

HFMD MISSION

To meet the needs and to enhance the quality of life for persons living with hemophilia, related inherited bleeding disorders and their complications

Inside this issue:

HFA Symposium	2
Annual Meeting (Continued from Cover)	3
Blood Brotherhood Attends Twins Game	5
Group Fitness & Scholarships Awarded	6
2017 HFMD Donors	8
Calendar of Events and Registrations & Deadlines	9
HTC Info & Staff HFMD Board & Staff	10
HFMD 2017 Walk Info	12



Animals, Ice Cream, & Information

Held at the new Hyatt Regency in Bloomington, our 2017 Annual Meeting opened the evening of Friday, April 21st, with an elaborate hamburger buffet. Then, experts from the Minnesota Zoo Zoomobile dazzled our group with a fascinating array of unique and tame animals. We learned about the feeding patterns of owls, and the natural habitat of a desert fox, just before an extremely long snake was displayed for some of our fearless youngsters to hold as a group.

Afterward members responded well to a Ben & Jerry's ice-cream stand and four carnival games, each of which had an animal theme. Some of these games of skill were quite challenging for all ages.

Our lineup of presentations on Saturday morning began with James Paist sharing some of HFMD's legislative accomplishments with health care policy; stressing the

importance of becoming your own personal advocate.

Next we had the pleasure of hearing motivational speaker and Life Coach, Jeremiah Rangel, present on tearing down invisible walls, and maximizing your personal strengths. Jeremiah was followed by Michelle Rice, NHF's Vice President of Governmental Affairs, who shared the latest information on changes in health care policy on the federal level. Both keynote speakers answered questions from curious members in our group.

After a busy morning it was time for a break to visit our exhibitors. Thank you to Accredo, Aptevo, ARJ Infusion, Axelacare, Bayer, Bioverativ, CSL Behring, CVS Specialty, Diplomat Specialty, Grifols, Novo Nordisk, Octapharma, Pfizer, & Shire.

Continued on page 3

2017 HFA Symposium “Hope Ignites!”

Providence, RI was the site for the 2017 HFA Symposium. Nearly 1,300 members of the bleeding disorders community came together April 6th – 9th to spend a weekend talking with familiar acquaintances and making new friends! This year’s symposium was also attended by HFMD’s Administrative Assistant, Kerry Budinger, and Board President, Casey MacCallum who were in Providence to listen to many speakers and attend numerous sessions geared toward chapter staff.

This year marked the first Symposium that HFA held in the New England area. The theme was “Hope Ignites!” According to HFA, they wanted to pay homage to the Rhode Island state motto of “Hope” since it’s also a great time of hope in the bleeding disorders community. “Ignites” was inspired by a signature fixture in downtown Providence, an art sculpture along the city’s waterfront known as *WaterFire*. Described as the city’s “most popular work of art created in the capital city’s 371-year history.” HFA featured a *WaterFire* event on the Final Night of the symposium, in order to showcase bleeding disorders to the entire city and igniting awareness of our community to a wider audience. At this event Casey MacCallum and Kerry Budinger represented HFMD by carrying the banner for the Hemophilia Foundation of MN/Dakotas during a banner ceremony for member chapters that was held before the *WaterFire* event.



Another wonderful surprise by the City of Providence was the number of downtown buildings lit up in red as a show of support for people living with bleeding disorders. All-in-all this is a fun and informative event for everyone in the bleeding disorder community.

By Kerry Budinger

THE VEINLINE IS MOVING TOWARD PAPERLESS!!!

The HFMD is asking for your help in an effort to go paperless! The Veinline is our way to keep our community informed of our activities and events. However, each year as our community grows it is getting more expensive to print and mail each issue. In an attempt to save costs while continuing to keep you informed we are asking community members to provide an email address in order to distribute more of our Veinline newsletters electronically. If you’d like to help us out and receive future issues of the Veinline via email instead of hard copy, please email us at info@hfmd.org and let us know the email address(es) where you would like to receive future newsletters?

Continued from page 1

The Child Life Programming was a big hit once again under the care and direction of Vicki Neis and her fabulous team. Children were more than happy to make drums out of five-gallon buckets, then decorate them before our drum corps began. The kids also played yard games outside with a parachute.

We would like to extend our gratitude to our event sponsors: Aptevo, Children's Hospital & Clinics, Mayo Clinic Foundation, & MHealth. While there were a number of highlights at this year's Annual, HFMD members were thoroughly engaged in the afternoon roundtable discussions moderated by thought provoking HTC clinic staff. These interactive roundtable discussions gave members the opportunity to share their stories with one another and to learn from each other's experiences.

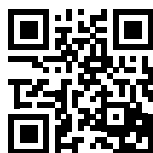
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Blood Brotherhood Attends Twins Game

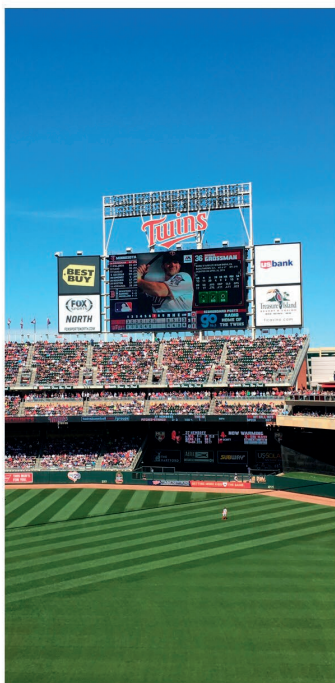


On Sunday, May 7th, the HFMD Blood Brotherhood headed out to the ballpark for a Minnesota Twins game at Target Field in Minneapolis. The day was cool, but sunny – a perfect day for a baseball game. After meeting at the front entrance and admiring the bronze statues of legendary Twins players, the group headed up to a very comfortable premier suite. Dr. Gary McClain of New York flew in to speak with the Blood Brothers and presented on “Communication Strategies for a Healthy Relationship.” The presentation was very well received and the HFMD is thankful to Dr. McClain for traveling the distance to speak with our group.

After Dr. McClain answered a few questions from the group, lunch was served. The guys enjoyed a

ballpark-style lunch of hot dogs, chips and dip, salad and popcorn with a sweet dessert of brownies and cookies. The Twins then took on the Boston Red Sox in a thrilling game with competitive play through eight innings until the Red Sox blew the Twins out of the park scoring ten runs in the top of the 9th inning. The Twins walked away with a heartbreaking loss of 17-6. Despite the loss, the Blood Brothers had a great time catching up with one another, meeting new members and taking in a day of baseball.

The HFMD would like to thank the Hemophilia Federation of America (HFA) and Shire for sponsoring this event. The next Blood Brotherhood event will be held in the fall – more information will be available soon at the HFMD website, www.hfmd.org.





Group Fitness Event at Bunker Beach

The HFMD started its summer event season on a cool note with a Group Fitness Event at Minnesota's largest water park, Bunker Beach Water Park in Coon Rapids, MN. The day was a chilly 65 degrees, but guests still enjoyed the many attractions of Bunker Beach including water slides, the wave pool and the lazy river. HFMD Executive Director, James Paist, began the event with a presentation on the National Hemophilia Foundation's "Playing It Safe" program – a program that provides ratings indicating which physical activities are considered safe and which are most dangerous for individuals with bleeding disorders. Physical activity is important for all people, but finding a safe activity for someone living with a bleeding disorder can be challenging. "Playing It Safe" aims to provide adults and children with valuable information regarding making the smart choice when it comes to physical activity.

After the presentation, lunch was served at the pavilion. The group gathered for conversation and enjoyed a lunch of hot dogs, hamburgers and veggie burgers. The group then enjoyed an afternoon of splashing, sliding, and riding waves at Bunker Beach. Thank you to everyone who made the trek to Coon Rapids for this special event.

By Brianna Hager, Event Coordinator



Post-Secondary Scholarships Awarded for 2017-2018 School Year

This year a number of wonderful candidates applied for the HFMD Post-Secondary Scholarship Award. In total five scholarship recipients were awarded \$1,400 each to assist with tuition expenses of the 2017-2018 school year at the college or vocational school they attend.

HFMD awards scholarships yearly. Watch our website and future issues of the Veinline for more information applying for the 2018-2019 school year's scholarship awards.

Congrats! 

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

2017 Calendar of Events

- July 29, 2017South Dakota Education Day
Thunder Road Amusement Park, Sioux Falls, SD
- August 13, 2017Step Out for Bleeding Disorders Fundraiser Walk
Como Park, St. Paul, MN
- August 24-26, 2017NHF's 69th Annual Meeting
Chicago, IL
- October 7, 2017Women's Conference
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 more exciting news and updates!

HFMD Program Registration and Deadlines

Since its inception HFMD has strived to offer a wide variety of programs and events as part of our mission to provide "programs and services for those living with hemophilia and related genetic bleeding disorders." These programs offer ideas on how those living with bleeding disorders can remain active, as well as providing a way for families to connect with others experiencing the same issues and concerns. These programs and events also serve to educate families and members on the social and medical implications of living with a chronic condition.

In the past few years HFMD is thrilled to have experienced a surge of attendance at our programs with many of them filling to capacity and some requiring waiting lists. Because of this HFMD requires completed registration forms before participants can be added to an event roster.

When planning our programs and events we are most often required to have a count of participants ahead of time for admission tickets, as well as meals ordered. This is why we need to have firm registration deadlines for events, and why it is very important for those who have registered for an event to notify us if they are unable to attend. Since April of this year HFMD has held four events and spent almost \$1,500.00 on costs for members that had registered and then not shown up. Notifying our office that you will be unable to attend prior to an event allows us to control our events costs, as well as offer an open slot to a family on a waiting list.

Given the number of programs we offer throughout the year, costs paid out for people who registered, but didn't show up increase very quickly. The \$1,500.00 HFMD has paid out in three months this year could have helped pay for lodging, mileage, medical expenses, or mortgage/rental assistance for a number of families through our Emergency Assistance Program. So, if you are registered for an event, but then cannot attend; we ask you to contact us as soon as possible. 651-406-8655 or email info@hfmd.org. Thank you for your cooperation.

Hemophilia Treatment Centers (Tri-State Area)

Center for Bleeding and Clotting Disorders University of Minnesota Health

420 Delaware Street SE - MMC 713
B549 Mayo Building
Minneapolis, MN 55455
612-626-6455

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Kelly Snedeker, Intake Coordinator
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WALK 11AM-1PM**

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