

#### 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 Group Fitness Event

What is a fun fitness activity to do in early November? How about bowling and lazer tag at Pinz in Oakdale, Minnesota? On November 2nd, the HFMD partnered with Children's Hospitals & Clinics to host a group of 52 for a morning of fitness, fun, and good food.



The event began at 10:00 a.m. with a group stretch led by Cheryl Hansen, PT. Cheryl got everyone limbered up with stretching exercises using Therabands to get us loose before hitting the lanes. Our hosts at Pinz were kind enough to give us a private bowling alley room known as Ten Pin Alley; a very comfortable space with a moonlight bowling feel.

*continued on page 2...*

## North Dakota to Develop NHF Chapter after Receiving Grant

The North Dakota Hemostasis and Thrombosis Center (NDHTC) has been awarded a Hemophilia Treatment Center (HTC) Capacity Building Grant from the National Hemophilia Foundation (NHF).

The purpose of this grant is to:

1. Help HTC's better fulfill their commitment to patients
2. Increase collaborative working relationships between HTCs and local chapter(s)
3. Support evidence-based practices that address measurable impacts in defined areas of patient and HTC needs.

The grant money, totaling \$63,572, will be utilized to achieve the following goals:

1. Establish outreach clinics in rural North Dakota and Northwestern Minnesota to improve patient access.
2. Develop a plan to coordinate patient care and provide bleeding disorder education to caregivers (e.g. emergency department providers, primary care providers, pediatricians, dentists, school staff, and daycare providers).
3. Develop an evidence-based education program for patients and families.
4. Develop a local chapter of NHF.

The NDHTC will continue its affiliation with HFMD for calendar year 2014 with the goal of establishing a North Dakota chapter of NHF, ending its affiliation with HFMD beginning in calendar year 2015.

The team at the NDHTC would like to thank the HFMD Board of Directors and Jim Paist for partnering with our clinic for nearly two decades to build a meaningful program for our bleeding disorder patients.

As the NDHTC looks toward the future, we are excited for the opportunity to further enhance our services through outreach, a renewed focus on education, and development of a local chapter to better meet the unique needs of our growing geographic service area.

We will keep you updated regarding our progress as details are available. Should you have any questions regarding this please feel free to contact the NDHTC at (701) 234-7544.

*By Jana Suder*

*Group Fitness Event continued....*

This ten lane room was filled out nicely with 5 people bowling on each lane. With any HFMD event, our members always look forward to having time to visit with each other, catch up, and meet new members. Several families bowling with young children got to utilize the lane bumpers and bowling ball slides. The sounds of spares, strikes, (and gutter-balls) rang throughout the morning. Then it was time to take a break to enjoy a surprisingly good pizza buffet and ceasar salad. After polishing off 14 large pizzas and an action-packed hour of bowling, our group was ready to play some lazar tag. While some managed to survive a bit longer than others in the lazar tag arena, a truly fun time was had by all. This HFMD Group Fitness Event was a big hit, and based on the feedback we received from participants, we plan to do it again next year! Our appreciation goes out to Angie Boyd, Cheryl Hansen, and Dr. Susan Kearny from Children's Hospitals and Clinics for helping to make this event a big success! Please keep an eye on the HFMD website for upcoming programs and events: [www.hfmd.org](http://www.hfmd.org)

*By Jim Paist*



## Mom's Group Outing

*The Hemophilia Mom's Group is an informal support network of mothers of children with Hemophilia, Von Willebrand's Disease, and other bleeding disorders sponsored by Children's Hospitals and Clinics of MN, Hemophilia Treatment Center.*



*We meet approximately 5 to 6 times per year at various locations across the Twin Cities. This past year we were lucky enough to have two HFMD sponsored groups. In February of 2013 our group went to the Way Cool Cooking School and bonded over learning how to cut an onion without crying and made a meal together. Most recently in December HFMD was gracious enough to sponsor a "ladies night out" activity at KidCreate in Woodbury. On this evening we shared a meal and worked on our artistic side by creating a holiday themed piece of art. Our goals of the group are simple, taking time for mom, socializing, and getting to know other moms, "who understand what it is like to parent a child with a bleeding disorder". If you are not receiving the mailing or email fliers with the Mom's Group announcements, please contact our HTC and we will make sure that you begin to receive them.*

*By Jill Swenson, Social Worker (Children's Hospitals & Clinics)*

**Save  
the Date**

**Fine dining,  
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dancing & music**

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of America**

**Hemophilia Foundation of  
Minnesota & Dakotas**



**14th Annual  
Hearts of Hope Gala  
Saturday, February 15, 2014**

**HFMD 14th Annual Hearts of Hope Gala**

**February 15, 2014**

**Radisson Blu Mall of America  
Bloomington, MN**

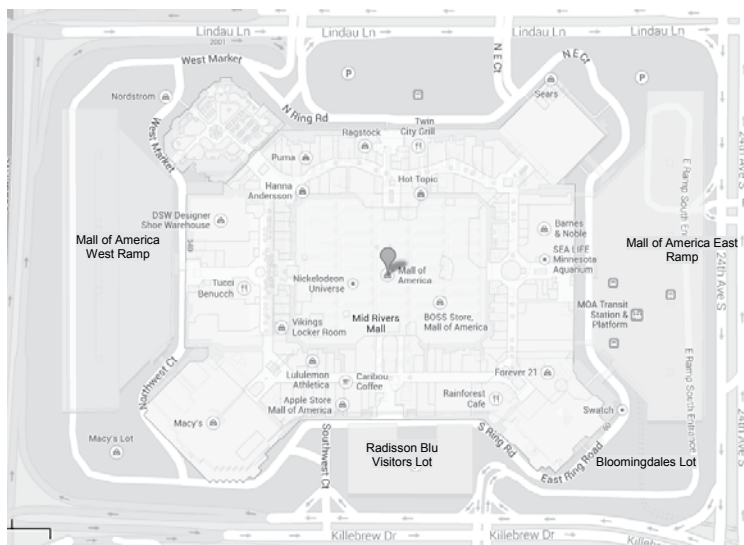
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**Lodging at the hotel will be \$129/night plus tax  
Call 952-881-5258 to reserve a hotel room by  
February 1, 2014**



*Look for Radisson Blu arrows on Killebrew Drive*

*Turn in between Macy's and Radisson Blu*





## BIG CHANGES COMING TO HEALTH INSURANCE ON JAN 1ST, 2014. ARE YOU READY?

For years, our bleeding disorders patients have had very few choices when it came to purchasing health insurance. But, the *Affordable Care Act* has changed all of that. **As of January 1, 2014, the pre-existing condition exclusion is now a relic of the past.** Minnesota's new insurance exchange website, called MNSure ([www.MNSure.org](http://www.MNSure.org)), has been online for two months and is working fine. In fact, a recent USA Today article stated that Minnesota "is now enrolling individuals through its health-insurance exchange by the thousands and at premium rates that are among the lowest in the country". Here are just some of the changes that will positively impact our community:

- Two state funded programs, **Medical Assistance** and **MinnesotaCare** have been expanded to accept people with higher incomes and asset limits. These two programs represent the "**Gold Standard**" of health insurance: Zero deductibles and tiny co-pays. If you think you may be eligible for either program, call your HTC social worker today.
- It used to be that private insurance plans were only available to our community through employment. This is no longer the case! **MNSure has over 20 separate insurance plans available** that everyone with a bleeding disorder now qualifies.
- The MNSure plans are divided into four categories: **Bronze, Silver, Gold, and Platinum**. Plan costs are determined by many factors, including age and where you live. There are also federal subsidies and tax breaks that you can find out about by logging into MNSure.org.

With all insurance plans, "**the devil is in the details**". To find out what these plans cover depends on many, many variables. The summary plans shown to you on MNSure are only a few pages long, but the actual policies are often over 200 pages in length. Your HTC social worker can help you make a list of questions to ask the insurance companies about specific plans of interest. Here are some things to consider:

- **Pharmacy factor coverage** is the single most important variable in choosing the right insurance plan!
- Bleeding patients tend to go to the emergency room and are admitted to hospitals more often!
- Many of our patients must have **expensive procedures** like CT-Scans, MRIs, steroid injections, and orthopedic surgery!
- Patients must make sure they have their **HTC providers in the new insurance provider network!**

For those of you who are on the **Minnesota Comprehensive insurance** plan (MCHA), please note that this program is ending effective 12/31/14. It may be in your best financial interest to select a new plan from MNSure.org sooner rather than later. Please check out [mchamn.com](http://mchamn.com) and call your HTC social worker to discuss your options.

There is tons of misinformation in the media about "Obamacare". It's a complicated and confusing subject and the program roll-out has been problematic, to put it kindly. Our bleeding disorders' community is faced with a huge challenge **to separate fact from fiction**, when it comes to making the right choice about health insurance. This is where your HTC social worker can help you. Please don't put this off. Start the discussion with your HTC social worker today!

*By Steve Calvit, MSW (University of MN Medical Center-Fairview)*



# Having issues with co-pays or gaps in coverage for your **hemophilia A** treatment???

## **We may be able to help.**

**Bayer** offers a range of programs that can help you **navigate insurance questions about your hemophilia A** treatment. If you're having issues with co-pays or gaps in coverage, we may be able to offer assistance. Speak with one of our case specialists to find out more.

Call **1-800-288-8374** and press 1 to speak to a trained **insurance specialist!**

## Women's Educational Event Held October 12th & 13th



The 8th Annual Women's Educational Event was held at the beautiful Oakridge Conference Center in Chaska. The women and girls who attended love this facility and its amazing food!

Saturday began with **Dr. Susan Kearney**, who is co-director at Children's Hemophilia Center in Minneapolis. She had *Nosebleed News* to share with the group. **Aubrey Manahan, RN** from Mayo Hemophilia Center then spoke about *Alternative Pain Control Methods*. The morning concluded with a talk from **Dr. Diane Dimon**, a CSL Behring speaker, titled *Relaxation & Meditation to Reduce Stress*. **Joni Osip, NP** from the Center for Bleeding & Clotting Disorders at the University of Minnesota started the afternoon with a humorous twist on *Women & Aging*. **Julie Heinrich**, a CSL Behring speaker who has von Willebrand disease and a platelet defect herself, told us how to *Survive & Thrive with VWD*.

Besides providing educational content to women with bleeding disorders, the event also provided plenty of fun activities. Breakout sessions this year included *Tai Chi* (led by **Melissa Schenек, PT** from the University of Minnesota), and manicures (provided by *MelisSalon*, Chaska). *Days for Girls* (organized by **Skye Peltier, PA** and **Angie Boyd**, both from Children's Hemophilia Center in Minneapolis) was an activity that included organizing and packing sanitary supplies for women in third world countries. The women loved this volunteering-type activity. After dinner this year we played *Minute to Win It*, which included competitions involving tissues, balloons, dice, and cookies. We ended the evening with a bonfire and great conversations around the fire pit.



On Sunday, **Sue Curoe, RN** from the University of Minnesota, led a morning walk around the lake followed by a stretching session. **Jana Suder, NP** from Sanford Health Hemophilia Center in Fargo, ND, then spoke about staying *Informed & Connected* by making the most of available resources. The group warmly welcomed back **Dr. Margaret Heisel-Kurth**, co-director of Children's Minneapolis Hemophilia Center, who discussed *Medical Articles Related to Women with Bleeding Disorders*.

The retreat ended with a wonderful brunch, and the women and teens revitalized. Thanks to all the speakers, HTC staff, and the women's outreach group from HFMD who helped make this event possible. A special thanks to **Mark Wiener**, from CSL Behring, for all his help and financial support with the event.



By Sue Curoe

## Blood Brotherhood Event

The HFMD held another Blood Brotherhood event on Sunday, December 1st at Poor Richards restaurant in Bloomington which included important information, good food and watching the Minnesota Vikings versus the Chicago Bears on big-screen TV's. We opened the event with the education component featuring Kim Isenberg from BaxterBioScience. Kim shared the latest updates about the ongoing changes in Minnesota's new health care insurance system. The guys were on the edge of their seats learning about how the changes could affect them and what their various options are for health insurance coverage.



Kim also brought NHF's toolkit for navigating your way in finding the best policy for yourself. This is a very helpful toolkit for anyone to use, and a link to this is copied on the HFMD website ([www.hfmd.org](http://www.hfmd.org)). After a busy question and answer time with Kim, it was time to order lunch and settle in for the opening kick-off. The Vikings taking on the Bears turned out to be one of the most thrilling games of the year. Six Blood Brothers were in attendance along with myself and HFMD Board President John Schulte. A fun time was had by all and we left Poor Richards stuffed, and with a better understanding of the ongoing changes in health care policy. A special thanks goes out to the Hemophilia Federation of America and Baxter BioScience for sponsoring our Blood Brotherhood program!

*By Jim Paist*

# Relax...

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NOT 2014

# SAVE THE DATE

## HFMD ANNUAL MEETING

MAY 2ND & 3RD

CROWNE PLAZA, MPLS WEST

3131 CAMPUS DRIVE, PLYMOUTH, MN 55441

FRIDAY NIGHT - CARNIVAL & BINGO

SATURDAY - INSPIRATIONAL SPEAKERS, EDUCATION,  
AND NETWORKING



**Keynote Speaker**  
Dr. Nigel Key



Food, friends, and  
fun for all ages!!!

### *Save the Date:*

### *Washington Days 2014 General Registration*

*NHF's annual Washington Days will take place Wednesday, February 26, through Friday, February 28, 2014.*

*Please note that online registration for Washington Days opens on Thursday, January 2, 2014.*

*For more information, you can visit the Advocacy section of our website: [www.hemophilia.org](http://www.hemophilia.org). We hope you will join us and other members of the bleeding disorders community from all across the country for another empowering and impactful advocacy event!*



# Baxter's vision is a life without bleeds

At Baxter, we will not stop until our vision of a life without bleeds is a reality for all.



Over the years, Baxter has been the leader in providing support and resources for the community.

Today, we are continuing to improve treatment for bleeding disorders. We have seven ongoing clinical trials, including those targeting hemophilia A, hemophilia B, inhibitors, and von Willebrand Disease.

For people with bleeding disorders, the future has never been brighter. As we increase the time between infusions, someday regular infusions, as we know them, may be distant memories.

To us, continuing to make a meaningful difference one person at a time is our passion and what's behind our unwavering commitment.

**Pursuing life without bleeds**

**Learn more about Baxter resources and support at [ThereForYou.com](http://ThereForYou.com).**

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**Mayo Comprehensive Hemophilia Center****Mayo Clinic**

Mayo 10-75E  
200 First Street SW  
Rochester, MN 55905  
507-284-8634 or 1-800-344-7726  
Ward.debra1@mayo.edu

Rajiv Pruthi, MBBS  
Vilmarie Rodriguez, MD  
Amy Eckerman, RN  
Aubrey Manahan, RN  
Dawn Olive, RN  
Melinda Otto, LSW  
Lyndsey Vandenberg, PT, DPT  
Michelle Kluge, Genetics Counselor  
Ivy Akogyeram, Pharm.D  
Deb Ward, Secretary

**North Dakota Hemostasis & Thrombosis Center****Sanford Health, Fargo, ND Region**

820 Fourth Street North  
Fargo, ND 58122  
701-234-2757  
jana.suder@sanfordhealth.org

Nathan Kobrinsky, MD  
Samuel Odame Anim, MD  
Jana Suder, DNP, NP-C, Program Coordinator  
Courtenay Misheski, RN Nurse Coordinator  
Nicole Bogrud, RN  
Tanya Ramacher, RN  
Kimberly Rasmussen, RN  
Cynthia Vingelen, RN, BSN  
Linda Thorseth, PT  
Diane Sjolander, CCRP Clinical Research Coordinator  
Kate Syverson, MSW, LCSW  
Mark Plencner, RPh Pharmacy Supervisor

**Hemophilia Treatment Centers  
(Tri-State Area)****Hemophilia and Thrombosis Center  
Children's Hospital and Clinics of Minnesota  
(CHCMN)**

2525 Chicago Avenue, CSC-175  
Minneapolis, MN 55404  
612-813-5940  
angela.boyd@childrensmn.org

Margaret Heisel Kurth, MD  
Susan Kearney, MD  
Steve Nelson, MD  
Michael Sprehe, MD, MPH  
Skye Peltier, PA-C, MPH  
Kim Jacobson, RN, CPNP  
Jocelyn Gorlin, RN, CPNP  
Jane Hennessy, RN, CPNP, MPH  
Kristen Appert, RN, CPNP  
Linda Litecky, RN  
Sue Purdie, RN, BSN  
Nicole Leonard, RN, BS  
Cheryl Hansen, PT, CLT  
Jill Swenson, LICSW  
Beau Crabb, Genetics Counselor  
Jennifer Lissick, PharmD  
Angie Boyd, HTC Program Coordinator  
Stephanie Davis, Administrative Assistant

**Center for Bleeding and Clotting Disorders  
University of Minnesota Medical Center, Fairview**

420 Delaware Street SE - MMC 713  
B549 Mayo Building  
Minneapolis, MN 55455  
612-626-6455  
htc@fairview.org

Mark Reding, MD  
Helen McIntyre, MBA Program Manager  
Ricky Chan, PA-C  
Joni Osip, RN, MS NP-C  
Vicky Hannemann, RN, BSN  
Susan Curoe, RN, MS  
Kerry Hansen, RN, BS  
Kim Baumann, MPT  
Stephen Calvit, MSW, M.Ed, LICSW  
Maggie Dreon, Genetics Counselor  
Sheryl Raygor, Administrative Secretary,  
Data Coordinator

**Sanford Health, Sioux Falls, SD Region**

1600 West 22nd Street  
P. O. Box 5039  
Sioux Falls, SD 57117  
605-312-1000

Mustafa Barbour, MD, Program Coordinator  
KayeLyn Wagner, MD  
George Maher, MD  
Jerilyn Moore, RN  
Grant Boltjes, PT  
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## NHF Partners with PSI in the CAC Program

Many consumers will likely turn to their hemophilia treatment centers (HTCs) for information about health insurance coverage options. We are happy to announce that the National Hemophilia Foundation (NHF) and Patient Services, Inc. (PSI) have partnered to assist consumers with enrollment in the marketplaces by having PSI designated as a certified application counselor (CAC) organization to ease this transition. CACs are one of the three types of assisters created under the Affordable Care Act. CACs are tasked with providing consumers with *impartial* information about the full range of coverage options (marketplace, Medicaid or CHIP) without recommending a particular plan. They will also help people apply for coverage through a qualified health plan in the marketplace.

PSI obtained its designation from the federal government on September 30th and will begin applying for similar designation in states with either their own marketplace or separate certification processes. To date, there are applications pending in eight state-based marketplaces. As the designated CAC organization, PSI is providing this opportunity to HTC personnel who are interested in becoming CACs. This will ensure that HTC social workers and other staff can focus their time on obtaining any necessary training and meeting the needs of their patients. NHF will provide PSI with communications, advocacy, research and other necessary support. NHF believes that our community will be well served by PSI in this role.

## MASAC Document #219 - MASAC Resolution on Need to Facilitate Dialogue Between HTCs and Payers to Improve Access to Care at HTCs

*The following recommendation was approved by the Medical and Scientific Advisory Council (MASAC) on October 5, 2013, and adopted by the NHF Board of Directors on October 6, 2013.*

MASAC applauds the willingness of the payer community to work with NHF to insure that patients achieve access to the full spectrum of essential services offered through the comprehensive care setting of a Hemophilia Treatment Center (HTC).

MASAC encourages all HTCs to support this dialogue and the sharing of their experiences and relevant data to improve a mutual understanding of the role of HTCs in the on-going provision of care between a patient's regularly scheduled yearly comprehensive care visits.

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## NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

HFMD  
750 South Plaza Drive  
Suite 207  
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Phone: 651.406.8655  
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1-800-994-4363  
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### 2014 Calendar of Events

February 15, 2014 .....	2014 Hearts of Hope Gala Radisson Blu, Bloomington
February 26-28, 2014 .....	NHF Washington Days Washington DC
March 27-29, 2014 .....	HFA Symposium Tampa, Florida
May 2-3, 2014 .....	HFMD Annual Meeting Crowne Plaza, Plymouth
July 13-18, 2014 .....	HFMD Summer Camp Camp Courage North
September 18-20, 2014 .....	NHF 66th Annual Meeting Washington DC

**\*\*The HFMD Board of Directors meets quarterly on the fourth Tuesday at 7:00 p.m.\*\***  
**Visit our web site, [www.hfmd.org](http://www.hfmd.org), for exciting news and updates!**