

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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South Dakota Family Day

HFMD & Sanford Health Children's Hospital of Sioux Falls, also known as the "Castle" hosted a third consecutive annual event on July 28th at the Thunder Road Amusement Park. Members, families, exhibitors, and HTC staff gathered under a large picnic pavilion to learn about the latest news and updates from HFMD before our keynote speaker Dr. George Maher who shared a fascinating presentation on current and new therapies to treat bleeding disorders.

Dr. Maher was introduced by clinic Social Worker, Nathan Anderson who also entertained our group throughout the day with his talented 3-person band, Short Notice. They harmonized together on many folk and light rock songs from the 1960s & 70s. It was a real treat to have live music at this action-packed event. Members and families had time to visit before and after speakers with Representatives from the 10

companies who exhibited at the event. After a delicious lunch and more time for our group to spend together, our families were ready to enjoy all of the rides and activities at Thunder Road.

We appreciate the support and cooperation from the following companies who exhibited with us:

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St. Croix River Boat Cruise

A group of 37 community members piled onto the Sweet Afton River Cruise Boat on a beautiful summer evening looking forward to a night on the St. Croix and enjoying a delicious dinner of ribs and chicken with all the trimmings! The loaded boat left the Hudson City Docks at 6:00 p.m. and headed south down the beautiful St. Croix River. While waiting for the dinner to be served guests wandered the upper and lower decks of the boat enjoying the river and its occupants. The boats of all sizes, birds in flight, and wild tree-lined river banks were enhanced by the presence of hot air balloons dotting the cloudless sky overhead. The group gathered inside the boat when dinner was ready and were treated to an informative education session on Factor in the Family presented by Stormy Johnson and Hope Woodcock-Hicks of Aptevo. After the presentation concluded and dinner was completed the group again spread out on the boat to enjoy the striking sunset while the boat slowly made its way back up the river on its return trip to the Hudson City Docks. HFMD would like to thank the cruise sponsor, Aptevo, for a wonderful evening! *By Kerry Budinger.*





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HFMD Summer Camp 2018

We had a new record of 73 kids at camp! Thank you to True Friends for getting creative to make more room. Once again, a fun learning experience was had by all thanks in part to our dedicated affiliated HTC clinic staff who each spend half a camp or the full 6 days at Courage North, July 8-13.

The kids had an amazing time playing together, running, laughing, and learning to self-infuse. We appreciate the support and sponsorship from Children's Hospital, Mayo Clinic, and University of Minnesota Health. And special thanks to the Buuck Family Foundation and all of the individuals who donated at our Gala to help support HFMD camp!



about camp. For three days I kept hearing "Mom, can I tell you about camp?" The best part for me was the fact that she was doing normal kid things in a group of peers and loving it. She doesn't often feel that way. It tickled me to hear how "Natalia" liked Chase. "Shoes" I saw the girls all dressed her up for the big dance. Thank you from the bottom of my heart. (Lucia's mom) Kathy Nunez

Dear Mr. Baiste, I wanted to thank you for providing scholarships for all children to attend the True Friends Hemophilia Camp. My daughter Lucia has not only Von Willebrand's but also significant mental health challenges. The respite camp provided me and the opportunities for my child are priceless. I can send her to camp knowing any medical or mental health issue that may come up will be handled by skilled & compassionate people. It thrilled me beyond belief to hear my daughter rave

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?



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A Twins Game at Target Field

HFMD hosted a joint Blood Brotherhood & Sisterhood event and education program at Target Field on Sunday, August 19th. Our group of 16 gathered to learn about the benefits of Kenesio taping from Kim Baumann, PT University of MN Health. This was an informative and interactive session as most of our members were not familiar with how Kenesio tape can help. Kim shared good information, and we learned how precise the tape needs to be applied.

Then it was time to settle in and watch our Twins take on the Detroit Tigers on this warm sunny day. While the game itself was quite entertaining, our group also had time to visit with each other, welcome a few new members and catch up. We are very grateful to HFA & Shire for sponsoring this event! Keep your eyes peeled for upcoming HFMD Blood Sister & Brother events.



Post-Secondary Scholarships Awarded for 2018-2019 School Year

This year a number of wonderful candidates applied for the HFMD Post-Secondary Scholarship Award.

In total six scholarship recipients were awarded \$1,666 each to assist with tuition expenses of the 2018-2019 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 2019-2020 school year's scholarship awards.

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These are donations received from January 1st - September 30, 2018.

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 Gustafson, Melissa
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 Ianello-Zimmer, Dena
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S39346 04/18



Colin Orth has been honored with the National Hemophilia Foundation 2018 Teen Impact Award. Colin is a 17-year-old who resides in Chippewa Falls, Wisconsin. He is in his Senior year at Chippewa Falls Senior High. Colin was born with severe hemophilia B, without a family history for the disease. He and his family have received their comprehensive care from the Mayo Clinic HTC ever since he was diagnosed at five months of age.

Colin was nominated for the Teen Impact Award due to his heightened efforts over the past year related to his self-infusions and his increased independence in his healthcare and hemophilia. For years, Colin received instruction and support for self-infusion at Camp Courage (later True Friends) as well as from his HTC in Rochester and his parents. Even with these supports and resources, Colin was reluctant to manage this part of his hemophilia. He was terrific at making healthy choices in his life. He was excellent with managing bleeds with R.I.C.E., but self-infusion eluded him. It even took several years of convincing him to move him away from his port-a-cath. They say, “Be patient” and offer continued opportunities, and kids will find their way. This has definitely happened for Colin. Just over a year ago, he set his sights on adult life, college, and, thus, self-infusion.

At the beginning of summer 2017, when Colin was 15, he received a super-duper boot camp in self-infusion at his annual visit. He then returned to camp that summer and received additional instruction and support. Upon his arrival home from camp, Colin took over his self-infusions! From that point forward, he started ordering his factor, scheduling his clinic visits, and leading his weekly self-infusions. The impact this has created for Colin and his parents is immeasurable. He has taken factor to school, sleep-away band trips, and more. He has infused in a variety of places, without needing his parents to leave work, travel long distances, or worry so much. This impact has been the increased level of relief and security for his parents.

This success and steps towards independence has not been without challenges. Colin is not successful with self-infusion 100% of the time. It’s a hard thing to do and his veins aren’t great. He has mental health challenges that sometimes get in his way. However, the set-backs have come with a positive impact. They have helped Colin become more comfortable with struggle and “failure”. He has learned that this is a process that requires patience and perseverance. This has taught him to be more resilient. This increased level of perseverance, resilience, and independence has impacted Colin’s advancements in academics, trumpet-playing, and mental wellness. Having hemophilia and making positives strides towards adult-level independence of his health needs is making a huge, positive, and important impact on the lives of Colin and his parents.

Colin will be presented with this award, along with the other teenage recipients, and given the opportunity to make a shore acceptance statement, at a banquet the evening before the start of the National Hemophilia Foundation’s annual convention in Orlando, Florida. The 2018 Teen Impact Award is made possible due to the efforts of Believe Ltd and sponsored by Shire along with supporting sponsors that include NCHS, CSL Behring, and Spark Therapeutics. Colin and his parents want to extend a HUGE THANK YOU to his Mayo HTC team, the many nurses and doctors who have supported him each summer at Camp Courage, as well as HFMD for their financial support of camp each summer. We could not have done any of this alone. By Angie & John Orth



Current Calendar of Events

October 11-13, 2018	70th Annual NHF Bleeding Disorders Conference Orlando World Center Marriott, Orlando, FL
October 18, 2018.....	Education Dinner at Benihana and Nickelodeon Mall of America, Bloomington, MN (full)
November 3, 2018.....	Group Fitness - Bowling and Lazer Tag PINZ Entertainment Center, Oakdale, MN
November 9-10, 2018.....	Parents Empowering Parents (PEP) Event St. James Hotel, Red Wing, MN
January 25-27, 2019.....	Winter Teen Event Camp Courage South, Annandale, MN
February 9, 2019.....	Hearts of Hope Gala Metropolitan Ballroom & Clubroom, Golden Valley, MN
April 26-27, 2019.....	Annual HFMD Member Meeting Airport Hilton, Bloomington, MN

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8th Annual Walk Fundraiser August 5th, 2018

HFMD Members and supporters from all parts of Minnesota and South Dakota came together to “Step Out for Bleeding Disorders” on a lovely Sunday morning at Como Park in St. Paul. Walk Teams and participants began strolling in at 10:00 a.m. to get their T-shirts and to partake in all of the fun activities happening at our Walk with Face-painting, balloon animals, a photo-booth, and fresh popcorn!

It is inspiring to see so many of our members and their families raising donations on their Walk pages to support HFMD programs and services for this bleeding disorders community. Over 250 participants gathered around the starting line at 10:55 a.m. (some with their dogs) getting ready for the 2.5 walk around Lake Como. Led by St. Paul Saint’s mascot Muddonna, our group “Stepped Out for Bleeding Disorders”. Most finished in about 45 minutes as our group lined up and settled in for Subway sandwiches which we include as a part of the Walk registration.



Our members and their Walk Teams raised over \$14,000 for HFMD through their Walk fundraising pages. And altogether with Sponsors and exhibitors, our 2018 Walk raised \$49,000 in gross revenue!

Thanks so much to all 21 volunteers who helped to put on such a great event, and we extend a very special thanks to our event sponsors and exhibitors.

**Welcome to the
HFMD Walk Fundraiser
“Step Out for Bleeding Disorders”**

Thank You! Walk Exhibitors

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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.

*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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