

"Life is a Fiesta" 2011 HFMD Annual Meeting

HFMD MISSION

We dedicate ourselves to advancing the quality of life of individuals and families affected by hemophilia or other bleeding disorders by providing a broad range of services and programs.

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Life indeed was a fiesta on Friday evening, April 1st when our event opened at the Minneapolis Airport Marriott with a taco buffet and carnival. We started the carnival with kids swinging at piñatas filled with candy and small toys. It took many swats from dozens of children to break open all five piñatas; but each child left this station with treats and goodies.

The carnival offered games of skill and chance for children and adults. Our exhibitors and volunteers helped to run the stations which stayed busy throughout the night. Basketball hoops, Wi games, and a sombrero hat toss were some of the most popular fiesta activities. Halfway through the carnival, it was time to start the salsa dancing. 4 Seasons Dance Studio led the demonstrations for those brave enough to get on the dance floor and learn how to salsa. People also had plenty of time to mingle, catch up, and meet new members of the community.



John Jarratt



Perry Parker

Saturday morning opened with a breakfast buffet and time to visit the exhibit tables. After sharing an HFMD presentation and slideshow with a look back on 2010 and the announcement of our Walk fundraiser, we introduced our first keynote speaker sponsored by Accredo Hemophilia Health Services. Mr. John Jarratt, M. Ed., L.P.C. was amazing as he presented "A Man and His Music," telling his personal story and playing the piano on stage. John connected with our members in so many ways as he talked about growing up with hemophilia and wanting to play baseball in between a variety of songs he played on the piano. His parents steered him toward music instead, which he has continued his entire life. This was a very special presentation that prompted a rousing standing ovation as Mr. Jarratt left the stage. He is a truly gifted speaker and a wonderfully talented musician. He entertained us and touched our hearts.

HFMD's 11TH ANNUAL HEARTS OF HOPE GALA May 21, 2011



Back to the 70's Theme

Please Join Us For Our 11th Year Celebration!

Location: Airport Marriott Hotel
Bloomington, MN

Time: 5:30 p.m. arrival

We promise delightful cuisine, a silent and live auction,
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The Safest Thing You'll Ever Do for Your Child

This is a story about a simple question that led to an interesting journey. I want to share it with you so that you can see that sometimes asking one question can lead you to unexpected places. I also hope the answer to the question may help you make the changes necessary to provide safety to your child with a bleeding disorder.

The question was: "Why don't the children in our hemophilia clinic wear Emergency Medical Identification (EMI)-like Medic Alert®?" I have been a nurse practitioner working with children with hemophilia/bleeding disorders for about 20 years. Throughout this time, one of my main responsibilities has been to educate families. In this role, I've been encouraged to advocate the use of EMIs. I noticed, however, at each comprehensive visit, that most children did not wear them. In addition, I found that there were no guidelines for the use of EMIs. So for example, what type and where should an EMI be placed on an infant?

I decided to research this further. Were there any studies that assessed the use of EMI in children? To my amazement there were no published studies about the use of EMI in children and only one which involved adults. That study was done in England. They asked First Responders (Emergency Medical Technicians etc) if they knew about EMIs. The result: though most knew a person could have an EMI on the body, few knew it could be placed off of the body, for example, in a car or wallet.

I decided I needed to do the study that was never done. With the help of two of my nursing colleagues: Casey Hooke PhD, RN, and Nicole Leonard RN, BSN, we developed a 30 item questionnaire. We asked hemophilia nurses what they taught families about EMI and if they thought EMIs were used by families. We invited 266 hemophilia/bleeding disorder nurses listed in the Center for Disease Control (CDC) Hemophilia web site to take the questionnaire we had posted on Survey Monkey. Ninety seven nurses completed the questionnaire. Most nurses had over ten

years experience in working with children with a bleeding disorder. A summary of the results included:

- Nurses consistently recommended EMI for children of all ages with hemophilia and other bleeding disorders. The brand most recommended is Medic Alert®.
- Most nurses were unsure how to recommend their use i.e. what type should be used on different ages of children and where they should be placed.
- More than half of the children did not wear EMIs, particularly in the infant age group. Anecdotally this was reported to be dangerous. One example given: "Head injury [in a] factor IX patient, given factor VIII: patient died."
- Those that did wear them often did not wear them on their body and used a tag or sticker for identification off of the body and placed in a wallet, purse, glove compartment or attached to the infant's car seat.
- For infants though school age, reasons for not wearing EMI included safety concerns (fear of choking/strangulation), parent's perceived lack of need, sizing and cost concerns. For adolescents the fear of being different was number one reason they were not worn.

We also found some related information which we were not expecting to find. This was somewhat like opening a Pandora's box. Findings included:

- There are no universal guidelines for First Responders (EMTs etc) to define where to search for EMIs in the case of an accident.
- Some states prohibit first responders from seeking in patients' wallet for medical information due to security reasons!
- Treatment is often well underway in the Emergency Room before an EMI not attached to the body is located such as in a wallet.

continued on page 7

Annual Meeting continued from cover

After a morning break with exhibitors, it was time to introduce our second keynote speaker; professional golfer Perry Parker, sponsored by CSL Behring. Not only is Mr. Parker a highly skilled golfer, he is a dynamic speaker with a terrific sense of humor. It was fascinating to hear Perry talk about playing sports and living with hemophilia. He talked about his competitive drive and what it takes to win professional golf tournaments and what it takes to make the PGA. Our audience (which included many parents of children affected) could really identify with Perry's message of excelling in a sport even though he has hemophilia. He fielded a number of thoughtful questions and comments. One of our parents told Perry what a great role model he is for the bleeding disorders community. Perry was inspirational, charismatic, and a whole lot of fun.

After an all-star line-up of speakers who complimented each other well, we settled in for lunch. With a record turnout of 250 people in attendance, the dining room was full. Afternoon breakout sessions included Top 20 Teens, the Blood Brotherhood for men facilitated by John Jarratt, a session for Women with Bleeding Disorders led by Rachel Miller, MD, and Treatments for Hemophilia led by Dr. Margaret Heisel – Kurth.

Our daycare team was led by Vicky Nies, RN, and they did a wonderful job in providing fun activities and good care for over 40 children ranging from infant to eleven years old.

What an event it was; with quality speakers, good food, networking, and fun. The HFMD would like to thank event planning co-chairs Vicky Hannemann & Kirstin Schmidt, and the planning committee: Angie Boyd, Steve Calvit, Nancy Golden, Carrie Kissoon, Steph Miller, and Deb Starling. We would also like

to extend our deepest appreciation to event sponsors Baxter BioScience, Bayer HealthCare, Novo Nordisk, Sanford Health, and the University of Minnesota Medical Center, Fairview.

By Jim Paist, Executive Director



"Life is a Fiesta"

PHOTOS



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continued from page 3

- There are no universal guidelines for the development of EMIs. Many EMIs look like plain jewelry and can be mistaken for such.
- There are no appropriate EMIs for infants. Most are too large to fit an ankle or wrist of an infant and all contain small parts, which are potential choking hazards!

What did we do with these results? I applied to National Hemophilia Foundation (NHF) for the Nursing Excellence Award Research Grant which allowed me to work with the Nursing Working Group of NHF (representatives from all regions of the United States) to develop Guidelines for the use of EMI for Health Care Professionals. I then presented this at NHF to nurses and to the Medical and Scientific Board (MASAC) of the NHF. The board voted to accept the guidelines and they are now the official recommendations posted on the NHF website at <http://www.hemophilia.org/NHFWeb/MainPgs/MainNHF.aspx?menuid=57&contentid=1644>.

A summary of the EMI guidelines include:

- For all age groups, EMI should be worn on the body instead of externally such as in a wallet, on a car seat, or in a caregiver's purse or diaper bag. An emergency medical identification card placed in one of those locations can accompany the child, but this should not replace EMI on the child.
- The EMI should be identified with a medical symbol (i.e. Caduceus) and look like an EMI so it will not be mistaken for a piece of jewelry.
- The EMI should be fastened securely but not tightly and should be assessed frequently to insure that the fit is snug but not tight.

- Presently there is no ideal EMI for infants under 1 year of age. All EMIs placed on a child < 3 years old which have emblems or clasps < 1 3/4 inches should carry the warning: "Not intended for children < 3 years old due to choking hazard."
- NHF does not endorse any specific brand of EMI, however being affiliated with a 24-hour on-call nonprofit program is encouraged.
- Specific guidelines are available at the NHF web site under MASAC Recommendation #201.

With the Nursing Working Group, we also developed a sequel to the first EMI study. In this second study, parents/caregivers of children with hemophilia/bleeding disorders provided their children's experience with EMIs. In November 2010 in New Orleans at the Annual NHF Meeting, we invited parents and caregivers to complete the questionnaire. With this added information, we hope to be able to share first-hand information with EMI developers in an effort to make better EMIs, particularly for infants.

In the mean time, the first part of the EMI study has been published in the journal *Haemophilia*, the official journal of the World Federation of Haemophilia. The title of the article is: "*Use of Emergency Medical Identification in the Pediatric Hemophilia Population: A National Study*" in the February 2011 issue.

So this is the story of our journey that started with one simple question. I'm hoping that you, as a parent will find this journey interesting and make changes concerning the use of EMI in your family if necessary. If you don't already: use an emergency medical identification and place it on your child's body and follow the EMI guidelines. If you want to have extra information in your wallet etc. that is great, but don't substitute it for the EMI that is worn on your child's body. It might be the safest thing you'll ever do for your child!

By Jocelyn Gorlin, RN, CPNP

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HFMD Scholarship Applications

The HFMD office will continue to accept scholarship applications for post-secondary education until the deadline, June 1, 2011. Forms are available by calling the HFMD office at 651-406-8655 or 1-800-994-4363, or on line at www.hfmd.org.

Scholarship eligibility requirements for applicants include (1) having an inherited bleeding disorder, (2) being a resident of Minnesota, North Dakota 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) being accepted into a post-secondary educational program.



CONTRIBUTIONS

The HFMD gratefully acknowledges our donors who have given so generously. Below are donations received from January 1, 2011 through March 31, 2011.

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HFMD Winter Basketball Clinic by Jim Paist



This fitness event has become a tradition for this organization as a good indoor option in the middle of winter. On February 12th, we hosted a basketball clinic at the Hancock Recreation Center in St. Paul. Physical Therapist Cheryl Hanson led our group of 35 people with a good stretch before beginning the drills. After a light shoot-around, HFMD volunteer coaches Aaron Reeves, Mark Hunter, and Matt Jaworski demonstrated proper technique in dribbling, passing, and shooting the ball. Then our coaches cranked things up by leading the kids in a number of practice games which involved all facets of basketball.



With participants ranging from age 4 to 43, we had a fun time, honed our skills and had some time to visit with each other after a low-calorie lunch of Subway platters. Now in our sixth year of holding quarterly group fitness events, the annual basketball clinic has become a favorite for many. Our group fitness program emphasizes fun and safe sports the whole family can continue to enjoy after attending one of our events.

Fargo Fitness program Update 2011

We had 2 fitness events this year. The first one was a bowling event January 15th, 2011 sponsored by Bayer HealthCare Pharmaceuticals and Axcelacare home care company. We had a total of 35 participants including staff and families. Again we had some really great scores with the help of the bumper pads. Unfortunately I forgot my camera and do not have pictures to show. This event concluded with a pizza party. I do believe everyone went home tired and full. It was great seeing all the families participate in this fitness event.

Our 2nd fitness event was a sledding and skiing event on February 12, 2011 sponsored by the HFMD. We had 38 participants scheduled to attend but the weather was about 20-25 below wind chill so our numbers dropped to 24 including staff. We had a few brave souls who challenged the elements but was certainly not an ideal day. The rest of us sat around the warm fire place and visited with other family members. The pizza was a hit so we all went home full but not necessarily tired. It was great seeing all the families there which gave them a chance to visit with other families with bleeding disorder.

These events have been a great opportunity for families with bleeding disorders to talk to other families especially during some difficult times. It is also a great opportunity for the staff to interact with the families in a social setting. Thanks to Bayer, Axcelacare and the HFMD for sponsoring these events.

By Kathy Kirkeby, PA, Sanford Health, Fargo HTC.



Jason and Joe Tarasewicz

Polar Bear Plunge

On Saturday, February 19, 2011 Jason Tarasewicz who has Hemophilia Severe VIII and is a sophomore at UMD took part in The Polar Bear Plunge, organized by Minnesota law enforcement as a unique opportunity for individuals, organizations and businesses to support Special Olympics athletes by jumping into frigid Minnesota waters. In 2011 more than 8,600 individuals took the plunge around the state to support Special Olympics Minnesota, together raising more than \$1,000,000. Supporters could participate in any of 14 Polar Bear Plunge locations, including the February 19th event in Lake Superior, Duluth, MN. Jason raised just under \$400 for the cause and participated with a college friend, Tyler

Reich dressing up as Greek Spartans for the event. Jason is pursuing a degree in Bio Chemistry with minors in Science and Business. Jason who has a love for music, continues to take classes and participate studying classical guitar. Jason enjoys the outdoor recreational activities in the Chequamegon Bay and Lake Superior area. He also enjoys partaking in charities which can help others.

By Joe Tarasewicz.

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How Sports Have Impacted My Life

By Matt Jaworski

GOT SPORTS? Well I sure do! Sports have been a HUGE part of my life ever since I set foot or should I say “cleat” on the T-Ball field many years ago. I am now twenty years old and truthfully...I don’t know what I’d do if someone came up to me and said “kid...you are done playing sports...of any kind”!!!??? To this day, sports are what I live for...playing them, watching them, reading about them...you name it. And by the way...I learned to read, reading the sports section in the Sunday paper. Oh yeah!!!

Let me give you a little background on me---“Jaws”---Jaws is a nickname I got at a very early age that has stuck with me through the years. There were two Matt’s on my baseball team early on, so the coach decided to call me “Jaws” short for Jaworski. Ok, now that’s out of the way here we go. I have severe Hemophilia A. I was diagnosed with it at nine months of age. I developed an inhibitor when I was four years old---it took a bit of time but thanks to the good care and treatment I received...all is well---and as you can see---didn’t slow me down for very long! I do prophylaxis every three days...I do vein puncture myself [I used to have a port and played sports with it for many years.]

I started out playing T-Ball, then went on to play little league baseball and play I did...all the way through high school. I was lucky enough to have made every All Star team, then when I got into high school, in my junior year playing varsity, WE WON STATE! That was just the best thing ever...I will never forget it...any of it!!! But...I wasn’t just into baseball...basketball was another love...there for a while I thought maybe that was the direction I would go but unfortunately I was on the “shorter” end of things for quite sometime and for some reason, height seems to matter in basketball. But I still love playing the game to this day! Then there was golf...oh yeah...for a while I thought maybe I would be the next big deal in golf but I found that the golf swing was starting to affect my baseball swing and I just couldn’t have that!

So...are you seeing a pattern here at all? And did I mention playing soccer, and...Dr. Heisel...please don’t read beyond this point...playing “football and hockey”...for fun! So...as you can see...I do love my sports. I am very competitive and motivated but for some reason, playing sports seems to relax me and let me have fun playing the game. I love being on the go and sports is my way of being able to do that BUT



Matt Jaworski

because I have Hemophilia, I just have to take some precautions, like making sure to give myself a factor before a game, stretching is important---I still have trouble to this day if I don’t stretch properly, and wearing the proper gear/protection. When I played baseball, I always wore sliding shorts [really padded ones] and knee pads for sure. Arm and ankle protectors wouldn’t be a bad idea either. Knee pads are a good idea for basketball – maybe even elbow guards – they have some cool gear out there now---check it out.

I’ve been pretty lucky all the way through as far as sports injuries...I had a couple of minor injuries but nothing that kept me from playing---I just factored up and away I went. I love being active and playing...even if it’s just putting on my rollerblades or running shoes and going around a block or two, or lifting weights. It is ALL GOOD...it is good for me inside and out and that is so important. Everyone should be active in one way or another but because of Hemophilia I think is SO important. All I know is how I feel and how being active has benefited me throughout my life. I really haven’t had a lot of bleeds. I had some target areas earlier on in my life but it seems since I have been active, been aware of my body and done factor as needed and “prepped” for games or whatever, I have been really doing great.

For the last two years I have been coaching girls and boy’s basketball also, boy’s baseball at a middle school in Coon Rapids. Which of course is my kind of job...I consider myself very lucky in that respect, and will be working for the second summer for the Brooklyn Park, Park Board supervising and coaching various sport camps for the younger kids. This all fits in with me so well by being able to be active, see other’s active and have a good time doing it!

So, I am going to end this by saying, listen to the medical staff, be in-tune to your body and what it’s telling you---factor-up pre and post if needed when playing sports, but most important...JUST GET OUT THERE AND GET MOVING!! It’s the best thing you can do for yourself and those joints!!!

Venline

NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

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2011 Calendar

- May 21, 2011.....Hearts of Hope Gala
Minneapolis Airport Marriott
Bloomington, MN
- July 10 – 16, 2011.....Summer Camp, Courage South
Maple Lake, MN
****Please note a change of location****
- August 6, 2011.....HFMD Walk
Como Park Pavilion
St. Paul, MN
- October 1, 2011.....Women with Bleeding Disorders Retreat
Oakridge Conference Center
Chaska, MN
- October 15, 2011.....Dakotas Retreat
Ramada Plaza Suites & Convention Center
Fargo, ND

****The HFMD Board of Directors meets every other month
on the third Tuesday at 7:00 p.m.****

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