

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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Register Today!

19TH ANNUAL

Hearts of Hope Gala

PLEASE JOIN US FOR A NIGHT OF FINE DINING,
DRINKS, AUCTIONS & DANCING BENEFITING THE

*Hemophilia Foundation of
Minnesota/Dakotas*

SATURDAY, FEBRUARY 9, 2019
6:00 PM - 11:00 PM

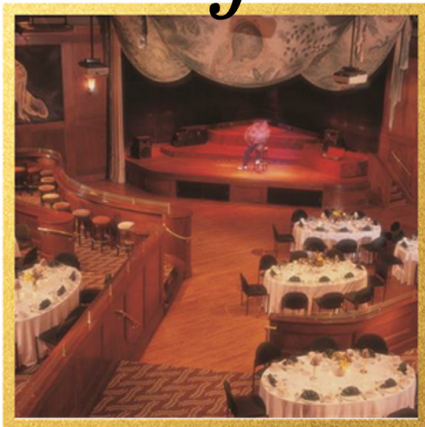
Metropolitan Ballroom & Clubroom

5418 WAYZATA BLVD, GOLDEN VALLEY, MN 55416

Click here

<https://hfmd.ejoinme.org/heartsofhope2019>

Or go to Events at:
www.hfmd.org



HFMD Group Fitness Event

Competition and pizza were on the forefront of our members' minds as they walked through the door of PINZ in Oakdale on November 3rd. We were hoping that the fun location would encourage members to venture out on a cold Saturday morning and were overjoyed when we packed the lanes of our private bowling room, 10 Pin Alley.

After a warm welcome from our gracious sponsor Diplomat's Dan Kallberg and our very own James Paist, HFMD's event coordinator, Melissa, tried her best at leading her first group stretch. Once everyone was warmed up and ready to go, it was time to bowl! Apart from a short break of dining on delicious pizza and salad, members bowled nonstop until our time of Laser Tag began. Melissa ushered one group at a time to the glow in the dark, two story arena where they were geared up and unleashed into the darkness to test their aim.

As the laser tag and bowling came to an end, and only veggie pizza remained, our members left with what we hope was a full belly and great memories made with their friends and loved ones. We would like to thank everyone who attended as well as our sponsor Diplomat Infusion Services for a great day!

By Melissa Andrisani



Experiencing NHF Bleeding Disorders Conference for the First Time

Submitted by, Jill Waldvogel, Sorelle's Mother

The 70th NHF Bleeding Disorders Conference was an experience we will never forget which brought my daughter and I deeper into the bleeding disorders community. My ten-year-old daughter has VonWillebrand's Type 2a. Our first experience with the bleeding disorders community was at the 2018 Hemophilia Foundation of Minnesota/Dakotas Annual Meeting in April. It feels so good for us to be a part of the bleeding disorders community. No one knows what it's like, unless you are directly affected by a bleeding disorder, so these conferences have been a true blessing for us to be able to collaborate, communicate, discuss, and sometimes cry together!

At the 70th NHF Conference, we started off with VWD Precon: VWD & the Whole Me. Sorelle (my daughter) was involved in collecting notes from tables to put on a huge rainbow wall up front. She also collected notes to share regarding what it feels like to have VWD. She is not usually an outgoing young lady, but she was in her element and moved swiftly from table to table, collecting thoughts on various aspects of having VWD. Together, we went to the VWD Reception Friday evening where we had beverages, snacks, and deep discussions, including my question, "Will my daughter be able to have a child if she desires to and is able to conceive?" Being with others that have experienced what we have not yet, and to be able to share in sometimes difficult questions, was the most beneficial part of the conference.

Sorelle was involved in the NHF childcare program that was provided and was entertained with great food, activities, and an overall fun day. We both never went hungry with the Shire Factor Fest and Novo Nordisk Family Night. These were the best parties ever and Sorelle and her new friend, Maya, danced for hours. I learned from each session I attended during the day and truly love the community that has been built over the past 70 years with National Hemophilia Foundation, even being fairly new members. I am so thankful for HFMD, NHF, and the bleeding disorders community. We are part of this family. My only regret was that Sorelle's dad (my husband) and brother were not in Orlando, too. (And by the way, the answer is yes!)



Benihana & Nickelodeon Universe

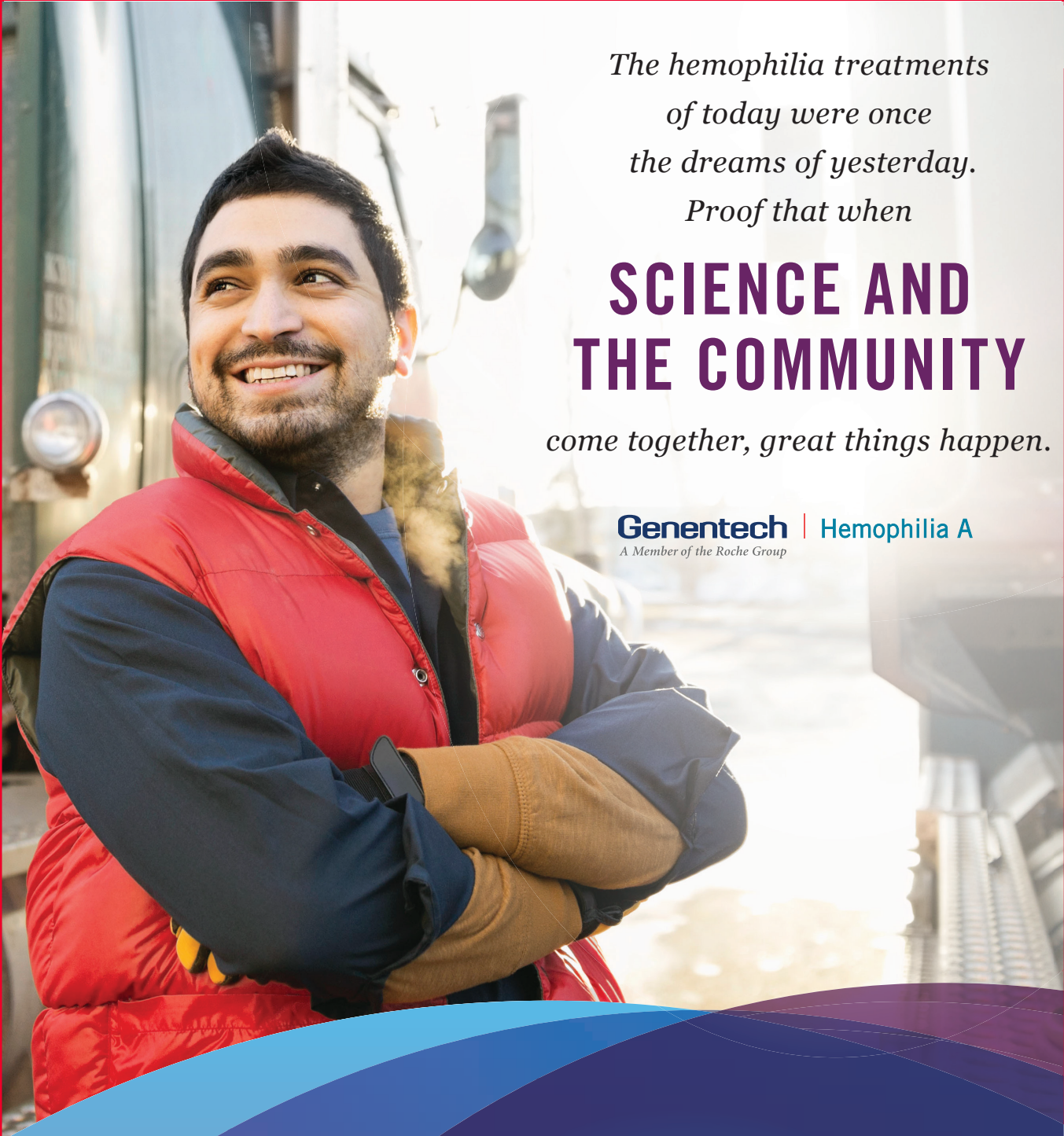
We were thrilled to offer our members two of our favorite things in one education dinner... hibachi and roller coasters! Together with Pfizer and CVS, HFMD hosted an education dinner at Benihana followed by unlimited rides at Nickelodeon Universe in Mall of America. We were full to capacity at the Benihana private dining room on October 18th.

Pfizer's Joe Schuch gave an inspirational presentation during dinner while attendees feasted on miso soup and salad followed by a hibachi grilled main course as well as all the lemonade they could drink. After Joe wrapped up, Missy Frey from CVS was pleased to have the floor to share her expertise and sound advice as an HTC Nurse.

As the presentations came to an end, you could feel the excitement coming from the children as our event coordinator, Melissa, came forward to inform the group it was time to hand out the wristbands for the highly anticipated Nickelodeon Universe. They all waited patiently and politely as each family got their bands, but once they were in their hands, there was a jovial dash for the restaurant's exit. Thank you to all who attended and our sponsors, Pfizer and CVS Specialty, for this fun filled evening!

By Melissa Andrisani





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of today were once
the dreams of yesterday.
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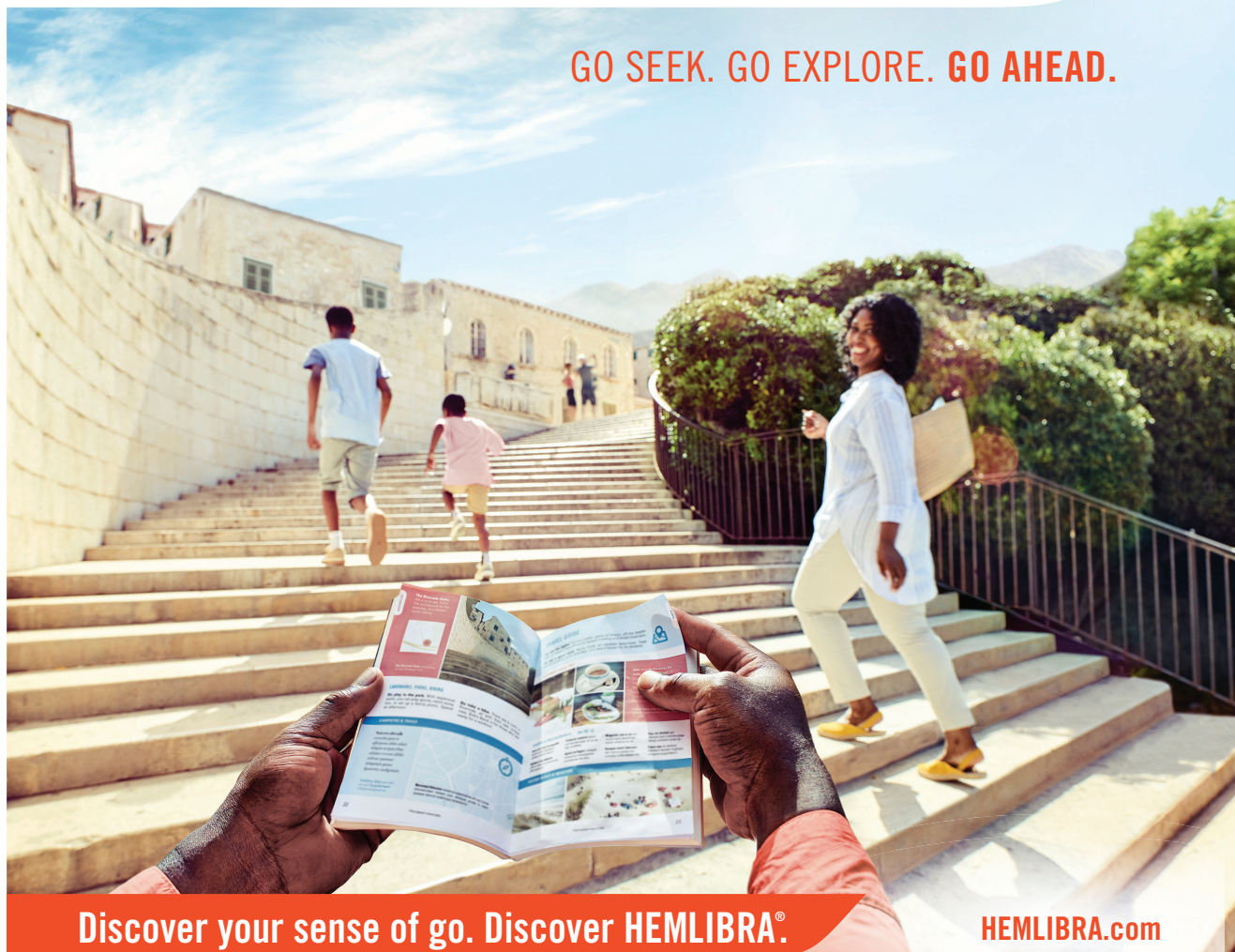


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What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII, and the dose and schedule to use for breakthrough bleed treatment. HEMLIBRA may cause serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including thrombotic microangiopathy (TMA), and blood clots (thrombotic events). If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

Please see Brief Summary of Medication Guide on following page for Important Safety Information, including **Serious Side Effects**.


HEMLIBRA
emicizumab-kxwh | 150
injection for subcutaneous use | mg/mL

Medication Guide
HEMLIBRA® (hem-lee-bruh)
(emicizumab-kxwh)
injection, for subcutaneous use

What is the most important information I should know about HEMLIBRA?

HEMLIBRA increases the potential for your blood to clot. Carefully follow your healthcare provider's instructions regarding when to use an on-demand bypassing agent or factor VIII (FVIII) and the recommended dose and schedule to use for breakthrough bleed treatment.

HEMLIBRA may cause the following serious side effects when used with activated prothrombin complex concentrate (aPCC; FEIBA®), including:

- **Thrombotic microangiopathy (TMA).** This is a condition involving blood clots and injury to small blood vessels that may cause harm to your kidneys, brain, and other organs. Get medical help right away if you have any of the following signs or symptoms during or after treatment with HEMLIBRA:

| | |
|------------------------------|----------------------------------|
| – confusion | – stomach (abdomen) or back pain |
| – weakness | – nausea or vomiting |
| – swelling of arms and legs | – feeling sick |
| – yellowing of skin and eyes | – decreased urination |
- **Blood clots (thrombotic events).** Blood clots may form in blood vessels in your arm, leg, lung, or head. Get medical help right away if you have any of these signs or symptoms of blood clots during or after treatment with HEMLIBRA:

| | |
|----------------------------------------|-------------------------|
| – swelling in arms or legs | – cough up blood |
| – pain or redness in your arms or legs | – feel faint |
| – shortness of breath | – headache |
| – chest pain or tightness | – numbness in your face |
| – fast heart rate | – eye pain or swelling |
| | – trouble seeing |

If aPCC (FEIBA®) is needed, talk to your healthcare provider in case you feel you need more than 100 U/kg of aPCC (FEIBA®) total.

See “What are the possible side effects of HEMLIBRA?” for more information about side effects.

What is HEMLIBRA?

HEMLIBRA is a prescription medicine used for routine prophylaxis to prevent or reduce the frequency of bleeding episodes in adults and children, ages newborn and older, with hemophilia A with or without factor VIII inhibitors.

Hemophilia A is a bleeding condition people can be born with where a missing or faulty blood clotting factor (factor VIII) prevents blood from clotting normally.

HEMLIBRA is a therapeutic antibody that bridges clotting factors to help your blood clot.

Before using HEMLIBRA, tell your healthcare provider about all of your medical conditions, including if you:

- are pregnant or plan to become pregnant. It is not known if HEMLIBRA may harm your unborn baby. Females who are able to become pregnant should use birth control (contraception) during treatment with HEMLIBRA.
- are breastfeeding or plan to breastfeed. It is not known if HEMLIBRA passes into your breast milk.

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, or herbal supplements. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

How should I use HEMLIBRA?

See the detailed “Instructions for Use” that comes with your HEMLIBRA for information on how to prepare and inject a dose of HEMLIBRA, and how to properly throw away (dispose of) used needles and syringes.

- Use HEMLIBRA exactly as prescribed by your healthcare provider.
- **Stop (discontinue) prophylactic use of bypassing agents the day before starting HEMLIBRA prophylaxis.**
- **You may continue prophylactic use of FVIII for the first week of HEMLIBRA prophylaxis.**
- HEMLIBRA is given as an injection under your skin (subcutaneous injection) by you or a caregiver.
- Your healthcare provider should show you or your caregiver how to prepare, measure, and inject your dose of HEMLIBRA before you inject yourself for the first time.

- Do not attempt to inject yourself or another person unless you have been taught how to do so by a healthcare provider.
- Your healthcare provider will prescribe your dose based on your weight. If your weight changes, tell your healthcare provider.
- You will receive HEMLIBRA 1 time a week for the first four weeks. Then you will receive a maintenance dose as prescribed by your healthcare provider.
- If you miss a dose of HEMLIBRA on your scheduled day, you should give the dose as soon as you remember. You must give the missed dose as soon as possible before the next scheduled dose, and then continue with your normal dosing schedule. **Do not** give two doses on the same day to make up for a missed dose.
- HEMLIBRA may interfere with laboratory tests that measure how well your blood is clotting and may cause a false reading. Talk to your healthcare provider about how this may affect your care.

What are the possible side effects of HEMLIBRA?

- See “What is the most important information I should know about HEMLIBRA?”

The most common side effects of HEMLIBRA include:

- redness, tenderness, warmth, or itching at the site of injection
- headache
- joint pain

These are not all of the possible side effects of HEMLIBRA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store HEMLIBRA?

- Store HEMLIBRA in the refrigerator at 36°F to 46°F (2°C to 8°C). Do not freeze.
- Store HEMLIBRA in the original carton to protect the vials from light.
- Do not shake HEMLIBRA.
- If needed, unopened vials of HEMLIBRA can be stored out of the refrigerator and then returned to the refrigerator. HEMLIBRA should not be stored out of the refrigerator for more than a total of 7 days or at a temperature greater than 86°F (30°C).
- After HEMLIBRA is transferred from the vial to the syringe, HEMLIBRA should be used right away.
- Throw away (dispose of) any unused HEMLIBRA left in the vial.

Keep HEMLIBRA and all medicines out of the reach of children.

General information about the safe and effective use of HEMLIBRA.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use HEMLIBRA for a condition for which it was not prescribed. Do not give HEMLIBRA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your pharmacist or healthcare provider for information about HEMLIBRA that is written for health professionals.

What are the ingredients in HEMLIBRA?

Active ingredient: emicizumab-kxwh

Inactive ingredients: L-arginine, L-histidine, poloxamer 188, and L-aspartic acid.

Manufactured by: Genentech, Inc., A Member of the Roche Group,
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For more information, go to www.HEMLIBRA.com or call 1-866-HEMLIBRA.
 This Medication Guide has been approved by the U.S. Food and Drug Administration
 Revised : 10/2018



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Current Calendar of Events

January 10, 2019 Education Dinner Sponsored by Bioverativ

Bonfire Wood Fire Cooking, Eagan, MN

(EVENT IS FULL)

January 26-27, 2019 Winter Teen Event

Camp Courage South, Annandale, MN

February 9, 2019 Hearts of Hope Gala

Metropolitan Ballroom & Clubroom,

Golden Valley, MN

March 12, 2019 Bleeding Disorder Awareness Day

1:00 p.m. in the Rotunda of the Minnesota

State Capitol, St. Paul

April 26-27, 2019 Annual HFMD Member Meeting

Airport Hilton, Bloomington, MN

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

Women's Educational Day Held October 6th

The Annual Women's Educational Day was held at the Machine Shed in Lake Elmo this fall on Saturday October 6th.

Our day started with a fun educational game called "Marvelous Me" led by Dawn Inman, RN, Mayo Hemophilia Treatment Center (HTC). Leigh Ann Greavu, a dietician from HealthEast, then gave a session titled, "You Are What You Eat". After a delicious buffet lunch, Kim Isenberg, from the Hemophilia Federation of America (HFA), discussed how our voices have weight in legislative advocacy. Dr. Joan Beckman, who is a new hematologist at M Health, followed with an Ask the Provider session titled, "Let's Talk Period". We concluded our day with a cooking activity led by Chef Tyler Jandrey who was very entertaining. We were then able to sample some of his recipes during dinner. Thanks to all the speakers, HTC staff, and the women's outreach group from HFMD who helped make this event possible. A special thanks to Jason Clarin, from CSL Behring, for his help and financial support of the event.

By Sue Curoe



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HEMOPHILIA
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SAVE THE DATE! HFMD BLEEDING DISORDERS AWARENESS DAY

Tuesday, March 12th, 2019

1:00 p.m. Capitol Rotunda

75 Rev. Dr. Martin Luther King Jr Blvd, St. Paul, MN 55155

This is YOUR DAY to make your voice heard & to
tell YOUR stories! Let lawmakers know how
important good health care is to us!

1:00 p.m. Rally for Bleeding Disorders & Rare
Disease Awareness

Meet with YOUR elected officials during the day.

RSVP to: info@hfmd.org or 651-406-8655



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