

2016 Hearts of Hope Gala

Thank you to all who joined us for the 2016 Hearts of Hope Gala at the elegant Radisson Blu in Bloomington. We were pleased to have 265 guests join us for an enjoyable evening of auctions, raffles, fine dining, memorable programming and ice cream! Thank you to our always entertaining Master of Ceremonies, Dick Bremer, for making the night's program a great success.



Thanks to the amazing work of our Gala committee and volunteers, the live and silent auctions were BIGGER and better than ever this year (I'm talking to you, giant teddy bear). The live auction featured items including a weekend stay in Chicago with Cubs baseball tickets, a rolling cooler stuffed with top shelf liquors and the most memorable item of the night, the giant teddy bear. Guests enjoyed taking photos with the bear during the silent auction before he found his forever home. The silent auction featured a wide-range of new and unique items from local restaurants, hotels, theatres and more.



The Diamond Drop raffle sponsored by Continental Diamond was once again a big hit! Thanks to the M Health staff, the Wine Wall raffle was a huge success and featured over 100 bottles of wine – more than we have ever had before! Thank you to the dedicated volunteers who sold raffle tickets for both the Diamond Drop and Wine Wall raffles.

HFMD Board President, John Schulte, began the Gala program with an invocation. Hosting for the fourth year, Dick Bremer opened the program with a humorous story about getting older and then auctioned off a signed Bert Blyleven baseball, to which he had Bert sign to a boy named "Sean" (mistakenly). HFMD Executive Director, Jim Paist, then took the time to recognize the event sponsors and feature them on stage.

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HFMD MISSION
To meet the needs and to enhance the quality of life for persons living with hemophilia, related inherited bleeding disorders and their complications.

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Study of 50 Years of Hemophilia Healthcare Outcomes Yields Surprises

Results from a new study indicate that despite 50 years' worth of advances in the area of comprehensive care for patients with bleeding disorders, males with hemophilia still grapple with significant health-related issues affecting their quality of life. The study, "Men with Severe Hemophilia in the United States: Birth Cohort Analysis of a Large National Database," was published online on March 16, 2016, in the journal *Blood*. The lead author of the article was Paul E. Monahan, MD, of the Gene Therapy Center at the University of North Carolina at Chapel Hill. Co-investigators included professionals from the hemophilia treatment center (HTC) network and the Centers for Disease Control and Prevention (CDC).

To better understand the connections between the many changes in hemophilia healthcare and the dynamics affecting overall health, Monahan and his team reviewed data collected from 4,899 men with severe hemophilia and 2,587 men with mild hemophilia. All of these men had received care at HTCs from 1998-2011. Data were organized into four time periods, or "eras," representing major healthcare developments and therapeutic breakthroughs relevant to people with hemophilia: Era A included the oldest group, men born prior to 1958; Era B grouped men born between 1958 and 1975; Era C included men born from 1976-1982; and Era D represented the youngest group, men born between 1982 and 1993.

The main findings of the study included:

- In Era D more than one in three men with severe hemophilia reported frequent bleeds (more than five bleeds in six months), despite being treated with the most modern therapies. One in four of these men also reported a recurrent bleed in a "target joint."
- Across all eras, compared to men with mild disease, those with severe hemophilia were about three times more likely to report activity limitations. Further, they were twice as likely to report some use of assistive devices to help them move around, such as a cane or wheel chair.
- In every era, the proportion of men with severe hemophilia that missed at least 10 days of work or school in the last year due to upper or lower joint problems was two or three times that of men with mild hemophilia.
- Nearly half of the men in Era A were disabled and unable to work. Moreover, men with severe hemophilia were about three times more likely to be disabled as their mild hemophilia counterparts in every era.
- Infection-related health problems due to hepatitis B, hepatitis C and HIV are common among men with severe hemophilia, particularly in the older eras.
- Of the 551 deaths reported during the study period, liver failure was the most commonly reported cause of death, regardless of hemophilia severity or era. Bleed-related deaths accounted for 14.6% of deaths in men with severe hemophilia and 10.7% of deaths in men with mild hemophilia across all eras.

The study also yielded some unexpected findings. The overall rates of joint bleeding remain relatively high, even with the availability of more effective treatments. Also, despite the proven effectiveness of prophylactic factor therapy in preventing joint damage, men in all eras continue to underuse this option.

"Clear disparities remain in terms of frequent bleeding and disability between men with severe hemophilia and mild hemophilia across every decade of adult life. We thought the difference in functional outcomes would have narrowed over the years; that is, men with severe hemophilia should look more like those with mild disorder given improved therapeutics and access to care, but this wasn't the case," said Monahan. "What needs examination is why—despite widespread availability of preventive and on-demand therapies for home use—we still see disparities. It speaks to the need for continued disease surveillance to monitor and inform hemophilia interventions and outcomes."

Source: PRNewswire, March 16, 2016

REGISTER TODAY FOR THE 2016 HFMD ANNUAL MEETING - APRIL 22 & 23 AT THE HILTON MSP AIRPORT/MOA IN BLOOMINGTON, MN. JOIN US FOR TWO DAYS OF EDUCATION AND FUN!

FEATURING...

FRIDAY NIGHT

- ★ **DINNER AT HILTON THEN SEA LIFE AQUARIUM FOR ALL MEMBERS!**

SATURDAY

- ★ **KEYNOTE SPEAKER:**
KEVIN HARRIS ON NUTRITION AND HIS PERSONAL STORY WITH HEMOPHILIA
- ★ **EXHIBITORS**
- ★ **CHILD & TEEN PROGRAMMING**
WITH THE FAMOUS VICKI NEIS CHILDCARE TEAM
- ★ **ASK THE DOCTORS PANEL**
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AND DR. MARGARET HEISEL-KURTH
- ★ **DISCLOSING YOUR BLEEDING DISORDER**
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- ★ **BLOOD BROTHERHOOD**
"YOUR LIVER AND VIRAL HEPATITIS"
DANIEL C. REILLY
- ★ **YOGA**
CHRISTINE PAUL, OYI

DEADLINE FOR REGISTRATION IS APRIL 11TH IF YOU NEED HFMD TO PAY FOR YOUR ROOM. IF YOU ARE COVERING THE COST OF YOUR ROOM, WE NEED YOUR REGISTRATION BY APRIL 15TH. REGISTER TODAY AT HFMD.ORG!

...Gala, continued from cover page

During dinner, Auctioneer Dave Nelson and Host Dick Bremer shared auctioneer duties and auctioned off sought-after items including a private wine tasting party from Total Wine and a half inning in the FSN Telecast booth with game tickets. Our Fund-a-Need featured a video of an HFMD member, a young woman who received assistance from the HFMD for a major dental procedure which led to a great new smile. Thanks to our generous guests, the Fund-a-Need raised over \$12,000 for our Patient Financial Assistance program. Ending the program, the diamond raffle winner was drawn and the Ben & Jerry's ice cream was served!

Thanks to all of you, the HFMD raised over \$100,000! We are so grateful for our staff, committee and volunteers who took the time to make the Gala a success. We would like to honor our Gala Committee members for their incredible work: Stacie Cowen (Co Chair), Jim Paist (Co-Chair), Dan Tinklenberg, Dayna Hansen, Dena Ianello-Zimmer, Jessica Hutchison, Josh Hemann, Kristina Rauenhorst, Kristy Heer and Skye Peltier
We would like to offer a special thank you to Perry Cowen for producing the wonderful Fund-a-Need video. By Brianna Hager, HFMD Event Coordinator

We appreciate of the amazing support from the following sponsors:

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Dr. Margaret Heisel-Kurth & Frank Kurth
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A PILLAR OF THE COMMUNITY

The HFMD extends our deepest gratitude to a truly amazing physician who after a monumental career is retiring at the end of this year. Dr. Margaret Heisel-Kurth has been treating children with bleeding disorders from Minnesota and western Wisconsin for over three decades; providing the highest level of medical care. Her dedication to pediatric patients and their parents has left a lasting impact on so many here in the HFMD community.



Children of all ages quickly identify with her; and smile when they see Dr. Heisel walk in for their appointment. The quality of care her patients receive is second to none. In addition to a compassionate and uplifting bedside manner, Dr. Heisel continually studied the latest advancements in medical treatment making sure each patient's health is the best it can possibly be.

Her skill and accomplishments as an outstanding hematologist were recognized by the National Hemophilia Foundation (NHF) in 2010 when Dr. Margaret Heisel-Kurth was presented with their Physician of the Year award on stage at the NHF Annual Meeting.

In addition to providing exemplary care for her patients, Dr. Heisel has been deeply involved with this organization in developing the programs and services we provide. As the founder of HFMD's Summer Camp for kids at Courage North (True Friends), Dr. Heisel was the chief architect of what is known as one of the very best camps in the country. Not just a builder of programs, Dr. Heisel has led our week of camp for the entire session nearly every year since 1991. That my friends is dedication to a cause!

With a heavy patient workload over the years, Dr. Heisel made time to volunteer for the HFMD as a speaker, planning committee member, and Board Director. As a catalyst in helping this bleeding disorders community to be extremely well informed; she imparted her vast knowledge in treating bleeding disorders as a presenter at numerous HFMD events. Through her leadership, Dr. Heisel built a strong partnership between Children's Hospitals & Clinics and the HFMD.

Dr. Heisel served on the HFMD Board (2009-2015) sharing her unique insight and creative ideas to help shape this organization in how we serve our bleeding disorders community today. During our annual all-day Board Business meeting Dr. Heisel was also known to multi-task, by knitting scarfs while participating in discussions. She has been a strong supporter of HFMD's Group Fitness Program and was diligent in making sure the activities we chose were safe and low risk to injuries.



Dr. Heisel contributed generously to our fundraising efforts organizationally and personally with her husband Frank. In many ways, and on various levels, Dr. Margaret Heisel- Kurth has positively impacted the HFMD. Her commitment to pediatric patients and to this organization has been remarkable. As an unwavering pillar and charismatic leader of this bleeding disorders community for over thirty years, the HFMD thanks you for all that you have done!

By James Paist, on behalf of the HFMD Board

Registration Begins for Camp Courage!

Registration is now open for the 26th Annual Hemophilia/Bleeding Disorder Camp at Camp Courage North! Camp will be held at Courage North in Lake George, MN from July 10 – July 15, 2016 for kids and teens with bleeding disorders ages 7-17.

Camp is a great opportunity for kids to:

- connect with other kids with bleeding disorders,
- learn more about their bleeding disorder,
- learn self infusion, and
- have a great time!

Activities include: swimming, boating, camp outs, fishing, canoeing, kayaking, biking, hiking, ropes course, arts and crafts, cooking, photography, games and much more!

Camp Applications can be found at www.hfmd.org, or contact your local HTC or HFMD's Administrative Assistant, Kerry Budinger at kerryb@hfmd.org or 651-406-8655.



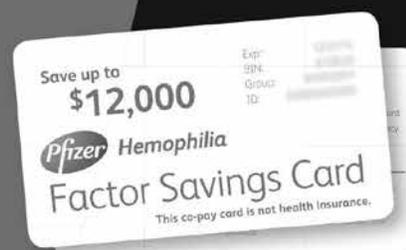
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^{*}Terms and conditions apply; visit PfizerFactorSavingsCard.com for complete terms and conditions. For commercially insured only. Medicare/Medicaid beneficiaries are not eligible.

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Indications

ELOCTATE, [Antihemophilic Factor (Recombinant), Fc Fusion Protein], is a recombinant DNA derived, antihemophilic factor indicated in adults and children with Hemophilia A (congenital Factor VIII deficiency) for: on-demand treatment and control of bleeding episodes, perioperative management of bleeding, and routine prophylaxis to reduce the frequency of bleeding episodes. ELOCTATE is not indicated for the treatment of von Willebrand disease.

Important Safety Information

Do not use ELOCTATE if you have had an allergic reaction to it in the past.

Tell your healthcare provider if you have or have had any medical problems, take any medicines, including prescription and non-prescription medicines, supplements, or herbal medicines, have any allergies, are breastfeeding, are pregnant or planning to become pregnant, or have been told you have inhibitors (antibodies) to Factor VIII.

Allergic reactions may occur with ELOCTATE. Call your healthcare provider or get emergency treatment right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash, or hives.

Your body can also make antibodies called, "inhibitors," against ELOCTATE, which may stop ELOCTATE from working properly.

The most frequently occurring side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort. These are not all the possible side effects of ELOCTATE. Talk to your healthcare provider right away about any side effect that bothers you or that does not go away, and if bleeding is not controlled after using ELOCTATE.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Brief Summary of full Prescribing Information on the next page.

This information is not intended to replace discussions with your healthcare provider.



FDA-Approved Patient Labeling

Patient Information

ELOCTATE® /el' ok' tate /

[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

Please read this Patient Information carefully before using ELOCTATE and each time you get a refill, as there may be new information. This Patient Information does not take the place of talking with your healthcare provider about your medical condition or your treatment.

What is ELOCTATE?

ELOCTATE is an injectable medicine that is used to help control and prevent bleeding in people with Hemophilia A (congenital Factor VIII deficiency).

Your healthcare provider may give you ELOCTATE when you have surgery.

Who should not use ELOCTATE?

You should not use ELOCTATE if you had an allergic reaction to it in the past.

What should I tell my healthcare provider before using ELOCTATE?

Talk to your healthcare provider about:

- Any medical problems that you have or had.
- All prescription and non-prescription medicines that you take, including over-the-counter medicines, supplements or herbal medicines.
- Pregnancy or if you are planning to become pregnant. It is not known if ELOCTATE may harm your unborn baby.
- Breastfeeding. It is not known if ELOCTATE passes into the milk and if it can harm your baby.

How should I use ELOCTATE?

You get ELOCTATE as an infusion into your vein. Your healthcare provider will instruct you on how to do infusions on your own, and may watch you give yourself the first dose of ELOCTATE.

Contact your healthcare provider right away if bleeding is not controlled after using ELOCTATE.

What are the possible side effects of ELOCTATE?

You can have an allergic reaction to ELOCTATE. Call your healthcare provider or emergency department right away if you have any of the following symptoms: difficulty breathing, chest tightness, swelling of the face, rash or hives.

Your body can also make antibodies called, "inhibitors," against ELOCTATE. This can stop ELOCTATE from working properly. Your healthcare provider may give you blood tests to check for inhibitors.

Common side effects of ELOCTATE are headache, rash, joint pain, muscle pain and general discomfort.

These are not the only possible side effects of ELOCTATE. Tell your healthcare provider about any side effect that bothers you or does not go away.

How should I store ELOCTATE?

- Keep ELOCTATE in its original package.
- Protect it from light.
- Do not freeze.
- Store refrigerated (2°C to 8°C or 36°F to 46°F) or at room temperature [not to exceed 30°C (86°F)], for up to six months.
- When storing at room temperature:
- Note on the carton the date on which the product is removed from refrigeration.
- Use the product before the end of this 6 month period or discard it.
- Do not return the product to the refrigerator.

Do not use ELOCTATE after the expiration date printed on the vial or, if you removed it from the refrigerator, after the date that was noted on the carton, whichever is earlier.

After reconstitution (mixing with the diluent):

- Do not use ELOCTATE if the reconstituted solution is not clear to slightly opalescent and colorless.
- Use reconstituted product as soon as possible.
- You may store reconstituted solution at room temperature, not to exceed 30°C (86°F), for up to three hours. Protect the reconstituted product from direct sunlight. Discard any product not used within three hours.

What else should I know about ELOCTATE?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use ELOCTATE for a condition for which it was not prescribed. Do not share ELOCTATE with other people, even if they have the same symptoms that you have.

44279-02

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Washington Days February 24-26, 2016 National Hemophilia Foundation For all Bleeding Disorders Your Health! Your Fight! Your Voice!

The National Hemophilia Foundation (NHF) hosted its annual legislative advocacy days on Capitol Hill. Hundreds of bleeding disorders advocates from coast to coast converged inside United States Senate and Congressional buildings of our nation's capitol to raise awareness of bleeding disorders, and to meet face-to-face with Senators, Congressional Representatives and their aides to express our public policy needs and appreciation.

A focal point of this year's Washington Days was the Red Tie Challenge which is celebrating March as national bleeding disorders awareness month, formerly hemophilia awareness month. NHF provided all advocates with sharp red ties to wear during congressional meetings and a red tie to give each Senator and Congressmen or Congresswoman asking them to take the Red Tie Challenge. The challenge is to speak about bleeding disorders awareness while wearing your red tie (any way you want) while being videotaped. Then to share your video-clip on social media, chapter websites, and with NHF. For more information: redtiechallenge.org

The conference opened Wednesday afternoon with an introduction to the Red Tie Challenge. Next were training sessions on how to communicate our message with elected officials, and how to do that in a concise and effective way in preparation for the Congressional meetings scheduled by NHF for Thursday.

I was a part of the Minnesota & Utah delegation, where we met with Senate and Congressional offices from both states. We began Thursday morning (the big Day on the Hill) in Senator Amy Klobuchar's office. Next was a meeting with the office of Congressman John Kline. Later in the day we met with legislative aides from the offices of Senator Mike Lee (Utah) and Al Franken (MN). Some of the legislative aides were more receptive than others with our request for the elected official to do the Red Tie Challenge. We also spoke about the importance of maintaining the current level of CDC funding to the Hemophilia Treatment Centers across the country, and how much that is appreciated by the bleeding disorders community.

Veterans of Washington Days know that wearing comfortable shoes is a must because there is a lot of walking involved to get from one Senate building to another. In between meetings on the Hill we frequently saw fellow Washington Days advocates who were easily identified with their shiny Red Ties. After an action packed day of meetings on the hill, advocates returned to the conference hotel (Marriot Metro Centre) for post-meeting briefings with NHF. Later that evening, NHF CEO, Val Bias addressed a large room full of bleeding disorders advocates with a positive message of hope and encouragement. HFMD would like to extend a special thanks to NHF for hosting another successful Washington Days.

By James Paist

The HFMD gratefully acknowledges our donors who have given so generously. These are donations received from January 1, 2016 through March 31, 2016. *If you have made a donation and your name is not listed, please contact HFMD.*

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Shari Slavec

Parents Empowering Parents

On January 22 – January 24, Jill Swenson (social worker) and Sue Purdie (nurse) of Children's Hospitals and Clinics partnered with Melinda Otto (social worker) and Dawn Rusk (nurse) of Mayo Clinic along with parent trainers Dave and Kris Rauenhurst and Jon and Aimee Grant to provide a joint Children's/Mayo Clinic Parents Empowering Parents (PEP) Program. With support from the HFMD and a grant from the national Parents Empowering Parents Program, we held a PEP weekend at the St. James Hotel in Red Wing, MN for a group of 7 parents.

The PEP program is designed to help parents improve their parenting skills amidst the difficulties of raising a child with a bleeding disorder. Not only are parents able to affirm existing positive parent/child behaviors, they learn new techniques for positive parenting and have an opportunity to connect with other parents who share similar struggles and joys of raising a child with a bleeding disorder.

The information-filled weekend started on Friday night with dinner and an opportunity to get to know one another followed by an introduction to the PEP Program and a brief session on the Basics of Bleeding Disorders. On Saturday and Sunday the group covered the topics of child development, parenting styles, skill strengthening, communication, self-esteem, challenges specific to parenting a child with a bleeding disorder and much more. We enjoyed a fun dinner out Saturday night and ended our weekend Sunday afternoon after exchanging contact information so that the participants could stay in touch following the program. We plan to get together again in the future to briefly review key program points and allow the participants the time to share how they have implemented what they took away from the weekend as well as an opportunity to continue to provide support to each other.

If you are interested in attending a future PEP weekend, contact the social worker at your Hemophilia Treatment Center.

Now Approved!



Available EARLY 2016

For more information, contact your
Octapharma Representative:

CORY MULLER

PHONE | 612-666-4001

EMAIL | Cory.Muller@octapharma.com

BLOOD BROTHERHOOD



On Sunday, April 3rd our Blood Brothers joined together at Target Center in downtown Minneapolis for a Minnesota Timberwolves game versus the Dallas Mavericks. The HFMD Blood Brothers enjoyed a delicious box lunch of sandwiches, pasta salad, apples, chips and cookies in our comfortable hospitality suite for the PT session. During lunch, Rob Himmerick, PT, DPT, SCS of the Fairview Institute for Athletic Medicine shared an interactive presentation on Physical Therapy. Thank you to Rob for making the session educational and entertaining! The guys then found their seats to enjoy watching the Timberwolves take the court and see their newest young stars in action. The Timberwolves didn't come out with a win, but it was a close game and fun was had by all! The HFMD would like to thank the Hemophilia Federation of America (HFA) and Baxalta for sponsoring this event.

Please join us for our next Blood Brotherhood session at the 2016 HFMD Annual Meeting – Friday, April 22-Saturday, April 23 at the Hilton MSP Airport/Mall of America in Bloomington, MN. Daniel C. Reilly will present “Your Liver and Viral Hepatitis” as a Saturday afternoon breakout session.



Hope to see you there!

By Brianna Hager

HFMD Travel Scholarship

NHF Annual Meeting

Orlando, Florida

July 21-23, 2016

HFMD can reimburse one individual for travel & lodging up to \$1,000 or more than one individual up to \$1,500.

One application selected each year

Eligibility Requirements

- You or immediate family member must have a bleeding disorder
 - Must be a patient at an HFMD affiliated Clinic
 - Priority given to those who have not previously attended NHF
 - Write a letter to HFMD stating how you would benefit from attending the NHF Annual Meeting
- Letters must be submitted to HFMD before May 1, 2016

Email to : info@hfmd.org

Mail to:

HFMD

750 South Plaza Drive, Suite 207

Mendota Heights, MN 55120

2016 HFMD Scholarship Applications



The Hemophilia Foundation is accepting scholarship applications for post-secondary education from now until June 1st.

Scholarship eligibility requirements for applicants include (1) having an inherited bleeding disorder, (2) being a resident of Minnesota 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) be accepted into a post-secondary educational program.

More information and forms for this scholarship and information on additional scholarships is available online at www.hfmd.org or by calling the HFMD office at 651-406-8655 or 1-800-994-4363.

Hemophilia Treatment Centers (Tri-State Area)

**Sanford Health, Sioux Falls, SD Region
South Dakota Center for Bleeding Disorders**
1600 West 22nd Street
P. O. Box 5039
Sioux Falls, SD 57117
605-312-1000

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**Mayo Comprehensive Hemophilia Center
Mayo Clinic**
Mayo 10-75E
200 First Street SW
Rochester, MN 55905
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eckerman@mayo.edu

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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

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2016 Calendar of Events

- April 22 & 23..... HFMD Annual Member Meeting
Hilton Airport/Mall of America, Bloomington
- June 25..... Group Fitness
Bunker Beach
- July 10-15..... Camp Courage North (True Friends)
- July 21 - 23..... NHF's 68th Annual Meeting
Orlando, FL
- July 24 – 28..... WFH World Congress
Orlando, FL
- August 7..... Step Out for Bleeding Disorders Walk
Como Park, St. Paul
- October 15..... Women's Conference
Hilton Airport/Mall of America
- February 18, 2017..... SAVE THE DATE for our 2017 Hearts of Hope Gala
Hyatt Regency, Bloomington, MN

****The HFMD Board of Directors meets quarterly on the fourth Tuesday at 7:00 p.m.****

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