

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.

Minnesota Family Retreat

The HFMD & Children’s Hospital & Clinics held a family education retreat on Saturday, February 6th, at the Radisson Hotel Conference Center in Plymouth. It was a great day of important medical information, good food, and fun. The event began at 10:30 a.m. with a 2009 year in review presentation by the HFMD Executive Director. The children were off to a day of bleeding disorders education and fun activities led by Vicki Neis, Child Life Specialist from Children’s. Then our group was treated to a very special presentation on the History of Hemophilia by Dr. Nathan Kobrinsky, hematologist and Medical Director of the Roger Maris Cancer Center/MeritCare in Fargo.

People were on the edge of their seats learning how hemophilia was treated from ancient Egyptian times to the present. After a short break, Physical Therapist Jeff Kallberg captivated our audience with a terrific presentation on good joint health as he connected with people by sharing his own personal story living with hemophilia.



Dr. Margaret Heisel-Kurth
& Dr. Nathan Kobrinsky

The second part of Jeff’s session was a karate demonstration which was co-presented with his 5 year old daughter Grace. After getting EVERYONE on the carpet to do stretching exercises, Jeff and Grace provided us with a very entertaining and interactive karate 101 class.

A delicious lunch was followed by afternoon breakout sessions. They included a physical therapy session with Cheryl Hansen, PT, a parent’s panel moderated by Jocelyn Gorlin, PNP, self-infusion demonstration, and a carrier panel moderated by Skye Peltier, PA-C. The HFMD would like to extend a special thanks to Cheryl Hansen of Children’s Hospital and Clinics for presenting on Joint Health and Recovery after a bleed, Steph Miller, Jan Petrovich, and Eileen Bostwick for a wonderful parents panel, Sue Purdie RN, Nicole Leonard RN, Linda Litecky RN, Jocelyn Gorlin and Skye Peltier for leading a well attended self-infusion session, and Skye Peltier for presenting on carrier session

After an action-packed day of breakout sessions, some played wallyball, others just relaxed until dinner, and a few HFMD members went for a swim. A pizza dinner was served before Magician Tom Anderson dazzled our group with some amazing tricks. He asked the children to sit up front to get a birds-eye view of his very entertaining show. It was a night to remember. Sunday morning over breakfast featured Dr. in the House with questions answered by Dr. Margaret Heisel-Kurth. This event was a big success thanks to all who volunteered. The HFMD received positive feedback from attendees who seemed to enjoy this Minnesota Family Retreat, now held every other year.

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Heir to the Throne



Perhaps one of the most well known people in history who lived with hemophilia was heir to the Russian throne; Alexei Romanov (pictured left). While his life ended tragically, the young Tsarevich and his hemophilia quite possibly affected the course of history.

As the heir to the 400 year old Romanov dynasty,

young Alexei not only had hemophilia but also had a lot of weight on his shoulders knowing someday he would become Czar. He was known to be a very smart and playful boy who enjoyed teasing his sisters and guests of the Royal Palace. He was adventurous and active, but his hemophilia would often keep him laid up in bed; as treatment then was quite different than it is today.

His mother Alexandra was the granddaughter of Queen Victoria of England; one of histories' most famous carriers. Having been born with severe hemophilia B, Alexei was frequently treated by the best doctors in Russia, but with little success. As a mischievous boy who loved to play, he suffered through bleeds often. Of course blood-clotting factor and profylaxis were not yet invented in the early 1900s.

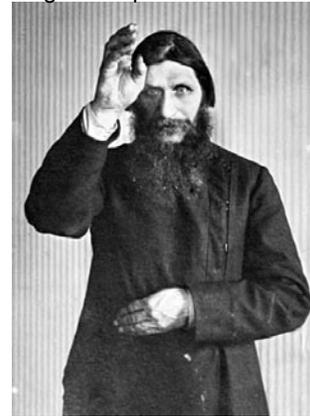
With an on going frustration from the lacking results of medical treatment and desperation to help her son, the Czarina Alexandra turned to a peculiar mystic who was thought by some to posses supernatural healing powers. His name was Grigori Rasputin. Rasputin was a monk from Siberia; an imposing figure with menacing eyes. Upon being commissioned by the Czarina to treat Alexei's hemophilia, Rasputin began to spend much time in the Royal Palace and in the company of the Czarina. Using mostly prayer and hypnosis, Rasputin's strange methods of treating Alexei appeared to be helping to treat young Alexei's hemophilia. Some historians have speculated that Rasputin may have also used leaches on occasion to treat Alexei's bleeds.

With Rasputin growing closer to the Royal Family, suspicion and rumors began to flow amongst Russian nobility and in the general population. The credibility

of Czar Nicholas and his judgment would be in doubt as many wondered what was going on with Rasputin spending so much time in the Royal Palace. The most damaging aspect of Rasputin's association with the Royal family was the widespread belief that the controversial mystic was having a high level of political influence over the Czar. There was great suspicion that Rasputin was advising Nicholas on crucial political and military decisions; as Russia was losing many lives in an unpopular war (WW1). In 1917 the Czar was overthrown by the Bolsheviks and the Royal Family was arrested and placed in captivity.

A number of political and economic factors can be attributed to the fall of the Czar and the end of the Romanov dynasty. One must consider the enormous disparity of wealth in Russia before 1917 and the fact that ultimately the people of Russia had been ruled by two families for nearly 1000 years; the Ruriks then the Romanovs. And Nicholas II's choice to apply an extremely autocratic approach to ruling the country did not help the Romanov cause.

Grigori Rasputin



But, the role Grigori Rasputin played in the unraveling of the Czar's control of the country should be given strong consideration when examining the fall of the Romanov dynasty. Upon seizing control of the country, the Bolsheviks kept the Czar and his family in captivity for several months allowing doctors to treat thirteen

year old Alexei's hemophilia. While the family's fate laid in doubt on July 17, 1918, soldiers entered into the families living quarters; and at that moment the entire Royal Family was brutally executed. The tragic murder of the Royal family and the abrupt end of Romanov rule has been studied by many historians; producing a number of interesting books about the royal family.

In the early 1900s, people born with hemophilia would rarely live to see the age of twenty. Truly amazing progress has been made since then with modern medical treatment and the advent of blood clotting factor. We are so fortunate today to have effective treatment for this life-threatening condition. It is fascinating to look back in history to learn about the different treatment methods that were used nearly 100 years ago, including those of a controversial monk named Grigori Rasputin.

By Jim Paist



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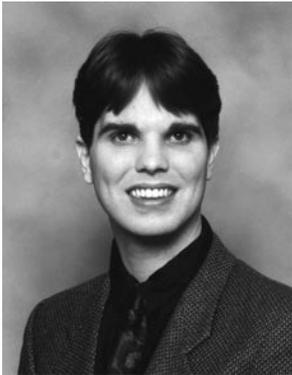
RSVP by
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HFMD office
At 651-406-8655 or
1-800-994-4363
Or hemophiliafound@visi.com



Memorials

Benjamin Towner

August 15, 1973 - January 29, 2010



Ben was a joy and a terror as a son, a challenge as a brother, a doting uncle and a fierce and dependable friend. He hurdled through his short life with cars - preferably with LOUD stereos, computers, science fiction and fantasy as consuming interests. Ben loved the intricacies of our language and tortured us

with puns. He earned certificates in everything Micro-Soft had to teach. Fairness and truth were touchstones and children were his passion.

Ben never let hemophilia dictate his choices. As a child he played soccer and was active in Cub Scouts and Boy Scouts. In his teens the bruises, swollen joints and the effects of arthritis caused by repeated bleeding into his joints slowed him down physically so computers, CB and ham radio, Star Trek and astronomy claimed his attention more than rough and tumble activities.

Ben was four months old when he was diagnosed with Hemophilia. His mother and his mother's mother were each adopted children so family medical history was a mystery. He never married or had children of his own. Hemophilia in his family would end with him.
By Amy & James Towner.

In Memory of Jim Brown

Jim Brown will always be remembered at this foundation and in our tri-state community. As a volunteer for the HFMD, Jim helped this



organization in so many ways. He was a board member of ours for two years and in this role he offered sound advice, good ideas, and a unique perspective as an industry representative and member of the bleeding disorders community.

With great precision and a thoughtful approach, Jim Brown helped to write the guidelines and bylaws for our Industry Relations Committee. With a quick wit and a very sharp mind, Jim made a positive impact on our board. His amazingly diverse career background also proved to be an asset in the various volunteer roles he filled for this organization. Jim served on several HFMD committees helping to raise money; and he would drive up from Lincoln every holiday season to help with our poinsettia sales.

Jim was the keynote speaker for our 2007 annual meeting sharing his incredibly inspirational "Success Comes in Cans not Can'ts" presentation. With severe hemophilia B, he truly motivated our audience with his personal story and powerful speech. Jim Brown had a very successful career as a nurse, attorney, CEO, and managed care representative. Jim Brown will be dearly missed by many in our community, but never forgotten. He was a loving husband, father, and grandfather. He is survived by his wife Barb, three daughters, and four grandchildren. Our thoughts and prayers are with the entire Brown family.



M i n n e s o t a

Thanks and Best Wishes to Terry Hammink

From the Center of Bleeding and Clotting Disorders-UMMC-Fairview

Joni Osip: “Terry has been a ‘rock’ at our center. I will miss his presence and all the work he has done for our patients over the last 7 years. He was my role model of kindness and calm. He taught people how to take care of themselves and when patients were incapable of self care, he gently offered to guide them through the process. Sometimes that meant a conference call, sometimes it meant driving the patient to the county office to re-establish insurance. He loved his job and it showed. He was an advocate for patients and his fellow team members and one heck of a Twins Fan. I will miss you my friend.”

Sue Curoe : “It has been a pleasure to work with Terry Hammink over the past several years. He has been warm and personable, yet very professional in his role as social worker at the Hemophilia Center at the University of Minnesota. He will be greatly missed upon his retirement in June.

Kim Baumann: “I have always appreciated Terry’s ability to connect with our patients in a caring but realistic manner. He is very helpful to our patients but also has high expectations for their independence. As a co-worker, I will miss his positive attitude, warm smile and ability to navigate the transportation systems in all the cities we travel to for meetings!”

Laura Hanson: “On my first day at CBCD, I met Terry and he was so welcoming. I knew he was a leader in our team, and someone with a wealth of knowledge. It has been an absolute pleasure working with Terry, and I hope to run into him at a Twins game this summer”

Ricky Chan: “For the short time that I have known Terry, my impression of him is that he is very enthusiastic about what he does. Terry is very knowledgeable and always willing to help. Terry also frequently goes beyond expectations and provides exceptional care for our patients. Terry is a valuable person at our center, and he will be missed by us and will surely be missed by our patients”.

From Dr. Mark Reding: “We have been so fortunate to have Terry as a part of our team over the last several years. From the very beginning, we could tell that there was something special about him and the way he approached his work. Although he already had years of experience, hemophilia was a new thing for Terry,

and I remember being impressed by how quickly he learned about all of the unique issues and challenges those living with hemophilia and their families face. More importantly, we have all learned from Terry. His compassion, devotion, enthusiasm, and professionalism have been unwavering and truly an inspiration for all of us. It has been a privilege to work with him, and we wish him the very best in his retirement”.



Vicky Hannemann and Kerry Hanson were out of town and unable to submit their thoughts about Terry. We know our sentiments express their feelings too.

Jim Paist – HFMD: “It was truly a pleasure working with Terry Hammink. Terry’s wisdom and thoughtful approach to his work has been a real credit to our patient assistance program. Terry has helped so many individuals and families from our community to get through difficult times and to find the resources they need. In addition to his many professional skills, Terry Hammink is a genuinely good guy who will be missed by all of us here at the foundation. We thank you for all of you have done for this community and wish you the very best with your future endeavors!

HFMD Intern - Jenna Trisko



Jenna Trisko is the new events coordination intern at HFMD. She completed her bachelor’s degree in 2007 in psychology from St. Cloud State University. She will be starting graduate school this fall at the University of North Dakota, and will study experimental psychology with an emphasis in animal behavior. Jenna is a devoted animal lover and strives to educate others on the importance of animal welfare and humane treatment. She is also committed to fundraising and grant writing and loves to work with various charitable organizations to make the world a better place. In Jenna’s free time she enjoys watching funny movies, going for walks, and spending time with her dog Emma.

Blood Brotherhood



“It is the best pill in my bag, the best friends I could have, the healthiest thing to come my way in a while.”

A Blood Brother (2009)

What Blood Brothers Are Saying About Blood Brotherhood

<http://voices.hemophiliafed.org/>

The Blood Brotherhood is the HFA’s flagship program for adult men with hemophilia and von Willebrand.

Designed to be a multi-avenue outreach to provide education, social support and a sense of community, the program reaches men with hemophilia in three ways.

- Online forum: <http://hemophiliafed.net/hfabb/>
- Face-to-face local Blood Brotherhood Meetings
- National Blood Brotherhood Call/Webinars

HFA’s Blood Brotherhood online forum is an internet message board for adult men only. The forum boasts of nearly 200 members discussing hundreds of topics. From co-infection to motor sports, the Blood Brotherhood forum provides the opportunity for men with hemophilia to connect, share, support, and just laugh. To become part of the Brotherhood, visit <http://hemophiliafed.net/hfabb/> to register and get connected!

The second component of the Blood Brotherhood centers on pilot sites that offer regular, group meetings. Much like the Blood Brotherhood forum, these pilot site meetings bring Blood Brothers together to connect and learn. Topic expert speakers and activities are presented that address a variety of health and wellness issues. If you are interested in joining a pilot site group or your local hemophilia organization would like to become a HFA Blood Brotherhood pilot site, contact us at programs@hemophiliafed.org.

The final component of the Blood Brotherhood program is the regularly scheduled National Phone/Webinar meetings. Topic experts provide education and facilitate discussion and Q&A around key topics that Blood Brotherhood members are asking about such as financial health, retirement planning, joint replacements, etc. For more information or to be added to this meeting list, please contact programs@hemophiliafed.org.

The Blood Brotherhood Program is supported by Cooperative Agreement Number 1U27DD000537-01 from CDC. The contents on this webpage are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

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MN RETREAT PHOTOS



2010 Hearts of Hope Gala

The HFMD held its tenth annual Hearts of Hope Gala on January 23rd at the Earle Brown Heritage Center in Brooklyn Center, MN. This exciting evening began with a terrific silent auction featuring a wide range of great items to bid on – everything from weekend getaways to seats at the new Twins ballpark.

At 7:00 p.m. our guests settled into the ballroom to enjoy a scrumptious steak dinner and an action-packed evening featuring Master of Ceremonies “Vacation” Joe Schmit and comedian Stevie Ray. Joe entertained our guests with his quick wit and charm. After dazzling our group with his great sense of humor, Joe introduced Dr. Mark Reding from the University of Minnesota Medical Center, Fairview. Dr. Reding spoke about his work as a hematologist at the Hemophilia Treatment Center, and also shared some updates about the latest research project he is leading. Then it was time for our live-auction. Not only did Stevie Ray wow our group with his comedy act, he partnered with our auctioneer Glen Fladeboe to lead our live auction and patient assistance pledge.

Although the poor driving conditions led to 31 cancellations, over 160 people braved the weather to support the HFMD. The silent auction was bolstered with a raffle to win a ½ carat diamond, donated by Continental Diamond. With one of our most unique live-auction items ever, artist Joe Selmer carved an amazing bear out of a four foot stump. Mr. Selmer enclosed inside a windowed cage at the front of our silent auction room, used an electric chainsaw to carve this wood bear statue to perfection. As guests watched this artist in action, Joe carved the bear in less than 90 minutes so it was ready for bidding during our live-auction. The live-auction also featured trips to Jamaica, San Diego, and four tickets to a 2010 Twins game.

A great time was had by all to raise money for this foundation. So many volunteers put their hearts into making this event a success. We would like to thank the Gala planning committee and everyone who shared their time for this event. 2010 Gala planning committee: Co-chairs Stacy Pike & Jim Paist, Beth Andersen, Pam Cella, Kathi Reeves, Matt Ling,

Nancy Golden, Stacie Cowen, Gayle & Bob Newman, Deb Melhado, Jadd Helma Lori Kunkel, Muriel Lynch, Skye Peltier and Mark Weiner. We would like to extend a very special thanks to our generous sponsors who helped to make this event a success. Diamond Level Sponsors; Baxter BioScience, Pfizer (formerly Wyeth), Platinum Level Sponsors; Bayer Health Care and Novo Nordisk, Gold Level Sponsors; CSL Behring and CVS Caremark and Silver Level Sponsors; Children’s Hospital & Clinics, Coram Health Care, and Walgreens-OptionCare.



Joe Schmit Table

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HFMD Post-Secondary Scholarship Applications are due June 1, 2010

Last year, the Hemophilia Foundation of Minnesota/Dakotas (HFMD) was delighted to award post-secondary scholarships to sixteen qualified recipients totaling \$9,600. This year, the HFMD will again be accepting 2010 post-secondary scholarship applications and these applications are due in our office no later than June 1, 2010.

For those students interested in applying, please contact the HFMD office for an application or visit our web site, 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 be 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.



We're Growing at Mid-West Cornerstone Healthcare!

Our goal has always been to assist our patients in leading a good quality of life and to do so with compassion and caring. We strive to have the best people available to provide service for patients, thus it is our pleasure to announce our newest staff additions.

Craig Looney, Sr. Accounts Manager

No stranger to the Hemophilia community, Craig comes with a wealth of experience that includes service to patients, insurance contracting, and acting as a liaison to patients, doctors, nurses and chapters. We are very excited to have Craig as part of our team, his enthusiasm and warm demeanor will surely be welcomed by our families. We know his expertise will be an incredible asset to our patients and to the entire community.

Noel Minor, Infusion Nurse Specialist

Noel will enhance the menu of services we are able to offer to our patients. Noel's education and experience will be an asset to our growing nursing department. With her many years of experience and participation in the Hemophilia community, Noel will also add a new dimension to services provided.

Oscar Bucaro, Latino Relations Assistant

With his ability to translate and relate to our diverse community, Oscar will without question be valuable in enhancing our service to Spanish-speaking persons. His experiences living outside the U.S. along with his background in sales and management will greatly compliment our Latino service team.

Stacey Eppenbach, Customer Service Representative

The primary goal for Stacey is to assure all patients receive impeccable service and care. His knowledge of products, service, and providers assists him in being an excellent advocate for our patients. Stacey's affiliation with chapters contributes teaching the importance of hemophilia education to enhance good quality of life.

*Please help us in welcoming these folks to our team;
they are eager to help you in your times of need.*



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Men's Night Out



As a part of our new collaborative efforts with the University of Minnesota, Fairview HTC to offer more programs and opportunities for men affected by hemophilia, we hosted a Men's Night Out on February 12th, 2010.

Paul & Greg Gilmer



This event opened at the RiverCentre in St. Paul with an HFMD presentation followed by a very informative session on maintaining good bone health, led by Kerry Hansen, RN. Attendees thoroughly enjoyed the medical education and

slides Kerry shared with us. Over dinner, the guys had time to visit with each other and talk about everything from hockey to health insurance. Just before 7:00 p.m., our group of 25 men headed through the skyway over to the Xcel Energy Center to watch the Minnesota Wild take on the Atlanta Thrashers.

We had 12 men affected by hemophilia, some friends, a few relatives, staff from HFMD and the HTC. Although the Wild lost a very close game, it was a great evening of



education and Wild hockey. Another Men's Night Out will be held during our Annual Meeting Friday evening, April 23rd, at Kips Pub to enjoy a Twins game and good food. For more information or to RSVP, please contact the HFMD.

FITNESS DAY - Fargo

North Dakota Hemophilia treatment center held their annual fitness day in Fargo, ND Feb 13th, 2010 at the Edgewood golf course. It turned out to be a great day with temps in the 20's and no WIND. We had 38 people attend the event which included sledding, snowshoeing, horse drawn sleigh rides and cross country skiing. For those who were not able to participate in the activities, the chalet offered a warm and inviting area to congregate with a fireplace and big flat screen TV showing the winter Olympics. Linda Thorseth, Physical Therapist, presented a stretching exercise before the activities started. There were a few of us who challenged cross country skiing. We were all concerned when Dr Kobrinsky took off alone on his skis but he found his way back. Not quite sure who won the "fall the most contest" but Sam Friedrich and Dr Kobrinsky were neck and neck with about 27-28 falls. Sledding was a big hit especially when they discovered the ice slope. I couldn't watch but we had no injuries. The pizza, salad, cookies and beverages were all great thanks to Pfizer and HFMD who sponsored the event. Thanks to our families for their commitment to the hemophilia community who made this a great success and will plan to have it again next year.

By Kathy Kirkeby, PA, Fargo HTC.



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

345 North Smith Avenue
St. Paul, MN 55102
651-220-6732

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Janice Baker, Genetics Counselor
Angie Boyd, HTC Coordinator

Sanford Childrens/ South Dakota Center for Blood Disorders

1600 West 22nd Street
P. O. Box 5039
Sioux Falls, SD 57117
605-312-1000

Michael Sprehe, MD
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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

Mark Reding, MD
Ricky Chan, PA-C
Joni Osip, RN, MS
Vicky Hannemann, RN, BSN
Susan Curoe, RN, MS
Kerry Hansen, RN, BS
Kim Baumann, MPT
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Mayo Comprehensive Hemophilia Center Mayo Clinic Hilton 106

200 First Street SW
Rochester, MN 55905
507-284-8634 or 1-800-344-7726
schmidt.kirstin@mayo.edu
eckerman.amy@mayo.edu

Rajiv Pruthi, MBBS
Vilmarie Rodriguez, MD
Kirstin Schmidt, RN
Amy Eckerman, RN
Melinda Otto, SW

North Dakota Hemophilia/ Thrombosis Treatment Center MeritCare Hospital

820 Fourth Street North
Fargo, ND 58122
701-234-2757

Nathan Kobrinsky, MD
Kathy Kirkeby, PA-C
Courtenay Misheski, RN
Linda Thorseth, PT

Diane Sjolander, CCRP
Cheryl Smith, LCSW
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HFMD
750 South Plaza Drive
Suite 207
Mendota Heights, MN 55120

Phone: 651.406.8655
Fax: 651.406.8656
1-800-994-4363

Email: hemophiliafound@visi.com

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2010 Calendar

- April 23-24, 2010.....HFMD Annual Meeting
Marriott Minneapolis West
St. Louis Park, MN
- July 11-17, 2010.....Summer Camp, Courage North
Lake George, MN
- August 6-8, 2010..... Dakota's Retreat, Smokey Hills
Osage, MN
- August 16, 2010.....HFMD 14th Annual golf Tournament
Minnetonka Country Club
Minnetonka, MN
- November 11-13, 2010..... NHF's 62nd Annual Meeting
New Orleans, LA
- November & December.....HFMD Poinsettia Sales

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!

