



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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Mayo Comprehensive Hemophilia Center Family Event

A weekend of fun, education and networking was had by all at the Metropolis Resort in Eau Claire, WI. We had 25 families, for a total of 83 people, ranging from infants to age 77 and every age in between.

Our Friday evening began with a South of the Border Mexican Buffet and an ice breaker game that required participation by all. Following dinner, the Chaos Water Park was a big draw as well as time for connecting with other families in the hospitality suite.

Saturday, following breakfast, the children went off to child care where they had a busy schedule of free play, gym time, snack, games, art and story time. The kids presented the HTC with a canvas painting to hang in our new office when we move this spring. While the children kept busy, the adults had some great educational sessions. Hemophilia treatment center updates were shared followed by Nancy Saslow, Integrative Therapist, who spoke to us about Integrative Therapies for Easing the Stress of Bleeding Disorders. We learned how to calm ourselves using breathing, pressure points, and received handouts so we can practice at home. Dr. Pruthi presented on Heart Disease in Persons with Bleeding Disorders and discussed the risk factors that we all face as we age. Saturday after a build your own sandwich lunch we were led in Yoga by Nancy Saslow. Again, we had participation by young and old.



The afternoon and evening many enjoyed the lazy river and slides in Chaos Water Park and the laser tag, indoor go carts and arcade games at Action City.

Our Saturday evening meal was a Heart Health Chicken buffet with build your own yogurt parfait for desert. During dinner, Alexandra Gregg R.D., L.D. from Mayo Clinic presented Healthy Meal Planning for Busy Families – Is it Possible? Alexandra took us on a mission to make healthy meals on the go and on a budget by planning, grocery shopping, and knowing which substitutions to make. We again hosted the night owls and social bugs at the hospitality suite where we shared stories, laughs and a Gorilla Pizza!

Sunday morning we held a Focus Group that consisted of twelve patients/family members to discuss the direction, growth, and changes at the Mayo Comprehensive Hemophilia Center.

By Kirstin Schmidt, R.N - Hemophilia Nurse Coordinator

HFMD Winter Fitness Event



We kicked off another fabulous year with an introductory cross-country ski clinic. The event was held in cooperation with Becca Gorlin, a Girl Scout earning her Gold Award. On January 14th approximately forty people gathered at Three Rivers District's Barker Park Reserve to learn about the sport. Some of the staff at Hemophilia and Thrombosis Clinic at the Children's Hospital and Clinics of Minnesota joined in on the fun! People learned about cross-country skiing and winter safety in a power point presentation given by Becca Gorlin.

continued on page 2...

...Fitness Event continued from cover



Then, Cheryl Hanson led the group in stretches. Unfortunately, the snowy weather did not hold on long enough for the group to ski. Luckily, the group was still able to enjoy the beautiful Minnesota outdoors on a long winter hike throughout the park. With a little imagination, kids were also able to learn the basics of skiing thanks to the staff at Baker Park. Kids strapped on skis and slid around on the carpet inside the chalet! Despite the unpredictable weather, everyone had a great time. Join HFMD in their Winter Fitness Event Series to learn about different sports and have a good time. A Special Thanks to Dr. Margaret Heisel, Angela Boyd, Cheryl Hanson, Susan Purdie, Bruce from Baker Park, and of course James Paist for making this event possible.

By Becca Gorlin

2012 HFMD Scholarship Applications



The Hemophilia Foundation is accepting scholarship applications for post-secondary education from now until June 1st. Forms are available on line at www.hfmd.org or by calling the HFMD office at 651-406-8655 or 1-800-994-4363.

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.

MANUFACTURING PLANT TOUR

I would like to thank HFMD and Grifols for giving me the opportunity to attend the Bleeding Disorders Advocates and Leaders Meeting at their US headquarters in Pasadena, California, in early December of 2011. This event allowed Grifols to share with us their history, culture, dedication and commitment to their blood donors and patients. It was a great opportunity to get to know their management and the other hemophilia constituents on the trip. It is through this type of dialogue, and events such as these, that manufacturers can learn how best to meet the needs of the donors, patient organizations and the patients they serve through their products, programs and services.



Grifols talked about beginning a new era for their company, building upon the combined experience of their founding companies. All the visitors learned that there is a vast amount of scientific experience in the development and production of plasma therapies. We visited one of their plasma collection centers and toured a manufacturing facility (see the gowned photo.) These extremely interesting tours provided an in-depth look at the production of their products and gave many of us more confidence in the safety of plasma derived hemophilia products.

By John Schulte



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Hearts of Hope Gala 2012

The HFMD held our Annual Hearts of Hope Gala fundraiser on Saturday, February 11th at the Minneapolis Airport Marriott. This year we featured a Diamonds to Denim theme where many guests came in blue-jeans and a nice shirt or jacket. The event opened with a silent auction which included nearly 75 exciting donated items from local businesses. There were weekend getaways, tickets to events, children's packages, and much, much more.

HFMD Event Coordinator Carrie Kissoon and two volunteers ran the Wine Wall where guests could buy a cork for a chance of winning a fine bottle of wine. We also had a Diamond Drop Raffle sponsored by Continental Diamond which was also a big hit. Office Manager Pam Cella and a team of volunteers stayed busy all night processing bid sheets and purchases. Several HFMD board members greeted guests as they arrived. When the silent-auction closed, guests got themselves seated in the ballroom to enjoy some fine dining, a live-auction and camp pledge. A very nice dinner invocation was led by David Moss.

Our generous sponsors were thanked up on stage. Then, auctioneer Andy Imholt opened the bidding on some truly outstanding items. Dinner with doctor's Margaret Heisel-Kurth, Susan Kearney, and Mark Reding was a wonderful item. Bidding was also very competitive on two Twins game tickets and a rare opportunity to spend ½ inning in the FSN television broadcast booth with Dick & Bert. We extend a special thanks to the Twins and Dick Bremer for donating that terrific package. The Duluth Air, Land and Sea package also drew some very high bids. Hands were shooting up across the ballroom during a riveting live-auction. A very compelling video of a young camper and his parents was produced by volunteer Perry Cowen followed by comments from Dr. Heisel and Dr. Kearney who spoke about camp for the pledge which raised over \$10,000!

Just before we were ready to wrap up the program, it was time to draw the lucky winner of the ½ carat diamond. Auctioneer Andy really milked the drama by slowly reading off the winning numbers. With anxious tension in the air, Vicky Hannemann jumped for joy when she realized it was hers.

HFMD Board member Mike Neubert thanked all of our guests before Total Entertainment DJ and their light-show kicked off the music and dancing. Lots of guests

worked their dance moves on the floor, while others took time to visit and enjoy the night.

So many people volunteered their time and energy to help make the event a success, and dozens of local business donated items or bottles of wine to help our cause. We would like to extend a very special thanks to Gala Committee Co-chair Stacie Cowen who put in an enormous amount of her time and skill. And a big thanks to the Planning Committee volunteers Nancy Golden, Stacy Pike, Deb Starling, Skye Peltier, Robie Wayne, and HFMD staff. We are deeply grateful to all who volunteer before and at the event, and to everyone who donated or got items donated for the auction. We recognize any amount paid over the item value as a donation to the HFMD.



A large part of the event's success was the sponsorship commitments from some generous companies. The HFMD thanks the following sponsors of our 2012 Gala: Baxter BioScience & Pfizer at the top Diamond Level, Bayer HealthCare & Novo Nordisk at the Platinum Level, and CSL Behring at the Gold Level. The Silver Level included Accredo Hemophilia Health Services, Biogen Idec Hemophilia, Children's Hospital & Clinics, Maguire Agency, Mayo Clinic, Sanford Health, U of MN Medical Center (Fairview), & Walgreens Infusion Services. Patron Level - Andersen Log Homes, BioRx, Cub Foods Foundation, Deano's Collision & Mechanical Specialists, Grifols, HomeTech Therapies, and Octapharma. Supporter Level John & Judy Belonis and National Coatings & Supplies. With 182 guests in attendance we met our fundraising goal for the event.

By Jim Paist

“Thicker Than Water” movie screening

On Saturday March 10th a group of approximately 40 people gathered at Children’s Hospital of Minnesota in Minneapolis to view the documentary “Thicker than Water”.

“Thicker than Water” chronicles a Minnesota family who’s son loves to play hockey and also has hemophilia. Tony is an 11 year old boy who has played hockey since a very young age, but with support from his family decides to quit playing now that he’s getting older and the game will involve checking. The movie addresses important issues with hemophilia and sports, but



also shows the importance of having a strong, supportive family. It includes interviews with Dr. Margaret Heisel Kurth, Medical Director at Children’s Hemophilia and Thrombosis Center and Joni Osip, RN, FNP, Program Manager of the Center for Bleeding and Clotting Disorders and the University of Minnesota, Fairview Medical Center.

After the movie there was a Q & A session with Dr. Heisel Kurth and Dr. Mark Reding, Director of the Center for Bleeding and Clotting Disorders at the University of Minnesota. This was fol-



lowed by lunch and time to connect with other families and staff.

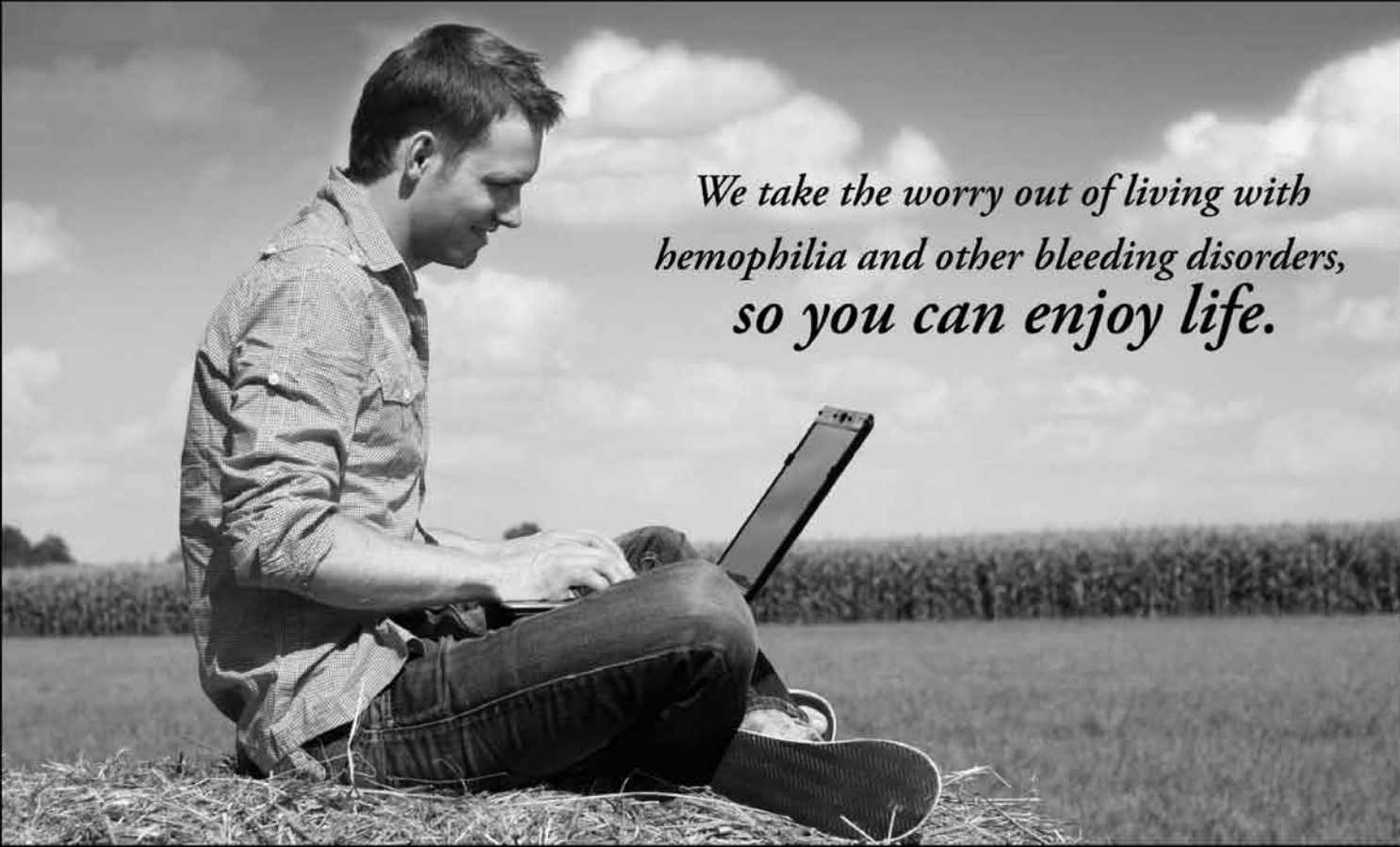
The kids were cared for by Vicki Neis, Children’s Child Life Specialist and volunteers.

Vicki did education and medical play with them while their parents and older kids watched the movie and had a discussion. Thanks to Dr. Heisel Kurth, Dr. Reding, Vicki Neis, HFMD and the staff at Children’s Hospitals and Clinics of Minnesota for taking part in this event! For more information or to order a copy of “Thicker than Water” please visit www.bradleyrappa.com.

By Angela Boyd



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Member News

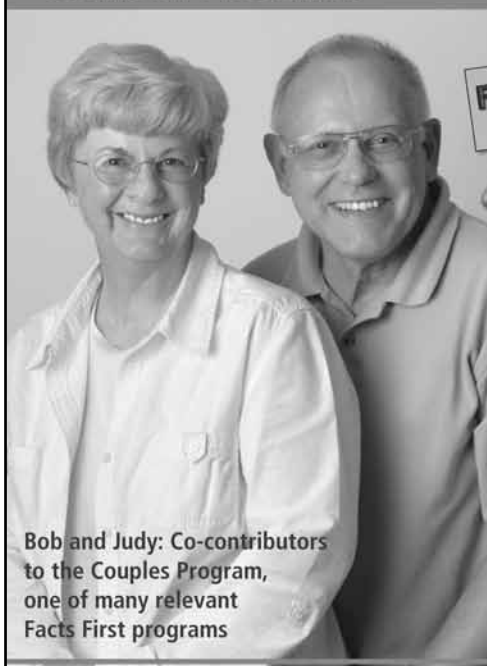
Saturday, February 18th, 2012

Jason Tarasewicz and his father Joe Tarasewicz took part in the annual Polar Bear Plunge, Duluth, MN.

Jason who has Hemophilia Severe VIII is a Junior at UMD took part in the Polar Bear Plunge, organized by Minnesota law enforcement as a unique opportunity for individuals, organizations, and businesses to support Special Olympics athletes by jumping into frigid Lake Superior waters. There was a record number of plungers and record number of pledges at the 2012 Duluth Polar Bear Plunge. More than a 1,000 people took the plunge into Lake Superior on Saturday. And over \$170,000 was raised. Jason raised just under \$400 for the cause and participated with his dad, and college friends. Note from dad. It was an experience of a lifetime. Most of all it was a very special moment and memory I had with my son.



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HFMD Annual Meeting 2012

“Anything Is Possible”

April 20-21

Minneapolis Airport Marriott

State Fair (theme) Carnival Friday, April 20th



**Education, Information, Networking,
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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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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
Kim Jacobson, RN, CPNP
Jocelyn Gorlin, RN, CPNP
Jane Hennessy, RN, CPNP
Kristen Appert, RN, CPNP
Linda Litecky, RN
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Nicole Leonard, RN, BS
Cheryl Hansen, PT
Jill Swenson, LICSW
Jennifer Roggenbuck, Genetics Counselor
Janice Baker, Genetics Counselor
Angie Boyd, HTC Coordinator

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Sioux Falls, SD 57117
605-312-1000

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

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hctc@fairview.org

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Public Policy Workshop

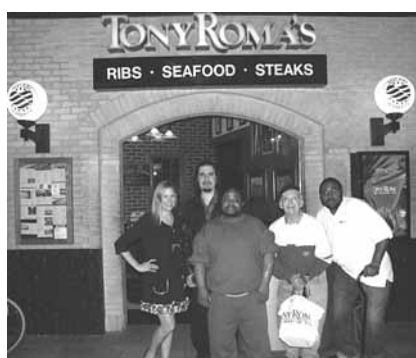
The HFMD held an education event focusing on the impacts of federal health care reform in Minnesota. This education workshop was held in a meeting room at the Timber Lodge Steakhouse in Bloomington on February 25th. It was sponsored by CSL Behring whose Director of Government Affairs, Mike Vogel presented on a new “exchange” plan which will likely become a part of the state health insurance system.



We were also honored to have Ms. Lauren Gilchrist, Special Advisor (health care) from the Governor’s Office to present and answer questions about changes in state health care policies. In addition to sharing a wealth of knowledge and information, Ms. Gilchrist was familiar with hemophilia. Her father is Dr. Gilchrist, now retired hematologist from the Mayo Clinic Hemophilia Treatment Center. Our group of 15 enjoyed a hearty meal after the presentations and fascinating Q & A period. The HFMD would like to thank Mike Vogel, CSL Behring, and Lauren Gilchrist for helping to make this a successful education event!

Blood Brotherhood Ribs & Nutrition Night

The HFMD has been a part of the Hemophilia Federation of America’s Blood Brotherhood program since July 2010. Through the BB program, the HFMD organizes a number of events for our adult men living with bleeding disorders ranging from chat sessions via teleconference to Twins and Timberwolves games. Each event is designed to offer a night out to reconnect with one another and to stay involved and active in our community. Through educational pieces and most importantly, a good time, Blood Brothers are able to share their experiences, offer ideas on how to cope, and always unite with a good laugh!



On Friday, March 23rd, our Blood Brothers met at the Mall of America for a lot of walking, a casual, but classy dinner at Tony Roma’s, and a night of nutrition discussion. While some arrived early to get some busy Mall of America shopping in, the rest of us met at Tony Roma’s at 6:00PM. Tony’s provided the group with a comfortable ambience and casual décor, but most importantly, quality service. We had the entire menu to choose from, including their signature Baby Back Ribs, steak, chicken, and seafood entrees. The food was delicious! In the course of dinner, we partook in an excellent discussion on the importance of nutrition. Kerry Hansen, RN, BS from the University of Minnesota Medical Center, Fairview provided us with two books that each Blood Brother was able to bring home for reference. We covered the “Weight Control”

book from the American Institute for Preventive Medicine and “The New American Plate” book - Meals for a Healthy Weight and Healthy Life, from the American Institute for Cancer Research. The group ended the night with a shared plate of mini deserts, ranging from red velvet cake to key lime tart. Though these items most definitely were not listed in our books, I’d have to say: sweet tooth = pleased!

If you or someone you know would like more information about our Blood Brotherhood program, please contact the HFMD or visit: www.hfmd.org and click on the Blood Brotherhood link.

by Carrie Kissoon

Veinline

NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

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2012 Calendar of Events

- April 20-21..... HFMD Annual Meeting
Minneapolis Airport Marriott
Bloomington
- July 22..... HFMD 2nd Annual Walk
Como Park Pavilion
St. Paul, MN
- August 5-10..... HFMD Summer Camp
Camp Courage, Maple Lake, MN
- September 21-23..... Dakota's Family Retreat
Smokey Hills Wilderness Retreat
Osage, MN
- October 5-6..... Women's Education Day
Oakridge Conference Center
Chaska, MN
- October 26-28..... Minnesota Family Retreat
Arrowwood Resort & Conference Center
Alexandria, MN

****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!

If you wish to continue receiving the Veinline newsletter via regular mail, you need not respond to this. Otherwise, please see below to contact the HFMD at hemophiliafound@visi.com or call (651) 406-8655. Thank you.

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