 Subd.4.: [HEMOPHILIA.] The commissioner shall develop a disease management initiative for Minnesota health care program recipients who have been diagnosed with hemophilia. In developing the program, the commissioner shall explore the feasibility of contracting with a section 340B provider to provide disease management services or coordination of care in order to maximize the discounted prescription drug prices of the federal 340B program offered through section 340B of the federal Public Health Services Act, United States Code, title 42, section 256b (1999).

Another high priority for HFMD this session at the Minnesota state Capitol is renewing a **prior authorization** exemption status that is set to expire (sunset) in July of 2005. HFMD will be actively working to permanently renew this exemption for persons with hemophilia in Minnesota. *“Subjecting plasma therapies to prior authorization compromises Medicaid recipients the access to the treatments necessary to treat such diseases as hemophilia, primary immune deficiency, and Alpha-1 Antitrypsin Deficiency (Alpha-1), while doing little to reduce Medicaid expenditures. The therapies within these classifications are distinct, sole-source products that have no generic biological equivalents that could be substituted under a prior authorization program. As a matter of public policy, it is crucial that the individuals threatened by the diseases that plasma therapies treat are not denied timely access to the treatments they need to keep them alive and functioning. Applying prior authorization to plasma therapies could have dire consequences for the patients relying on these therapies; a patient with intra-cranial bleeding who is in need of a blood-clotting therapy cannot wait the maximum 24 hours that prior authorization could take to approve or deny his or her therapy.”* Excerpts from the Plasma Protein Therapeutics Association (PPTA), Issue Brief, May 2004.

**You Can Make a Difference!!! Call HFMD TODAY to get involved & for more information on issues that affect you. (651) 406-8655**

# *HFMD 5th Annual Hearts of Hope Gala*

*Please Join Us  
Saturday, January 22nd, 2005  
6:00 p.m.  
Hilton Hotel, Bloomington, MN  
An evening of fine dining, live music,  
dancing & auctions*

**Honorary Co-Chairs**

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Dr. Vilmarie Rodriguez

**Emcee**

Cathy Wurzer  
(Host of Almanac)

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Nancy Golden	Ray Makepeace	Mark Wiener
Vicky Hannemann	James Paist	Peggy Wier
Liz & Bill Kallberg	Jessie Poundstone	

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Hemophilia Health Serv.	\$3,000
Option Care	\$3,000
ZLB Behring	\$3,000
Curative Health Services	\$1,200
Maguire Agency	\$1,200
<i>Additional Sponsors TBA</i>	

**Registration Form**

Names \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

\$75.00 Individual Ticket

\$600.00 Tables of Eight

Total enclosed \$\_\_\_\_\_.

Make check payable to HFMD

Hemophilia Foundation of Minnesota and the Dakotas

750 S. Plaza Drive, Suite 207, Mendota Heights, MN 55120

## Sunny Skies and Warm Weather prevailed for our 8<sup>th</sup> Annual Tournament!

One hundred and twelve golfers secured their golf bags and drove off for a 1:00 p.m. shotgun start at the 8<sup>th</sup> Annual HFMD Golf Tournament which was held September 20<sup>th</sup> at Indian Hills Golf Club. The first, second and third place teams received gift certificates to Indian Hills and competition on the course included both Longest Putt and Closest to the Pin.

This year, our tournament was chaired by Jeff Kandt and serving as our Master of Ceremonies, was Kert Severson. The Raffle Committee, co-chaired by Peggy Wier and Jessica Scofield, did a fantastic job in soliciting items for our raffle and, for the very first time, a silent auction was held which brought in over \$1,300 for HFMD. All in all, this was a very successful event bring in over \$37,000. A special thank you goes to Peggy Wier, from Baxter BioScience, and Nancy Golden, from Bayer HealthCare, for helping to defray costs for printing and signage.

On behalf of the bleeding disorders community, thank you to our various sponsors, dedicated volunteers and enthusiastic golfers who helped to make this another successful event for HFMD. Mark your calendars now for the 2005 tournament, which will be held on September 19<sup>th</sup> at Indian Hills Golf Club, Stillwater, MN.

### 2003 Golf Committee:

Jeff Kandt, Chairperson  
 Dick Bone, Community Volunteer  
 Nancy Golden, Bayer HealthCare  
 Carolyn Hanson, Community Volunteer  
 Lori Kunkel, Hemophilia Resources of America  
 Lori Ann Lavigne, Wyeth Pharmaceuticals  
 Craig Looney, American Red Cross  
 Bud Makepeace, Past HFMD Board President  
 Jessica Scofield, Hemophilia Health Services  
 Deb Starling, Option Care  
 Dan Tinklenberg, HFMD Board Member  
 Mark Wiener, ZLB Behring  
 Peggy Wier, Baxter BioScience



Front row from left to right: Peggy Wier, Jessica Scofield, Vicki Billups-Oberkrom and Nancy Golden. Back row from left to right: Bud Makepeace, Mark Wiener, Pam Leathart, Karin Erickson, Lori Ann Lavigne, Deb Starling and Jeff Kandt.

### Volunteers:

Lori Ann Lavigne, Volunteer Chair  
 Dick Bone  
 Vicki Billups-Oberkrom  
 Karin Erickson  
 Nancy Golden  
 Terry Hammink  
 Lynnette Johnson  
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#### Hole Sponsors: \$500

SD Center for Blood Disorders at Sioux Valley Children's  
 and Sioux Valley Health System Foundation

**Emergency Assistance:**

To be eligible, a person with hemophilia or other inherited bleeding disorder must either: 1) be under the care of a physician or 2) use assistance funds for costs associated with receiving medical treatment. Assistance is open to persons with bleeding disorders, their immediate family members, and those with related complications e.g., HIV & Hepatitis C.

*We encourage eligible people of our tri-state community to apply, but must note that funds are limited and that every request may not be fulfilled.*

**Post Secondary Scholarships:**

Applications will be distributed to our four regional HTC's in January of 2005. HFMD will begin accepting applications for educational scholarships in March with a deadline of submitting applications by May 6, 2005. The Scholarship Committee will review applications through the month of May, then scholarships will be awarded in early June.

**Summer Camp 2005:**

In partnership with the health care professionals from the Fairview University Hospital Hemophilia Treatment Center, HFMD has had a rich history of sending boys and girls with bleeding disorders to summer camp at Courage North, in Lake George Minnesota. Children between the ages of 7 and 17 are eligible for six days of fun and education at camp. Please contact your hemophilia treatment center (HTC) to enroll your child in our summer camp for 2005. The scheduled dates are July 10 -16, 2005.

*Hemophilia Foundation of Minnesota/Dakotas  
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**Pam Leathart**  
Office Manager

# *The 13<sup>th</sup> Annual Meeting of HFMD*

*April 8 & 9, 2005*

*Mark your Calendar*

*and Join Us!*

*At the  
Holiday Inn Select  
Bloomington, MN*

# Education, Networking and Fun

## **Summer Camp Update:**

Bleeding Disorders Camp 2004  
 Courage North  
 Lake George, MN

The 14<sup>th</sup> annual bleeding disorder camp was held in July. Sixty-Five boys (seven were counselors-in-training) and 7 girls attended camp this year. There was one child on the waiting list that was not able to attend due to a limit in the number of campers that the facility can accommodate. In 2005, we will continue to limit the camp to 60 boys (plus counselors-in-training) and 10 girls so it's important to get your applications in early and cancel if your child is not able to attend.

The health center certainly saw its share of action. We have really gotten quite skilled at getting the children infused and back to their camp routines. In the morning, during prophylaxis, there are at least three nurses and one physician in the health-center infusing factor. The children are brought to the health-center after breakfast and are grouped by cabins at different time intervals. We take the opportunity to teach self-infusion as time allows. This past year, one of our adult counselors with hemophilia was instrumental in encouraging kids to self-infuse. If the children take the time to learn different steps of self-infusion, their name is announced at lunch or dinner and they are awarded a certificate of accomplishment.

Each year, we have a counselors-in-training group (CIT). This year seven of our veteran campers were CIT's. This means they undergo hands-on training to be future camp counselors. The CIT's must be between the ages of 16 and 17, and have attended hemophilia camp the previous year. To be accepted as a CIT, the camper also has to demonstrate a certain level of maturity and enthusiasm. As CIT's, they sleep in the staff quarters, attend meetings and act as mini-counselors under the guidance of a staff counselor. They work very hard and learn the challenges of working with young children. Courage North pays each CIT \$100 for their week of work. Many of our CIT's find it such a rewarding experience, they return to Courage North as regular camp counselors in later years.

*By Joni Osip. Ms. Osip is an R.N. and M.S. with the Fairview - University Hemophilia & Thrombosis Center*

## **Medora Retreat 2004:**

Families Basked In The Sunshine at the Medora Retreat!

The Hemophilia Foundation of MN/Dakotas (HFMD) in collaboration with the North Dakota and South Dakota Hemophilia Treatment Center's sponsored the third annual Medora Retreat for Dakotans with bleeding disorders and their families on September 10 - 12, 2004. It provided opportunities for the forty-five attendees to become better educated on bleeding disorders as well as to network with others.



Group photo of 2004 North Dakota Retreat.

Dr. Nathan Kobrinsky, physical therapist Linda Thorseth, and R. Ph. Mark Plencner discussed ten case studies of people with bleeding disorders. Later, Dr. Jakica Tancabelic gave a presentation on "Women With Bleeding Disorders." In addition, educational materials from industry were available on display tables. The weather was warm and sunny, providing attendees the opportunities to swim, shop, ride horseback, tour the Chateau de Mores, dance at the Medora Street Dance, watch a Park Ranger slide presentation on Theodore Roosevelt National Park, and enjoy the scenic beauty of the Badlands of Theodore Roosevelt National Park.

Participants were pleased to have the opportunity to meet and visit with Jim Paist, HFMD's new executive director. Watch for information on the fourth Dakotas Retreat in the next Veinline.

*By Bob Stone, HFMD Vice President*

## **Stretching Is Important:**

As we encourage increased participation in daily exercise, sports activities, PhyEd classes, and community recreation for people with bleeding disorders, we must also increase the importance we place on injury prevention through stretching. Stretching both before and after an activity and/or on a daily basis will help to maintain healthy muscles and muscle balance. Regular stretching can alleviate the tightness that is often felt after participation in a sports activity as muscles stiffen and tighten. Stretching can also help alleviate the muscle tightness that is common in growing teenagers as their bones grow faster than their muscles. Finally, stretching is an important piece to include in a “return to activity” program after an injury or bleed.

What is the best way to stretch? The answer to this question varies from person to person. Variables such as bleeding history, type of activity, previous joint injuries and/or surgeries must all be considered in developing an appropriate stretching program. Therefore, consultation with a physical therapist is recommended to develop your ideal exercise program. However, there are some basic guidelines that are helpful for everyone to follow:

- Each stretch should be held at least 30 seconds in a static position-no bouncing.
- A mild feeling of discomfort and tightness is common while stretching, however, PAIN is a warning sign and you should STOP the stretch if this occurs.
- You should feel the stretch in the appropriate muscle. If you do not, stop and reposition until the desired result is obtained. Appropriate body position is critical in achieving the desired stretch.

A common complaint in growing teenagers is tight muscles. This is especially common in the hamstrings and gastroc-soleus (calf) muscles on the back of the legs. The cause of this complaint is two fold. First, growing teenagers will often experience tightness in muscles as their bones grow faster than their muscles. Daily stretching can help alleviate some of this imbalance. Secondly, the hamstrings and calf muscles are both two-joint muscles. Two-joint muscles have the job of moving two separate joints. For example, the hamstrings provide movement at both the hip and knee. This can present a tightness problem because two joint muscles are rarely put through their full range of motion. If a muscle that is not properly stretched throughout full range is then suddenly “forced” to move through this full range it will often result in an injury, sometimes referred to as a “pulled” muscle. Therefore, proper stretching is crucial, especially in active teenagers who “demand” a lot of their muscles.

When a muscle injury does occur, such as a muscle strain or tear, care must be taken to allow for healing and safe return to activity. This is especially important in an individual with a bleeding disorder because such an injury can result in a bleed. Once again, a trained professional should be consulted when an injury occurs. Any program designed to allow an individual to safely return to their previous activity level, should include a stretching component. This is critical since a muscle that has been injured and needs to be rested for a period of time will respond by shortening and tightening. Gradual elongation of the muscle through gentle stretching will help to prevent a repeat injury when activity is resumed.

While incorporating exercise into everyday life has many benefits for both children and adults with bleeding disorders, it does bring an increased need for safety awareness. Approaching a physical activity with healthy, balanced muscles obtained through regular stretching will provide a component of this safety.

*By Kimberly Baumann. Ms. Baumann is a Physical Therapist with the Fairview - University Hemophilia & Thrombosis Center in Minneapolis.*

**Brain Testing for the Young:**

The research team at Children's Hospitals and Clinics in Minneapolis and St. Paul, in conjunction with the Comprehensive Hemophilia Center, is undertaking a new research study regarding the effects of hemophilia on the brain. The study will link state-of-the-art brain imaging with special testing of brain function in young people with severe and moderate hemophilia. This is the first-ever study done in a population of boys and young men who receive prophylaxis to prevent excessive joint and muscle bleeding and who do not live with HIV.

Children with hemophilia may experience bleeding in their brains but show no obvious signs of impairment. No studies to date have been undertaken to determine cognitive function in children with hemophilia who may have experienced a "silent" brain bleed. However, a number of studies have addressed academic and cognitive functioning in the general hemophilia patient population. One researcher found that academic and adaptive skills were lower than expected in hemophilia patients. Another study reported that lower achievement is related to the functional severity of hemophilia. Amy Shapiro, a physician in Indiana, evaluated the academic achievement, quality of life, physical functioning, prophylaxis treatment, and number of bleeding episodes of boys with severe factor VIII deficiency. Children who had a low number of bleeding episodes had better total achievement, mathematics scores, physical functioning scores, and lower school absenteeism.

Recurrent intracerebral bleeding in patients with hemophilia has been associated with physical brain abnormalities and can be detected by magnetic resonance imaging (MRI). Whether observed physical brain changes are caused by the intracerebral bleeds or the hemophilia treatment itself remains in question. One study performed cranial MRIs on 124 boys with moderate to severe hemophilia. Twenty-two (17.7%) of these patients had lesions that were likely related to hemophilia and/or its treatment.

The Behavior Rating Inventory of Executive Function™ (BRIEF™) is a neuropsychological screening questionnaire designed to assess a child's ability to plan, organize, and think flexibly (executive functioning). The results of this questionnaire will be used, in conjunction with the results from the MRI exam, to determine if a brain bleed has affected a child's executive functioning abilities.

*By Christopher L. Moertel, MD  
Lead Physician, Hematology and Oncology  
Children's Hospitals and Clinics, St. Paul*

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**South Dakota Center for Blood Disorders Update:**

We have had an eventful for busy 2004! Our first annual Dakotas Family Retreat was held in May and with assistance from our friends in North Dakota, it was a great success. Drs. Tancabelic and Stout, along with other members of the team, provided educational opportunities to 15 families. Hopefully we will have an even bigger and better retreat in 2005.

Our center continues to grow and see an ever-increasing number of patients. Therefore, we are adding an outreach clinic in Watertown, SD. Dr. Tancabelic and Julie Wetering, RN, will travel there once a month to deliver care to a previously underserved area.

A new patient educational brochure has been developed for our ITP patients, and should be helpful in providing much needed information. We have gathered statistics on our ITP patient population over the past five years, and hope that this information can provide some insight with regard to treatment methods.

Drs. Stout and Tancabelic have conducted a state-wide survey of OB/GYN physicians to determine whether there had been a significant change in clinical practice in the past five years related to diagnosis of women's bleeding disorders. We will continue to develop a paper to report our findings.

We look forward to seeing some of you at upcoming educational and networking events.

*By Julie Wetering. Ms. Wetering is an R.N. with the South Dakota Center for Bleeding Disorders.*

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**Contributors:**

The HFMD gratefully acknowledges our donors who have so generously contributed to the Chapter and we are listing deposits made from January 1, 2004 through November 30, 2004. However, if we have inadvertently made a mistake, please accept our apologies and contact us at 651-406-8655 or 1-800-994-4363.

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M i n n e s o t a

*continued on page 11*

### **NHF Annual Meeting in Dallas:**

After having returned from the NHF Annual Meeting in Dallas, I wanted to share some of the exciting things from the Meeting. It was fantastic to see so many members from our community and Board of Directors in attendance. An excellent time was had reconnecting with old friends, making new friends, gaining valuable information on bleeding disorders, and discovering new tools to use as we deal with changes in the provider and reimbursement climate.

As we already know, there are proposed changes coming in the reimbursement arena. Our community is dealing with this on both a National and local level. One presentation of interest to me involved an overview of the advocacy services available on a state level, and also allowed attendees to provide valuable input on crucial issues as NHF plans for the future. NHF remains committed to providing assistance with advocacy on legislative issues, at the state level, that impact the bleeding disorders community.

I received valuable information and contacts on issues involving “Standards of Care Legislation”, high risk pools, sole source provider of clotting factor drugs, prior authorization, and other pertinent issues affecting our community. This information, along with the valuable resources offered from the NHF and MARC Associates, Inc., will be of great assistance as we face these issues in Minnesota and the Dakotas.

*By Brenda A. Neubauer, HFMD Board Member*

### **NHF Board Member:**

#### **Highlights from Dallas**

#### **Elizabeth Kallberg Elected to NHF Board**



Longtime volunteer leader of the Minnesota/Dakota chapter, Elizabeth Kallberg was elected to serve on the National Hemophilia Foundation (NHF) Board of Directors in late October. Liz and fourteen others were formally recognized in Dallas for their election onto the board, as they quickly got down to business with much to cover over the weekend in Dallas. HFMD would like to

congratulate Elizabeth for being elected to the NHF Board, and we are truly honored to have someone with such rich experience and strong character representing this chapter on the NHF board.

## **Interested in Volunteering for HFMD?**

We are securing volunteers to help with the following:

- Women’s Education/Outreach Programs
- The 2005 Hearts of Hope Gala
- Mailings
- Daycare for Events

Call the HFMD office at 651-406-8655 or  
1-800-994-4363

#### **About This Publication:**

The *Veinline* Magazine is a publication of the Hemophilia Foundation of Minnesota/Dakotas (HFMD). It is published four times a year. The material and ads in the *Veinline* are provided for your general information only. HFMD does not give medical advice or engage in the practice of medicine. HFMD recommends that you consult your physician or local treatment center before beginning any form of treatment. Send all comments, suggestions and future article submissions to: *Veinline Magazine*, c/o HFMD, 750 South Plaza Drive, Suite 207, Mendota Heights, MN 55120

*continued from page 9*

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 Terry Hammink  
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 Richard Jasperson  
 Paul Jaworski  
 Anita Johnson  
 Erick & Jill Johnson  
 Lorraine Johnson  
 LeRoy Juve  
 Michael Kelly  
 Lucille King  
 Kris Klein  
 Jim Knappe-Langworthy  
 Kent & Julie Krabbenhoft  
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 Debra Majeski  
 Andrew Makepeace  
 Deborah Moser  
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Mary Schmitz  
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 Kevin Smith  
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 Robert & JoAnn Stone  
 Jerry & Georgia Svien  
 Dyack Swanson  
 Surendra Trividi  
 Peter Vitale  
 Jack & Louise Warden  
 William Weiers  
 Craig & Judy Wendland

**Hemophilia Treatment Centers:  
 (Tri-State Area)**

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 Carrie Kindert, CCLS  
 LeAnn Schneider, PT

## HFMD Calendar 2004 - 2005

November/December 2004

Poinsettia Sales

January 22, 2005

Hearts of Hope Gala

Hilton Minneapolis/St. Paul Airport

Minneapolis, MN

February 25 - 27, 2005

Alexandria Family Retreat

Arrowwood Resort, Alexandria, MN

April 8 - 9, 2005

HFMD Annual Meeting

Holiday Inn Select, Bloomington, MN

June 11 - 12, 2005

South Dakota Family Retreat

Best Western Ramkota Hotel

Sioux Falls, South Dakota

July 10 - 16, 2005

Camp for Kids

Courage North

Lake George, MN

August 2005

North Dakota Retreat

Date and location to be announced

September 19, 2005

HFMD 9<sup>th</sup> Annual Golf Tournament

Indian Hills Golf Club, Stillwater, MN

October 27 - 29, 2005

57<sup>th</sup> Annual NHF Convention

San Diego, California

(Contact the HFMD office if interested in attending)

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

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