



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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CAMP 2011

Another great week of camp for kids with Hemophilia and Bleeding Disorders took place on July 10-16th 2011. This year camp was held at a new location – Camp Courage in Maple Lake, MN. The facilities at Maple Lake worked well for our group, and it was great to have the indoor pool and large gym since it rained a few days!



Fifty-six campers from all over Minnesota, Wisconsin, North and South Dakota were in attendance including many “first-timers”! There were many very young campers who tried self-infusion, showing GREAT amounts of Courage! Campers who try self-infusion are given awards during special mealtime ceremonies and earn a place in history by getting their names on “The Big Stick”, a big walking stick (see picture).

Some highlights of the week included a performance by magician Tom Anderson (sponsored by HFMD),

a special outdoor concert by the Minnesota Sinfonia, “The Big Stick” self-infusion program, and of course the Friday night Carnival.

By far the best part about camp is seeing the kids support each other and learn from each other. Two of the ways that the kids support each other are through the Mentor program and the C.I.T.

(counselor in training) program.

Melinda Otto, Social Worker from Mayo and Jill Swenson, Social Worker from Children’s organized the Mentor program this year. They paired first time campers with experienced campers and facilitated a couple activities to help the new campers adjust to camp life and have another familiar face for the week. Many of the mentors also helped teach the young

campers about self-infusion, sharing their first-hand knowledge and tips they have learned through the years! Thanks to all of our volunteer mentors, you did great!

The C.I.T. program was very robust this year with over a dozen C.I.T.s! It is great to have a community of kids who are so willing to help out and be role models. C.I.T.s take on leadership roles in different areas, some helped out the counselors in cabins and some helped out in other areas. Thanks to everyone who was a C.I.T. this year!

continued on page 4

HEARTS OF HOPE GALA

On May 21st, the HFMD held our 11th annual Hearts of Hope Gala at the Minneapolis Airport in Bloomington. This fundraising event opened with a silent auction with a wide variety of quality items including wine baskets, overnight stay packages, unique books, and restaurant gift certificates. Just over 160 guests mingled and bid on the items to help raise money for this organization. With a Back to the 70s theme nearly one quarter of our group dressed toward the theme.

Eyewitness News Sportscaster Joe Schmit entertained our group with some hilarious jokes and his natural wit. Joe also spoke about hemophilia, HFMD's programs, his involvement with the organization and why we are all here tonight. Then, when the live-auction began Joe worked the floor with Auctioneer Andy Imholt to sell some very exciting live-auction items. Three sets of Twins tickets were a big hit as were a fully stocked handmade wine rack, a mountain bike, and Toro Personal Pace lawnmower. A most intriguing live-auction item was dinner with Dr. Margaret Heisel-Kurth and Dr. Mark Reding. During one of the lighter moments of the evening, dressed in his blue 1970s Nehru tuxedo jacket, Joe Schmit hopped on the mountain bike and did a slow lap around the ballroom as people were bidding on it.

The live-auction was followed by an inspirational slide-show and pledge to support the HFMD summer camp for children with bleeding disorders. Just before the pledge began, teenage camper Ahmed Abdullahi had the courage to get up on stage and speak to our audience about his seven years as an HFMD camper and the impact it has had on his life. Auctioneer Andy was extremely persuasive and charming in working the room for pledges. The camp pledge raised nearly \$9,000 that evening. After HFMD Board President Dan Tinklenberg thanked everyone, it was time for DJ Jai, strobe lights, and Back to the 70s music and dancing.

A very special thanks to our event sponsors: Baxter BioScience at the \$10,000 Diamond Level, Bayer HealthCare and Novo Nordisk at the \$5,000 Platinum level, CSL Behring and CVS Caremark at the \$3,000 Gold Level. Our \$1,200 Silver level sponsors included Children's Hospital, Mayo Clinic, U of MN Medical Center -Fairview, Sanford Health and Walgreens. We would also like to thank volunteer Gala committee members Stacie Cowen, Skye Peltier, Mark Wiener, Kathi Reeves, Beth Andersen, Deb Starling, Bob & Gayle Newman, Deb Melhado, and HFMD Intern Carrie Kisson. Many local businesses donated quality items for the auctions to help support our cause. Our deepest appreciation goes out to all who donated items. *See next page*



Joe Schmit and Ahmed Abdullahi

More photos on page 3

GALA PHOTOS



The HFMD extends a heartfelt thank you to the following companies and individuals who donated terrific items to our Gala auction.

Acme Comedy	Maguire Agency
Air Museum	Mall of America
Airport Marriott	Minnesota Twins
Andersen Log Homes	MN Timberwolves & Lynx
Arrowwood Resort	Mystic Lake Casino & Hotel
Bob Newman	Park Tavern
Brave New Workshop	Pat & Liz Myers
Canterbury Park	R. F. Moeller
Carol Peltier	Red Hawks
Children's HTC Staff	Red River Zoo
Christopher Banks	Renaissance Festival
CorePower	Robert Kalman
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Drs. Heisel & Reding	Sam Arntsen
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Guthrie Theater	Toro Company
Joel & Kris Manns	Treasure Island Resort & Casino
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CAMP 2011...*continued from front cover*

Many of the new kids who come to camp have never met another child with hemophilia, what a revelation for them to be in an environment where factor and prophylaxis are a normal part of life for so many. When kids are in getting their factor infusions, they don't just come in and get their factor and leave. They come with their cabin mates, mentors, C.I.T.s and they leave as a group. If one camper's infusion is taking longer, or they are having trouble with pokes, the other kids help them and cheer them on until it's done, and they leave as a group. There is no rule saying you have to wait, the kids just do it because they don't want anyone to feel left out. This was a year of transition, but it didn't feel that different because the kids are what make the camp.

Camp would not be possible without the help of many individuals, companies and organizations.... We would like to thank awesome Alumni Volunteer Matt Jaworski, Mimi and Tom Fogarty and all of the staff at Camp Courage, HFMD, all of the staff at the Hemophilia Treatment Centers in Minnesota, Wisconsin, North Dakota and South Dakota and, last but not least, everyone on the Camp Planning Committee and Camp Education Committee!

Our deep appreciation goes out to the following camp sponsors: Baxter BioScience, Novo Nordisk, Children's Hospitals & Clinics, Sanford Health, University of MN Medical Center- Fairview, Pfizer, CSL Behring, & Bayer HealthCare. Also a special thanks to Baxter Bioscience, Bayer, and Pfizer for donating emergency factor for the health center at camp. And thanks to all of the pharmaceutical companies, pharmacies and homecare companies for all of the great giveaway items! See you next year!

By Angie Boyd, Hemophilia Treatment Center Coordinator, Children's Hospitals & Clinics.



EVENTS

HFA Symposium 2011

In April, I attended the Hemophilia Federation of America's (HFA) Annual Meeting. This was my first time at an HFA event, and I was very pleased with the programming, the welcoming environment that they created, and the wonderful people that I met.

I attended the meeting with the intent to learn more, both as a mom of a six year old with severe hemophilia B, and also as a member of the HFMD Board.

From the perspective of a mom, I'm always eager to learn what is ahead for our son. People are so eager to share what they have learned, both in terms of what has worked for their family, and even sometimes as important, what hasn't worked. Personally, I feel this networking is as valuable as the educational sessions. Throughout the course of the meeting, HFA offered various breakout sessions ranging from healthcare reform, advancements in treatment options (which was very informative and gave me renewed hope for future treatment options), and a session on how living with a chronic condition impacts the family structure. I also attended a session on media relations, which was intriguing to me as a member of the Board. It provided practical tips on how to get your organization's name more visible in the public eye, which will boost fundraising efforts and contributions. Increased fundraising equals increased opportunity for educational series, fitness events, scholarships, and all of the other services HFMD provides.

In closing, I would recommend that everyone attend some type of organized event such as this annual meeting, or even more importantly, an HFMD annual meeting, which is held every April. I recognized speakers at HFA that we have recently had at our annual meeting. This says a lot about the caliber of speakers and education that we are able to provide locally. If you have any questions about HFA, or the programs they offer, you can check out their website at <http://hemophiliafed.org/>, or contact HFMD for additional information.
By Stephanie Miller

June 16 -

Community Education Event

The HFMD partnered with Baxter BioScience to hold a Facts First community education event focused on the impact of national health care reform and how it affects us. The event was held at Crave in St. Louis Park where nearly 40 attendees turned out. The session was led by Frank Quentieri who has a background in public policy and nursing. As you may know, the Affordable Health Care Act of 2010 included a number of positive changes for the hemophilia community such as the elimination of lifetime health insurance caps and the end of preexisting conditions as a barrier to coverage. Mr. Quentieri delivered an informative presentation highlighting the most significant changes affecting individuals and families with bleeding disorders. The HFMD would like to extend a special thank you to Baxter BioScience and Stacie Cowen for organizing this community education event. (Stacie Cowen, Clemencia Casas, Frank Quentieri pictured right)



2011 Calendar

August 6, 2011.....	HFMD's "Step Out for Bleeding Disorders" Walk Como Park Pavilion St. Paul, MN Registration at 8:30 a.m. and Walk at 10:00 a.m.
August 20, 2011.....	Group Fitness Canoe Event Lake Calhoun, Mpls 10:00 a.m.
August 27, 2011.....	Camper Alumni Reunion (contact HFMD for more info)
October 1-2, 2011.....	Women with Bleeding Disorders Retreat Oakridge Conference Center Chaska, MN
October 15, 2011.....	Dakotas Retreat Ramada Plaza Suites & Convention Center Fargo, ND
November 19, 2011.....	HFMD Board Retreat Location TBD
February 11, 2012.....	Hearts of Hope Gala

****The HFMD Board of Directors now meets quarterly on Tuesday's at 7:00 p.m.
The next meeting date will be September 27th****

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

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HFMD Awards Post-Secondary Scholarships

The Hemophilia Foundation of Minnesota/Dakotas was pleased to award 11 post-secondary scholarships in 2011 to students within our bleeding disorders community. During the month of July, the HFMD reviewed applications, the recipients were named, and the applicants were notified by mail. Scholarship checks will be mailed to the school they are attending.



HFMD Scholarship Eligibility Requirements

- Must be a person with an inherited bleeding disorder.
- Must be a resident of Minnesota, North Dakota or South Dakota, and/or a patient of one of the Hemophilia Treatment Centers in these states.
- Must use the HFMD Scholarship to pursue a course of post-high school education.
- Completed scholarship application, letters of recommendation, and transcripts must be received by HFMD no later than June 1, 2012.

PATIENT RESOURCES

"Multiple ankle surgeries couldn't stop me from golfing." — David

"Playing music helps keep me active." — Frank

"Health insurance can be time-consuming, but I find time to deal with it." — Jay

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* Contributions made through the HFMD Walk donation website (www.firstgiving.com/hfmd) are not reflected on this list, but will be applied in the next issue of the Veinline.

“Make it Count”

Happiness is being able to do what I want to do
Life is full of challenges and obstacles

We were chosen for a reason
it never seems like a blessing
maybe we have it all wrong

But what would life be like if things were different
would we have the insight and the compassion
that we have now, we would be a different person.

Treat us with respect and don't say things that hurt
words feel worse than injury and last longer

To be treated with care and love is what we all need
Don't be afraid to open up, solitude is a lonely road

We are all people, some just different than others
and we know this all too well
Please take this to heart and try and understand

Life may not be what we had in mind
we look deep within ourselves
its up to us to make it count.

Anonymous



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Pre-Existing Conditions Insurance Plans (PCIPs) For HFMD Constituents

Are you without insurance due to a pre-existing condition? Never fear -- PCIP is here!

Congress created the Pre-existing Conditions Insurance Plan (PCIP) to tide uninsured people with health problems over until 2014, when provisions in the Patient Protection and Affordable Care Act (PPACA) ban use of health status information in insurer efforts to sell and price health insurance. PCIPs will provide coverage for people with serious health problems at standard market rates. They offer a bridge to 2014, when the new health insurance Exchanges, which must accept all comers, are to open. Plenty of people with pre-existing conditions (like bleeding disorders) are struggling to find affordable insurance. These plans offer a real alternative, but consumers are only now becoming aware of them.

PCIPs are state and federal programs for people previously deemed uninsurable because of pre-existing conditions. Minnesota and North Dakota both chose to have the federal Department of Health and Human Services (DHHS) administer the PCIP within their respective borders. South Dakota chose to run their own PCIP, which they call the "Federal High Risk Pool." There are some tough restrictions. Here is what you need to know:

FINDING A PLAN The new plans did not replace current state high-risk pools, which have long offered insurance to people with pre-existing conditions. All three states serviced by the HFMD Chapter have state high risk pools (MCHA, CHAND, and SD Risk Pool) already in place. But the premiums in the new PCIP programs are generally much lower. That is why experts had worried that the new plans could be overwhelmed by a deluge of desperate applicants. But the fact is, PCIPs got off to a slow start (for example, about 95 people have enrolled in South Dakota to date), and many consumers still have no idea they exist. In January, premiums in the federally run plans were reduced nearly 20 percent. Since then, enrollment in all of the new plans has increased about 50 percent nationwide to about 13,000 members.

To find the PCIP program in South Dakota, go to <http://fedhighriskpool.sd.gov/>. For those without computers, you can call (605) 773-3148. To find a PCIP program in Minnesota, North Dakota (and about 20 other states), start with the federal government's Web site, <http://pcip.gov/>, which offers an interactive map, and lots of application information and details about each of the state plans that DHHS administers. For those without computers, you can call the federal Department of Health and Human Services at 866-717-5826 to find out information about other states' PCIPs under DHHS administration.

COMPARING PLANS The PCIP programs for Minnesota and North Dakota are administered by GEHA (Government Employees Health Association, a non-profit organization). There are three options you can choose from: Standard with \$2000 deductible for medical / \$500 ded for drugs; Extended with \$1000 deductible for medical / \$250 ded for drugs; and HSA (Health Savings Accounts). These are tax-exempt accounts where you deposit funds for eligible medical expenses). Coverage is identical in all plans. There are both in-network and out-of-network provisions. (Providers who have a contract with GEHA are in-network). The deductibles, co-insurance, and co-pays vary between in-network and out-of-network providers.

For South Dakota there is only one PCIP choice, called "Federal High Risk Pool." It is run by the Dept of Insurance Bureau of Personnel in Pierre. This PCIP includes comprehensive coverage for hospital care, primary and specialty services, and prescription drugs.

It is a \$2,000 deductible medical plan, with a \$1,500 deductible for pharmaceuticals. There is a 25% / 75% co-insurance clause with \$4,250 out-of-pocket maximum for medical, and drug co-payments ranging from \$10 to \$150 per prescription depending on where drugs fall in the three-tier set up (generic, brand, and specialty).

ELIGIBILITY RESTRICTIONS PCIP plans were not intended to solve the health insurance mess. They were intended as a temporary Band-Aid, and they have some frustrating limitations.

You must be uninsured for at least six months to be eligible for a plan. That means people already enrolled in MCHA, CHAND, or South Dakota Risk Pool or private insurance cannot apply, even though the new PCIPs would be far less expensive. In addition you must be a U.S. citizen, and have a pre-existing condition. People who are on COBRA or whose benefits have only recently expired are also not eligible. (Do you dare wait for six months to pass by?...not my recommendation, by the way!)

Plans run by the federal government and those administered by individual states have slightly different application procedures. To qualify for a federally run plan, you will need proof that you have applied for individual insurance and that a carrier denied you coverage because of a pre-existing condition, or proof that a carrier approved coverage but with a rider that excluded payment for your pre-existing condition. **(Do not buy a policy with such a rider, as you will no longer be eligible for a PCIP.)** An uninsured patient may have to apply for insurance simply to get proof of denial letter to enroll in a PCIP. These plans don't have a presumptive illness list.

If you are newly uninsured, have a pre-existing condition and are shopping for private insurance in the individual market, keep a record of any denials you may receive. If you do not find insurance on your own and you live in a state that requires denial confirmation, you will then have the documentation you need.

State-run plans (like South Dakota's Federal High Risk Pool) have less stringent eligibility requirements. Some require proof of denial, but in others, people with certain pre-existing conditions like a bleeding disorder qualify for coverage more or less automatically. That's because hemophilia is listed on the state's presumptive illness list. All you need is a doctor's signature on the application form to verify your bleeding disorder diagnosis.

COST CONSIDERATIONS The federal government set aside \$5 billion to subsidize the new PCIPs. Even with the subsidies, an individual premium in the federally run standard plan can seem costly, but is less expensive than the regular high risk pool rate. PCIP premiums range from \$156 to \$671 for Minnesota, and \$133 to \$571 for North Dakota (all dependent on age and plan deductible choice).

State-run plans determine their own premiums based on what the private insurance market charges insurable members. In South Dakota, premiums for the PCIP range from \$141 to \$626 per month.

The purpose of this article was to let you know that if you are without insurance due to a pre-existing condition, there are new options and choices for you at reasonable premiums. Education is powerful, and now you have the information to make informed decisions about your insurance needs.

Submitted by: Bobbie Kincaid
HFMD Volunteer
HFMD Industry Member

Veline

NEWSLETTER OF THE HEMOPHILIA FOUNDATION OF MINNESOTA AND THE DAKOTAS

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August 6th, 2011

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Visit our Walk Website at:
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For more information contact HFMD at 651-406-8655, 1-800-994-4363 or
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