NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

HEMOPHILIA FOUNDATION OF MINNESOTA/DAKOTAS

Veinline

WINTER 2018

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

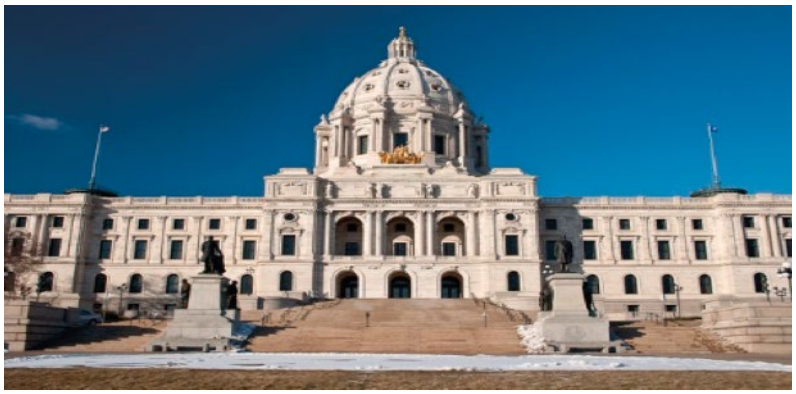
Inside this issue:

HFMD Bleeding Disorders Awareness Day

Thursday, March 22nd, 2018

9:00 a.m. Capitol Rotunda

St. Paul, Minnesota



Attention: Bleeding Disorders Community, Family, & Friends

This is <u>YOUR DAY</u> to make your voice heard & to tell <u>YOUR stories</u>

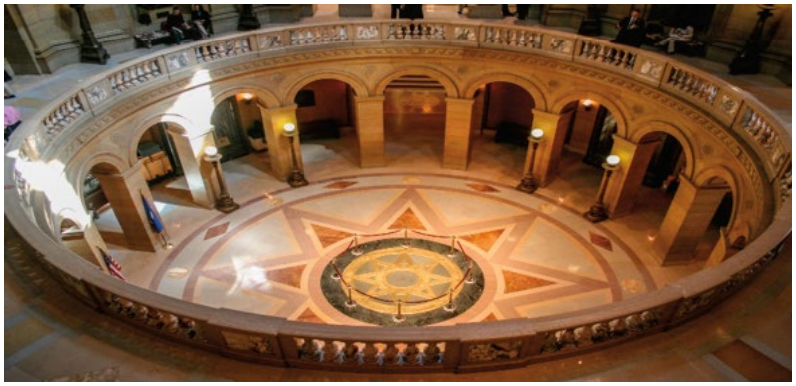
We will let lawmakers know how important good health care is to us

9:00 - 11:30 a.m. Rally for Bleeding Disorders Awareness

12:00 p.m. Lunch will be provided

Meetings with YOUR elected officials throughout the day

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



Fajitas & Football

Our theme for the Blood Brotherhood event we held on Sunday December 3rd at Rojo Mexican Grill in Edina was Fajitas and Football. This event also featured a presentation by Kerry Hansen, Nurse Clinician from the University of Minnesota – MHealth. Kerry shared updates on new therapies in treating hemophilia with inhibitors. This new therapy is known as non-replacement therapy.

After the presentation, it was time to watch the Minnesota Vikings vs. the Atlanta Falcons on a big-screen TV in our meeting space. Our group of Blood Brothers enjoyed appetizers, main entrees and fried ice cream for dessert. Guys had time to catch up with each other while the Vikings soundly beat the Falcons. A special thanks to the Hemophilia Federation of America and Shire for sponsoring this event and our ongoing program for adult men with bleeding disorders.

Region V West Conference Held in Bloomington

Great Lakes Hemophilia Foundation hosted a regional meeting of 14 federally funded Hemophilia Treatment Centers (HTCs) from Minnesota, Wisconsin, Illinois, South Dakota and North Dakota November 15-17. The meeting offered networking and educational sessions on case studies, racial bias, new treatments and more.

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COMMUNITY SUPPORT

Patient advocacy, community workshops, educational in-service for school and hospital ED, and support workshops.

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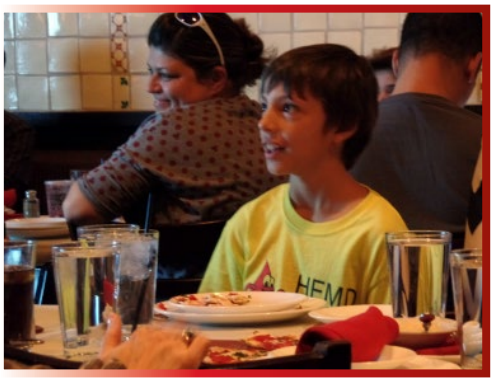
Group Fitness & Nutrition Program

Ways to Wellness, located in Woodbury, Minnesota; and part of the Woodwinds Hospital is a unique physical rehabilitation & therapy center. And some just attend it as their neighborhood gym. It features a new state of the art fitness center with a wide range of exercise equipment, training rooms for yoga, kettle bells, and pilates. It also features The Kitchen Table; a cutting edge cooking facility led by Chef Jeremy intended to teach healthy cooking techniques and recipes to groups up to 30.

The HFMD held our Ways to Wellness Day on Saturday, October 28th, where Chef Jeremy chopped, stirred, and seasoned his demonstration for our group through a five-course Tour of Asia meal. Every item was healthy and organic. After we enjoyed all we could eat from the meal, most of our group went next door for a yoga session. This event embodied the goals of HFMD's group fitness and nutrition program. This event was sponsored by a grant from the Colburn-Keenan Foundation. We thank them for their generosity.

Tucci Benucch and Nickelodeon Universe

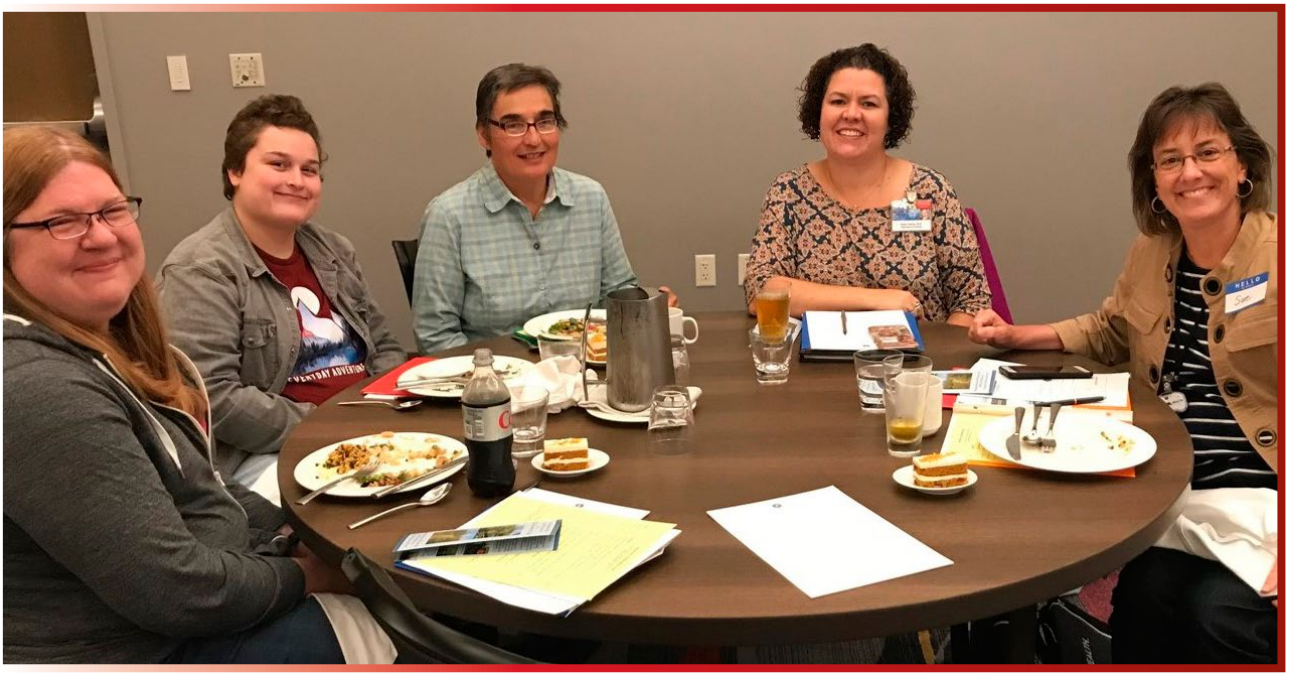
On a windy fall evening a group of 45 community members gathered together for a wonderful Italian meal at Tucci Benucch at the Mall of America. This is the third year that this event has been held and it remains very popular with our families. The evening began with arrival of guests at 5:30 p.m. As people trickled in, appetizers of Margherita pizza and bruschetta were served to the guests and drink orders were taken. After enjoying a delicious Italian salad, our guests settled in for the entrées of chicken parmesan and ravioli, and pasta primavera.



Pfizer's Joe Schuch talked to the group about Overcoming Challenges. As the group conversation became more and more lively during the meal, Joe had to take some of his own advice to keep the audience engaged. However, he persisted and was able to elicit great questions and stories from our community members as they related solutions they have for issues faced by families living with a bleeding disorder.

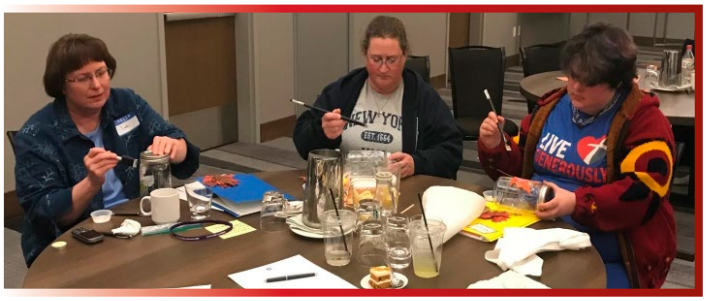
Soon after the dessert of chocolate drizzled cheesecake and apple fritters with ice cream was served, the group was ready to gather their things and enjoy the rides at Nickelodeon Universe. Families received 3-hour wristbands to ride all the rides they could before finally heading home after a fun and exciting night with Pfizer and HFMD.

Women's Educational Event Held October 7th



The Annual Women's Educational Event was held at the Hyatt Regency in Bloomington this fall on Saturday October 7th.

Our day started with a fun educational game of *Never Have I Ever* led by **Dawn Inman, RN**, Mayo HTC. **Chelsey Jungbluth, MS CGC**, Children's HTC, then gave a very informative talk on Genetics. We finished our morning with a session on *Self Advocacy & Challenges of VWD* by **Madonna McGuire Smith, CSL** speaker from the Hemophilia Foundation of Oregon.



During lunch, **Dr. Surbhi Shah**, hematologist from M Health, led an *Ask the Provider* session which focused on *Iron Basics*. After lunch, **Dr. Gary McClain**, HFA (Hemophilia Federation of America) speaker, discussed *Communication Strategies for a Healthy Relationship.* **Skye Peltier, PA-C,** M Health, then led an insightful *Journaling Jam* session. Our education ended with *Disclosing Your Bleeding Disorder* presented by Cathy Tiggs, social worker & NHF speaker.

Sue Curoe, RN, MS, M Health, then led a fun fall leaf project, *Mod Podge Magic*. Our retreat ended with a relaxing 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 & Mark Wiener**, from CSL Behring, for their help and financial support of the event.

By Sue Curoe

Is it time to reconsider your treatment for hemophilia A?

[a]Based on data for Q2 2015-Q1 2016; accounts for net gains and losses of patients switching to and from standard half-life rFVIII available for at least one year.[1]

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Please see Prescribing Information for complete storage instructions.

[b]guardian™1: a multicenter, multinational, open-label, single-arm efficacy and safety trial in 150 patients (aged 12 to 65 years) with severe hemophilia A on a prophylactic treatment regimen who were exposed to turoctocog alfa for a mean of 85 exposure days (ranging from 11 to 172 exposure days).[2]
guardian™3: a multicenter, multinational, noncontrolled, open-label safety, efficacy, and pharmacokinetic trial in 63 previously treated pediatric patients (aged 0 to 11 years) with hemophilia A in which patients were exposed to turoctocog alfa for a mean of 60 exposure days (ranging from 20 to 104 exposure days).[3]
[c]guardian™2: a prospective, open-label, uncontrolled extension trial investigating the safety and efficacy of turoctocog alfa in 55 pediatric, 23 adolescent, and 122 adult patients with severe hemophilia A for a mean of 361.6 exposure days. The data cutoff date was December 31, 2013.[4]
[d]Patients with previous inhibitors were excluded from the trials. Individuals with hemophilia A may develop inhibitors to FVIII. Monitor patients taking Novoeight® for inhibitor formation.[5]

Indications and Usage

Novoeight® (Antihemophilic Factor [Recombinant]) is indicated for use in adults and children with hemophilia A for control and prevention of bleeding, perioperative management, and routine prophylaxis to prevent or reduce the frequency of bleeding episodes.

Novoeight® is not indicated for the treatment of von Willebrand disease.

Important Safety Information

Do not use in patients who have had life-threatening hypersensitivity reactions, including anaphylaxis, to Novoeight® or its components, including hamster proteins.

Anaphylaxis and severe hypersensitivity reactions are possible. Patients may develop hypersensitivity to hamster proteins, which are present in trace amounts in the product. Should symptoms occur, discontinue Novoeight® and administer appropriate treatment.

Development of activity-neutralizing antibodies (inhibitors) may occur. If expected plasma factor VIII activity levels are not attained, or if bleeding is not controlled with an appropriate dose, perform an assay that measures factor VIII inhibitor concentration.

The most frequently reported adverse reactions (≥0.5%) were injection site reactions, increased hepatic enzymes, and pyrexia.

Please see Brief Summary of Prescribing Information on following page.

References: 1. Data on file. Novo Nordisk Inc; Plainsboro, NJ. **2.** Lentz SR, Misgav M, Ozelo M, et al. Results from a large multinational clinical trial (guardian™1) using prophylactic treatment with turoctocog alfa in adolescent and adult patients with severe haemophilia A: safety and efficacy. *Haemophilia.* 2013;19(5):691-697. **3.** Kulkarni R, Karim FA, Glamocanin S, et al. Results from a large multinational clinical trial (guardian™3) using prophylactic treatment with turoctocog alfa in paediatric patients with severe haemophilia A: safety, efficacy and pharmacokinetics. *Haemophilia.* 2013;19(5):698-705. **4.** Lentz SR, Cerqueira M, Janic D, et al. Interim results from a large multinational extension trial (guardian™ 2) using turoctocog alfa for prophylaxis and treatment of bleeding in patients with severe haemophilia A. *Haemophilia.* 2016;22(5):1-5. **5.** Novoeight [package insert]. Plainsboro, NJ: Novo Nordisk Inc; 2015.

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The HFMD gratefully acknowledges our donors who have given so generously.
These are donations received from January 1, 2017 through December 31, 2017.

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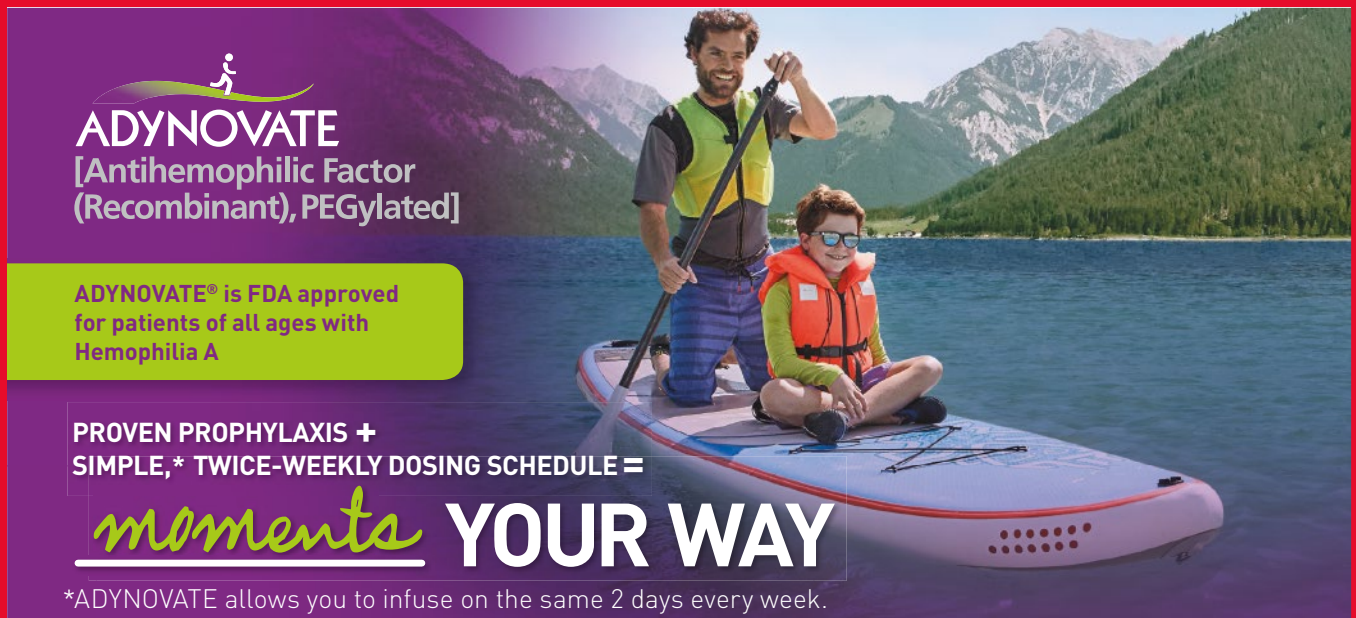

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[Antihemophilic Factor (Recombinant), PEGylated]

ADYNOVATE® is FDA approved for patients of all ages with Hemophilia A

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The pediatric study of children <12 years of age (N=66) evaluated the immunogenicity, efficacy, PK (as compared to ADVATE® [Antihemophilic Factor (Recombinant)]), and safety of ADYNOVATE twice-weekly prophylaxis (40-60 IU/kg) and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.[1,2]

The pivotal trial of children and adults ≥12 years (N=137) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis (40-50 IU/kg) vs on-demand (10-60 IU/kg) treatment, and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.[1]

+Children (<12 years) experienced a median overall ABR of 2.0 (IQR: 3.9) and a median ABR of zero for both joint (IQR: 1.9) and spontaneous (IQR: 1.9) bleeds[1,3]

+38% (n=25) of children (<12 years) experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds[1]

Talk to your doctor and visit ADYNOVATE.com

ADYNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

Indications

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

DETAILED IMPORTANT RISK INFORMATION

You should not use ADYNOVATE if you:
- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

You should tell your healthcare provider if you:
- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

You can have an allergic reaction to ADYNOVATE.
Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

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 the following page for ADYNOVATE Important Facts.

For full Prescribing Information, visit www.ADYNOVATE.com.

References: 1. ADYNOVATE Prescribing Information. **2.** Mullins ES, Stasyshyn O, Alvarez-Román MT, et al. Extended half-life pegylated, full-length recombinant factor VIII for prophylaxis in children with severe haemophilia A. *Haemophilia*. 2016 Nov 27. doi: 10.1111/hae.13119 [Epub ahead of print]. **3.** Data on file.

Shire

ADYNOVATE
[Antihemophilic Factor (Recombinant), PEGylated]

Patient Important facts about

ADYNOVATE® [Antihemophilic Factor (Recombinant), PEGylated]

This leaflet summarizes important information about ADYNOVATE. Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare provider, and it does not include all of the important information about ADYNOVATE. If you have any questions after reading this, ask your healthcare provider.

What is the most important information I need to know about ADYNOVATE?

Do not attempt to do an infusion to yourself unless you have been taught how by your healthcare provider or hemophilia center.

You must carefully follow your healthcare provider's instructions regarding the dose and schedule for infusing ADYNOVATE so that your treatment will work best for you.

What is ADYNOVATE?

ADYNOVATE is an injectable medicine that is used to help treat and control bleeding in children and adults with hemophilia A (congenital Factor VIII deficiency). Your healthcare provider may give you ADYNOVATE when you have surgery. ADYNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNOVATE is not used to treat von Willebrand disease.

Who should not use ADYNOVATE?

You should not use ADYNOVATE if you:

- Are allergic to mice or hamster protein
- Are allergic to any ingredients in ADYNOVATE or ADVATE® [Antihemophilic Factor (Recombinant)]

Tell your healthcare provider if you are pregnant or breastfeeding because ADYNOVATE may not be right for you.

How should I use ADYNOVATE?

ADYNOVATE is given directly into the bloodstream.

You may infuse ADYNOVATE at a hemophilia treatment center, at your healthcare provider's office or in your home. You should be trained on how to do infusions by your healthcare provider or hemophilia treatment center. Many people with hemophilia A learn to infuse their ADYNOVATE by themselves or with the help of a family member.

Your healthcare provider will tell you how much ADYNOVATE to use based on your individual weight, level of physical activity, the severity of your hemophilia A, and where you are bleeding.

Reconstituted product (after mixing dry product with wet diluent) must be used within 3 hours and cannot be stored or refrigerated. Discard any ADYNOVATE left in the vial at the end of your infusion as directed by your healthcare professional.

You may have to have blood tests done after getting ADYNOVATE to be sure that your blood level of factor VIII is high enough to clot your blood.

How should I use ADYNOVATE? (cont'd)

Call your healthcare provider right away if your bleeding does not stop after taking ADYNOVATE.

What should I tell my healthcare provider before I use ADYNOVATE?

You should tell your healthcare provider if you:

- Have or have had any medical problems.
- Take any medicines, including prescription and non-prescription medicines, such as over-the-counter medicines, supplements or herbal remedies.
- Have any allergies, including allergies to mice or hamsters.
- Are breastfeeding. It is not known if ADYNOVATE passes into your milk and if it can harm your baby.
- Are pregnant or planning to become pregnant. It is not known if ADYNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNOVATE may not work for you).

What are the possible side effects of ADYNOVATE?

You can have an allergic reaction to ADYNOVATE.

Call your healthcare provider right away and stop treatment if you get a rash or hives, itching, tightness of the throat, chest pain or tightness, difficulty breathing, lightheadedness, dizziness, nausea or fainting.

The common side effects of ADYNOVATE are headache and nausea. Tell your healthcare provider about any side effects that bother you or do not go away.

These are not all the possible side effects with ADYNOVATE. You can ask your healthcare provider for information that is written for healthcare professionals.

What else should I know about ADYNOVATE and Hemophilia A?

Your body may form inhibitors to Factor VIII. An inhibitor is part of the body's normal defense system. If you form inhibitors, it may stop ADYNOVATE from working properly. Consult with your healthcare provider to make sure you are carefully monitored with blood tests for the development of inhibitors to Factor VIII.

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

The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist about ADYNOVATE. The FDA-approved product labeling can be found at www.shirecontent.com/PI/PDFs/ADYNOVATE_USA_ENG.pdf or 855-4-ADYNOVATE.

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.

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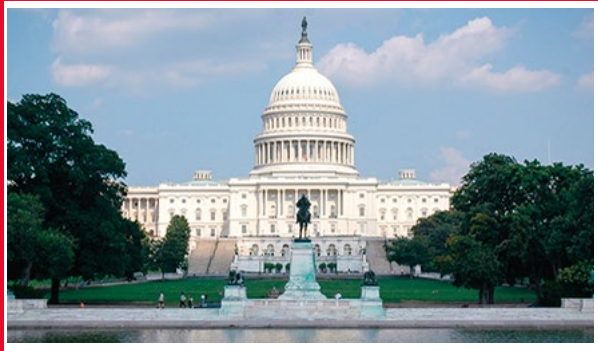
HFMD
HEMOPHILIA FOUNDATION OF MINNESOTA/DAKOTAS



HFA's 2018 Annual Symposium

The 2018 Hemophilia Federation of America's Symposium is an annual community-centered educational event that draws hundreds of members from the bleeding disorders community together to share information, learn new advancements, and build a network of support!

This year's event will take place in Cleveland, OH on April 26-29, 2018 with a theme of "Together We Rock!" Symposium hosts and organizers are excited to introduce participants to all that Cleveland has to offer.

HFA offers travel scholarships to first time attendees who need financial assistance. For more information on the Symposium and to register visit HFA's website at http://www.hemophiliafed.org/programs/meetings-events/educational-symposium.

NHF Washington Days

The National Hemophilia Foundation (NHF) will host our annual Washington Days advocacy event March 7-9, 2018 on Capitol Hill in Washington, DC. NHF's Washington Days is an opportunity for people affected by bleeding disorders to advocate for issues that are important to them. Last year's Washington Days had more than 500 volunteer advocates from 47 states that met with legislators and staff to discuss maintaining key patient protections in the Affordable Care Act (ACA).

The hotel for 2018 Washington Days lodging and trainings will be the Hyatt Regency at Capitol Hill, 400 New Jersey Ave NW, Washington DC 20001.

For more information and to register for the event see NHF's website at www.hemophilia.org/Events-Educational-Programs/Washington-Days.

2018 Calendar of Events

January 20, 2018 ..... PINZ Bowling and Laser Tag
Oakdale, MN *Event is full

February 17, 2018 ..... Hearts of Hope Gala
Radisson Blu, Bloomington, MN

March 22, 2018 ..... Bleeding Disorders Awareness Day on the Hill
Capitol Rotunda, St. Paul, MN

April 20-21, 2018..... HFMD Annual Member Meeting
Marriott Airport, 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 more exciting news and updates!

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NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

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SAVE THE DATE

HFMD ANNUAL MEETING
APRIL 20-21, 2018

AIRPORT MARRIOTT
2020 AMERICAN BLVD EAST, BLOOMINGTON, MN 55425

JOIN US FOR MUSIC AND PRIZES, AND THE LATEST UPDATES AND INFORMATION FROM THE BLEEDING DISORDERS COMMUNITY

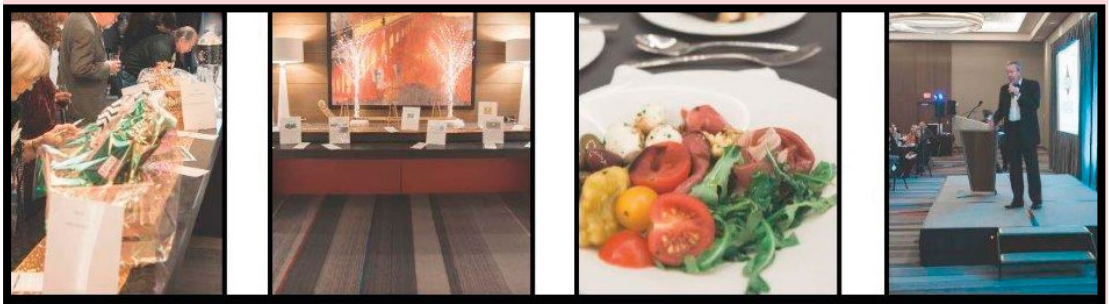
Join us for the HFMD Annual Meeting, April 20-21 at the Airport Marriott in Bloomington, MN.

Friday night will feature dinner followed by magic, games and dancing!

Saturday will feature education sessions, panels and plenty of networking!

THIS EVENT IS FOR INDIVIDUALS AND FAMILIES WITH BLEEDING DISORDERS

WE HOPE TO SEE YOU IN APRIL!



18th Annual Hearts of Hope Gala Fundraiser

February 17, 2018
Radisson Blu, Mall of America
Bloomington, Minnesota

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