



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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The Benefits of Karate

By Andrew Drake, age 16



Karate, some people think it is just a "dumb" thing because you have to pay attention to someone. I think it is fun because you get to meet new people and make some new friends. But before I joined karate, I had dealt with some serious problems at school like bullying and being angry and sad. As school was getting unbearable; the HFMD, through their patient assistance program, helped me to join karate to build my self-confidence with some of the bullies at school.

My initial reaction was "Ya, I'll give karate a try." Then as I joined karate, I found that it helps with more than what people think. I found that it helps with enjoying yourself and teaches you discipline and a better mind-set for life. So I have been in karate for almost three months and it has improved my self-image and I look a lot thinner than I did before I started karate.

So it really helps with controlling weight too. Also since I joined karate, I have had people leave me alone in school so the bullying has slowed down for now until they forget that I am in karate.

But in karate you have to use the skills you learned for the right situations or right reasons; and to learn self-defense, discipline, and to build self-confidence.

In karate there is a phrase for that and it is "Might For Right." Also, I guarantee you will make at least one new friend in your experience in karate. In karate you earn black and red stripes to advance to the next belt rank. The black stripes mean that you have shown that you know how to do your one-steps, self-defense, basics, and the form. The red strip is for attitude and discipline in the class and outside the class.

continued on page 3

HFMD 2011 ANNUAL MEETING

APRIL 1ST & 2ND



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John Jarratt



Perry Parker

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A Session for Women

A Blood Brotherhood Program (led by John Jarratt)

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BLOOD Brotherhood
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Karate - continued from page 1

In karate at first you start off as a student with a no belt then the belt ranks go as shown: white, gold, green, purple, brown, blue, red, then the all mighty black belt. If you want you can go up to 10th degree black belt if you want to but at any black belt level you are considered a master and not a student. But at green belt you have a choice if you want to start sparring or not.

So, if you want to join karate I would encourage you to do so because I chose to join because I liked it. I saw people having fun in class and I said I would like to join and I have been hooked ever since. So, I'm not trying to pressure you to do something you don't like to do but I am saying to give new things a try and if you like them then awesome; but if you don't like them then try some other new things like boy scouts or something like that.

I was told that karate was not to learn how to beat up other kids but it is to learn discipline, self-defense, and how to do things the right way. So if you are in hairy situations when a bully is picking on you and are a person who hasn't taken karate or are just stubborn and will let the bully get to them, it is better to have discipline then you might loose the bully because you are disciplined enough to know not to stoop to their level. So once again I encourage people to try new things and to enjoy life because life is short and life can be gone in a flash, so live life to its fullest and cherish every moment.

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Rock Climbing Fitness Event

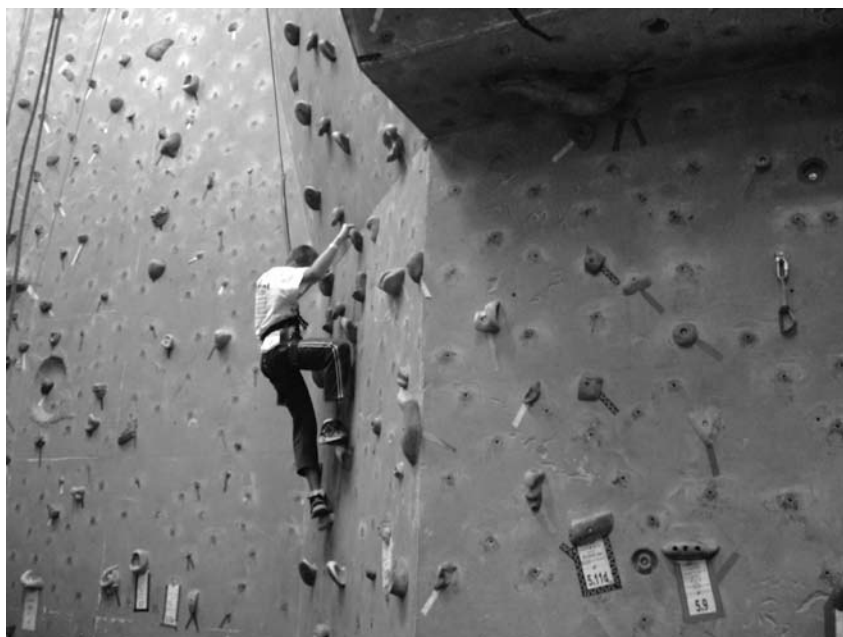
On Saturday, October 16th, HFMD along with Children's Hospitals and Clinics of Minnesota, Bayer Health-Care and ACCUA held an indoor rock climbing fitness event at Vertical Endeavors in St. Paul.

The day started out with a presentation by Jeff Kallberg, PT from ACCUA talking about the importance of physical fitness, strength, and balance especially for people with hemophilia. He demonstrated some exercises to improve proprioception, or balance.

Then it was out to the climbing area! After a short instruction session with a Vertical Endeavors instructor on how to use the belay (the process of securing and safeguarding a rope for a climber), the group was free to start climbing the walls.

After climbing for an hour and a half the participants re-grouped for lunch and to talk about their adventures on the climbing wall. Jeff Kallberg wrapped things up with a discussion on how to take care of your body after you do a new type of physical activity.

The participants all had a great time trying this new sport! Special thanks to Nancy Golden with Bayer, Jeff Kallberg PT from ACCUA and the staff at Vertical Endeavors!



Left to Right – NHF CEO Val Bias, Dr. Margaret Heisel-Kurth, and NHF Board Chair Stephen Bender.

Physician of the Year

At the 2010 National Hemophilia Foundation Annual Meeting in New Orleans, Dr. Margaret Heisel-Kurth was presented with 2010 Dr. Kenneth Brinkhous NHF Physician of the Year Award.

With an amazing career as a hematologist and oncologist, Dr. Heisel-Kurth is so deserving of this great honor. We at the HFMD know what a wonderful person and physician she is, and most certainly her patients and their parents hold Dr. Heisel in the highest regard.

Congratulations Dr. Heisel!

Dakotas Family Retreat



In the deep woods of northwestern Minnesota, the HFMD returned to the rustic setting of the Smokey Hills Wilderness Retreat just outside of Park Rapids to hold the 2010 Dakotas Family Retreat August 6th – 8th. Friday evening, attendees settled in the conference/community center to enjoy grilled hamburgers, hot dogs, and chips. A special Thanks to Mark Wiener for spending nearly two hours over a hot grill to help feed our guests.

During the casual dinner our group had time to visit exhibitor booths and reconnect with each other. Saturday morning opened with HFMD updates and the introduction of keynote speaker Dr. Margaret Heisel-Kurth. Dr. Heisel-Kurth gave an informative presentation on aging and then opened things up for questions and answers. Next our group had the pleasure of listening to Cody Morrow, a younger man with hemophilia who has played sports all of his life. Cody really connected with our audience sharing his personal story. Then, Physical Therapist Jeff Kallberg delivered a fascinating presentation on good joint health which included slides of damaged joints versus healthy joints. After lunch, Jeff managed to get everyone on the floor for stretching before he and his daughter Grace held an interactive karate demonstration for our group.

With a strong lineup of speakers, our attendees gained valuable knowledge with a wide variety of information. During breaks, people had time to visit with exhibitors to learn about their products and services. In the evening, folks watched several movies in the conference theatre. The HFMD would like to thank the Dakotas Retreat planning committee for all of their time in putting this event together. We truly appreciate the support of our sponsors and exhibitors:

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HFMD Poinsettia Sales



HFMD Poinsettia Sale raised nearly \$2,500 over the holidays. Thanks to a broad range of support from our community, we had another successful fundraiser. We'd like to thank Linder's Greenhouses for providing the plants—they were beautiful! The foundation also wishes to thank the volunteers who coordinated sales at their facilities. They are: Kirstin Schmit at Mayo Clinic, and the 3M CARES Volunteers Carol Winch and Marie Storhaug for their commitment to the foundation. This annual fundraiser helps to support our programs for children and adults living with hemophilia in our tri-state area.

HFMD Scholarship Applications

Knowing that education is usually necessary for people to attain the kind of work they dream of, the Hemophilia Foundation will again be accepting scholarship applications for post-secondary education beginning January 31, 2011. Forms will be available, at that time, by calling the HFMD office at 651-406-8655 or 1-800-994-4363, or on line at www.hfmd.org.

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) being accepted into a post-secondary educational program.

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Blood Brotherhood Update

The latest event we held for our Blood Brothers (BB) included a gathering at TCF Bank Stadium to see the Minnesota Gopher football team take on Penn State in mid-November. Although the home team lost, our attendees enjoyed the game



and the opportunity to chat with each other. HFMD intern Bethany Pearson did a terrific job in coordi-

nating this event. The following week, we held a BB conference call where the men who dialed in got to share how they cope with stress. The guys really opened up in how a bleed can create stress

in their lives and they shared various things they do to help alleviate the stress. Some found music and art helpful at times, while other mentioned talking to someone, or immersing themselves in a book or a movie. It was a great session facilitated by Steve Calvit, MSW, University of MN Medical Center, Fairview.

By Jim Paist.

Our Deepest Appreciation

The HFMD expresses our gratitude to all who have made donations to this organization in 2010. Through individuals, corporate sponsorship, and foundation grants; the HFMD had a very productive year carrying out programs and services for the bleeding disorders community in our tri-state area. In addition to the financial support we received, we are very grateful to everyone who volunteered to help make our programs and events a success. Thank you!

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NHF Annual Meeting 2010

Long before I knew I would be attending the National Hemophilia Foundation's annual meeting in New Orleans (November 11-13), I already had a couple connections to it: as a hemophiliac, and having a father from the south (Alabama). So when I was invited to go, I was excited to be going south for the first time since 1991. My sister, Rose, accompanied me as my assistant, and together we had quite the time in the Crescent City! The use of a three-wheel scooter during my stay made mobility much easier.

Thursday we attended a session on Aging With Hemophilia. Men with hemophilia, like men in the population generally, are living longer. (I, myself, am 51.) Older hemophiliacs face the same challenges as other men: the risk of bleeding from needed medications, for instance, or the necessity of a colonoscopy, and the difficult decisions regarding the use of heparin or surgery to treat heart conditions. There was some good news, though: If I heard it right, deaths from heart problems are less common in hemophiliacs.

Some of the information was rather technical and went over my head. It would be helpful if they had printouts of the information they have on the overheads. I am a note-taker, but it's easy to get involved in that and lose the flow of the session. Printouts would allow participants to give their full attention to the speaker.

Later that evening we attended the Opening Meeting, which featured an address from Val Bias (CEO of NHF). Among the topics was the launching of the Victory For Women campaign, Education, Advocacy, and Awareness for women with bleeding disorders. As it ended, the event took on a Mardi Gras feeling - noisy and festive!

Friday, Rose and I went on a self-guided tour of the French Quarter. The buildings are attractive but the sidewalks are, in some places, in such poor shape as to be dangerous. While I didn't have a "po' boy," I did have my first-ever crab cake.

Then we toured the exhibit booths. There were plenty of freebies, but perhaps the most unusual was the glow-in-the-dark Frisbee. That afternoon we sat in on a session titled Ouch! That Still Hurts! - about pain and its management. This is a topic that has long fascinated me. It is amazing how many ways there are to address pain. Perhaps the most important place to begin is to acknowledge that pain is REAL. Then there are so many ways to approach its treatment.

We were scheduled to return Saturday, but our flight was cancelled due to inclement weather in Minnesota. So we took advantage of the extra day to attend a session called Joint Disease Interventions. The shuttle driver in New Orleans gave us a nearly endless stream of suggestions for places and things to go, see, do, and eat. The hotel people were also extremely helpful - even to the point of putting an extra mattress on my bed to make it easier for me to get out of it. The airline and airport people could not have been nicer or more helpful - except for one man at the Minneapolis airport.



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Overall, we had a great time - in our own way. I would like to offer a huge "Thank You!" to Rose; without her help at virtually every stage the experience would have been infinitely more difficult. I also owe Joni Osip RN, MS (Program Manager, U of MN Center For Bleeding and Clotting Disorders, Fairview) and HFMD my gratitude; their assistance made my trip possible.

By Larry Maddox.

Hemophilia Treatment Centers (Tri-State Area)

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Women's Retreat 2010

The Oakridge Conference Center in Chaska was the location for the 5th Women's Retreat held in October. The fall colors were wonderful! We had a good turn out of women with bleeding disorders, and several teens were also in attendance. The keynote speaker this year was Dr. Carrie Terrell, who is an OBGYN at the University of Minnesota. The women really thought her talk was informative and they enjoyed hearing her perspective. Patrice Flax, who is National Hemophilia Foundation's manager of education, then spoke about the new women's initiative "Victory for Women," followed by Jim Paist's talk about Women's programming at the local level at HFMD.



Kristin Prior, who is a carrier of Hemophilia and also has vonWillebrand disease shared her story, as well as, talked about psychosocial issues involved with a bleeding disorder, and then gave a patient's perspective on treatment options. Dr. Margaret Heisel, a pediatric hematologist at Children's Minneapolis Hemophilia Center, spoke during our "Ask the Provider" session. It provided a wonderful opportunity for women with questions about bleeding and treatment. A session about Mindful Eating was also offered by Jenny Breen from the Center for Spirituality and Healing at the University of Minnesota.

Besides providing educational content to women with bleeding disorders, the retreat also provided plenty of fun activities. Breakout sessions this year included Theraband® exercise, karate, aroma therapy, and knitting. After dinner, the women and teens shared pictures with each other and played an exciting game of bingo. The retreat ended with a fabulous brunch offered at the Oakridge. There was no shortage of fabulous food during the weekend. Thanks to all the speakers, HTC staff, and 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, (University of Minnesota Medical Center, Fairview)



WALK FOR THE HFMD
AUGUST 6TH, 2011
COMO PARK, ST. PAUL

The Hemophilia Foundation of Minnesota/Dakotas will be hosting the first **Walk for HFMD** in 2011. Join us on Saturday, August 6th, at Como Park to raise money in support of HFMD's mission: *advancing the quality of life of individuals and families affected by hemophilia and other bleeding disorders by providing a broad range of services and programs.*

Support our cause by forming a team, be a team captain, or walk with family, friends, or co-workers. People of all ages are encouraged to participate. Sponsorship opportunities are also available. More information to follow.

There will be entertainment, prizes, food, and fun for everyone. Families could also enjoy a day at the zoo after the walk.

For more information about this event, contact
HFMD at 651-406-8655 or 1-800-994-4363
or hemophiliafound@vlsi.com

SAVE THE DATE



Editor's Notes

Dear Veinline Readers,
Once in a while, there is an oversight or omission with our articles reporting on HFMD activities and events. In writing our golf tournament report last issue, I regretfully left out the name of a key volunteer from the golf planning committee. Stacie Cowen did so much in planning, getting items donated, and in bringing her family members to golf and support the event; I felt it was important to correct this omission. The report on our Dakotas Family Retreat was also left out of our last issue, so please enjoy reading it on page 5. The Veinline welcomes articles submitted by members of this community to share personal stories like Andrew's. If you have a compelling story to share, please send it to my attention at the HFMD office.

Sincerely,

Jim Paist
HFMD
Executive Director

HFMD Sponsors from January—December 2010

The Hemophilia Foundation of Minnesota/Dakotas wishes to extend a very special thanks to all of our sponsors who have financially supported our programs during 2010. Their support enables HFMD to achieve our mission *as 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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Prophylaxis

Bleed prevention for people with moderate to severe bleeding disorders

This is an introductory description of what prophylaxis means when applied to the care of people with bleeding disorders. It is directed towards people with bleeding disorders and their families who, with their health care team, will be making decisions about their plan of care. The goal is to provide basic information that will start the discussion about what the best factor plan is for you and your family member.

The word prophylaxis comes from the Greek ‘prophylaktikos’ which means “to guard against”. In today’s health care it refers to a treatment that is intended to prevent or minimize a disease complication. A patient given antibiotics prior to the onset of an infection is said to be on “prophylactic antibiotics”. In a person with a severe bleeding disorder prophylaxis is the regularly scheduled infusion of factor to prevent bleeding episodes. If scheduled factor infusions were started prior to any or after one or two bleeding episodes it is referred to as primary prophylaxis. When it is started later in childhood or in an adult it is called secondary prophylaxis.

The scheduled infusion of factor was first started in the late 1950’s in Sweden. The use of this approach increased over time and clinical studies allowed comparison of outcomes. The outcomes monitored are usually the number of bleeds, patient joint scores (objective medical evaluation of the status of a joint), and patient quality of life between people using a prophylactic approach to treatment versus those who treat on-demand/episodic treatment. The results support scheduled infusions of factor as the best way to avoid the serious complications of severe bleeding disorders. Many current national and international treatment guidelines recommend prophylaxis as “optimal” therapy (i.e. World Health Organization, World Federation of Hemophilia, and National Hemophilia Foundation).

Despite the fact that regularly scheduled factor infusions are thought to be optimal treatment there is no universal agreement on what that schedule is and how much factor to use for a particular bleeding disorder. Different schedules and dosing regimens have been studied, and although there is no perfect plan, much has been learned. It is important that once a regimen is started that there is ongoing evaluation. Accurate record keeping of factor infusions and bleeding episodes provide crucial information for you and your HTC team to make any needed adjustments in your plan. Certain situations may arise, such as breakthrough bleeding or problems with venous access, which should prompt immediate contact with your team. Frequent communication by phone or e-mail in between clinic visits will keep the plan current and up to date.

If prophylaxis is considered the optimal treatment why isn’t it prescribed for every one?

There are hurdles to this treatment approach that have been identified and these need to be reviewed by you and your treatment team prior to making a decision. The period of time that the factor infusion is ‘protective’ from bleeding is limited, so maintaining protection often required infusions several times per week. The schedule is described by some as too labor intensive and difficult to maintain. Although the pharmaceutical industry has worked to make the infusions convenient and easy it still required significant time and commitment. Another issue is venous access. Successfully completing venipuncture several times a week for those with challenging veins or certain physical disabilities is a difficult task that may, at least temporarily, prevent prophylaxis. There is the option of central venous catheter but these ‘ports’ while usually eliminating the access issue, come with their own set of risks that have to be considered (i.e. infection, clotting, or mechanical malfunction). The cost of prophylaxis is also considerable so questions concerning insurance coverage and managing the financial burden are another source of challenge.

Potential advantages of prophylaxis

Decreased number of bleeds
 Prevention or stabilization of joint damage
 Decrease in time missed from work/schools
 Potential increased participation in leisure activities

Hurdles to Prophylaxis

Venous access issues
 Significant commitment of time and focus
 Insurance/cost barriers
 Physical limitations

So, given the possible hurdles to scheduled factor infusions, when is prophylaxis the right plan for you? A decision regarding a factor treatment plan involves discussion with the HTC team about multiple issues:

- What is your current joint status? One of the serious complications of a bleeding disorder is damage to joints caused by repeated bleeds into the joint space. Preserving healthy joints or preventing further damage is an important consideration in deciding on a factor infusion plan.
- What is happening in your daily life? What physical activities do you engage in that might put you at risk for bleeding?
- What are your school, play, and/or work demands in the coming months? Lifestyle can influence what level of protection from bleeding you may need.

The potential scheduling hurdles reviewed before, questions regarding venous access, ability to maintain the schedule, and the financial resource situation, all have to be evaluated when making a decision

All of these considerations are related and are subject to change which makes the need for ongoing evaluation very important.

One recent review of prophylaxis presented the following figure:

Treatment Regimen

• Infrequent On-demand

• Frequent On-demand

• Irregular Secondary Prophylaxis

• Secondary Prophylaxis

• Primary Prophylaxis

Therapeutic Objective

Prevent life-threatening bleeds
 Prevent crippling arthropathy/joint damage

Prevent target joints by limiting the number of joint bleeds per year in any joint

Maintain orthopedic/radiologic score below an age-specific target

Enable light physical exercise on certain days
 Enable practically normal life activities and psychosocial development without overprotection

Enable a completely normal life with unlimited replacement therapy

(Lyung, Blood Reviews. 2009 267-274)

Although the treatment regimen spectrum portion of the figure accurately displays the range of factor infusion treatment options, the “therapeutic objective” portion cannot capture the individual circumstance that will impact the appropriateness and feasibility of any plan.

The decision that you make with your HTC team regarding a factor infusion plan is a complex and important one that requires detailed and honest communication. Make sure that all your questions are answered and the plan is clear.

Center for Bleeding and Clotting Disorders
 University of Minnesota Medical Center, Fairview
 612-626-6455

Venline

NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

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2011 Calendar

January 29, 2011.....	Blood Brotherhood Fitness Event ACCUA, Savage Physical Therapy & Famous Dave's 10:00 a.m. – 1:00 p.m.
January 29 & 30, 2011.....	Mayo Comprehensive Hemophilia Center Family Retreat Metropolis Resort Eau Claire, WI
February 12, 2011.....	Basketball Clinic, Hancock Rec Center, St. Paul 10:00 a.m. to 1:00 p.m.
April 1 & 2, 2011.....	HFMD Annual Meeting Minneapolis Airport Marriott Bloomington, MN
May 21, 2011.....	Hearts of Hope Gala Minneapolis Airport Marriott Bloomington, MN
July 10 – 16, 2011.....	Summer Camp, Courage South Maple Lake, MN **Please note a change of location**
August 6, 2011.....	HFMD Walk Como Park Pavilion St. Paul, 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!