NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

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SUMMER 2010

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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Our annual event opened Friday evening with a carnival inside the ballroom of the Minneapolis Marriott West. Fun was had by all as kids and adults enjoyed different game stations featuring basketball shooting, golf putting, a duck pond, Wii games, and ice-cream. The carnival was also highlighted by Pumpkin the Clown who entertained our guests making impressive balloon animals for every child.

As an added affect, delightful carnival music was playing throughout the night. HFMD board members and event exhibitors volunteered to run the busy stations. Our carnival committee did a terrific job in organizing the festivities. Thank you Kirstin Schmidt, Nancy Golden, and Stephanie Miller!

Saturday morning began with breakfast and a slide-show presentation from HFMD Executive Director Jim Paist. Next, our group of over 200 was treated to a fascinating panel "A Real Life Perspective" with Orville Richter, Beth Andersen, and Cody Morrow. As an 80 year old with hemophilia, Orville shared stories of how his hemophilia was treated in rural North Dakota when he was young. He took us through his life touching on a number of episodes where he dealt with serious bleeds, including a time where doctors had to sow cotton onto his gums to stop the bleeding.

Beth Andersen shared her story as a mother of a son with hemophilia. Beth talked about the surprise she and her husband Jon experienced when they discovered their son was born with hemophilia. However, as a very active and athletic 13 year-old, Jared doesn't let his bleeding disorder slow him down. Cody Morrow (age 22) spoke about his experience playing sports all of his life while living with hemophilia. Cody' presentation was truly compelling and inspirational. Our panelist's did a fantastic job engaging our audience with their personal stories.

HFMD 2010 Annual Meeting

"Life is a Carnival"

April 23rd & 24th



A break with our exhibitors was followed by a presentation from Ann Garwick, Ph.D. RN "How to Navigate the Ups & Downs of Life". After lunch, there were three breakout sessions for people to choose from: 1) Joint Health (Supported by Novo Nordisk) Speaker: Jen Maahs, PNP, MSN - Indiana Hemophilia Center, 2) Parent's Panel - Self Infusion Challenge Moderator: Margaret Heisel Kurth, MD, 3) Women's session – Information for Carriers and More Moderators: Skye Peltier, PA-C, and Sue Curoe, RN. Our 2010 Annual Meeting adjourned at 3:30 p.m. on Saturday with a number of attendees commenting on how much fun they had. This event was made possible with support from our generous sponsors and exhibitors. Our deep appreciation goes out to event sponsors Baxter BioScience, Bayer HealthCare, Pfizer, Novo Nordisk and the U of M Medical Center, Fairview. Exhibitors: Accredo Hemophilia Health Services, AHF Home Care, Baxter BioScience, Bayer HealthCare, BioRx, Coram Specialty Infusion Services, CSL Behring, CVS Caremark, Grifols, Novo Nordisk, Pfizer, Talecris, and Walgreens. By Jim Paist

Hemophilia Foundation of Minnesota and the Dakotas Is proud to announce its:

Fourteenth Annual Golf Tournament

Will help to support HFMD and its Community Programs

Monday, August 16, 2010 12:30 pm Shotgun start

A chance to draw for a \$10,000 Putt. The Putt will be held at 12:20 p.m.
4-Person Scramble Format

Minnetonka Country Club

24575 Smithtown Road, Shorewood, MN 55331

Along with golf, feel free to bring your tennis rackets as the tennis courts will be available to our group.



Master of Ceremonies Tom Halden... Fox 9 News



Directions: I-494 and exit on Hwy. 7 West (North of Crosstown - 62 and South of 394). Follow Hwy. 7 West for 6 miles. You will pass under 1 small bridge and turn right at the next stop light onto County Rd 19. Follow 19 for approx. 1 mile and take a left at the stop light on Smithtown Road. Go past Country Club Road and Minnetonka Country Club is the first driveway on your left.

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Names (List All)	
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Fee \$175.00 x # of Persons on Registration Full Foursome: \$700.0	0
\$35.00 Dinner only - No golf	
This year the total players fee of \$175.00 will include the longest drive and	l a chance to

This year, the total players fee of \$175.00 will include the longest drive and a chance to draw for a \$10,000 Putt. Each player will receive one mulligan, which is non-transferable.

Total Enclosed \$ __ _ _ _ _ _ _

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Hemophilia Foundation of Minnesota and the Dakotas 750 South Plaza Drive, Suite 207, Mendota Heights, MN 55120

Spanish Speaking Event

On Saturday, June 5th, HFMD and the Children's Hospitals and Clinics of Minnesota Center for Bleeding and Clotting Disorders in partnership with Baxter BioScience held an educational session and picnic for our Spanish speaking members. The event was held at Hyland Park in Bloomington.

The day started off with a barbeque lunch from Famous Dave's and a presentation in Spanish by Clemencia Casas, Spanish Educator from Baxter on "Joint Health and Exercise/Sports Choices". Dr. Margaret Heisel Kurth was also in attendance to answer questions and provide additional information.

After lunch, the kids worked on art projects led by Jocelyn Gorlin and a great group of teens from GirlScout Troop # 10266 from Hopkins and Minnetonka. They then went outside and played in the HUGE chutes and ladders play area, despite rain showers!

After Clemencia's presentation the families thanked Terry Hammink and wished him well as he is retiring. Terry started this group several years ago and has been an integral part of planning these events. Thanks again Terry for 7 incredible years!

Then it was time for some physical activity... Clemencia led a stretching session complete with yoga mats to lie down on the floor and stretch. She also handed our resistance bands and showed the group several useful exercises.

It was a good thing we stretched out because next on the agenda was dancing!! Clemencia turned on the Mexican music and no one was shy about getting out on the dance floor. All in all everyone had a great time!

Thanks to Clemencia Casas and Stacie Cowen from Baxter, GirlScout Troop #10266 for child care, the Gorlin family, Dr. Margaret Heisel Kurth, Terry

Hammink MSW, & Stephanie MacPhail Spanish Interpreter/ LEP Coordinator from Children's. And special thanks to the families who participated! By Angie Boyd, HTC Coordinator



(Children's Hospitals & Clinics).

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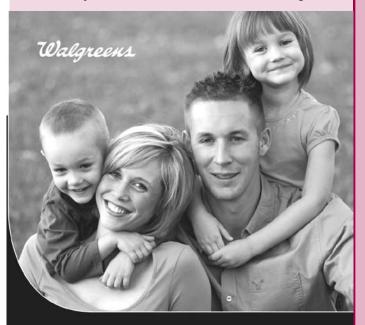
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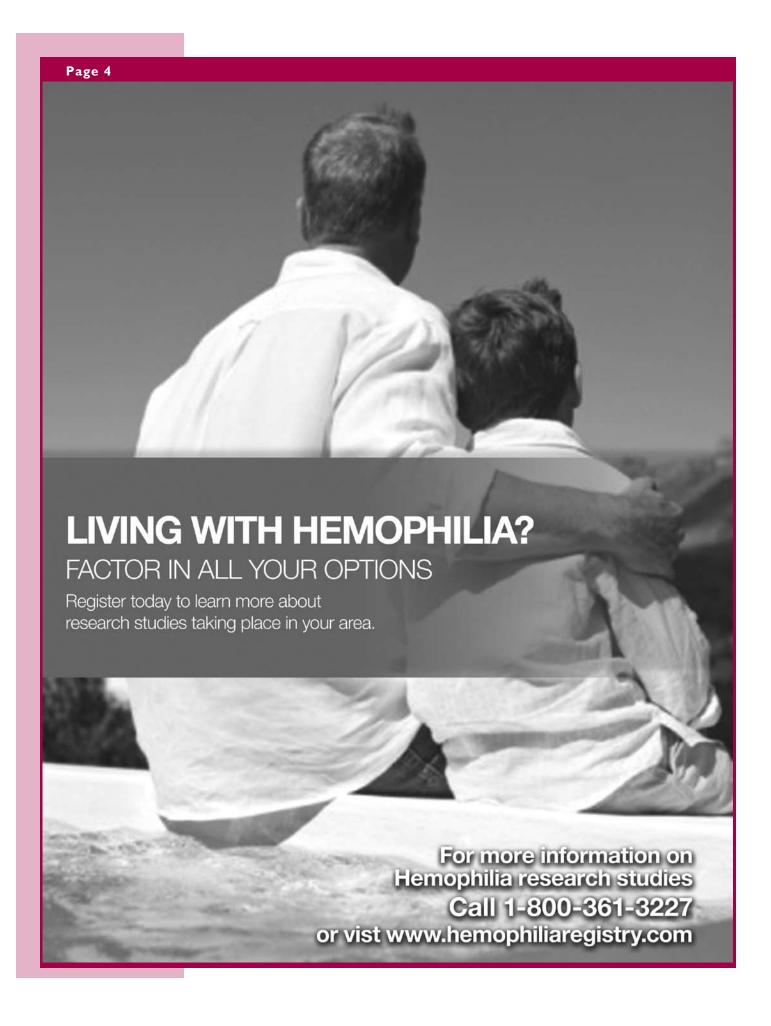


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Healthy Food Choices + Regular Exercise = A Healthier You! By Kim Baumann

A calorie is a calorie is a calorie...

Whether it comes from fat or carbohydrate, a calorie is a calorie. Maintaining your current weight requires that you take in (eat) the same amount of calories you burn. Losing weight requires that you eat less calories and increase your physical activity. Many people think that eating all reduced fat or fat-free foods will limit their calorie intake. This has 2 potential problems: 1) often people eat more of the lower fat food than they would of the regular item and 2) just because it is fat-free, doesn't mean it is calorie-free. Here are a few examples of foods compared to their reduced fat varieties:

- 2 Tbsp. of regular peanut butter =191 calories vs. 2 Tbsp. of reduced fat peanut butter = 187 calories
- ½ cup regular vanilla frozen yogurt = 104 calories vs. ½ cup of nonfat vanilla frozen yogurt = 100 calories
- 2 Tbsp. caramel topping = 103 calories vs. 2 tbsp. of fat-free caramel topping = 103 calories

(complete list available through the CDC website)

So how do we burn those calories away?

There are many ways to exercise and burn calories...walking may be one of the best. Walking doesn't require any special equipment or protective gear, no special training is needed and it is readily available to most people. Walking is also an activity that can be done almost anywhere and can be continued across the lifespan. On average, we burn about 2000 calories a day. Any extra calories we take in need to be burned through extra activity. Walking one mile burns an additional 100 calories.

How many lengths of a football field does it take to burn off the following food items? 1 football field=300 feet=5.6 calories

Food	Lengths to Walk
1 Lays potato chip	1
1 M & M candy	1
1 oreo cookie	9
1 apple	11
1 cup skim milk	16
1 beer-12 oz. light	17
Chicken breast-3 oz.	25
1 can pop-12 oz.	28
1 bagel-plain without topping	36
Fast food medium fry, large frosty,	239 (13 miles)
single hamburger with everything	

(Source unavailable)

Octapharma USA Announces FDA Approval of wilate® - the First Replacement Therapy Developed Specifically for von Willebrand Disease

Octapharma USA announces the U.S. Food and Drug Administration has approved wilate® for the treatment of spontaneous and trauma-induced bleeding episodes in patients with all types of von Willebrand disease (VWD). Wilate® is a newly developed, high-purity, double virus inactivated von Willebrand Factor/Coagulation Factor VIII Concentrate (Human) that demonstrated efficacy for all types of VWD including pediatric patients in four prospective clinical trials utilizing both objective and subjective criteria.

Wilate® is indicated for the treatment of spontaneous and trauma-induced bleeding episodes in patients with severe VWD as well as patients with mild or moderate VWD in whom the use of desmopressin is known or suspected to be ineffective or contraindicated.(1) Wilate® is the first double virus inactivated VWF/FVIII (von Willebrand Factor / Factor FVIII), high-purity concentrate, utilizing the solvent/detergent (S/D) process and a special terminal dry-heating (TDH) system. The selected purification processes isolates the VWF/FVIII complex under highly protein-protecting conditions, resulting in a 1:1 ratio of VWF:RCo (ristocetin cofactor) and FVIII activities that is similar to normal plasma. No albumin is added as a stabilizer. Wilate® is exclusively derived from large pools of human plasma collected in U.S. FDA approved plasma donation centers.

CSL Behring Junior National Championship

Earlier this year, the HFMD was honored to be selected as one of four 2010 regional Junior National Championships sites. On Saturday, June 26th the HFMD co-hosted this wonderful golf and baseball clinic/competition with CSL Behring for children ages 8-17. The clinics were led by former PGA golfer Perry Parker and former minor league baseball player Jessie Schrader. Both athletes have hemophilia. Our event was held at the Oakmarsh Golf Club, Lake Elmo, MN.

The morning began with registration and fresh fruit. Perry Parker led golfers and parent caddies over to the driving range for a demonstration while Jessie Schrader took the baseball participants to a grassy field for some catch and batting instruction. Both Perry and Jessie focused on teaching the fundamentals of each sport spending quality time with every child participant. It was also impressive to see the skill level of the kids as we have some talented young athletes in our community.

After lunch, it was time for 9 holes on the course and more baseball clinic at a nearby ball-field. Each child golfer had an adult caddie who was also there to mentor, cheer, and drive the golf-cart. While there may have been a few swings and misses and a shot or two off course, our youth golfers made some great drives and putts. It was a beautiful day out on the greens and a real treat to have Perry share his skills. Over at the baseball clinic, Jessie (a.k.a. Schra-diddie) pitched batting practice to each kid as the rest fielded a position along with some parents. Even our host of the day, Mark Wiener of CSL Behring stepped up to the plate to take a few swings against Jessie.

At the end of the baseball clinic, the kids challenged parents and Jessie to a scrimmage. We regrouped in the Oakmarsh clubhouse to listen to Perry Parker and Jessie Schrader share their compelling stories about being a professional athlete living with hemophilia.



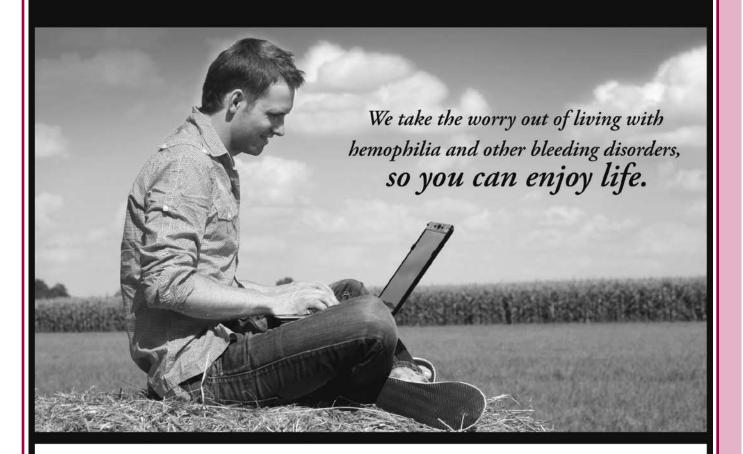
It was fascinating to hear Perry speak about his 15 years on the PGA. He talked about what a thrill it was for him to golf with players like Tom Watson, Greg Norman, Tom Lehman, and he even golfed with Tiger Woods. Perry was inspirational, informative, and humorous. Jessie also motivated our group telling us how he excelled as a pitcher in high school and college setting all-time strike-out records throwing over 90 miles per hour. Jessie spoke about some of the injuries he sustained playing baseball and talked about his recovery process from bleeds. It was such a pleasure to hear from these great guys who took time to fly to Minnesota to share their skill and personal stories.

After speaking, Perry and Jessie introduced each child athlete and awarded them with a medal. Then, first, second, and third place awards were given to the winners. All of the kids were truly winners as they each did their best, played hard (but safe) and treated all of their fellow players with respect. We thank Mark Wiener and CSL Behring for all of their marvelous work and efforts in holding this exciting event for our community. This event was a part of HFMD's ongoing fitness program where we hold group fitness events. Join us for canoeing at Lake Calhoun on July 31st! By Jim Paist

Internship News

The HFMD would like to express our deepest appreciation to spring intern Jenna Trisko who is leaving in mid-July to pursue graduate school at the University of North Dakota in Grand Forks. Over the past five months with the HFMD, Jenna has produced some impressive results. She secured several important grants for this organization and did an amazing job designing and creating our exciting Journey Around the World education program for our 2010 summer camp. Jenna went all out in profiling seven countries and in gathering items symbolic to each country. She was also very helpful in the office assisting HFMD staff. We wish Jenna the very best. We would like to welcome our new Event Coordinator Intern Bethany Pearson who will be working with us on a part-time basis through the end of this year. Bethany is a student at Metro State University studying Business Administration. We initiated this internship program last summer and it has been extremely beneficial.

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Hemophilia Carrier Talk at the HFMD 2010 Annual Meeting – By Sue Curoe

The focus of this year's Women's breakout session was "Hemophilia Carriers". Skye Peltier, PA-C, from the Hemophilia Treatment Center at Children's Hospital, Minneapolis, led the discussion. Information presented included genetics of Hemophilia, factor levels usually associated with bleeding issues, and treatment options. The session was well attended by women carriers. Kathleen Roach, NHF Regional Director, also attended the session and was very interested in the Women's programming in our area.

Our next Women's programming event will be the Women's Retreat on October 2nd & 3rd at the Oakridge Conference Center in Chaska, MN. It will be our 5th retreat! Our keynote speaker will be Dr. Carrie Terrell, OBGYN at the University of Minnesota. Other speakers will include Jim Paist from HFMD; Patrice Flax, who is the Manager of Education at NHF & in charge of the Women's Initiative; and Margaret Heisel-Kurth, who is our well-known pediatric hematologist at Children's-Minneapolis HTC. Other fun sessions like Aroma therapy, Mindful Eating, Knitting, and Exercising with Therabands will also be included. The retreat is reserved for women and teens with bleeding issues. Invites are being sent out through the Hemophilia Centers.

Women's Outreach conference calls to plan these events are held every other month. If you are interested in becoming involved in this planning or would like to see other programming developed, please contact Sue Curoe, RN at the University of Minnesota, Center for Bleeding and Clotting Disorders (612-626-2751).

If you are a carrier of Hemophilia with bleeding issues and have not yet been connected to a Hemophilia Center, please contact the Center in your area for an appointment.

Children's Hospital-Minneapolis 612-813-5940

Children's Hospital- St. Paul 651-220-6732

Mayo Comprehensive Hemophilia Center 1-800-344-7726

MeritCare Hospital Hemophilia & Thrombosis Center in Fargo, North Dakota 701-234-7544

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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 11 completed applications for post-secondary school this year from members within our 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 were awarded to the recipients and mailed to the school of their choice during the second week of July. Over the years, HFMD has received notes from these students letting us know how appreciative they are of the scholarship. One recipient wrote "I plan on pursuing a degree in nursing. For someone like me with a bleeding disorder, I know the impact of all medical caretakers and I want to make an impact on someone else's life."

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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2010-2011 Calendar

July 11-17, 2010.......Summer Camp, Courage North Lake George, MN

July 31, 2010.......Group Fitness Event
Canoeing at Lake Calhoun
10:00 a.m. - Call HMFD to R.S.V.P.

August 6-8, 2010.......Dakota's Retreat, Smokey Hills Osage, MN

August 16, 2010.......HFMD 14th Annual Golf Tournament Minnetonka Country Club Shorewood, MN

November 11-13, 2010.......NHF's 62nd Annual Meeting New Orleans, LA

November & December.......HFMD Poinsettia Sales

April 1 & 2, 2011.......HFMD Annual Meeting Minneapolis Airport Marriott Bloomington, MN

May 21, 2011.......Hearts of Hope Gala Minneapolis Airport Marriott Bloomington, MN

The HFMD Board of Directors meets every other month on the third Tuesday at 7:00 p.m.

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