NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS



Women's Educational Event Held October 11th & 12th

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 **9th** Annual Women's Educational Event was held at the Oakridge Conference Center in Chaska. The women and girls who attended truly love this opportunity to get educated and socialize with each other.



Saturday began with **Dr. Rajiv Pruthi**, hematologist from Mayo Hemophilia Treatment Center, discussing *Iron Deficiency & Menorrhagia Treatments*. Lynne Szott, RN, CCM, who is a CSL-Behring speaker, gave sessions on the *Affordable Care Act* and *Health Care Management*. Then **Ann-Marie Nazzaro**, PhD, from the *Foundation for Women and Girls with Bleeding Disorders*, informed us on how their group is preparing current and future providers. Hands on sessions included Art Therapy which focused on body image and was led by therapist Sarah Watson, LLPC, and *Staying Fit with Things from Home*, led by physical therapist Kim Baumann, MPT from the Center for Bleeding & Clotting Disorders at University of Minnesota Health.

Besides providing educational content to women with bleeding disorders, the event also provided plenty of fun activities. The gals from **MelisSalon** of Chaska were back offering manicures and wonderful conversation. We also played *Minute to Win It*, which included competitions involving spaghetti, marshmallows, cotton balls and petroleum jelly. We ended the evening with a bonfire, hot chocolate, and tasty s'mores.



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Coburn-Keenan Foundation sponsors Romarheim Family Attendance at NHF's Annual Meeting

HFMD 4th Annual "Step Out for Bleeding Disorders" Minnesota Walk held on Sunday, August 3, 2014 was a HUGE success, with our Walk Teams raising over \$21,000! The first place prize for the team raising the most funds was a trip to the National Hemophilia Foundation's Annual Meeting in Washington, DC donated by the Colburn-Keenan Foundation. Our first place winners were Team Burke-Romarheim who brought in over \$5,000! The Romarheim family enjoyed this educational trip in September. The following is Kari Burke-Romarheim's accounting of their experience.

Our family shares sincere gratitude [to the Coburn Keenan Foundation] for the experience we had at the NHF Annual Meeting in Washington D.C. We would never have considered attending this event without the funding provided by the foundation. Thank you! Our children still talk about it, especially our 6 year old, who actually brought pictures to his 1st grade class for "show and tell" and talked about his time at the conference and time in Washington D.C. His favorite part was going to the top of the Washington Monument!



For me personally, it was a very emotional, powerful, empowering, uplifting and educational experience. I was very excited for the opportunity for our whole family to travel together, and our oldest son was extremely excited and talked about it for weeks in advance!

So many things impacted me. One of the first experiences was going to the "new families" lunch. We sat with a couple who was probably in their 50's. Our oldest son (6-years) got to meet and talk to a hemophiliac who was much older and had a much different life situation than our boys have now. It was powerful to hear Andreas ask him if he had a port, and why he didn't have a port. One of my hopes for the event was that our boys would realize that they are not the only ones with hemophilia or with ports. And, the whole event was nothing but positive for all of us!

I felt supported and I learned so much. I appreciated the parent round tables and being able to talk to other parents to hear their stories that resonated with our life, to getting tips about how to use music and art to help with living with a bleeding disorder.

One of greatest experiences for me, was our night at the National Zoo where we got to eat next to the lions and tigers and our final night spent at the Smithsonian National Air and Space Museum. Our boys liked having dessert there and seeing the planes and rocket ships, and seeing the movie in the Omni theater. All of that was wonderful. Yet, for me, the most powerful was that I knew and experienced people who actually care enough and want to support families like ours...families that live with a chronic disorder every day and that for us (and all the other families that were there), to even have one evening where we feel special and cared for....that is priceless...

Thank you. Beyond words. Thank you. -*Kari Burke-Romarheim*

.... Women's Educational Event continued from cover

On Sunday, **Sue Curoe, RN, MS** from University of Minnesota Health led a morning walk around the lake. The women look forward to this walk all year, and the fall colors were vibrant. The group warmly welcomed back **Dr. Margaret Heisel-Kurth**, hematologist from Children's Minneapolis Hemophilia Center. She led an *Ask the Provider* session and discussed pain issues. The group loved her words of wisdom.

The retreat ended with a 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 & Dena Ianello-Zimmer**, from CSL Behring, for all their help and financial support with the event.



HEMOPHILIA FOUNDATION OF MINNESOTA/DAKOTAS

By Sue Curoe





Register for this year's Gala by completing the registration form below and mailing it to us; or by calling our offices at 651-406-8655.

Hearts of Hope Gala February 21, 2015	
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\$ 75 x number of guests = \$ OR	
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If you are attending the event with other guests, please complete the following to facilitate seating at the same table.*

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We do not have a preference, please arrange seating for us.

*Every effort will be made to seat guests according to their preference, however, we are unable to guarantee seating at the same table.



HFA Symposium 2015 is coming to St. Louis!

In 2015, we want to recognize the unique perspectives that every patient, family, and caregiver brings as we celebrate a *Gateway to a Stronger Communit*y! We are excited for the first time to team up with one of our member organizations, <u>Gateway Hemophilia Association</u>, to bring you the most dynamic and largest Symposium to date!

Symposium is an annual community-centered educational event that draws hundreds of members from the bleeding disorders community together to share information, learn new advancements, and build a network of support! Each year, we offer travel scholarships to first time attendees who need financial assistance.

We hope you will join us for this special celebration to reconnect and meet new community members in St. Louis! Visit HFA's website to learn more and register: <u>http://www.hemophiliafed.org/programs/meetings-events/educational-symposium</u>.



NATIONAL HEMOPHILIA FOUNDATION

WASHINGTON DAYS



The National Hemophilia Foundation's (NHF's) Washington Days is the premiere advocacy event on Capitol Hill for the bleeding disorders community. Join more than 300 individuals with bleeding disorders and their families as we

educate our elected officials about the unique needs of the bleeding disorders community. Washington Days is a great opportunity to have your voice heard, network with other families from around the country and learn the key issues affecting our community.

NHF will hold Washington Days 2015 on Wednesday, February 25, 2015, through Friday, February 27, 2015, at the Crystal Gateway Marriott in Arlington, Virginia. Registration opened on Tuesday, January 6, 2015. We have secured a group rate of \$189 a night at the hotel. You must register by Friday, January 30, 2015 to secure this discounted rate. For more information and to register, please visit NHF's website at https://www.hemophilia.org/Events-Meetings/Washington-Days.

Choice Making 101 - The Course We Never Had

When your alarm clock goes off at 5:00 A.M., you make a choice, even before you're fully awake: do you hit the snooze button or get out of bed? Staying in bed for nine more minutes would be great, but if you snooze too many times, then you'll be late for work or school. This is only the first decision of your day, and one study shows that we each may make hundreds of decisions every day.

Since few schools offer "Choice Making 101", few of us may truly grasp that all choices are a trade. For some choices, the trade stands out like a whale in a swimming pool: you give up some money to get a candy bar, for example. Yet we don't have to be very old at all before our choices get far more complex, and these trades get much harder to see. So getting an "A" in CM-101 means always seeing clearly what you're giving up and always knowing what you're getting.

Those of us wrestling with a bleeding disorder could probably teach CM-101: deciding whether or not to take a risk to our health to get a chance to do something fun is a choice that we face almost every day, especially when we're young.

But earning that "A" or being able to teach the class also means not sugar-coating our trades to make the benefit look much better than it is or the cost seem smaller than it is. Almost all of us have so often been told not to risk our health that we may sometimes justify a risky activity by pumping up how much fun we'll get from it or dismissing how badly we might get hurt doing it.

Worse, we sometimes try to make a benefit do something that it just can't do when we choose an activity that we know won't make us happy: we may choose to do a risky behavior just because someone told us not to, and we don't really consider whether this activity itself is something we would really enjoy. Eventually, we learn to choose activities that we enjoy rather than enjoying the defiance associated with participating in a risky activity.

The "A" in CM-101 means that if we choose to play football or other high-contact sports, then we've carefully weighed the value of playing the sport against the risks that we may pay for even years in the future, and that we've also weighed all of the reasonable precautions, like taking the field only every other play, or becoming the punter, or wearing extra protective padding.

If you get that "A" in CM-101, then you won't pay \$200 for a \$1 candy bar, and you won't risk trading bleeding incidents for things that you don't greatly value. Your older self will thank you for the good choices that you make today.

By Donald Glascock (HFMD Board)

Group Fitness Event at Pinz

On Saturday, November 1st, the HFMD partnered with Children's Hospital & Clinics to host our 2nd annual bowling and lazar tag outing at Pinz in Oakdale. Because it was such a fun event last fall, it was no surprise our guest list quickly filled and we had to start a waiting list.

Physical Therapist, Cheryl Hansen opened the event with a rigorous group stretch to get everyone loose and limber enough to bowl.



Once again, we had our own lanes at the 10-Pin Alley within the massive Pinz complex. With over 50 member/families ready to roll, the fun began with strikes, spares, and help from bumpers. Some of our younger bowlers also utilized ball slides at the top of their lane.

The pizza buffet and salad started at noon, and most of our bowlers put a few slices on their plate and took it back to their lane. After lunch, we did two rounds of very competitive lazar tag. It was 3 hours of food, fun, and catching up with each other. HFMD members truly enjoy visiting at our events. They often learn from each other and become friends. Group Fitness at Pinz 2014 was a blast, and we plan to hold it again next fall. Please see our Veinline and website calendars for upcoming HFMD events.

By Jim Paist

HFMD Board Updates



We had our Annual Board Business meeting on Saturday, November 15th at the Embassy Suites in Bloomington. While the Board meets six times per year, this is a mandatory in –person meeting where we spend a full day tackling policy and governance issues. Discussing the new North Dakota NHF chapter (their plan to be effective January 1st, 2015) was one of our many agenda items. We understand there is a desire in North Dakota to have more programs and events, and the HTC plan to facilitate a new chapter to accomplish these goals.

Two HFMD Board members have decided to step down due to time and

family commitments We extend our deepest thanks to Dr. Margaret Heisel-Kurth and Mike Neubert who each played such a key role on this Board for the past 6 years. They may not be Board members now, but both plan to remain involved with the HFMD. Casey MacCallum was elected to fill the Board Vice President seat vacated by Mike Neubert. We are in the

process of recruiting another HTC Rep to fill the seat vacated by Dr. Heisel-Kurth.

We set our 2015 budget, covered a number of policy items, and listened to an informative presentation from Jenna Berneck, Executive Director of Community Health Charities, MN (pictured below). HFMD is a charter member organization of CHC, which is a federation of chronic illness charities whom employees can donate to, from their workplace. If CHC is not a giving option at your workplace, please contact us, or CHC to see if that employer may consider including CHC in their payroll giving program. *By Jim Paist*

Hemophilia Treatment Centers (Tri-State Area)

Hemophilia and Thrombosis Center Children's Hospital and Clinics of Minnesota (CHCMN) 2525 Chicago Avenue, CSC-175

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Dear HAMD Donors,

On behalf of the Hemophilia Foundation of Minnesota and the Dakotas, I want to thank each and every one of you for supporting this organization in 2014. We had a phenomenal year with individual donations received because so many of you chose to support the HFMD. It is your generosity that enables us to carry out our programs, events, and services for this bleeding disorders community. Your donations to the HFMD are tax deductible, and deeply appreciated!!!

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2015 Calendar of Events

January 10-11, 2015	Children's Hospital Education Event Doubletree Hilton, St. Paul
February 21, 2015	Hearts of Hope Gala Radisson Blu, Bloomington
March 26-28, 2015	Hemophilia Federation of Americas Symposium Hyatt Regency, St. Louis, MO
April 10-11, 2015	.HFMD Annual Meeting Crowne Plaza, Bloomington
June 2015	Group Fitness Bunker Beach (Date TBA)
July 12-17, 2015	Camp Courage North (True Friends)
August 2, 2015 (Tentative)	Step Out for Bleeding Disorders Walk Como Park, St. Paul
The HFMD Board of Directors me	ets quarterly on the fourth Tuesday at 7:00 p.m.

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