



#### 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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The HFMD & Children's Hospital of Minneapolis held a cross-country ski-clinic and outing on Saturday, February 23rd at French Park in Plymouth, MN. This event was led by Jocelyn Gorlin, PA, who opened with a wonderful power-point presentation instructional on how to prepare and learn cross-country skiing. Jocelyn began with tips on bundling up and wearing layers of clothing that won't stay wet if you fall. "Cotton is rotten" for this generally safe and family friendly sport. She demonstrated proper technique and how to maximize each step with your skis and poles in sync. This can be easier said than done for some beginners. Jocelyn and her daughter Becca also created a fantastic brochure about the benefits of cross-country skiing which is posted on our website under Programs.

After Jocelyn's helpful presentation and everyone getting fitted for skis & poles, Cheryl Hansen, PT, led our 35 participants in a vigorous group stretch to get us nice and loose before we hit the trails. French Park has 3 main trails to choose from. Most of our group choose trail #1 on which is just a little over one mile in distance, which some of our skiers circled several times. This trail had deep ruts which makes it much easier to move than cutting your own path in fresh snow. We were fortunate to have a picture perfect



winter day as it was 35 degrees and sunny after a light snowfall from the day before.

Some of the families in attendance were cross-country skiing for the first time, while there were others with experience who skied effortlessly at a faster pace. Whether you were moving slow or fast, it is great outdoor exercise where you can take in a bit of nature during a long Minnesota winter. After about an hour on the trails, HFMD skiers began to file back in to the indoor meeting space where we started. As everyone settled in for some Broadway Pizza and salad, Dr. Margaret Heisel Kurth, shared an informative presentation on living with bleeding disorders. It was a day that featured exercise, education, and networking. This event is a part of the HFMD Group Fitness Program to promote good health through fun, safe, family-friendly exercise. The HFMD would like to extend a special thanks to Jocelyn Gorlin, Dr. Jed Gorlin, and Dr. Margaret Heisel-Kurth for volunteering to make this another great event.

*By Jim Paist*

## 2013 HEARTS OF HOPE GALA

Wow, what a Gala it was! 240 Guests came to support the HFMD on Saturday, February 9th at the Embassy Suites (airport) in Bloomington helping us to have our most successful Gala fundraiser in years. Through sponsorships, auctions and a truly amazing camp pledge, we raised \$104,000.

With a Diamonds to Denim theme, the evening opened with a busy silent auction in the hotel's junior ballroom. The bidding was very competitive as most items sold over value! In addition to a wide range of fantastic silent auction items, our guests partook in the Wine-wall raffle and Diamond Drop raffle sponsored by Continental Diamond.



During the silent auction, guests had plenty of time to mingle, bid, and enjoy a cocktail amongst friends. A special thanks goes out to the volunteers who did a great job in setting up the silent auction room Saturday morning. It looked spectacular! At 7:30, the silent auction closed and everyone made



their way to the cozy main ballroom for fine-dining and a program led by our Master of Ceremonies Dick Bremer. With a full house and very little elbow room, Dick took the

stage. Not only was he funny, charming and very entertaining, Dick also shared his personal connection to the hemophilia community which hit home with so many of us. As the FSN Television Broadcaster of our local baseball team, Dick is very

comfortable on stage and in speaking to large audiences.

After setting an inspirational tone for the evening, Dick joined auctioneer Colonel Dave Nelson in leading our live-auction. The bidding was intense on 6 items including a man-cave on wheels, a tour of the FSN Broadcast Booth at Target Field with Dick & Bert, and the grand finale featuring a Duluth Weekend entitled "air, land, and sea". Guests were extremely generous with final bids going well over value. This led up to a special moment to raise money for our summer camp for children with bleeding disorders. The pledge began with a wonderful video of our campers in action at Camp Courage in 2012. This brilliant video produced by Perry Cowen truly captured the essence of the HFMD summer camp, which also included interviews of our campers who had some memorable quotes.

With an event camp pledge goal of raising \$10,000, our generous guests blew that out of the water with heartfelt donations amounting to over \$23,000!

It was amazing to see the outpouring of support from nearly everyone in the ballroom who donated to HFMD summer camp coming up July 14-19 at Courage North in the deep pines of Lake George, MN. This overwhelming show of support led to a feeling of electricity in the air in what people can do to help children affected by hemophilia and other chronic bleeding disorders. With a great sense of accomplishment for the evening, it was time to relax and enjoy the DJ music from Total Entertainment. Some guests hit the dance floor, while many took time to talk amongst friends inside and outside of the ballroom.

We would like to thank Mr. Dick Bremer for his generosity in hosting our event and making it such special evening. He was also a major donor during the camp pledge. It was a real treat to have Dick make the call for our 2013 Hearts of Hope Gala!

HFMD staff Carrie Kissoon & Lisa Carlson spent months focusing on the preparation of the event to make sure we had enough auction items and to see that all went smoothly for the entire event. We would like to thank and recognize our volunteers on the 2013 Gala Planning Committee: Co-chair Stacie Cowen, Dan Tinklenberg, Stacy Luken (formerly Pike), Nancy Golden, Dena Ianello-Zimmer, & Brenda Adamson. As a new member of the Gala Planning Committee, Dan Tinklenberg was instrumental in lining up a major sponsorship, getting several sports related items donated, and in bringing several tables of friends and family. HFMD Board members also stepped up in donating auction items and in bringing lots of family and friends.

Beyond the committee and Board, there were so many other volunteers and supporters who helped to get auction items and wine donated. Thanks to all who volunteered and helped to make the event so successful!



*A big difference in this year's Gala was a substantial increase in event sponsorship. So many companies and clinics decided to sponsor the HFMD Gala this year. We would like to thank the following benefactors for their generous support of our 2013 Hearts of Hope Gala:*

#### **\$10,000 Diamond Level**

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On February 9th, our bleeding disorders community came together dressed in diamonds and denim to raise money for the HFMD. Members, sponsors, many HTC staff, and friends of this organization celebrated together to support our cause. It was a night to remember, and we hope to see all of our guests next February for the 2014 Hearts of Hope Gala. *By Jim Paist*

# NHF Washington Days – Telling Our Story

By: Emily Boyer

What an amazing country we have the opportunity to live in. Not only do we have a capitol city that shows strength and greatness, but also we have the opportunity to meet face-to-face with our elected officials. We have the opportunity to talk about our needs, our concerns, and our opinions; and our elected officials, and their staff, listen patiently, ask questions, and extend an offer to help.



Emily Boyer, Sen. Amy Klobuchar, James Heer

But most importantly, we have the opportunity to tell our stories. And nearly 325 people headed to Capitol Hill to tell their stories and to advocate on behalf of the bleeding disorder community. This year's Washington Days focused on continued funding for the federal hemophilia programs, which include funding for outreach and prevention, as well as Hemophilia Treatment Center surveillance and collaborative care.

In addition, we were advocating for the Patients' Access to Treatment Act, legislation that would eliminate private insurance companies from covering factor concentrates and other needed medications under specialty tiers, usually known as tier 4. Specialty tiers do not contain a monthly fixed co-payment, but require the patient to pay a percentage, usually ranging from 25 to 35%. This provided a wonderful backdrop to explain to how expensive our or our children's treatment is, and that unlike most medical conditions we do not have an alternative drug to fix or prevent debilitating and expensive side effects later in life. This bipartisan legislation not only benefits the bleeding disorder community, but many others with high drug costs.



Sen. Klobuchar, Casey MacCallum

Although the majority of our time was spent advocating, we also had the opportunity to participate in a first-time attendee workshop, an "Advocate Recognition Dinner" to celebrate the advocacy efforts of state chapters, and seminars about the implementation of the Affordable Care Act and other state specific issues.



Casey, Dawn Rotellini (NHF), James, Emily

The bleeding disorders community may be small in numbers, but we have a powerful story. We each have a story that goes beyond budget spreadsheets and policy initiatives, a story that is worth telling and retelling. I would encourage each of you to contact your state and federal legislators to tell your story, and to never think that our elected officials do not care, because all we need to do is tell our story.



## Minnesota's State Legislature Creates Exchange Forum

This year, in compliance with the Affordable Care Act (ACA) of 2010, Minnesota's state legislature created a public health insurance exchange forum for all of Minnesotans to utilize. About half of the states will have federally operated health insurance exchanges while the other half had their state legislature form their own with various individual features. Starting this fall, October 1, 2013, uninsured Minnesotans or people who buy individual plans in Minnesota will be able to go on to the website for the exchange, [www.mn.gov/hix](http://www.mn.gov/hix), insert their personal information such as income level, age, dependents who need coverage etc., and then browse a variety of plans and select the plan that best fits their needs. No one can be turned away from the exchange or any other health insurance plan because of pre-existing conditions and every plan offered will meet an essential health benefit standard. The health insurance exchanges will also provide an opportunity for people buying health insurance to get federal tax credits to subsidize their insurance if they meet the criteria which is a family income up to four times the poverty level or \$92,200 for a family of four and \$44,680 for a single person in 2012. Since the health insurance exchange bill passed the state legislature, the website is fully functional with an informative section for frequently asked questions and you can even enter your information into the website to find out what kind of a subsidy you might be eligible for if you bought your health insurance through the exchange this fall.

*By Alicia Gedan, HFMD Public Policy Intern*

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The HFMD gratefully acknowledges our donors who have given so generously. Below are donations received from January 1, 2013 through March 31, 2013.

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## A Winter Event for the Blood Brotherhood



On Saturday, January 12th, we held an indoor event at the Golf Zone in Chaska, MN. The morning began with a fascinating presentation on good cardiovascular health and weight training led by Physical Therapist Kim Baumann.

In a comfortable meeting space at the Golf Zone, Kim shared some very helpful handouts touching on the proper amount of time needed daily and weekly for regular exercise and better health. Then she broke out the

thera-bands, a long stretchy rubber-band used for weight resistance training in lieu of free-weights or machines. The inexpensive thera-bands can fold up small enough to carry in your pocket, or take anywhere.

Kim demonstrated a number of different thera-band exercises and led the guys through a few intense repetitions. Then she saved some time for questions and answers. After a good workout, it was time to hit the putt-putt greens for some miniature golf, 18 holes. The HFMD would like to thank the Hemophilia Federation of America and Baxter BioScience for sponsoring the Blood Brotherhood program for adult men who happen to have hemophilia. *By Jim Paist*



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## Mayo Comprehensive Hemophilia Center Family Event

Another successful and fun family weekend education event was held at the Metropolis Resort in Eau Claire, WI. In attendance were 26 families, totaling 82 people, ranging from toddlers to seniors.

This annual event began on Friday evening with a taco bar dinner and brownies followed by a thrilling show put on by illusionist/comedy magician Tom Anderson. Young and old alike were thoroughly entertained and amazed! Later in the evening, the Chaos Water Park was a popular spot for the families to relax, unwind, and forget about the winter weather that had threatened to impede travel that weekend. A spacious hospitality suite was also set up for families and staff to network and socialize both Friday and Saturday evenings.



Following breakfast on Saturday, the children attended child care with nannies from College Nannies & Tutors. They were kept busy with books, puzzles, Play-Doh, beads, Legos, games, snacks, and a movie. During this time, the adults attended educational sessions where Hemophilia Treatment Center updates were shared including introductions to new staff members Deb Ward, Dawn Olive, and Aubrey Manahan. Our first speaker, Dr. Tom Henry from Menomonie Street Dental in Eau Claire, spoke about hemophilia and dental health. He emphasized the importance of proper dental hygiene across the lifespan, particularly for patients with bleeding disorders. Everyone even got a new toothbrush and floss to take home and get practicing! Our second speaker, Bob Bardwell, is an author, motivator, and elite athlete. He gave an inspiring and entertaining presentation "Against All Odds," and spoke of being a victor rather than a victim. Our final speakers of the day were Cyndi Wisted and Beth Geissler, Mayo Clinic physical therapists, who presented "Tricks to Stay Fit". They



discussed setting goals for lifelong exercise, work life balance, stress management, and nutrition. After a lunch of deli sandwiches and cookies, Cyndi and Beth also led attendees in an optional "fitness hour" of light aerobic exercise, strength training, and stretching.

During the afternoon and evening, many of the families and staff enjoyed the Chaos Water Park and the multitude of activities including indoor go karts, laser tag, and arcade games at Action City.

Our Saturday dinner was an Italian buffet followed by make-your-own ice cream sundae bar. Saturday evening consisted of free time for families to enjoy either the water park or arcade. The Hemophilia Treatment Center staff again hosted the hospitality suite where we shared stories, laughs, and the second annual, much-anticipated, gigantic Gorilla Pizza!



A Focus Group was held on Sunday morning and included Hemophilia Treatment Center staff and ten patients/family members. The time allowed for discussion of continued improvements to center services and upcoming events in addition to providing a forum for patients and families to voice their suggestions or concerns.

Plans are already underway for our 2014 Mayo Family Event!

*By Deb Ward*

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# POLAR PLUNGE

On Saturday February 16th, 2013 Team "JT'S", Jason Tarasewicz and his father Joe Tarasewicz once again teamed up against the frigid waters of Lake Superior. They did this to help



support the Special Olympics with their time and money. Both Jason and his dad Joe enjoy the outdoor recreational activities in the Chequamegon Bay and Lake Superior area. Jason is a student at the University of Minnesota Duluth studying Biochemistry, and he also has Hemophilia type A. The University of Duluth leads the way in state Polar Bear Plunge money. Nearly 1,000 people made a very cold leap to support the Special Olympics and raised over \$170,000 Saturday.

*By Joe and Jason Tarasewicz*

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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.

## SCHOLARSHIPS

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NHF Annual Meeting

October 3-5, Anaheim, CA

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One applicant selected each year.

#### Eligibility Requirements

- You or immediate family member must have a bleeding disorder
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- Write a letter to HFMD stating how you would benefit from attending the NHF Annual Meeting
- Letters must be submitted to HFMD before June 15th, 2013



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CSL Behring LLC, 1020 First Avenue, P.O. Box 61501, King of Prussia, PA 19406-0901 USA | [www.CSLBehring.com](http://www.CSLBehring.com)

# Walgreens

## Hemophilia Care at Home

- Local Pharmacies
- Hemophilia-Trained Nurses and Staff
- Nationwide Services
- Patient Support 24/7

For comprehensive services

Call: 866-436-4376 or

Fax: 888-688-3593

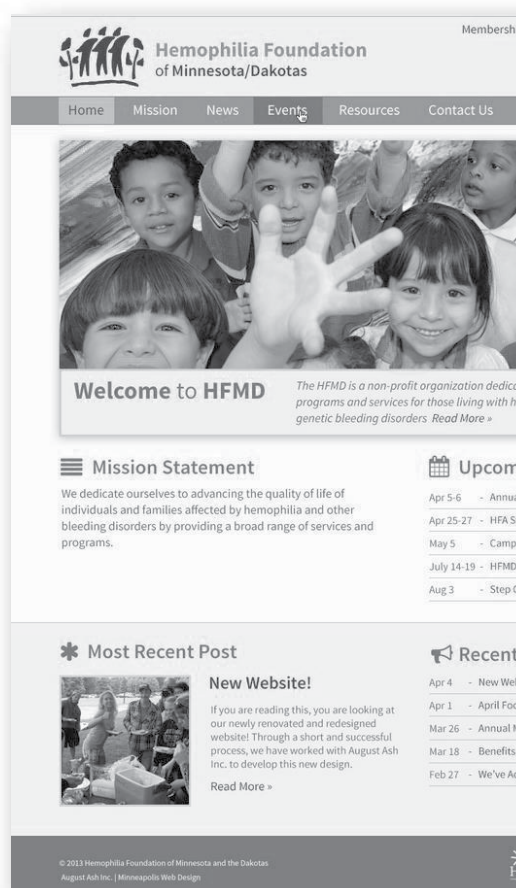
En Español: 800-456-1923

WalgreensHomeCare.com/bleedingdisorders

member of  
**Community  
Health Charities**  
Minnesota

## HFMD New Website!

Same address: [www.hfmd.org](http://www.hfmd.org)



### Key Features

- Concise
- Interactive
- Relevant

Coming  
Soon!

• May 2013

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

HFMD  
750 South Plaza Drive  
Suite 207  
Mendota Heights, MN 55120

Phone: 651.406.8655  
Fax: 651.406.8656  
1-800-994-4363

Email: [hemophiliafound@visi.com](mailto:hemophiliafound@visi.com)

**We're on the web!**  
**[www.hfmd.org](http://www.hfmd.org)**



Donations can be made by sending them to the HFMD office or on our website [www.hfmd.org](http://www.hfmd.org) using the PayPal donate button.



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## 2013 Calendar of Events

- April 25-27, 2013..... Hemophilia Federation of America  
Symposium 2013  
Dallas, TX
- May 5, 2013..... Camps of Courage & Friendship Open House
- CAMP COURAGE NORTH 3 p.m. to 5 p.m.  
CAMP FRIENDSHIP 1 p.m. to 3 p.m.  
CAMP EDEN WOOD 3 p.m. to 5 p.m.  
CAMP NEW HOPE 2 p.m. to 4 p.m.  
CAMP COURAGE 3 p.m. to 5 p.m.
- May 16, 2013..... Baxter's Facts First Educational Dinner  
Radisson Blu  
Bloomington, MN
- June 16, 2013..... Blood Brotherhood Event  
Target Field  
Minneapolis, MN
- July 14-19, 2013..... HFMD Summer Camp  
Camp Courage North
- July 28, 2013..... Step Out for Bleeding Disorders  
Lindenwood Park  
Fargo, ND
- August 3, 2013..... Step Out for Bleeding Disorders  
Como Park Pavillion  
St. Paul, MN
- October 3-5, 2013..... NHF's 65th Annual Meeting  
Anaheim, CA

**\*\*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!