

## 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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## Washington Days

This year, over 400 supporters of the bleeding disorders community gathered on Capitol hill in Washington D.C. for National Hemophilia Foundation's annual Washington Days advocacy event March 27th- 29th. Minnesota's group consisted of all fresh, new faces eager to meet with legislative officials to discuss the support of HR 1010 and issues surrounding the Affordable Care Act, short-term health insurance plans, and pre-existing conditions. Our day started with coffee and a meet and greet with Senator Amy Klobuchar. Five more meetings followed, speaking to legislative assistants from the offices of Senator Amy Klobuchar, Senator Tina Smith, Representative Colin Peterson, Representative Betty McCollum, and Representative Ilhan Omar. To our surprise, Representative McCollum had signed onto HR 1010 the night before our meeting, and every other legislature's office we spoke to was aware of the issues brought up and offered their support where they can give it. Brian, Kyle, and Rachael Duval were key community members

who shared their personal experiences on the costs of medications, the availability of affordable healthcare for someone with a pre-existing condition, and how they go through daily life while living with severe Hemophilia. Being able to share personal stories from the community to legislative members who did not have as much knowledge about bleeding disorders was essential for being successful in the meetings and gaining support for limiting short-term healthcare plans and blocking any restrictions on pre-existing conditions to ensure the best healthcare possible for individuals with bleeding disorders. Along with the Duval family, HFMD's Intern Aubree Douglas, Childrens Hospital's Pharmacy Technician Latrice Daniel, and North Dakota's own Executive Director, Emily Ouellette, joined forces to help advocate for the bleeding disorder community here in Minnesota.

– By Aubree Douglas, Intern, Hemophilia Foundation of Minnesota/ Dakotas

## Fine Dining & Formal Wear for a Great Cause!



Our 19th annual Hearts of Hope Gala fundraiser was held on February 9th, 2019 at the Metropolitan Club & Ballroom; a charming and cozy (non-hotel) venue which proved to be a big hit with so many of our guests.

The evening opened with a busy silent auction, augmented by a wine wall raffle led by our friends at the University of MN Health Center for Bleeding & Clotting Disorders. We had a nice cheese & cracker station as guests built up their appetites from the bidding and schmoozing.

We also raffled off a fully stocked liquor cart featuring over \$800 in high end bottles of spirits donated by the HFMD Board & Gala Committee.

The memorable banquet served by D'Amico Catering also drew rave reviews with the most-tender of beef tenderloin, and a delicious and nutritious Neapolitan embraced by our vegetarian, gluten free, and vegan guests.

This new venue was all ours for the night, and some commented on the benefits of exclusivity of a facility. It was time to settle in for the program and feast. To open the program, we wanted to show our talented host and his wife Heidi our appreciation for their seven consecutive years of heart-felt generosity and dedicated support of the HFMD. Dick & Heidi Bremer were presented with an award of Extraordinary Commitment to this organization, followed by a thunderous round of applause from our group.

Dick opened the program with his A game; sharing entertaining stories from the Twins FSN broadcast booth, and beyond. While his stories kept us laughing, he always brings it back to the reason we are all here tonight; to raise donations for the HFMD. And that we surely did with Auctioneer Mathew Schultz who provided lead vocals on the live-auction with Dick, and did a nice job on the Fund a Need to help support our Patient Financial Assistance Program, and a very special overseas



mission. The Fund a Need raised over \$12,000 in total, with the first \$5,000 raised going to support the humanitarian mission of Dr. Susan Kearney & the Children's Hospital HTC who are helping to establish a Hemophilia Treatment Center in Addis Ababa, Ethiopia. The pictures Dr. Kearney shared were quite compelling in a video produced by HFMD Event Coordinator, Melissa Andrisani.

HFMD Board President, Casey MacCallum led the top sponsor thank you on stage for our Diamond, Platinum & Gold level sponsors. With all levels, 16 companies sponsored our 2019 Gala fundraiser, and we are so grateful to the following companies.

With a small staff, our Gala planning committee and everyone who volunteered were huge in helping to pull off this event which went quite well. Thank you Gala committee & volunteers!

HFMD Gala Committee: Kris Rauenhorst, Kim Baumann, Dayna Hansen, Todd Hedlund, Rich Lanz, Bri Veik, Layne Henningsgaard, Melissa Andrisan, Kerry Budinger, & James Paist.

It was a wonderful night to remember, and we liked the venue so much, we booked it for **February 22nd, 2020 our Gala Fundraiser** – So, please mark your calendars today!

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## HFMD State Advocacy Day



March 12th, 2019 at the Minnesota state capitol rotunda saw rare disease advocates come together to join forces as one for Bleeding Disorders & Rare Disease Awareness Day Minnesota.

I want to begin by thanking Erica Barnes of the Rare Disease Action Network of Minnesota (RAN) who reached out to the HFMD toward the end of 2018 asking if they could join us at the capitol for our state advocacy day to work together in getting the Chloe Barnes Bill passed and signed in 2019. We share many common goals related to health care policy.

This bill would establish a Rare Disease Advisory Board which would weigh in on key policy issues affecting individuals and families affected by rare diseases, including hemophilia and other chronic bleeding disorders. The composition of this state advisory board would include physicians, experts, researchers, clinicians, and patients affected by rare disease. The bill was named after Erica's daughter Chloe, who sadly passed away from a rare disease at a very young age.

As a community very small in numbers, HFMD has always been a proponent of coalition building, because there is much greater strength in numbers. That point was so true when HFMD played an inspirational role in the elimination of lifetime health insurance caps at the national level in 2008. So, we warmly welcomed the support of RAN, and a host of other rare disease advocates; including Rae Blaylark, Executive Director of the Sickle Cell Foundation. Rae shared a riveting speech on stage that brought a positive surge of energy to our groups.

Our lineup of speakers included myself, Dr. Susan Kearny, Casey MacCallum, and Brian Duval; a 17-year-old with severe hemophilia who showed a highly advanced stage presence in sharing his personal story in the capitol rotunda. Advocates from other rare disease groups shared their stories on stage beginning with Erica Barnes who truly set a tone of hope with her families' personal story. Chief author of the bill in the Senate, Jeremy Miller addressed our group and expressed his compassion and dedication to families affected by rare disease. He also stressed his optimism in getting this bill passed in 2019! State Representative Nick Zerwas took the stage to tell his amazing personal story in surviving a serious heart condition at birth; which nobody thought he could overcome. He was a champion of our cause at our state advocacy day last year as well, and we are so grateful to his ongoing support!

Advocates from each facet of our community turned out in support, but yet our total number was much less than what we CAN DO. While we had a handful of our members and families there in support, HFMD urges all members of this bleeding disorders community to show up in mass at the Minnesota state capitol in March of 2020 to tell your stories and to advocate for full access to health care for all patients and families affected by bleeding disorders and other rare diseases. The specific date (which could be March 12th) to be announced, as the capitol rotunda needs to be reserved the year of the event.

*By James Paist*

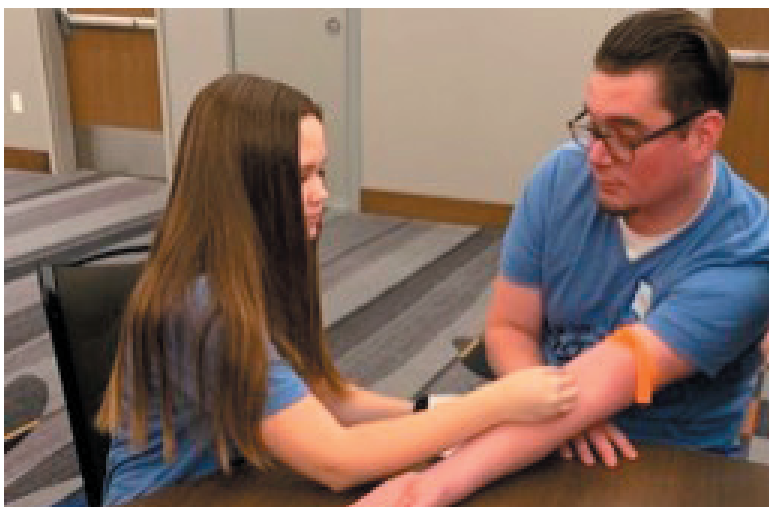


# Mayo Clinic HTC Family Event: “Life’s an Adventure”

## *2019 Mayo Clinic Comprehensive Hemophilia Treatment Center Family Event*

The Mayo Clinic Hemophilia Treatment Center held their Family Event from February 1-3 at the Hyatt Regency in Bloomington, Minnesota. The theme was “Life’s An Adventure” and included keynote speaker, Chris Bombardier. Chris shared his inspiring story of living with Severe Hemophilia B and successfully climbing all Seven Summits! Debbie Fuehrer, a Mayo Clinic Mind-Body Medicine Counselor shared her story as well as tips for resiliency and stress management. Dr. Rajiv Pruthi, director of the Mayo Clinic Hemophilia Center, discussed new treatment options and management strategies for patients with bleeding disorders.

Following a morning of education, conference attendees had the opportunity to sign up for individualized instruction on self infusion before the evening entertainment began. Families traveled to the Mall of America for dinner and fun! They were able to choose a 3 hour pass to Nickelodeon Universe, or a “Fly Over America” ticket.



## CoRe Conversation Dinner



“Braving Change” was the topic presented by Bioverativ’s Jess Scofield Hutchison at Bonfire Restaurant in Eagan. HFMD was happy to see the group in attendance participate so openly in this important discussion. We heard many stories about our members’ experiences and helpful ways to navigate changes in our lives. Thank you to those who joined and we look forward to seeing many more of you at our upcoming events!

## Top Golf



It was a beautiful, sunny Saturday on March 23rd, a perfect day for golf. HFMD was excited to host a Blood Brotherhood and Sisterhood event at the new Topgolf in Brooklyn Center. We were joined by Sue Curoe, RN, MS and Tim Boonstra, Pharmacist, who started the day off with an exciting game of Bleeding Disorder Jeopardy. After a winning team was crowned, the group went outside to enjoy the weather and work on their golf swings. In between turns, they were treated to a BBQ buffet with gooey chocolate chip cookies for dessert. Thank you to everyone who participated in this fun outing!



## NHF Leadership Conference 2019

This conference is hosted by NHF for chapter staff and Board members. This year part of the focus was how to tell your story in the most effective way.

Almost 9 years ago my journey into the world of bleeding disorders began. I have learned a lot and continue to learn daily from the community. The opportunity to attend the NHF's Leadership Conference this year in Denver was just the ticket I needed to expand my knowledge of being on such an amazing board as HFMD. In Denver, March 19th -21st, I was able to meet with several other chapter leaders and learn new things to try at HFMD.

The main focus of the conference was Story Telling. How to effectively tell your story as well as that of the community. I learned that even though I know my story and can tell it without pause, was I really getting my point across? In the world today, it is not only important to tell your story, but it is vital to get people to listen. I was able to take away really impactful information on how to do this. I have been telling our story for so long, I had lost the reason behind why I was telling our story. I was able to meet others and learn some new ways to do this. I feel I have a better understanding of how I can use my story for advocacy concerns and fundraising. I also, learned that it is ok to share others stories and the community's stories for the same mission.

While HFMD does an excellent job to get our communities stories heard, it needs the support from members of our community to attend events and get out there and share our stories.

*By Kris Rauenhorst, HFMD Board, VP.*

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## Ode to a Bottle

It's time for the factor to mix  
because I'm once again in a fix.  
Not a bottle of root beer do I hold,  
but rather something more pricey than gold.  
For whenever I hold a factor bottle,  
it's Hemophilia's neck I'd like to throttle.

What was it this time, let's review:  
perhaps a cause familiar to you.  
My thigh against a bedpost in the dark?  
My knee and bumpy pavement in the park?  
A countertop corner did my thigh bump?  
Certainly possible: there's now a lump.

Often my choices cause trouble:  
my toes in a dropped sink's rubble.  
And with respect to moving a swing set  
my toes knew my plan I would soon regret.

We with bleeding disorders need to plan  
so that our days go as smooth as they can.  
With more planning and wisdom as our model  
then our lives will depend less on a bottle.  
To anyone who might compare your worth,  
there aren't enough factor bottles on earth.

*By Donald Glascock*

GO SEEK. GO EXPLORE.  
**GO AHEAD.**



Discover your sense of go. Discover HEMLIBRA®.

[HEMLIBRA.com](https://HEMLIBRA.com)

#### 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
  - weakness
  - swelling of arms and legs
  - yellowing of skin and eyes
  - stomach (abdomen) or back pain
  - nausea or vomiting
  - feeling sick
  - 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
  - pain or redness in your arms or legs
  - shortness of breath
  - chest pain or tightness
  - fast heart rate
  - cough up blood
  - feel faint
  - headache
  - numbness in your face
  - 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,  
 1 DNA Way, South San Francisco, CA 94080-4990  
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For more information, go to [www.HEMLIBRA.com](http://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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These are donations received from January 1st - March 31, 2019.

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## Hemophilia Treatment Centers (Tri-State Area)

**Children's Minnesota - Center for Bleeding and Clotting Disorders**  
**2530 Chicago Ave S, Suite 175**  
**Minneapolis, MN 55404**  
**612-813-5940**

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**Mayo Comprehensive Hemophilia Center**  
**Mayo Clinic**  
**Mayo 10-55E**  
**200 First Street SW**  
**Rochester, MN 55905**  
**507-284-8634 or 1-800-344-7726**

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**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 or 800-850-0064**

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**University of Minnesota Health**  
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**Minneapolis, MN 55454**  
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**HEMOPHILIA  
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# ADYNNOVATE

[Antihemophilic Factor (Recombinant), PEGylated]

ADYNNOVATE® is FDA approved for children and adults with Hemophilia A

PROVEN PROPHYLAXIS +  
SIMPLE, \* TWICE-WEEKLY DOSING SCHEDULE =

*moments* **YOUR WAY**

\*ADYNNOVATE allows you to infuse on the same 2 days every week. Work with your doctor to determine an infusion schedule that is appropriate for you.

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 ADYNNOVATE twice-weekly prophylaxis (40-60 IU/kg) and determined hemostatic efficacy in the treatment of bleeding episodes for 6 months.<sup>1,2</sup>

The pivotal trial of children and adults ≥12 years (N=137) evaluated the efficacy, PK, and safety of ADYNNOVATE 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.<sup>1</sup>

+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.<sup>1,3</sup>

+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.<sup>1</sup>

Talk to your doctor to see if ADYNNOVATE treatment may be right for you and visit [ADYNNOVATE.com](http://ADYNNOVATE.com)

## ADYNNOVATE [Antihemophilic Factor (Recombinant), PEGylated] Important Information

### What is ADYNNOVATE?

- ADYNNOVATE 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 (HCP) may give you ADYNNOVATE when you have surgery.
- ADYNNOVATE can reduce the number of bleeding episodes when used regularly (prophylaxis).

ADYNNOVATE is not used to treat von Willebrand disease.

### DETAILED IMPORTANT RISK INFORMATION

#### Who should not use ADYNNOVATE?

Do not use ADYNNOVATE if you:

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

Tell your HCP if you are pregnant or breastfeeding because ADYNNOVATE may not be right for you.

#### What should I tell my HCP before using ADYNNOVATE?

Tell your HCP 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 ADYNNOVATE passes into your milk and if it can harm your baby.
- Are or become pregnant. It is not known if ADYNNOVATE may harm your unborn baby.
- Have been told that you have inhibitors to factor VIII (because ADYNNOVATE may not work for you).

### DETAILED IMPORTANT RISK INFORMATION (cont'd)

#### What important information do I need to know about ADYNNOVATE?

- You can have an allergic reaction to ADYNNOVATE. 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.
- Do not attempt to infuse yourself with ADYNNOVATE unless you have been taught by your HCP or hemophilia center.

#### What else should I know about ADYNNOVATE 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 ADYNNOVATE from working properly. Talk with your HCP to make sure you are carefully monitored with blood tests for the development of inhibitors to factor VIII.

#### What are possible side effects of ADYNNOVATE?

- The common side effects of ADYNNOVATE are headache and nausea. These are not all the possible side effects with ADYNNOVATE. Tell your HCP 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](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

**Please see Important Facts about ADYNNOVATE on the following page and discuss with your HCP.**

**For full Prescribing Information, visit [www.ADYNNOVATE.com](http://www.ADYNNOVATE.com).**

**References:** 1. ADYNNOVATE 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*. 2017;23(2):238-246. 3. Data on file; Shire US Inc.



## ADYNOVATE<sup>®</sup>

[Antihemophilic Factor (Recombinant), PEGylated]

### Patient Important facts about

#### ADYNOVATE<sup>®</sup> [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<sup>®</sup> [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](http://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](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.**

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## **Current Calendar of Events**

April 26-27, 2019 ..... Annual HFMD Member Meeting  
Airport Hilton, Bloomington, MN

May 16, 2019 ..... Education Dinner Sponsored by Takeda  
Mallory's, Hudson, WI

June 15, 2019 ..... Waterpark Event  
Apple Valley Aquatic Center, Apple Valley, MN

July 7-12, 2019 ..... HFMD Summer Camp  
Camp Courage, Lake George, MN

July 27, 2019 ..... South Dakota Family Education Day  
Great Plains Zoo, Sioux Falls, SD

September 29, 2019 .... Step Out for Bleeding Disorders Fundraising Walk  
Harriet Island Pavilion, St. Paul, MN

October 26, 2019 ..... Women's & Teens Education Event  
Saint Paul Hotel, St. Paul, MN

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Visit our web site at [www.hfmd.org](http://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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## 2019 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](http://www.hfmd.org) or by calling the HFMD office at **651-406-8655 or 1-800-994-4363**.

