

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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Bleeding Disorders Camp 2013

The Annual Summer Camp for kids and teens with Bleeding Disorders was held on July 14-19, 2013 at Camp Courage North in Lake George, MN. A total of 50 kids between the ages of 7 – 17 attended camp this year. Campers came from all over Minnesota, North & South Dakota and Wisconsin. It was great to be back at Camp Courage North!

“The Big Stick” self-infusion award program was a great success again this year with 10 kids successfully sticking themselves with an I.V. Congratulations and good work to all of those campers who achieved “The Big Stick” and got their name on the traveling trophy! Thanks to all of the nurses and medical staff who helped campers learn to self infuse.

Cheryl Hansen, Physical Therapist from Children’s Hospitals and Clinics of Minnesota and Cindy Wisted, PT from the Mayo Comprehensive Hemophilia Center put on a fun interactive educational program for the campers to learn about fitness and joint health.



HTC Social Workers Melinda Otto (Mayo), Jill Swenson, (Children’s), and Kate Syverson (Sanford) planned and implemented the Leadership Program along with camp staff. Each new camper was paired with an older camper to construct and paint a boat to race in the “Rain Gutter Regatta” at the end of camp. As a part of the leadership program, older campers and CITs (Counselors in Training) attended a wrap session with several adult volunteers who shared their experiences with the campers.

A HUGE THANK YOU to Sam Fredrich, Jeff Kallberg, Casey MacCallum, Cody Morrow, and Kelly Young for volunteering their time to help with this program!! Also thanks to all of the volunteers and CITs, your time and energy is essential to having a great camp year after year!

Campers had a great time swimming, canoeing, biking, camping, and doing all kinds of other fun activities throughout the week!! Camp was a Rainforest Jungle theme complete with bongo drums and a giant gorilla (costume) running around camp! Thanks for HFMD for sponsoring campers and for providing a DJ from Kids Dance for the final night party!!



The HFMD is grateful to the following companies who sponsored 2013 Camp: Buuck Family Foundation, Novo Nordisk, Sanford Health, U of MN Fairview, Baxter BioScience, & CSL Behring. The HFMD is also very thankful to all of the generous donors who made camp pledges at our Gala. Thanks to Bayer, Octapharma, and Pfizer for donating emergency factor for our health center!! Thanks to all of the companies who donated items for the campers! And one final THANKS to all of the camp staff, medical staff, and volunteers!

For more information about Bleeding Disorders camp contact your Hemophilia Treatment Center (HTC). By Angie Boyd

SAVE THE DATE:

The dates for next year are Sun. July 13- Fri. July 18th, 2014 at Camp Courage NORTH in Lake George, MN!

DAKOTA'S EDUCATION EVENT

Over the weekend of July 27th, the HFMD hosted an informative and fun family weekend education event at the Holiday Inn Express in Fargo, ND. There were 13 families in attendance, totaling 51 people, as well as exhibitors from 13 different companies.

The event began on Saturday morning, where families could check-in, enroll their children in childcare for the weekend, as well as register for the first annual HFMD fundraising walk in Fargo. Vicky Neis of Children's Hospitals in the Twin Cities and her sister Patty traveled to Fargo to run her Child Care programming. After registration and some time for visiting, a delicious lunch of sandwiches and soup was served.

Lunch was followed up with a riveting presentation from Dr. Nathan Kobrinsky regarding the various types of bleeding disorders. He went into great detail on the interaction of platelets and blood cells. Many of the attendees are patients of Dr. Kobrinsky and their families. Dr. Kobrinsky's presentations at HFMD events are always well received. The second speaker, Jeanette Cesta, gave an intriguing speech to the group about her own struggles with bleeding disorders, as well as a helpful guide on how to better manage your own health issues. After Ms. Cesta's speech, attendees broke into "round table discussion groups" and talked about common challenges and solutions regarding their bleeding disorders until the event came to a close around 5:00.



Dr. Kobrinsky



Sherri & Carson Ouellette

Following the Saturday's education event, families met back for a mouth-watering turkey dinner, complete with turkey, stuffing, potatoes and gravy, cranberry sauce, corn and, of course, some tasty deserts. Once everyone was finished with dinner, the group went over to the Trollwood Performing Arts center for the closing night performance of "Shrek: The Musical." The Broadway-style play featured an extremely talented cast made up of students from the Trollwood Performing Arts School. With intricate costumes and a stunning outdoor stage and set, the play was a joy to watch for all audience members, young and old. Although the performance stretched out into the late hours of the evening, families in attendance agreed that it was worth the delayed bed times.

The next morning, families reconvened at Lindenwood Park for Fargo's first annual fundraising walk. With over 100 participants, face painters, a balloon twister, Fargo's Y-94 radio station, a beanbag toss, and many other fun activities, the walk was a great way to bring the Fargo family education event to a close.

"Hemophilia doesn't stop me from having fun."

— Charlie, 7 years old, loves windy days

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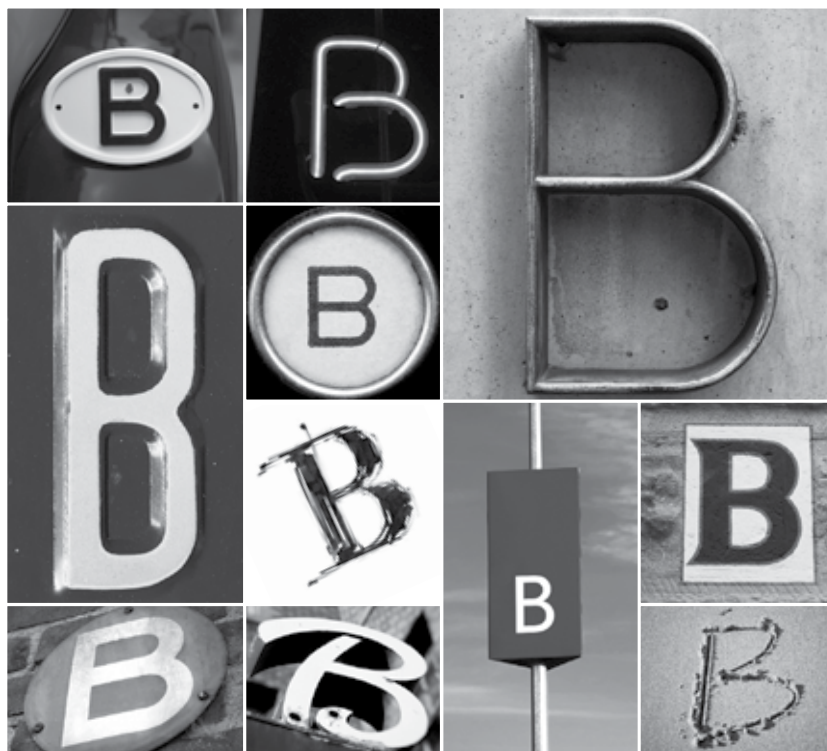
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We would like to thank Sanford Health Fargo for co-sponsoring the event with us, the Holiday Inn Express of Fargo, Dr. Kobrinsky, Jeanette Cesta, all of our volunteers and attendees, as well as our exhibitors; Accredo Hemophilia Health Services, Baxter BioScience, Bayer HealthCare, Biogen Idec, Bio Rx, CSL Behring, CVS Caremark, Grifols, Kedrion Biopharma, Novo Nordisk, Octapharma, Pfizer and Walgreens. We look forward to our next Dakotas family event!

By Rachel Wille (HFMD Intern)

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Ward.debra1@mayo.edu

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Vilmarie Rodriguez, MD
Amy Eckerman, RN
Aubrey Manahan, RN
Dawn Olive, RN
Melinda Otto, LSW
Lyndsey Vandenberg, PT, DPT
Michelle Kluge, Genetics Counselor
Ivy Akogyeram, Pharm.D
Deb Ward, Secretary

North Dakota Hemostasis & Thrombosis Center

Sanford Health, Fargo, ND Region

820 Fourth Street North
Fargo, ND 58122
701-234-2757
jana.suder@sanfordhealth.org

Nathan Kobrinsky, MD
Samuel Odame Anim, MD
Jana Suder, DNP, NP-C, Program Coordinator
Courtenay Misheski, RN Nurse Coordinator
Nicole Bogrud, RN
Tanya Ramacher, RN
Kimberly Rasmussen, RN
Cynthia Vingelen, RN, BSN
Linda Thorseth, PT
Diane Sjolander, CCRP Clinical Research Coordinator
Kate Syverson, MSW, LCSW
Mark Plencner, RPh Pharmacy Supervisor

Hemophilia Treatment Centers (Tri-State Area)

**Hemophilia and Thrombosis Center
Children's Hospital and Clinics of Minnesota
(CHCMN)**

2525 Chicago Avenue, CSC-175
Minneapolis, MN 55404
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, MPH
Kim Jacobson, RN, CPNP
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Nicole Leonard, RN, BS
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Jennifer Roggenbuck, Genetics Counselor
Janice Baker, Genetics Counselor
Angie Boyd, HTC Coordinator

Center for Bleeding and Clotting Disorders

University of Minnesota Medical Center, Fairview

420 Delaware Street SE - MMC 713
B549 Mayo Building
Minneapolis, MN 55455
612-626-6455
htc@fairview.org

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Stephen Calvit, MSW, M.Ed, LICSW
Matthew Bower, Genetics Counselor
Sheryl Raygor, Administrative Secretary,
Data Coordinator
Helen McIntyre, MBA Program Manager

Sanford Health, Sioux Falls, SD Region

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P. O. Box 5039
Sioux Falls, SD 57117
605-312-1000

Mustafa Barbour, MD, Program Coordinator
KayeLyn Wagner, MD
George Maher, MD
Jerilyn Moore, RN
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HFMD Affiliated Social Worker Conference

The HFMD Patient Financial Assistance Program is operated in collaboration with the Social Workers from our five affiliated Hemophilia Treatment Centers. The hardship requests that we consider are submitted by an HTC Social Worker on behalf of an individual or family from this bleeding disorders community.

If the financial assistance request fits within the HFMD program guidelines, it may be approved for support. Some requests include assistance with medical bills, medical equipment, utility shut-offs, and transportation support for hospital and HTC clinic visits.

While our patient financial assistance program has been working well, the program guidelines have not been formally reviewed since 2006. The primary goal of this conference was to ask for feedback from the HTC Social Workers on how our guidelines and process could be improved to better serve our community members experiencing an unexpected non-reoccurring financial hardship. Their recommendations will be taken to the HFMD Board of Directors for consideration on November 16th.

The HFMD Affiliated Social Worker Conference was held September 19th & 20th at the Radisson Blu in Bloomington, MN. In addition to bringing the Social Workers together to get their feedback on our financial assistance program, Jim Paist, Board President John Schulte, Board Treasurer Kris Manns, and HFMD member Jan Petrovich also participated in the discussions. This conference was sponsored by a grant from the Hemophilia Alliance Foundation.

The event started Thursday over lunch at the hotel restaurant. Jim Paist opened on the program background and outlined the goals of the conference. Next, willing to come out of retirement for

the day, former U of MN – HTC Social Worker Terry Hammink shared a very detailed and personal history of the HFMD financial assistance program. Terry talked about how the program evolved to what it is today, and how he would work with patients to look at all potential support resources from state and county programs, before submitting any assistance request to the HFMD.

Another important aspect of the conference was bringing all five affiliated Social Workers together to get to know each other and for each of them to share their approach to considering and submitting a financial assistance requests to the HFMD. These five professionals are Nathan Anderson from the Sioux Falls HTC, Steve Calvit – U of MN (Fairview), Melinda Otto – Mayo Clinic, Kate Severson – Sanford Health Fargo, and Jill Swenson – Children's HTC (Mpls). "I appreciated the opportunity the HFMD provided that allowed me to network and exchange ideas with the other affiliated social workers. It was great to come away knowing the other social workers, each with their own unique skill set, a bit better. We all left with a few more "tools in our chests", knowing that we can contact each other in the future for consultation. I believe that the collaborative work we did at the conference will help to improve the provision of assistance to those in the bleeding disorder community served by the HFMD." (Melinda Otto). cont. pg.7



Jill Swenson, Kate Syverson, Melinda Otto, Steve Calvit, & Nate Anderson

As a part of scrutinizing our program guidelines, we looked at several other hemophilia chapter guidelines from other states to see if there were elements from those that we may want to incorporate into ours.

Throughout the two days, we made good progress on making recommended adjustments to the program guidelines, and we also agreed that a standard HFMD application form was needed for all patient applicants to complete as a part of the new process. Each participant brought good ideas to the table and a better understanding of the program was established. "HFMD deserves praise for inviting regional HTC social workers for a two day conference in Minneapolis to discuss revisions in the HFMD Financial Assistance program. Many of the social workers had not met each other before so it was a wonderful opportunity for us to meet and begin working together on issues of common concern like the upcoming changes in health insurance." (Steve Calvit)

The HFMD would like to thank all of the participants, and a very special thanks to the Hemophilia Alliance Foundation for helping to make this possible!

By Jim Paist

A

Social workers met today

You bet!, we had a lot to say

We discussed program compliance

Thanks to funds from the Alliance

Making statements, raising questions

Considering so many suggestions

Guided by our leader Jim

P

We throw guidance back at him

Treated well and working hard

Here, please take my business card

O

Luxury accommodations

We give high praise with commendations

Hemophilia A to Z

e

We sure like HFMD!

m

By Nate Anderson, SW

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HFMD WALKS - 2013

We had a busy summer here at the HFMD office, with not one, but two fundraising walks! On July 28, we held our first annual “Step Out for Bleeding Disorders” fundraising walk in Fargo ND, and our third annual walk in St. Paul, just a week later on August 3rd!

FARGO



The Fargo walk was held at the beautiful Lindenwood Park, nestled on the banks of the Red River. With a crowd of over 100 families, children, community members, and even a few dogs wearing event T-shirts, our first annual walk in Fargo was a huge success. After registering, participants received a neon green t-shirt, and then enjoyed a day filled with entertainment, with everything from a bean-bag toss competition to a balloon artist that twisted balloon hats that were nearly three feet tall. Fargo's Y-94 radio station was also present, adding a lot of energy and fun to the event. As the walkers returned, they were treated to a feast of pizza, which was generously donated by Spicy Pie Pizza, a local Fargo establishment, as well as an endless supply of ice-cold water, provided by Sanford Health. Our Fargo Walk supporters raised over \$5,500 from both online and onsite donations, we couldn't have asked for a better first annual walk in Fargo! We're already thinking about next year's walk and can't wait to make it even bigger and better than the first.



ST PAUL

Our third annual “Step Out for Bleeding Disorders” fundraising walk at Como Park in St. Paul took place on Saturday, August 3rd, only a week after the walk in Fargo! Drawing in nearly 350 participants, we had yet another extremely successful walk! With face painters, a balloon artist, photo booth, mascot appearances from Nordy of the Minnesota Wild, Chuck E. Cheese and Crunch of the Minnesota Timberwolves, the 92-KQRS radio van, and all sorts of other activities, everyone at Como Park had a fantastic time.



Continued on page 9

With our two Walks combined, the HFMD raised over \$69,000 in total. Sponsorship from generous companies raised \$30,500, companies exhibiting raised \$11,000, and our fantastic online Team fundraisers for both Walks raised \$24,000, and at event donations brought in the rest. This was our most successful Walk fundraiser ever!

At our St. Paul walk, we were also lucky enough to have exhibitors from 13 different companies come and set up displays. Our St. Paul exhibitors included Accredo Hemophilia Health Services, Baxter BioScience, Bayer HealthCare, Biogen Idec, Bio Rx, Coram Specialty Infusion Services, CSL Behring, CVS Caremark, HFA, Kedrion Biopharma, Novo Nordisk, Octapharma, and Pfizer.



After participants completed the walk, Subway sandwiches, bottled water snow cones were ready and waiting to keep everyone refreshed. With both online and onsite donations, making it our most successful walk yet! We were extremely pleased with the outcome of this year's walks and have nothing but high hopes for walks in years to come



We would like to extend our deepest appreciation to our Walk sponsors:

Long Strides:

Pfizer, CSL Behring, Bayer, and Baxter.

First Steps Level:

Biogen Idec, Children's Hospitals & Clinics, CVS Caremark, U of MN Medical Center Fairview, Novo Nordisk, Mayo Clinic Factor Program, and Sanford Health Fargo.

Path Sign:

Grifols

The HFMD would like to thank all of our tremendous volunteers, attendees and donors, Subway of Mendota Heights, Byerly's of Ridgedale, 92-KQRS, Y-94 of Fargo. We look forward to future walks and appreciate the support that we have received from our members who "Step Out for Bleeding Disorders" to support the HFMD!
By Rachel Wille (HFMD 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 September 30, 2013.

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**Save
the Date**

**Fine dining,
auctions,
dancing & music**

**Radisson Blu Mall
of America**

**Hemophilia Foundation of
Minnesota & Dakotas**



**14th Annual
Hearts of Hope Gala
Saturday, February 15, 2014**

FDA Grants Orphan Drug Status to Alnylam's Hemophilia Therapy

In August, Alnylam Pharmaceuticals, Inc., announced that the US Food and Drug Administration (FDA) had granted Orphan Drug Designation to ALN-AT3 for the treatment of hemophilia A. The company, based in Cambridge, Massachusetts, is developing ALN-AT3, a subcutaneously administered (injection just under the skin) RNAi therapy that targets antithrombin (AT) as a way to treat hemophilia A or B, hemophilia A or B with inhibitors, and other rare bleeding disorders. AT is a small plasma protein molecule that inactivates factor Xa and thrombin, which are needed for blood clotting.

ALN-AT3 incorporates Alnylam's proprietary gene-silencing technology called RNAi, or RNA interference. Discovered by scientists in the late 1990s, RNAi is a natural process in which cells turn off, or silence, the activity of specific genes. ALN-AT3 silences certain genes associated with AT generation, "switching off" the protein's production.

At the XXIV Congress of the International Society on Thrombosis and Haemostasis, June 29-July 4, in Amsterdam, Alnylam shared preclinical data from animal trials. The studies revealed that ALN-AT3 improved thrombin generation in mice and nonhuman primates.

Alnylam plans to file an investigational new drug application for ALN-AT3 in late 2013. It will initiate a Phase I clinical trial in humans in early 2014.

"We are very pleased that the FDA has granted Orphan Drug Designation for ALN-AT3 now for both the treatment of hemophilia A and hemophilia B. As a subcutaneously delivered RNAi therapeutic, we believe it represents an innovative approach for the management of hemophilia and has great potential to make a meaningful impact in the treatment of this often debilitating bleeding disorder," said Saraswathy (Sara) Nochur, PhD, Senior Vice President, Regulatory Affairs and Quality Assurance at Alnylam. "ALN-AT3 is a key program in our 'Alnylam 5x15' product development and commercialization strategy, and we look forward to advancing this promising RNAi therapeutic into the clinic in the months to come."

Sources: The Wall Street Journal, August 14, 2013, and Alnylam news release dated August 20, 2013

Mount Sinai Researchers Discover HCV Can Replicate in Macaques

Researchers from the Icahn School of Medicine at Mount Sinai in New York may have created a new animal model for the study of the hepatitis C virus (HCV)—pigtail macaques. Macaques live in Africa and Asia, and are closely related to humans and chimpanzees. For decades investigators who have been trying unsuccessfully to develop new animal models, other than humans and chimpanzees. The team of researchers led by Matthew Evans, PhD, and Valerie Gouon-Evans, PhD, discovered that by differentiating stem cells into liver cells, they could infect pigtail macaques with HCV. These findings represent a significant breakthrough.

First, Gouon-Evans, an Assistant Professor in the Department of Developmental and Regenerative Biology at Mount Sinai, collaborated with a team at the Fred Hutchinson Cancer Research Center in Seattle to convert macaque stem cells into liver cells. Next, Evans, an Assistant Professor in the Department of Microbiology at Mount Sinai, and his team attempted to infect these cells with HCV in a petri dish. They observed that these differentiated cells were able to support HCV infection and replication, but not as effectively as in human liver cells.

"Now that we know that HCV infection in macaque cells is possible, we wanted to find out why it only worked in liver cells that were derived from stem cells," said Gouon-Evans. "By identifying where in the viral life cycle the infection is dysfunctional, we can develop an effective animal model of HCV."

Investigators found the cause--changes in a cell surface receptor in the macaques. This obstacle was overcome by genetically introducing the human version of this receptor in macaque cells.

Next, the Mount Sinai team will infect macaques with the altered HCV. Through genetic manipulation, this modified HCV will encounter more functional receptors, allowing for more efficient replication.

"Our discovery shows that by manipulating either host or viral genetics we can efficiently infect macaque cells," said Evans. "These findings may open doors for the field of HCV research, lead to new animal models, and hopefully vaccines and therapies."

The study, "Hepatic Cells Derived from Induced Pluripotent Stem Cells of Pigtail Macaques Support Hepatitis C Virus infection," was published online July 26, 2013, in the journal *Gastroenterology*.

Source: Mount Sinai press release dated July 26, 2013

NHF, Coalition for Accessible Treatments Advocate for H.R. 460

In September, the Coalition for Accessible Treatments (CAT, of which NHF is a member) hosted two briefings to discuss the release of a new study on specialty tiers and why this insurance practice impedes patient access to treatments. CAT comprises 20 patient and provider groups advocating for the passage of H.R. 460, the Patients' Access to Treatments Act. The bill prohibits private insurers from charging patients more in cost-sharing for drugs on the 4th, or specialty tier, than they do for drugs on the 3rd tier.

The briefings focused on the release of a new study by Avalere, a healthcare consulting firm in Washington, DC, on the potential impact the bill would have on premiums and cost-sharing in private health insurance plans. Avalere's study, estimates that H.R. 460 will increase premiums on average \$3 per year for plans with specialty tiers, absent any other changes to the benefit design.

The briefings also featured consumers, including bleeding disorders advocate Nathan Wilkes, who shared personal stories on why specialty tiers are so challenging for individuals with high-cost, chronic conditions. Following the briefings, NHF joined other CAT members in meeting with Congressional staff to increase the number of co-sponsors on H.R. 460 and to identify Senate champions to introduce companion legislation. NHF and the Hemophilia Federation of America (HFA) sent a joint letter to Congressional leaders asking them to schedule a hearing on H.R. 460, so that it can begin to move through the legislative process.

NHF will continue to advocate for passage of H.R. 460. We will update the community as the bill progresses.



The HFMD invites you to join us for a Group Fitness Event at Pinz in Oakdale for Lazar-tag, Bowling, and Lunch. *There is no charge for HFMD members.*

Food, Fun, & Exercise with us at



Saturday, November 2nd, 2013

10:00 a.m. - 1:00 p.m.

Pinz Bowling—7520, 32nd Street, Oakdale, MN 55128

10:00 a.m. Private Meeting Room

"Think you have good aim? Try our state of the art, glow in the dark laser tag arena – Zap City. Fun for all ages, zap your opponents and targets without being zapped yourself"

RSVP to the HFMD before October 25th

(651) 406-8655 or email to:

hemophiliafound@visi.com.

There is limited space. RSVPs will be taken on a first come first serve basis.



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Board/Staff News

We would like to extend a very special thanks to Rachel Wille, our Event Intern over the summer. Rachel did a fantastic job with both of our Walk events and was instrumental in carrying out our Dakotas Education event in Fargo. It was a pleasure having Rachel on staff over the summer, before she had to return back to school at Drake University in Iowa.

The HFMD is excited to welcome Carson Ouellette to our Board of Directors. Carson is studying political science at Concordia College in Moorhead. He and his family are longtime HFMD members and Carson is also active with the National Hemophilia Foundation Youth Leadership Program (NYLI).

Hemophilia Foundation of Minnesota/Dakotas Board of Directors 2013

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**NEWSLETTER OF
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MINNESOTA AND
THE DAKOTAS**

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

Phone: 651.406.8655
Fax: 651.406.8656
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2013 -2014 Calendar of Events

- | | |
|-------------------------|--|
| November 2, 2013 | Group Fitness Event
Laser Tag & Bowling at Pinz in Oakdale
10 a.m. Call HFMD to R.S.V.P. |
| February 15, 2014 | 2014 Hearts of Hope Gala
Radisson Blu, Bloomington |
| May 2-3, 2013 | HFMD Annual Meeting
Crowne Plaza, Plymouth |

****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!