

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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Women's Education Event

The Women's Bleeding Disorder Event was held on October 5 & 6 at the beautiful Oakridge Conference Center in Chaska. We had a nice turnout of women and teens with bleeding disorders, and the colors and weather were great!



Breakout sessions this year included self defense & karate (led by **Dawn Witcraft**), manicures (*MelisSalon*, Chaska), and decorating frames and headbands. This year we had an evening bonfire with s'mores which led to great conversations around the fire pit.



Saturday began with **Dr. Karin Larsen**, LP who is an assistant professor at the University of Minnesota Reproductive Center. She spoke about issues of sexual functioning related to women with bleeding disorders. **Dr. Lisa Baumann**, University of Minnesota Hematology fellow, then talked about bleeding disorders and pregnancy.



The morning concluded with a talk from **Kathryn Reese**, Hemophilia Regional Coordinator from Great Lakes Hemophilia Foundation. She discussed the *Victory for Women* program and how women can get involved in the bleeding disorder community. **Diane Rankin**, CSL Behring speaker who has von Willebrand disease herself, led the afternoon session *Taking Charge of Your Health*. The women and teens then were able to share their story. This share session was led by **Skye Peltier, PA** at Children's Hospital in Minneapolis and **Sue Curoe, RN** at University of Minnesota. Besides providing educational content to women with bleeding disorders, the event also provided plenty of fun activities.

On Sunday, after a beautiful walk around the lake, **Cassie Weness**, nutritionist from Nutritional Weight & Wellness spoke about *Changing Your Nutrition to Reduce Aches & Pains*. **Dr. Margaret Heisel-Kurth**, pediatric hematologist at Children's Minneapolis Hemophilia Center, was the final speaker at the event. She led the *Ask the Panel* session with **Diane Rankin** and **Sue Curoe**. The women attendees continue to love Dr. Kurth's expertise and education.

The event ended with a fabulous Oakridge 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, RN, MS



Dakotas Family Education Event

Our annual gathering returned to the rustic setting of the Smokey Hills Wilderness Retreat located in the deep woods of Northwestern Minnesota in the small town of Osage. With a large log-cabin style conference center, and a capacity of 100 attendees, our education sessions were held in a very relaxed and comfortable venue. This much anticipated HFMD event is held in partnership with the Sanford Health Hemophilia Treatment Center and their wonderful medical staff. We were also joined by the representatives of companies who exhibited and sponsored.

The event began on Friday evening, September 21st as members began to arrive and check into their cabins after 5:00 p.m. With a big day of important education sessions ahead on Saturday, Friday evening was set for our group checking in and getting together for hot dogs, hamburgers, and catching up with each other. Most of the families and individuals who attend this classic event know each other, and some are even related. But, this group is always eager to welcome in new families who are participating for the first time. Along with a couple of new families, Dr. Anim and his three boys attended the event for their first time.

During our group breakfast on Saturday morning, Child Life Specialist Vicki Neis (of Children's Hospital, Mpls) set up the lower level of the conference room for "daycare" also known as child-life programming. Vicki has been kind enough to run the child programming for a second year straight for this Dakotas event. Under Vicki's care, the children play and have loads of fun, but they also learn the basics about having a bleeding disorder through clever games she plays with the children. While we may have heard an occasional yelp or shout for joy upstairs in the conference room, we knew that Vicki and her team had things under control in the lower level daycare space.

New Nurse Coordinator, Jana Suder from the Fargo HTC, played an important role in helping to plan and organize this year's event. She hit the ground running even though this was her first time being involved with this event. Jana brought her husband Rock and her two daughters who stepped in to help Vicki with daycare. They were a big help with the busy daycare room. Even though on maternity, Courtenay Misheski made a cameo appearance on Saturday morning with her new baby. PT, Linda Thorseth also joined our group with her husband Maynard.

Saturday morning sessions began with an opening address and HFMD updates from Jim Paist, who then introduced our Keynote Speaker, Dr. Nathan Kobrinsky. Back by popular demand, Dr. K. captivated our group presenting on living with a bleeding disorder and different ways to cope with it. While the focus of his subject was a very real matter, he keeps it light with a great sense of humor and timing. There is never a shortage of questions for Dr. Kobrinsky after he presents. Not only is he an incredibly talented physician, he is also a brilliant speaker.

After a break with time to visit our exhibitors, it was our pleasure to hear from Jeff Salantai, a younger man with hemophilia who climbed Mt. Kilimanjaro with a group for the Save One Life cause (led by Laurie Kelley). Sponsored by BioRx, Jeff got our attention early on with spectacular pictures of this mammoth mountain in Africa. Jeff proved to be a wonderful storyteller; almost giving our audience the feel they were there during the big climb. Sharing the severely rugged challenges his group encountered, Jeff was animated and entertaining with his description of the bone-chilling obstacles they overcame. After fielding some thoughtful questions from our group, some were so fascinated with Jeff's story they stuck around to ask him more.

After a hearty lunch at the Smokey Hills café, our group returned back to the conference center to hear from Nurse Educator, Linda Pollhammer (sponsored by Pfizer) who spoke about Healthy Lifestyle Choices: The Role of Medication Adherence. As many of our members know, we don't always stay on task in adhering to things you can do regularly to help your condition. We all have busy lives and it's easy to forget or let something go in relation to dealing with a bleeding disorder. Linda stepped up to the plate with great energy to talk about the importance of living a healthy lifestyle and doing everything you can to keep your peak health. She had valuable information and our members appreciated her lively presentation.

By mid-afternoon, there was time for our members to enjoy a variety of activities Smokey Hills has to offer. The playground centered in the middle of a perimeter of cabins was a big hit with the kids. With swings, slides, a big wooden ship to climb on, and a play train with a horn that could be heard anywhere within earshot of the property; this was the activity of choice for most of the children during free-time.

After a Saturday evening dinner and Sunday morning breakfast, everyone said their goodbyes and headed back home. While our group this year was a bit smaller in numbers, there was great information, ample time to visit with each other and a good time had by all. The HFMD would like to extend a special thanks to the medical staff at the Fargo HTC (Sanford Health) and to our other sponsors Bio Rx, Novo Nordisk, & Pfizer.

Our Dakotas Family Education Event has now been going strong for over ten years, and in large part due to the dedication and efforts of HFMD member Bob Stone who has been a driving force in helping to plan and organize this event since it began. We look forward to another successful Dakotas event in 2013 with the date and location to be announced soon.

By Jim Paist

Photos on page 4



DIAMONDS TO DENIM

Hearts of Hope Gala

February 9, 2013

Embassy Suites Minneapolis Airport
7901 – 34th Avenue S.
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Contact The HFMD to reserve your seat.

NHF 2013 "Mapping Our Future"

The National Hemophilia Foundation (NHF), held their Annual Meeting in Orlando Florida November 8-11. The conference was held at the gigantic Marriott World Center located just a few miles from Disney World. With over 3,000 attendees, there weren't enough available sleeping rooms at the Marriott, so many participants stayed at the Caribe Royal nearby with ongoing shuttle service to the conference roughly every 15 minutes.

The NHF Annual Meeting not only draws "consumers" individuals and families affected by hemophilia and other chronic bleeding disorders, it also attracts many Hemophilia Treatment Center (HTC) staff, Chapter staff, and related industry members (pharmaceutical & home care company) from all over the country. This grand conference is a good reflection of the hemophilia community in America.

With a diverse balance of attendees, the NHF offers a variety of education tracts; a Consumer tract, HTC tract, and a Chapter Staff/Board Member tract. Each education tract features very talented presenters and medical experts who present on some of the latest methods in treating bleeding disorders. Treatment therapies and medicines are of great interest to all attendees. In addition to the high level of information in all aspects of treating and dealing with bleeding disorders, Company Representatives from coast to coast exhibit at the conference to share information about their home care services and blood-clotting factor products.

The Opening Session in the Grand Ballroom on Thursday evening featured a keynote address from NHF CEO Val Bias. Speaking to an audience of over 2,000, Val shared the vision of NHF for the hemophilia community in the future. His inspirational message was received well. Upon the closing remarks from Mr. Bias, the gates of the exhibit hall were ready to open. It was a sight to see as 2,000 attendees exited the Grand Ballroom and poured into the much anticipated exhibit hall just next door.

The exhibit hall at the conference was consistently busy with loads of information, networking, and fun activities for all. The exhibit hall also presents opportunities for attendees to see what new products and services are available from the companies exhibiting.

In addition to the medical information at the conference, there are sessions focused on psycho-socio aspects of living with a bleeding disorders, and motivational speakers who can speak about great challenges they have overcome outside of the hemophilia world.

As a Chapter staff person, I attended sessions featuring information about fundraising, Board development, and public policy advocacy. NHF secured a number of talented presenters with various areas of expertise. Another important element that I have always appreciated with this

conference is to spend time with other Chapter staff to find out what other Hemophilia Foundations and Associations are doing with their programs and services for members. HFMD Board President, John Schulte joined me in attending many of these helpful sessions.

John and his wife Barbie also attended a number of Consumer tract sessions, while their son Cole participated in the teen programming which included fun group activities mixed in with some education sessions. While it is wonderful to meet new people at these national conferences, it is also good to see familiar faces from our affiliated HTCs from Minnesota and the Dakotas. Children's Hospital of Minneapolis, University of MN Medical Center Fairview, Mayo Clinic, and Sanford Health Fargo all had good representation from staff at the conference in Orlando. Even with over 3,000 people bustling about the conference, it is always easy to spot someone you know and spend a little time to catch up.

The HFMD applauds NHF for hosting another successful national conference. We would also like to thank all of the company sponsors and exhibitors who helped to make all of it possible. NHF's 65th Annual Meeting will be held October 3-5, 2013 in Anaheim, CA. The HFMD will be accepting letters of interest in 2013 to apply for our travel scholarship reimbursement for one individual or family affected by hemophilia or other chronic bleeding disorder. Please contact the HFMD for application information.

By Jim Paist

Gordon Richison

(May 3, 1951 - December 20, 2012)

GORDON RICHISON, age 61, of Huntley, died Thursday, December 20, 2012, at Fairview Medical Center in Minneapolis. Funeral services will be held on Thursday, December 27, 2012, at 1:30 PM, at Community Covenant Church of Huntley, with Pastor Dennis Anders officiating. Burial will be in Basey Methodist Cemetery, Winnebago. Visitation time will be one hour before services at the church on Thursday. Spencer Owen Funeral Home of Winnebago is assisting the family with the arrangements. Web tributes may be left at www.spencerowen.com

Gordon was born May 3, 1951, in Winnebago, the son of Glen and Allie (Royalty) Richison. He was a 1969 graduate of Huntley High School and later earned his degree in accounting. He worked at Maurice Accounting for a short time before working in the accounting department at the Huntley Elevator. In the mid 1980's he started working with Baarts Trucking where he remained for 23 years until he retired for health reasons. Gordon was a member of the Center Creek Gun Club, the Odd Fellows. He enjoyed electronics, various kinds of music and especially enjoyed good friends and good conversations.

Gordon is survived by his mother, Allie Krause of Huntley, his step brother, Gary Krause of Winnebago, his step sister, Jolene (Stephen) Anderson of Mankato, his step mother, Marjorie Richison of Winnebago, and several cousins. He was preceded in death by his father.

2012 MN Family Education Event

On October 26th – 28th, 2012, twenty Children’s Hospital and Clinics of Minnesota HTC families took part in the MN Family Event at Arrowwood Resort in Alexandria, MN. As families trickled in, one-by-one, they were greeted by a smile from Arrowwood’s staff, Angie Boyd from Children’s Hospital, and Carrie Kissoon from the HFMD. Upon registration check-in everyone was presented with family dinner passes to Arrowwood’s Lake Café, serving a delicious interactive build-your-own pasta and stir-fry bar, where chefs prepared everyone’s meals right before their eyes on open flames. The all-you-can-eat dessert bar wasn’t too shabby either. All families enjoyed the freedom to enjoy the resort and the indoor waterpark, “The Big Splash”, as they so desired.

On Saturday, everyone came together in the ballroom for breakfast and to get the kids settled into the Kid’s Program, led by Vicki Neis, Child Life Specialist from Children’s Hematology/Oncology Clinic. Being Halloween weekend for those that celebrated, Vicki provided a Halloween-themed, fun-filled, educational day for the kids including, “Skelton and Bones” art projects, What Does Blood Look Like? (making fake blood!), and Spooky Medical Mystery Bags! The kids had a great time and learned about their bleeding disorders through this medical play. One parent quoted, “The kids loved it!”

Meanwhile the adults and older teens attended a keynote session with Kim Isenberg, Senior Manager of Reimbursement and Advocacy with Baxter on “Charting your Health Insurance”. Kim explained and clarified what can sometimes be a confusing topic. As one family put it, Kim provided a “colorful commentary about the current status of the Minnesota exchange.” Her expertise was greatly appreciated by the families.



Following Kim’s presentation, Dr. Sue Kearney from Children’s spoke about prophylaxis and shared a web-cast from the World Federation of Hemophilia. To round out the morning program, our special guest Dr. Levani Makhaldiani from the Republic of Georgia shared his experience with hemophilia care in his home country. His presentation was a sobering reminder of how lucky we are to have good access to factor and hemophilia care in the United States. As one family put it, Dr. Makhaldiani’s presentation “made our family remember how blessed we are, even with hemophilia.” Thank you to Dr. Levani for sharing his story and for his commitment to helping the patients in Georgia. One of the highlights of Dr. Makhaldiani’s year in the United States was the time he was able to spend at Camp Courage

during the Hemophilia & Bleeding Disorders week.



After lunch the group split into two breakout sessions. One breakout session was on “Transitions”, led by Skye Peltier PA-C, MPH, Jill Swenson, LICSW, and Kim Jacobson, RN, CPNP. The group played a quick team-building game and then discussed transitions throughout different life stages and issues that may occur at different ages. Parents expressed that they enjoyed the games and the fun had, but most importantly they loved the chance to talk and listen to other parents about the transitions involved with families living with a bleeding disorder. The other breakout session was on “Self Infusion”, led by Sue Purdie, RN and Nicole Leonard, RN. Sue and Nicole taught and guided those that were ready through I.V. infusion. They provided great resources to all, such as the new NHF site www.stepsforliving.com. Several brave parents and kids tried infusion and self-infusion on themselves and each other!!! Infusion by a parent and self-infusion by a child is a huge step in gaining independence from the hospital and clinic and for the kids – from their parents and care-givers. Great job everyone – what a successful session!

After the breakout sessions, families had some free time to rest or explore the resort - most headed back to “The Big Splash” waterpark for more fun!! After the delicious taco bar for dinner some families and kids participated in “Movie Night” while others headed back to the waterpark. On Sunday morning the group reconvened for breakfast and an “Ask the Dr.” session with Drs. Heisel-Kurth, Kearney, and special guest, Dr. Mark Redding from the University of Minnesota, Fairview - Center for Bleeding and Clotting Disorders. The Dr.s covered many topics including inhibitors and the new research on icing bleeding joints.

Thank you to the staff of HFMD and Children’s Hospital and Clinics of Minnesota HTC for organizing and hosting the 2012 MN Event at Arrowwood! Thank you to everyone who attended and to all of our presenters! Watch for plans for the next Children’s Hospital and Clinics of Minnesota HTC Family Event in 2014.

By Angie Boyd & Carrie Kissoon

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DAKOTAS

FAMILY EDUCATION

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Patty Gavin	Carl Wegener	Linda Feldt	Erik Kubitschek
Amy Gilbertson	Melissa Wistrom	Laurie Finnegan	<i>continued on page 10</i>
		Nancy Fisher	

contributions continued...

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Editor Notes

The HFMD Gala invitation was sent out last month.

Please contact us if you did not receive one.

The invitation was printed with the unintended omission of one of our Silver Level sponsors; Bio Rx. We extend our apologies to Bio Rx for this oversight.



2013 HFMD Scholarship Applications

The HFMD will be accepting post-secondary education scholarship applications beginning January 30, 2013. Application forms will be available, at that time, by going online to our website www.hfmd.org, call 651-406-8655 or 1-800-994-4363, or email request a form to hemophiliafound@visi.com

Scholarship eligibility requirements for applicants include (1) having an inherited bleeding disorder, (2) being a resident of Minnesota, North Dakota or South Dakota, and being a patient of one our affiliated Hemophilia Treatment Centers in these states, being a participant in HFMD programs and services, and (3) being accepted into a post-secondary educational or vocational program.

Please see the HFMD website for additional scholarship opportunities for 2013.

WHAT IS YOUR ABR?

ANNUAL BLEED RATE



Minimize the impact of bleeds on your life.

The first step you can take to help lower your bleeds is knowing your ABR, or the number of times you bleed in one year.

Talk with your healthcare provider about your current ABR and how you can set goals to help reduce or eliminate it.

To learn more about ABR and ways to take charge of your health contact your Baxter representative today:

Stacie Cowen
(612) 701-5880
stacie_cowen@baxter.com

Visit us at www.thereforyou.com

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

Email: hemophiliafound@visi.com

We're on the web!
www.hfmd.org

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Donations can be made by sending them to the HFMD office or on our website www.hfmd.org using the PayPal donate button.



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2013 Calendar of Events

- | | |
|---------------------------|--|
| January 12, 2013..... | Blood Brotherhood
Physical Therapy & Golf Zone
Chaska, MN |
| February 9, 2013..... | Hearts of Hope Gala
Embassy Suites – Airport
Bloomington, MN |
| February 22-24, 2013..... | Mayo Clinic Family Event
Metropolis Resort
Eau Claire, WI 54701 |
| February 23, 2013..... | Cross Country Ski Clinic
French Regional Park, Oakwood Room
Plymouth, MN 55441 |
| April 5-6, 2013..... | Annual Meeting
Crowne Plaza
Bloomington, MN |
| April 25-27, 2013..... | Hemophilia Federation of America
Symposium 2013
Dallas, TX |
| July 14-19, 2013..... | HFMD Summer Camp
Camp Courage North |

****The HFMD Board of Directors meets quarterly on the fourth Tuesday at 7:00 p.m.****

Visit our web site, www.hfmd.org, for exciting news and updates!