NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS



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Spring

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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SUNDAY, AUGUST 13, 2017

COMO PARK. E. PICNIC PAVILION 1199 MIDWAY PARKWAY, ST. PAUL, MN 55103 REGISTRATION IOAM

WALK 11AM-1PM

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Washington Days: Fear Not!

Among the many ways that the HFMD serves took great care of me during this short trip. you and me is by advocacy: this chapter of the National Hemophilia Foundation (NHF) tries hard to voice your needs and mine to the right folks at the right time to ensure that we're heard when it counts.

One place where it counts is in Washington, D.C., and especially this year, as many of us in the bleeding community are very concerned about planned changes to our insurance: how much it might cost, what it might cover, and whether the Medicaid Expansion will be continued.

The rub is that real folks from the bleeding community need to make this trip to provide this voice, and this year, I was one of the folks asked to travel.

I was feeling fairly nervous, but fortunately the NHF has a long streak of organizing these yearly Washington Days events, and they

The NHF ran some great introductory sessions for us on the afternoon that we arrived, and they fed us quite well. The next day, volunteers from the NHF or the Hemophilia Federation of America (HFA) guided us in small state-organized groups to the five or so offices in the House or Senate buildings on our pre-set schedules. In our case, we met with aides for the various Minnesota Senators and Representatives, and shook hands with a few of their bosses.

The NHF provided some notes which I found helpful when discussing my concerns tied to possible changes in our health insurance legislation, and our brief meetings were generally well-received, even by politicians who were clearly leaning away from my concerns.

continued of page 3...



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Also, we each selected some of our respective war stories, shortened to a couple of minutes, for sharing in these meetings, so that these legislative aides would get a feel for the consequences of their legislation. By the end of the day, I felt connected to my fellow group members through hearing their stories, and I felt much less reserved about sharing mine.

The morning of the third day offered some great NHF Chapter sessions, which wrapped at noon. We then exchanged contact information with our new friends in the NHF, HFA, and fellow advocates, and headed for the area airports.

The big lesson here is that Washington Days are not to be feared: they are a chance to grow your friendships, walk about 15,000 steps in good sneakers, learn some humility from others' challenges with their bleeding disorders, carry very few metal objects in your pockets, and try your hand at expanding the perspectives of your law-makers. My only negative experience during the entire trip involved a few harried frequent flyers at Reagan National who clearly needed some "Minnesota Nice" lessons: apparently they did not eat enough catsup.

Advocacy

HFMD launched our first Virtual Day on the Hill where we urged members to contact their state Senators and House Representatives and tell them how important access to proper health care is for those affected by bleeding disorders. Also to ask for their representatives thoughtfulness and compassion for people with chronic conditions as new health care policies are being constructed and finalized. HFMD Advocacy Committee volunteers played a key role in initiating this effort and in writing a compelling letter for members to customize for themselves. We asked our members to become their own strongest advocate in this ever-changing landscape of health-care policy. Members responded and HFMD also contacted the Governor's office which resulted in Governor Dayton making an official declaration of March 22nd, 2017 as Hemophilia Awareness Day.

By James Paist



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2017 Hearts of Hope Gala

Thank you to all who joined us for the 2017 Hearts of Hope Gala at the brand new Hyatt Regency in Bloomington. We were pleased to have 255

guests join us for an exciting evening of auctions, raffles, fine dining, and fun! Thank you to our wonderful Master of Ceremonies, Dick Bremer, for making the night's program a swinging success.

Thanks to the amazing work of our Gala committee and volunteers, the live and silent auctions featured many new and exciting items in 2017. The live auction featured World Champion Chicago Cubs baseball tickets donated by Ron and Paula Coomer, a family trip to Walt Disney World in Orlando, Florida with Spirit Airlines tickets

and a two-night stay at the gorgeous Hyatt Regency Grand Cypress, an evening in Saint Paul featuring a Padelford Riverboat sunset cruise, and more. Favorites from the silent auction included a Minnesota Wild team signed hockey stick, brewery packages, gift certificates from popular local restaurants and exclusive hotel stays.

HFMD featured a new raffle this year: an elegant liquor cabinet stocked with high-end liquors. The cabinet was generously donated by Richard Rauenhorst. The fantastic M Health staff coordinated the Wine Wall raffle again this year. The raffle was a hit and featured a variety of fine wines. Thank you to the wonderful staff at M Health for their hard work. Also, a huge thank you to our dedicated volunteers who sold raffle tickets for both the liquor cabinet and Wine Wall raffles.

HFMD Board President, Casey MacCallum, started the Gala program with a beautiful invocation. Five-time HFMD Master of Ceremonies, Dick Bremer, gave an update on the 2017 Minnesota Twins roster and shared a personal story of his family's experience with hemophilia. HFMD Executive Director, Jim Paist, then recognized the event sponsors and featured them on stage to say thank you for their significant contributions.

New to the HFMD gala, Auctioneer Matthew Schultz, continued the program with the Funda-Need benefitting HFMD's Summer Camp for

> Kids and the Patient Financial Assistance Program. The Fund-a-Need featured an emotional video on HFMD's Summer Camp created by Perry Cowen. Thanks to our generous quests, the Fund-a-Need raised over \$15,000! Matthew Schultz and Dick Bremer then auctioned off many sought-after live auction items including a couple surprises – a signed Bert Blyleven baseball and a half-inning in the FSN North Booth with Twins tickets. Jim Paist ended the program with the liquor cabinet raffle drawing and surprised the winner with a colorful shot glass.

Thanks to all of you, the HFMD raised over \$100,000! We are so grateful for our staff, committee and volunteers whose hard work made the Gala a success. We would like to honor our Gala Committee members for their incredible work: Dan Tinklenberg (Co Chair), Jim Paist (Co-Chair), Stacie Cowen, Dayna Hansen, Todd Hedlund, Kristy Heer, Josh Hemann, Jessica Hutchison, Dena lanello-Zimmer, Casey MacCallum, Kristina Rauenhorst, Richa Sastry and John Schulte. We would like to offer a special thank you to Perry Cowen for producing the beautiful Fund-a-Need video.

Be sure to save the date for the 2018 Hearts of Hope Gala to be held on Saturday, February 17 at the Radisson Blu in Bloomington, Minnesota.



By Brianna Hager, HFMD Event Coordinator

List of Gala Sponsors on page 8.

MAYO HTC FAMILY EVENT 2017 "IT'S ICE TIME"











It's Ice Time at the Mayo Family Event.

Mayo HTC held their annual family event on
February 10-12 at the Rochester Kahler Apache.
28 patients from 24 families were present. In
total, 8 different bleeding disorders were
represented. The theme was ICE (instruction,
conversation, entertainment). We learned how to
safely stay active, relieve some stress and share
our own experiences on staying well. Our Child
Life team did an excellent job with programming
for the kids! The evening concluded with
attending the local Rochester Ice Hawks game!

By Dawn Rusk



The pediatric study (N=73) evaluated the efficacy, PK, and safety of ADYNOVATE twice-weekly prophylaxis and determined the ability to treat bleeding episodes for 6 months^{1,2}

- +Sixty-six patients [32 patients aged <6 years and 34 patients aged 6 to <12 years] received 40-60 IU/kg of ADYNOVATE prophylactically, twice weekly²
- +38% (n=25) of children experienced zero total bleeds; 73% (n=48) experienced zero joint bleeds; and 67% (n=44) experienced zero spontaneous bleeds¹

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 ADYNOVATÉ 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 following page for ADYNOVATE Important Facts.

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

References: 1. ADYNOVATE Prescribing Information. Westlake Village, CA: Baxalta US Inc. 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 US Inc.

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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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If you have made a donation and your name is not listed, please contact HFMD.

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2017 Hearts of Hope Gala

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Hello Talk

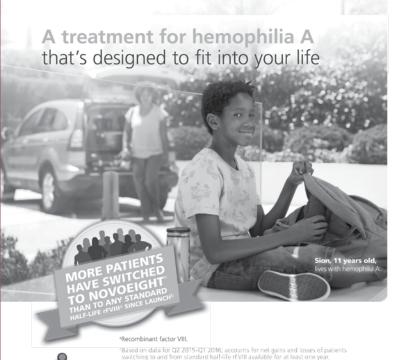
On a very cold evening in early January, HFMD members gathered to warm up at the Rojo Mexican Grill in Edina, Minnesota for the Hello Talk event. Hello Talk is a Shire educational program for individuals with bleeding disorders. The Hello Talk event featured a presentation on managing pain from Skye Peltier, MPH, PA-C, of the Center for Bleeding and Clotting Disorders at the University of Minnesota Medical Center, Fairview. Skye shared her personal story of living with a bleeding disorder and held a discussion



with the group about how pain affects their daily lives and effective pain management. During the presentation and discussion, the group enjoyed delicious food including chips and salsa, tacos, enchiladas, fajitas, and homemade flan and churro ice cream.

The HFMD would like to thank Stacie Cowen, Richa Sastry, and Shire for sponsoring this event and for inviting our members to participate. We would also like to thank event speaker, Skye Peltier, for her interactive and informative presentation.

By Brianna Hager



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Indications and Usage

Novoeight® (Antihemophilic Factor (Recombinant)) is an injectable medicine used to control and prevent bleeding in people with hemophilia A. Your healthcare provider may give you Novoeight® when you have surgery.

Novoeight® is not used to treat von Willebrand Disease.

Important Safety Information

You should not use Novoeight® if you are allergic to factor VIIII or any of the other ingredients of Novoeight® or if you are allergic to hamster proteins.

Call your healthcare provider right away and stop treatment if you get any of the following signs of an allergic reaction: rashes or hives, difficulty breathing or swallowing, tightness of the chest, swelling of the lips and tongue, light-headedness, dizziness or loss of consciousness, pale and cold skin, fast heartbeat, or red or swollen face or hands.

Before taking Novoeight®, you should tell your healthcare provider if you have or have had any medical conditions, take any medicines (including non-prescription medicines and dietary supplements), are nursing, pregnant or planning to become pregnant, or have been told that you have inhibitors to factor VIII.

Your body can make antibodies called "inhibitors" against Novoeight", which may stop Novoeight" from working properly. Call your healthcare provider right away if your bleeding does not stop after taking Novoeight".

Common side effects of Novoeight® include swelling or litching at the location of injection, changes in liver tests, and fever.

Please see Brief Summary of Prescribing Information on following page. Novoeight[®] is a prescription medication. 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.

Visit Novoeight.com today to learn more.

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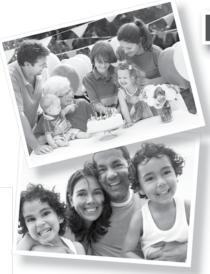
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2017 HFMD Scholarship Applications

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.

HFMD Office Gets a Facelift

HFMD recently signed a new contract with the building owners to continue to lease our current office space. HFMD has been in this office space in Mendota Heights for over 10 years. It has served us well, but recently has begun to show the wear and tear that can happen in a space where items are moved in and out as we hold our events.

As part of the new lease agreement, Gaughan Companies, agreed to update the office with new paint, carpet and a new work surface in the reception area. So, for a few days in March we cleared out the office and let them go to work. As of this writing we are back in the space and enjoying our new look.

By Kerry Budinger

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Coaquiation Factor IX (Recombinant), Albumin Fusion Protein

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NEWSLETTER OF THE HEMOPHILIA **FOUNDATION OF MINNESOTA AND** THE DAKOTAS

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2017 Calendar of Events

April 21-22, 2017...... 2017 Annual Member Meeting

Hyatt Regency, Bloomington, MN

May 7, 2017..... Blood Brotherhood

Minnesota Twins Baseball Twins Field, Minneapolis, MN

June 15th, 2017..... Education Dinner Cruise (limited space)

Johnathan Padelford Harriet Island, St. Paul, MN

July 9-14, 2017..... Summer Hemophilia Camp

Camp Courage North, Lake George, MN

July 29, 2017..... South Dakota Education Day

Thunder Road Amusement Park, Sioux Falls, SD

August 13, 2017...... Step Out for Bleeding Disorders Fundraiser Walk

Como Park, St. Paul, 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!