

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 Annual Meeting 2013

"You Can Make a Difference"

Our Annual Meeting was kicked off on the evening of April 5th with a taco buffet and "Minute to Win It" competition at the Crowne Plaza in Bloomington. After enjoying a great dinner, families formed teams to compete in several competitions. This "Minute to Win It" game-show event was led by local comedian Amber Preston who kept our group laughing as she clowned around with the contestants while doing the sideline play by play.

The competitions included trying to flip a cookie from your forehead into your mouth in 60 seconds, and who could unravel the most crepe paper in a minute. Keeping 3 balloons off of the ground by tapping them was another big hit. While it was a light and loose time, the level of competition from our members was fiercely intense. Each team was serious about winning, and contestants gave it everything they had as our member audience cheered them on. You can see video footage of the chaos by clicking on the "Minute to Win It" link on our web-site.

We opened Saturday morning with a slideshow presentation of HFMD programs and events over the past twelve months.

Then it was time for our keynote speaker, Jeanette Cesta, who not only shared her personal story about living with a bleeding disorder and having children with bleeding disorders; she also shared very helpful information on what you can do to be an advocate for your family and for yourself. Sponsored by Octapharma, Jeanette wove in a nice blend of humor and real life issues into her presentation. It was a treat to have Jeanette present.

After a break with our exhibitors, we had a public policy panel featuring Jan Petrovich (mother of a son with hemophilia) Casey MacCallum (has hemophilia), and Alicia Gedan (HFMD Public Policy Intern). Each presenter shared important information about how you can make a difference in affecting public policy at local and federal levels. Jim Paist also shared the amazing story of HFMD member Brenda Neubauer of Bismarck who was instrumental in

advancing the current federal law eliminating life-time caps on health insurance.

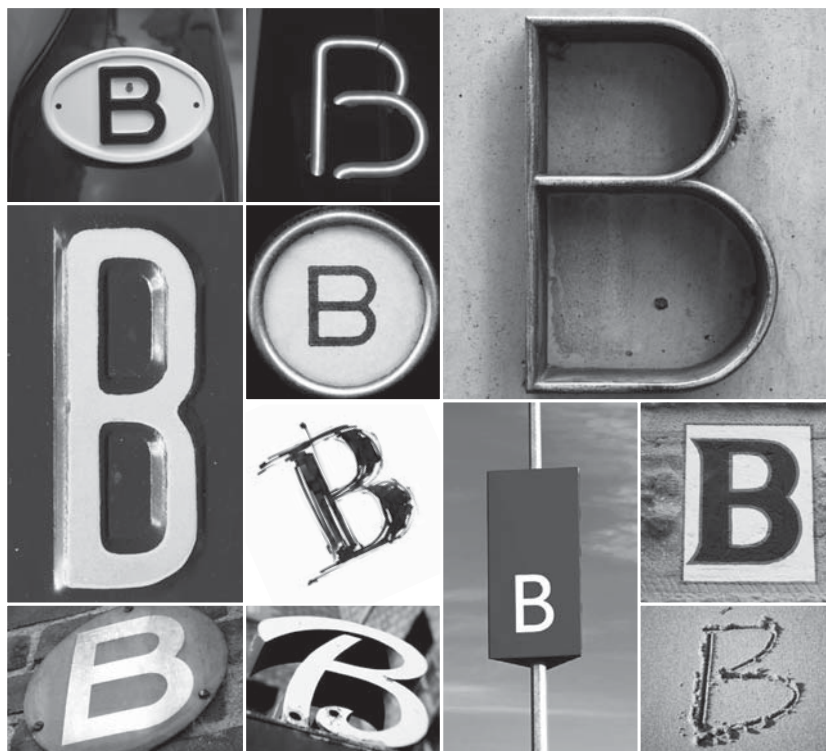
We had a very special moment over lunch when

Bob Newman was presented with the HFMD Lifetime Achievement Award.

continued on page 3



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HFMD Annual Meeting 2013 *continued from page 1*

Bob has been involved with the HFMD for decades as a volunteer, Board President, and Blood Brother. He is also a very talented artist, and is 84 years old living with severe hemophilia. In accepting his award, Bob was greeted with a resounding standing ovation from our group of 175 attendees. This special occasion was also videotaped by HFMD Event Coordinator Carrie Kissoon and can be viewed on our website.



Our afternoon breakout session featured Dr. Margaret Heisel Kurth, a Social Media workshop led by Aaron Flatt, a Blood Brotherhood led by Kerry Hanson RN and Cheryl Hansen PT, and a women's session led by Jeanette Cesta.



This event was planned by staff and our committee volunteers who we would like to thank: Committee Co-chair Vicky Hannemann, Amy Eckerman, Angie Boyd, David Moss, June Reese, Jana Suder, Courtenay Misheski, Nancy Golden, and Vicki Neis.



We would like to extend a special thank you to our event sponsors: Children's Hospitals & Clinics, Sanford Health, University of MN Medical Center Fairview, and Baxter BioScience. We also thank the following companies for exhibiting with us: Accredo, Biogen Idec, Bayer HealthCare, Baxter BioScience, Bio Rx, CVS Caremark, CSL Behring, Grifols, Kedrion, Novo Nordisk, Octapharma, Pfizer, and Walgreens. The 2014 HFMD Annual Meeting will be held at the very nice accommodations of the Crowne Plaza Plymouth (formerly Radisson) on May 2nd & 3rd 2014, so please mark your calendars for another great time of education, networking and fun!



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A Day at the Ballpark for the Blood Brotherhood


By Rachel Wille



On Father's Day, Sunday, June 16th, members of the Blood Brotherhood joined together for a baseball game at Target Field. The Minnesota Twins took on the Detroit Tigers on a sunny afternoon, while 13 members and two of their fathers cheered them on. The Blood Brothers were able to enjoy the game in style from the comfort of one of Target Field's suites, complete with comfortable seating, bottomless hot dogs, brats and chicken fingers and, most importantly, air conditioning.

The event began with an engaging presentation from Daniel Reilly, Director of the Hepatitis Program at Axiom Therapeutics. Mr. Reilly flew in from Denver to speak to the Blood Brothers on the liver and viral hepatitis. He covered everything from the functions of the liver, to the various types, side effects and treatments of hepatitis. A short question and answer session was held after the presentation.

The day continued with an exciting game of baseball. Although the Twins lost the game, the Blood Brothers had a great day at Target Field. 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.



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— Charlie,* 7 years old, loves windy days

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Summer Community Education Event

The HFMD partnered with Baxter BioScience on May 16th to host a Facts First community education event at the brand new Radisson Blu Hotel next to the Mall of America. Physician Assistant, Skye Peltier of Children's Hospitals and Clinics shared an interactive presentation on maintaining good joint health.

Skye opened with a clever anatomy group quiz fashioned after the TV game-show Jeopardy. Attendees formed teams at their tables to answer anatomy questions Skye had posted on the wall from various body categories. While our members knew many of the answers, there were some that stumped our teams which led to some great in depth discussions about good joint health.

This was a fun way to learn about our skeletal system and joint interactions. Our cozy group of 16 included several families and individuals affected by hemophilia and other chronic bleeding disorders. Our members also had some time to catch up with each other during the dinner. The food at the Radisson Blu was delicious, and everyone seemed to really enjoy this event. Local Baxter Representative Stacie Cowen did some nice work in putting this all together.

We would like to thank, Stacie, Baxter BioScience and Skye Peltier for making this a very informative education event. Please keep an eye on our website event calendar for future education workshops like this. *By Jim Paist*



Relax...

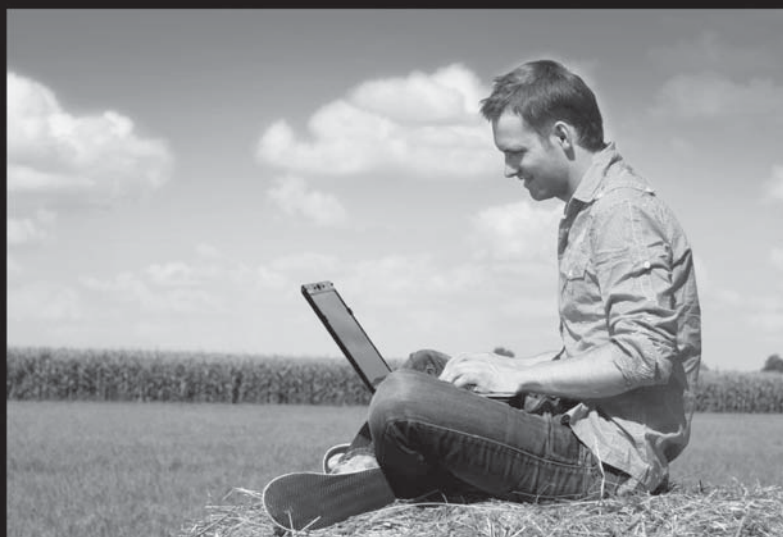
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angela.boyd@childrensmn.org

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The HFMD gratefully acknowledges our donors who have given so generously. Below are donations received from January 1, 2013 through June 30, 2013. *Please note: The donations from the "Walk" website will be included in the next issue.*

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Board & Staff News

The HFMD would like to thank Stephanie Miller for sharing so much of her time to serve as our Board Treasurer over the past five years. Steph was so thoughtful and thorough in going over our monthly financial statements and preparing those reports for the Board. While Steph is staying involved as an HFMD member, she and her husband Jim have two young boys, Nathan and Lucas, who also need her attention.

We will miss having Steph on the Board and the positivity she brought to the meetings. The good news is that Kris Manns, who preceded Steph as HFMD Treasurer, is now ready to return to the HFMD Board in that very important Officer role. At our Board meeting in April, the following officers were re-elected to their posts. John Scott Schulte – President, Mike Neubert – Vice President, and Liz Meyers as Board Secretary.

In staffing news, Event Coordinator Carrie Kissoon is on maternity leave after having her second child Kaia Jo Kissoon. Congratulations to Carrie, her husband Jai and son J.J. with their new baby girl. Carrie will be returning to the HFMD in early December, just in time to resume work on our 2014 Gala.

With Carrie on leave, we were pleased to bring in our new Event Coordinator Intern, Rachel Wille. Rachel began her term in mid-May and has been deeply involved in helping to plan our two Walks coming up in Fargo on July 28th, at Lindenwood Park, and at Como Park in St. Paul on August 3rd. Rachel has been a big help in the office working on a variety of event projects. She will be returning back to Drake University in Iowa as a senior at the end of August.



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Visit our Walk Website at: www.firstgiving.com/hfmd

For more information, contact HFMD at 651-406-8655, 1-800-994-4363 or hempophiliafound@visi.com

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Visit our Walk Website at: www.firstgiving.com/hfmd

For more information, contact HFMD at 651-406-8655, 1-800-994-4363 or hempophiliafound@visi.com

Baxter's Rixubis is First New rFIX Therapy in 15 Years

In June, the US Food and Drug Administration (FDA) approved Rixubis, a recombinant factor IX (rFIX) therapy for treatment in patients with hemophilia B who are 16 years old or older. Rixubis, manufactured by Baxter Healthcare Corporation, is the first new rFIX treatment in 15 years. It is the only rFIX product approved for the control and prevention of bleeding episodes and for routine prophylaxis (twice weekly) to prevent or reduce the frequency of bleeding episodes. It is also approved for perioperative management.

“As the first recombinant coagulation factor IX indicated specifically for routine prophylaxis to prevent bleeding, Rixubis becomes a new weapon in our arsenal to protect Hemophilia B patients,” said Karen Midthun, MD, director of the FDA’s Center for Biologics Evaluation and Research. “This approval provides patients and physicians with an alternative treatment option to prevent or reduce the frequency of bleeding episodes.”

The efficacy of Rixubis was evaluated in a multi-center study of 73 male patients between 12 and 65 years old. The subjects had severe hemophilia (< 1% FIX) or moderate hemophilia (< or = to 2% FIX), and received the drug for routine prophylaxis or as needed for symptoms of bleeding (on demand) for a minimum of 150 days. The 59 patients in the prophylaxis study had a 75% lower annual bleeding rate compared to the 14 subjects receiving on-demand treatment.

During the study, no patients developed antibodies, or inhibitors, to the drug and there were no reports of anaphylaxis, a life-threatening reaction that can occur in patients with hemophilia B. Side effects occurred in < 1% of patients and included distorted taste, pain in an extremity and atypical blood test results. An additional study in a pediatric population is currently being conducted.

Source: FDA news release dated June 27, 2013 (Reprinted from NHF News Newsletter Stories)

HFMD Awards Post-Secondary Scholarships



Knowing that an education is usually necessary for people to attain the kind of work they dream of, the Hemophilia Foundation was delighted to receive 13 completed applications for post-secondary school this year from members within our bleeding disorders

community. During the month of July, the Scholarship Committee reviewed all applications, the recipients were named, and the applicants were notified by mail. Scholarship checks will be awarded to the recipients and mailed to the school of their choice by the end of July.

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

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**NEWSLETTER OF
THE HEMOPHILIA
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2013/14 Calendar of Events

July 14-19, 2013.....	HFMD Summer Camp Courage North
July 27, 2013	Dakota's Family Education Event Holiday Inn Fargo, ND
July 28, 2013	HFMD Walk Fundraiser Lindenwood Park Fargo, ND (1st Annual in Fargo)
August 3, 2013	HFMD Walk Fundraiser Como Park Pavilion St. Paul, MN (3rd Annual in St. Paul)
August 17, 2013	Group Fitness Event Canoeing at Taylors Falls 10 a.m. Call HFMD to R.S.V.P.
October 3-5, 2013	NHF's 65th Annual Meeting Anaheim, CA
October 12-13, 2013	Women's Education Event Oakridge Conference Center Chaska, MN
February 15, 2014	HFMD Hearts of Hope Gala Radisson Blu Bloomington, MN
May 2-3, 2014	HFMD Annual Meeting Crowne Plaza, Plymouth, MN

****The HFMD Board of Directors meets quarterly on the fourth Tuesday at 7:00 p.m.****
Check out our NEW web site: www.hfmd.org, for exciting news and updates!