

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 and Fun - Sioux Falls, South Dakota

The HFMD partnered with Sanford Health Children's to host an outdoor education event at Thunder Road amusement park. The event got off to a fantastic start with 71 RSVPs which exceeded everyone's hopes and expectations.

Saturday, July 30th was a picture perfect summer day of 80 degrees and clear blue skies. We held our event under a large picnic pavilion that was just big enough for our South Dakotan group. While most of our attendees were families who are treated at Sanford Health Children's, a.k.a. the Castle, we also had some members from the South Dakota area who are patients at other clinics, including Mayo in Rochester, MN

The event opened with a member of each family introducing their respective families. An important part of this event was giving our South Dakota families the opportunity to get to know each other. Next, it was time to introduce our keynote speaker, Mathia Rall who is the Child Behavior Specialist from Sanford Children's. Mathia was brilliant in getting our group engaged immediately with an interactive presentation which captured everyone's attention over the rumbling engines of go-carts and tilt-a-whirls.

After Mathia's presentation, Jim Paist shared an overview of HFMD's programs and services encouraging people to attend our events in the Twin Cities while singling out a handful of SD families who don't let that 4 hour drive get in the way of attending our events. HFMD was also represented by Board President Casey MacCallum and his family who came to support the effort and to help greet so many new South Dakota members. Our Event Coordinator, Brianna Hager played a big role in planning this Sioux Falls special and was terrific in handling the logistics for our delicious buffet style fried chicken lunch from well known local establishment Bob's chicken whose food lived up to the high standards we had heard about from our clinic partners.

In addition to the impactful presentation from Mathia Rall, Sanford Children's clinic staff came out to support and help to host. Dr. Wagner shared some words of wisdom with our group and her colleagues spent quality time with families throughout the day (in between rides). HFMD would like to thank Sanford Children's with special thanks to Social Worker Nathan Anderson, R.N. Kasey Gathier, and Mathia Rall who helped to plan and carry out this exciting and fun family event. All 71 attendees thoroughly enjoyed the go-carts and so many other rides at Thunder Road of Sioux Falls.

By Jim Paist



6th Annual “Step Out for Bleeding Disorders

More than 300 guests joined the HFMD for a beautiful, sunny day at Como Park on Sunday, August 7th for the 6th Annual “Step Out for Bleeding Disorders” Walk fundraiser. The Walk brought together the hemophilia and bleeding disorders community for a day of fitness, fundraising and fun! Thank you to all who attended and fundraised!

Walk registration began at 10 a.m. and guests enjoyed time with exhibitors, balloon making with Pickles the Clown, music from KQRS, selfies with Timberwolves’ mascot Crunch, photos with superheroes, Captain America and Spider-Man, and face painting with Jennifer Paist. Walk teams gathered in the pavilion for pre-Walk treats and refreshments courtesy of our wonderful kitchen staff led by Jess Hutchison and Walk committee member, David Singer. Teams grabbed their super, silver Walk t-shirts and headed for the starting line for the Noon start. Captain America, Spider-Man and Crunch helped HFMD Executive Director, Jim Paist and HFMD Board President, Casey MacCallum, kick off the Walk – Crunch blared his horn and everyone raced off! Walkers enjoyed a 2.5 mile stroll around Lake Como and returned to the finish line for Subway sandwiches, cookies and more fun!

Thanks to the incredible efforts of our 27 Walk teams over \$60,000 was raised for HFMD programs and services. **THANK YOU** to all of the teams, families, individuals, virtual walkers and donors who supported the 2016 Walk – without you none of this would be possible! HFMD honored the top three Walk teams for their fundraising efforts. Our first place team, Team Naumann, raised \$2,230 and won a \$1,500 travel reimbursement to the 2017 NHF Conference in Chicago, IL and 25 free six-inch sub coupons from Subway. Our second place team, Team Charlie, raised \$1,828 and won a two-night stay at the Embassy Suites Bloomington with four Water Park of America tickets and 15 free six-inch sub coupons from Subway. Our third place team, Team Happy Feet, raised \$1,770 and won a ladder golf game and 10 free six-inch sub coupons from Subway. Thank you to the top three and all of our Walk teams for your amazing fundraising and recruiting efforts!

We look forward to our 7th Annual “Step Out for Bleeding Disorders” Walk next year and hope that you will join us!

Thank you so much to our generous sponsors and exhibitors!

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Save the Date

Diamonds to Denim

17th Annual Hearts of Hope Gala

February 18, 2017

Hyatt Regency Bloomington

Join us for an evening of fine dining,
auctions & fun!



HEMOPHILIA
FOUNDATION
OF MINNESOTA/DAKOTAS

HFMD community members -

WE NEED YOUR HELP!

The **17th Annual Hearts of Hope Gala** will be held on Saturday, February 18th at the brand new Hyatt Regency in Bloomington. The Gala committee is busy preparing for the event and would like to ask for your help in getting sponsors and items donated to the live and silent auctions.

If you have a local business connection (restaurant, salon, event center, etc.) or have a talent yourself and would like to donate an item, please contact Brianna at briannah@hfmd.org.

Unfortunately, we are unable to accept artwork.

Thank you for your assistance!



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We might be able to provide treatment at no cost if you[‡]:

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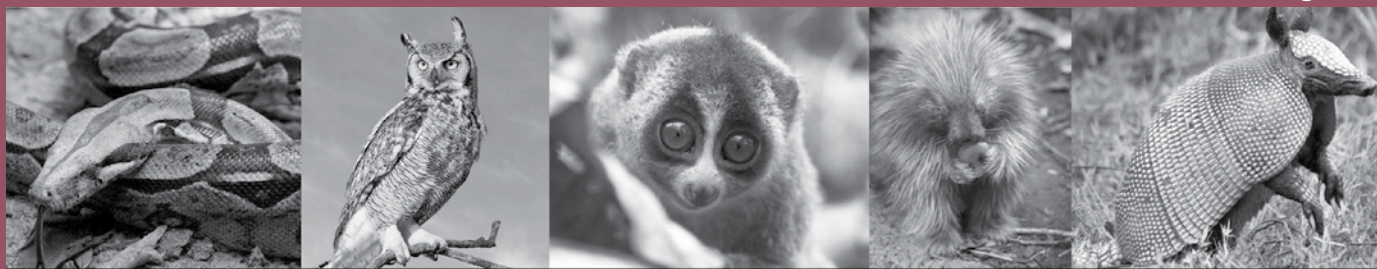
8:00 AM-8:00 PM (ET) Monday-Friday. Spanish-speaking Case Specialists are also available.

*The Free Trial Program is available to newly diagnosed patients and patients who are currently using other therapy. Participation in the Free Trial Program is limited to 1 time only. This program is complimentary and is not an obligation to purchase or use a Bayer product in the future. Reselling or billing any third party for the free product is prohibited by law.

†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.

‡The program does not guarantee that patients will be successful in obtaining reimbursement. Support medication provided through Bayer's assistance programs is complimentary and is not contingent on future product purchases. Reselling or billing any third party for free product provided by Bayer's patient assistance programs is prohibited by law. Bayer reserves the right to determine eligibility, monitor participation, determine equitable distribution of product, and modify or discontinue the program at any time.

§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.



SAVE THE DATE

HFMD ANNUAL MEETING APRIL 21-22, 2017

**HYATT REGENCY BLOOMINGTON
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Learn about support programs like HemMobile™, Patient Affairs Liaisons, scholarship assistance, and the educational speaker series.

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If you have any questions about the use of the Pfizer Factor Savings Card, please call 1.888.240.9040 or send questions to: Pfizer Factor Savings Program, 2250 Perimeter Park Drive, Suite 200, Morrisville, NC 27560. For more information, please visit www.HemophiliaVillage.com.

†The Pfizer RxPathways Savings Card is not health insurance. For a complete list of participating pharmacies, visit PfizerRxPathways.com or call the toll-free number 1.877.744.5675.

There are no membership fees to participate in this service. Estimated savings is 36% and depends on such factors as the particular drug purchased, amount purchased, and the pharmacy where purchased. Pfizer RxPathways is a joint program of Pfizer Inc and the Pfizer Patient Assistance Foundation™.

*Terms and conditions apply. You must be currently covered by a private (commercial) insurance plan. For questions about the Pfizer Hemophilia Trial Prescription Program, please call 1.800.710.1379 or write us at Pfizer Hemophilia Trial Prescription Program Administrator, MedVantx, PO Box 5736, Sioux Falls, SD 57117-5736. You may also find help accessing Pfizer medicines by contacting the Pfizer RxPathways Program.

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*ALPROLIX has been proven to help patients prevent bleeding episodes using a prophylaxis regimen.

Indications and Important Safety Information

Indications

ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein] is a recombinant DNA derived, coagulation factor IX concentrate indicated in adults and children with hemophilia B for:

- On-demand treatment and control of bleeding episodes
- Perioperative management of bleeding
- Routine prophylaxis to reduce the frequency of bleeding episodes

ALPROLIX is not indicated for induction of immune tolerance in patients with hemophilia B.

Important Safety Information

Do not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX.

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 and all your medical conditions, including if you are pregnant or planning to become pregnant, are breastfeeding, or have been told you have inhibitors (antibodies) to factor IX.

Allergic reactions may occur with ALPROLIX. 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 ALPROLIX, which may stop ALPROLIX from working properly.

ALPROLIX may increase the risk of formation of abnormal blood clots in your body, especially if you have risk factors for developing clots.

Common side effects of ALPROLIX include headache and abnormal sensation of the mouth. These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider right away about any side effect that bothers you or does not go away, and if bleeding is not controlled using ALPROLIX.

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.



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ALPROLIX [Coagulation Factor IX (Recombinant), Fc Fusion Protein], Lyophilized Powder for Solution For Intravenous Injection.

FDA Approved Patient Information

**ALPROLIX® /all' pro liks /
[Coagulation Factor IX (Recombinant),
Fc Fusion Protein]**

Please read this Patient Information carefully before using ALPROLIX 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 ALPROLIX?

ALPROLIX is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital Factor IX deficiency.

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

Who should not use ALPROLIX?

You should not use ALPROLIX if you are allergic to ALPROLIX or any of the other ingredients in ALPROLIX. Tell your healthcare provider if you have had an allergic reaction to any Factor IX product prior to using ALPROLIX.

What should I tell my healthcare provider before using ALPROLIX?

Tell your healthcare provider about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- are pregnant or planning to become pregnant. It is not known if ALPROLIX may harm your unborn baby.
- are breastfeeding. It is not known if ALPROLIX passes into breast milk or if it can harm your baby.
- have been told that you have inhibitors to Factor IX (because ALPROLIX may not work for you).

How should I use ALPROLIX?

ALPROLIX should be administered as ordered by your healthcare provider. You should be trained on how to do infusions by your healthcare provider. Many people with hemophilia B learn to infuse their ALPROLIX by themselves or with the help of a family member.

See the **Instructions for Use** for directions on infusing ALPROLIX. The steps in the **Instructions for Use** are general guidelines for using ALPROLIX. Always follow any specific instructions from your healthcare provider. If you are unsure of the procedure, please ask your healthcare provider. Do not use ALPROLIX as a continuous intravenous infusion.

Contact your healthcare provider immediately if bleeding is not controlled after using ALPROLIX.

What are the possible side effects of ALPROLIX?

Common side effects of ALPROLIX include headache and abnormal sensation in the mouth.

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

ALPROLIX may increase the risk of forming abnormal blood clots in your body, especially if you have risk factors for developing blood clots.

Your body can also make antibodies called, "inhibitors," against ALPROLIX, which may stop ALPROLIX from working properly. Your healthcare provider may need to test your blood for inhibitors from time to time.

These are not all the possible side effects of ALPROLIX. Talk to your healthcare provider about any side effect that bothers you or that does not go away.

How should I store ALPROLIX?

Store ALPROLIX vials at 2°C to 8°C (36°F to 46°F). Do not freeze.

ALPROLIX vials may also be stored at room temperature up to 30°C (86°F) for a single 6 month period.

If you choose to store ALPROLIX at room temperature:

- Note on the carton the date on which the product was 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 product or diluent after the expiration date printed on the carton, vial or syringe.

After Reconstitution:

- Use the reconstituted product as soon as possible; however, you may store the reconstituted product at room temperature up to 30°C (86°F) for up to 3 hours. Protect the reconstituted product from direct sunlight. Discard any product not used within 3 hours after reconstitution.
- Do not use ALPROLIX if the reconstituted solution is cloudy, contains particles or is not colorless.

What else should I know about ALPROLIX?

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

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Ziplining - Story on page 13



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HFMD's 26th Annual Summer Camp

HFMD's 26th Annual Summer Camp for kids was held at Camp Courage North on July 10-15, 2016. Forty-three campers from Minnesota, South Dakota and Wisconsin came together on the shores of beautiful Lake George for an unforgettable week-long experience.

Campers enjoyed a mostly sunny and dry week at camp (with a couple rainy days). Camp kicked off on Sunday with an all-camp bonfire complete with songs, skits and marshmallows over the fire. Throughout the week, each cabin participated in activities and campers joined together for delicious, family-style meals and special events. Campers enjoyed tubing, swimming, arts & crafts, time on the ropes course, ball games, biking and so much more. Some campers even chose to take the daily "Polar Plunge" in the freezing lake!

Many campers learned to self-infuse at camp this year – both inside the health center and outdoors in our new screen porch! Those that self-infused for the first time achieved the honor of adding their name to the "The Big Stick", a great tradition for all of those who have self-infused at camp. Thank you to all of the incredible nurses and medical staff who taught the campers to self-infuse. It is a big achievement for our campers!



Chelsy Jungbluth, Genetic Counselor from Children's, held an exciting educational program on genetics and hemophilia. Campers learned about genetics through creating their own dog and observing how variations in DNA lead to the inheritance of different traits. Social Workers Melinda Otto and Dawn Rusk from Mayo Clinic and Jill Swenson from Children's led the camp mentorship program. Experienced campers teamed up with new campers and participated in activities including making a team t-shirt and playing games. Thank you to Chelsy, Melinda, Dawn and Jill for leading these fun programs!



Five campers participated in the Adventure Trip with Kerry Hansen of M Health. The three-day, two state journey included camping, a canoeing excursion in Wisconsin's Brule River and hiking the trails of Minnesota's Interstate State Park. Thank you, Kerry for leading our campers on this trip!

Thank you to all of the volunteers, counselors, camp staff and health center staff for making this year's camp such a terrific experience! The HFMD would like to thank the following for their sponsorship of camp: ARJ Infusion, Children's Hospitals and Clinics of Minnesota, M Health, Mayo Clinic, and generous individual donors.

With the cool fall air coming in, we are looking forward to another warm summer on the lake at Camp! See you all in 2017!

By Brianna Hager

Ziplining with HFMD

Saturday, September 24th dawned a cloudy and dreary day, but that didn't deter the 20 individuals who decided to brave the weather to soar above Sand Creek in Jordan, MN! Our group met at 11:00 a.m. to enjoy a picnic lunch near the zip line start platform. As we ate, another group was taking their turn at the zip line. Every 30 seconds someone would fly by on their way across the creek. Even though the food was fresh and delicious there were several members who were too nervous to enjoy their whole meal in anticipation of what awaited them!



Sand Creek Adventures staff did a great job instructing the group on how to gear up correctly. Staff then checked everyone to make sure they were strapped securely into their harnesses and that helmets were on snugly. After gearing up it was time to take the plunge just as the sun broke through the clouds! One of our mom's took the lead and jumped out over the 100 ft. high bluff to fly over beautiful Sand Creek! Not to be outdone, her kids and husband followed close behind. The rest of the group then took their turn to zig-zag across the bluffs on the 3-leg run.

There were a few in the group who had zip-lined before, but for most this was their first time! Even though there were many nervous faces and more than one person needing extra time to muster up some courage, everyone faced their fear and jumped! After completing the 3 runs the group made their way back to the parking lot with looks of exhilaration and excitement! Many were ready to go again, but will have to wait until next year!

By Kerry Budinger



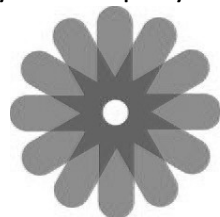
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2016-2017 Calendar of Events

- November 5, 2016.....Blood Brotherhood Cooking Class
Hyvee, Oakdale, MN
- January 21-22, 2017.....Children's Hospital Minnesota Family Education Event
Radisson Water Park of America, Bloomington, MN
- February 10-11, 2017.....Mayo Clinic Family Education Event
(Mayo Clinic patients only)
Kahler Hotel Apache Plaza, Rochester, MN
- 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!