

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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Education Dinner Cruise Hosted by HFMD & Sponsored by Octapharma.



On the warm sunny evening of June 16th, the HFMD welcomed 75 members of all ages. HFMD staff Kerry Budinger & Brianna Hager greeted our guests at the registration table, and nobody missed the boat! Once all of our group boarded just after 6:00 p.m., the giant paddlewheel propelled us on our way up the mighty Mississippi River.

Our presenter for the evening is a well-known speaker in the bleeding disorders world, Jeanette Cesta. She shared "Community Connections" an interactive presentation which began with her personal story.

After some initial hesitation to speak in front of everyone, several in our group opened up sharing how their personal stories related to Jeanettes'. While engaged in this uplifting and inspirational presentation, we enjoyed a delicious grilled chicken dinner prepared by Padelford chefs.

Later in the evening members had time to visit and reconnect since their last HFMD event. Padelford Captain, Matt Spence, narrated historical sights and landmarks as we headed down river on our way back to the dock. It was truly a fun and relaxing group event. HFMD would like to thank Cory Muller and Jeanette Cesta of Octapharma for presenting and sponsoring this very unique event.

By Jim Paist



HFMD
Hemophilia Foundation
of Minnesota/Dakotas
Step Out
for Bleeding Disorders

HFMD WALK FUNDRAISER

SUNDAY, AUGUST 7, 2016

COMO PARK, EAST PICNIC PAVILION

1199 MIDWAY PARKWAY, ST. PAUL, MN 55103

REGISTRATION & FUN 10AM-12PM

WALK 12-2PM

The 2016 HFMD Walk Fundraiser is fast approaching and we need your support! Sign up your Walk team, join a team, donate or register as an individual or family today! Help the HFMD continue to provide the services we are so proud to offer! Not able to attend the walk? Sign up as a virtual walker, or donate.

STEP OUT FOR BLEEDING DISORDERS!



REGISTER TODAY AT WWW.FIRSTGIVING.COM/HFMD
FOR MORE INFORMATION CONTACT THE HFMD AT: 651-406-8655 OR INFO@HFMD.ORG

2016 HFMD Annual Meeting

The 2016 HFMD Annual Member Meeting was held April 22nd & 23rd at the Hilton MSP Airport/Mall of America in Bloomington, MN. Nearly 200 HFMD members joined HTC staff and exhibitors for a weekend of informative sessions, engaging programming and a night at Sea Life Aquarium! On Friday evening, HFMD members enjoyed a taco buffet complimented by super foods. After dinner, participants were bused to Sea Life Aquarium (formerly Underwater World) to enjoy an evening under the sea. First, members enjoyed the hands-on experience of petting sting rays. The Aquarium then led in to a dark room filled with tubes of glowing jellyfish and sea horses followed by a bright room filled with vibrantly colored tropical fish and corals. The next exhibit was a member favorite - the ocean tunnel. This area housed a variety of saltwater creatures including sharks, turtles and fish. The sea life were able to freely swim right over your head - it was quite an experience! The next tunnel featured local underwater friends found in freshwater lakes including sturgeon, bass and a variety of other creatures found in Minnesota. The tour ended with a Rainforest experience and a close up encounter with an Amazonian crocodile. Our families thoroughly enjoyed the experience and some even went home with a few souvenir sharks (from the gift shop, of course).

Day two of the Annual Meeting began with our guests enjoying a plate of delicious breakfast goodies and some one-on-one time with our exhibitors. HFMD Executive Director, Jim Paist, and HFMD Board Secretary, Donald Glascock, then led the opening address and updated our members with the HFMD year-in-review, along with the 2016 "Step Out for Bleeding Disorders" Walk kick off! After the opening address, parents brought their children to the always incredible HFMD Childcare team led by Vicki Neis, CCLS. The theme for children's programming was "Star Wars." Our younger kids started the day with the "Karing for Kids" program sponsored by Accredo and visited the Minnesota Wildlife Refuge Center in the afternoon. The teens enjoyed a unique experience – fencing with the University of Minnesota Fencing Team! After lunch, the teens sat down with Board Member, Carson Ouellette, to discuss Youth Leadership. In the tradition of "Star Wars," all of the kids enjoyed a light-saber fight and received posters from the new movie.

While the kids were "using the force" in children's programming, the adults were enjoying an inspirational presentation from Keynote Speaker, Kevin Harris, along with Nutritionist Carmen Honnef, RD, CD. Kevin spoke about his life with hemophilia and explained how changes to his diet and exercise have drastically changed his health, reducing the number of bleeds he experiences. Thank you to Emergent for sponsoring our keynote address, and Kevin Harris and Carmen Honnef for speaking with our members.



After a break with exhibitors, the General Assembly began with the always popular "Ask the Doctors" session. The panel featured Dr. Margaret Heisel-Kurth, Dr. Susan Kearney and Dr. Rajiv Pruthi. Dr. Susan Kearney led the panel with a presentation on the findings from a recent hemophilia study. The panel then took questions from HFMD members. HFMD Board Vice President, Casey MacCallum, presented Dr. Margaret Heisel-Kurth with a lifetime achievement award for her work with the hemophilia community. Dr. Heisel-Kurth will retire at the end of 2016.



continued on page 3...

...Annual Meeting, continued from page 2

Next, members enjoyed a build-your-own sandwich lunch and time with the exhibitors. The group then split up for the afternoon breakouts including “Disclosing Your Bleeding Disorder” with Cathy Tiggs, MSA, LISW of the National Hemophilia Foundation; a Blood Brotherhood breakout session, “Your Liver and Viral Hepatitis,” with Daniel Reilly; and a calming afternoon of Yoga with Christine Paul, OYI of Mind and Body Solutions. A huge thank you to our Annual Meeting Planning Committee Co-Chairs, Amy Eckerman & Jim Paist, and the committee: Alexis D’Valle, Angie Blue, Jessica Hutchison, Jill Swenson, Kris Manns, Kasey Gauthier, Troy Gleason, Vicky Hannemann and Vicki Neis.

The HFMD would like to give a special thank you to our event sponsors: Children’s Hospitals and Clinics of Minnesota, M Health, and Mayo Clinic. We would also like to extend a big thank you to our exhibitors: Accredo, ARJ Infusion, Axelacare, Baxalta, Bayer HealthCare, Biogen, BioRx, CSL Behring, CVS Specialty, Emergent, Grifols, Hemophilia Federation of America, Novo Nordisk, Octapharma, Option Care, and Pfizer.

Please join us for the 2017 Annual Meeting – Friday, April 21 & Saturday April, 22 at the brand new Hyatt Regency in Bloomington, MN! We look forward to seeing you there!



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If you have private insurance, you may be eligible for the \$0 Co-pay Program.

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[†]The Free Trial Program includes up to 6 free doses to a maximum of 5,000 IU for new patients and 40,000 IU for previously treated patients.

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[§]People with private, commercial health insurance may receive co-pay or co-insurance assistance based on eligibility requirements. The program is on a first-come, first-served basis. Financial support is available for up to 12 months. Eligible patients can re-enroll for additional 12-month courses. The program is not for patients receiving prescription reimbursement under any federal-, state-, or government-funded insurance programs, or where prohibited by law. All people who meet these criteria are encouraged to apply. Bayer reserves the right to discontinue the program at any time.

Group Fitness Event at Bunker Beach



The Hemophilia Foundation of Minnesota/Dakotas kicked off our summer event season with a Group Fitness Event at Minnesota's largest waterpark, Bunker Beach Waterpark in Coon Rapids, MN. Nearly sixty HFMD members enjoyed a hot and sunny day at the park. Our group was joined by Cheryl Hansen, PT CLT of Children's Hospitals and Clinics of Minnesota for a pre-swim Physical Therapy session under the South Beach

Pavilion. Cheryl roused the group with stretching and then everyone hit the pool!

After a short swim, lunch was served at the Pavilion. Our group gathered for conversation and enjoyed a lunch of hot dogs, hamburgers, corn dogs and veggie burgers – all served with chips, water and a special taffy dessert. After lunch, our families enjoyed cruising down the lazy river, swimming in the wave pool, and zipping down Bunker Beach's six waterslides. Our group also had fun climbing the aqua climbing walls and playing water basketball and sand volleyball.

Thank you to our families for making the trek to Coon Rapids for this special event! We enjoyed getting to see everyone and learning more about our families. We look forward to seeing you at our next Group Fitness event! Keep an eye on our website calendar.



By Brianna Hager, HFMD Event Coordinator

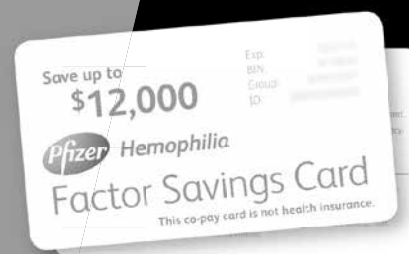


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Indications

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

Important Safety Information

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

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

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

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

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

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

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

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



FDA-Approved Patient Labeling

Patient Information

ELOCTATE® /el' ok' tate /

[Antihemophilic Factor (Recombinant), Fc Fusion Protein]

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

What is ELOCTATE?

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

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

Who should not use ELOCTATE?

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

What should I tell my healthcare provider before using ELOCTATE?

Talk to your healthcare provider about:

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

How should I use ELOCTATE?

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

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

What are the possible side effects of ELOCTATE?

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

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

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

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

How should I store ELOCTATE?

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

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

After reconstitution (mixing with the diluent):

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

What else should I know about ELOCTATE?

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

44279-02

Manufactured by:

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Cambridge, MA 02142 USA

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ELOCTATE® is a registered trademark of Biogen.



Bleeding Disorders Alliance of North Dakota (BDAND) P.O. Box 548, Fargo, ND 58107

Dear Friends,

I want to take a moment to fill you in on the progress being made by the Bleeding Disorders Alliance of North Dakota (BDAND). On April 21, 2016, we were approved as a 501(c)(3) tax exempt nonprofit organization by the Internal Revenue Service (IRS). This means that we may accept donations that are tax exempt, and can be written off as charitable contributions by the donor.

Since receiving this designation, we have hit the ground running. We completed the requirements necessary for a fledgling chapter to be recognized as an affiliate chapter with the National Hemophilia Foundation (NHF).

We will also be kicking off our annual walk with the first ***Stroll along the Red*** on Saturday, August 13. We welcome you all to join us at Lindenwood Park in Fargo, ND. Registration will begin at 10:00 a.m., and we will begin walking at 11:00 a.m. Refreshments will be served following. For more information, please visit our Facebook page by searching Bleeding Alliance of North Dakota, or BDAND. Like our page to receive news about all upcoming events.

If you have any questions, or just want to chat, do not hesitate to reach out to me!

Sincerely,

Carson Ouellette
BDAND
President
701-350-1729
Bleedingalliance.nd@gmail.com

Hemophilia Treatment Centers (Tri-State Area)

**Center for Bleeding and Clotting Disorders
University of Minnesota Health**
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Minneapolis, MN 55455
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South Dakota Center for Bleeding Disorders**
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George Maher, MD
Sam Milanovich, MD
Kasey Gauthier, RN, CPN, CPHON
Grant Boltjes, PT
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(CHCMN)**
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Event Coordinator

Education Dinner May 21st sponsored by Bayer HealthCare

The HFMD partnered with Bayer HealthCare to feature Emergency Treatment presented by Joni Osip.

The event was held at Chevy's Tex Mex restaurant where local Bayer representative Todd Hedlund greeted guests before the dinner and presentation. HFMD members enjoyed delicious food while learning about being prepared for emergencies.

We thank Joni, Todd, and Bayer Healthcare for
sponsoring this education event.



**HEMOPHILIA
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The HFMD gratefully acknowledges our donors who have given so generously.
These are donations received from January 1, 2016 through June 30, 2016.
If you have made a donation and your name is not listed, please contact HFMD.

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**NEWSLETTER OF
THE HEMOPHILIA
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MINNESOTA AND
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Email: hemophiliafound@visi.com



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2016-2017 Calendar of Events

- July 21 - 23..... NHF's 68th Annual Meeting
Orlando, FL
- July 24 - 28..... WFH World Congress
Orlando, FL
- August 7..... Step Out for Bleeding Disorders Walk
Como Park, St. Paul
- September 24..... Coalition for Hemophilia B
Minneapolis, MN (more details TBA)
- October 15..... Women's Conference
Hilton Airpor/Mall of America
- February 18, 2017..... SAVE THE DATE for our 2017 Hearts of Hope Gala
Hyatt Regency, Bloomington, MN
- April 21-22, 2017..... SAVE THE DATE for the 2017 Annual Meeting
Hyatt Regency, Bloomington, MN

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

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