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Welcome GLHF's new Executive Director

Great Lakes Hemophilia Foundation
Headline News - May 2011



Please join GLHF in welcoming Danielle Lietner Baxter as the new Executive Director of the Great Lakes Hemophilia Foundation (GLHF). Danielle brings to GLHF fifteen years of fundraising, volunteer, and program management experience. Most recently Danielle served as the Executive Director of the Crohn's and Colitis Foundation of the Minnesota/Dakotas. Danielle possesses the experience, passion, and determination to help GLHF achieve a new level of service to families with bleeding disorders. She is an energetic and exceptional leader who will inspire collaboration and build on GLHF's record of accomplishments.

Danielle will begin on May 31, 2011.

Farewell from Mary Anne Schall

Serving the Bleeding Disorders Community for Over 20 Years

Great Lakes Hemophilia Foundation
Headline News - May 2011



As I step down, please know that it has been a rare privilege to work with you over the past twenty years. I have seen GLHF grow and change to meet the needs of the bleeding disorders community. When I first joined GLHF, services focused primarily on males with hemophilia. Today, in addition to serving the hemophilia community, GLHF provides services to individuals with von Willebrand disease, platelet function disorders, and other factor deficiencies. With advances in treatment, GLHF has expanded its emphasis to embrace not only treatment but also early intervention and prevention. In addition, this year -- for the very first time, GLHF will host a Wisconsin Family Camp. Family camp will serve as a preparatory venue for families who have not experienced camp and may be hesitant about sending their kids.

I am grateful for the support of our families, GLHF volunteers, the Foundation Board of Directors, and the GLHF staff. I leave with many wonderful memories and a deep respect for all that this supportive community has shared -- ideas, time, and expertise. GLHF has a proud heritage and a bright future. For allowing me to play a small role, I am most honored. Thank you!

Warm regards,
Mary Anne

Wisconsin Legislative Day

Great Lakes Hemophilia Foundation
Headline News - May 2011

Karin Daniels, Program Services Coordinator



On Wednesday, April 20th the bleeding disorders community gathered in Madison, Wisconsin for the Wisconsin Legislative Day at the Capitol. Clients met with their State Representatives after a morning training focusing on the key issues we are facing in the state and the importance of advocacy. Kevin Moore, Executive Assistant for the Department of Health Services, spoke to the group and outlined issues current affecting the state.

Clients spoke on behalf of the Wisconsin bleeding disorders community on two specific issues. The first request was to maintain adequate **funding for the Wisconsin Chronic Disease Program (WCDP)**. The WCDP helps to pay for the uncovered costs of clotting factor concentrates, based on need as a "last resort", after all other payers have paid. WCDP is a proven long standing program (over 25 years) that has enhanced the health care for some of our most vulnerable citizens.

The second request was pertaining to **Medicaid** and addressed concerns about Medicaid changes (co-pays, access, coverage of all clotting factor concentrates and access to high quality pharmacy care). The current budget requires a \$494 million dollar cut that needs to be found by the state. We have concerns that this will negatively impact the bleeding community. Because treatment is so expensive, increased premiums, co-pays, percentages or ceilings can be devastating. It's important that the different clotting factor concentrates continue to be covered by Medicaid. There are many "unknowns" right now, and we suggested that any short-term savings would not make sense for the bleeding disorders community. With adequate funding the long term savings far outweigh the short term because with improved outcomes individuals have a decrease in emergency room visits and costly hospitalizations, along with an increase in employment capabilities that allow for private employer insurance options.



What's Next?

join in

Become a member of the GLHF Advocacy Committee by contacting Karin Daniels at 414-937-6782 or kdaniels@glhf.org.

stay tuned

Watch for Action Alerts on legislative happenings affecting the bleeding disorders community.

stay in touch

Stay in touch with your representatives by calling, writing, or scheduling an informal meeting in your area -- a face attached to an issue is crucial when decisions have to be made.

remember

Advocacy is needed not only today, but every day in this changing political landscape.

View the latest GLHF podcast on Advocacy at:

<http://www.glhf.org/podcasts/PODCASTS.htm>

Growing Older Proactively

Managing other health issues as you age with hemophilia

Great Lakes Hemophilia Foundation
Headline News - May 2011

By Sarah Aldridge

Originally Published in *Hemaware*, April 2011



Growing older with hemophilia can feel less like the golden age and more like the rust years. Stiff joints, heart issues and other aging-associated concerns can increasingly complicate life.

Bob Berger, 72, of Ponte Vedra, Florida, has severe **hemophilia B** and **hepatitis C (HCV)**. Hospitalized with diverticulosis, saclike swellings in his colon, he hemorrhaged so much he needed several pints of blood. He has been treated for prostate cancer and had skin biopsies. But his most pressing concern is a leaky mitral valve in his heart. Bob teaches economic and business law at Flagler College in St. Augustine and will undergo valve replacement surgery in May, after his classes end.

Before contacting the University of South Florida (USF) Adult Hemophilia Center in Tampa, Berger was frustrated with the care he received elsewhere. He was dismayed when the heart surgeon's nurse cancelled an appointment the week before surgery. "That didn't sit too well with me," he says.

"Bob had a heart catheterization scheduled, and he wasn't planning to see him?" says Marla Berger, Bob's wife. "They didn't understand hemophilia." At USF the Bergers' concerns were validated. "They said that under no circumstances should we go ahead with anything until all of the steps were in place. I felt much better about that," Marla says.

As you age it can be even more important for you to advocate for yourself and access the resources at your hemophilia treatment center (HTC).

Health Issues of Aging

People with hemophilia often have other health conditions that must be managed carefully. In a review of previous research studies, published in *Haemophilia* in 2009, Barbara Konkle, MD, and her co-authors identified five main co-morbidities (concurrent medical conditions) that occur in older people with hemophilia: cancer, cardiovascular disease, joint disease, liver disease and renal (kidney) disease. Konkle is a hematologist at the Hemophilia Care

Program at the Puget Sound Blood Center and a professor of medicine at the University of Washington School of Medicine in Seattle.

Heart Health

Having hemophilia does not prevent you from having cardiovascular disease. "Studies show that men with hemophilia get as much atherosclerosis, or hardening of the arteries, as men without hemophilia," Konkle says. Although men with hemophilia are less likely to have heart attacks, they do have them, she says.

High blood pressure is more common in men with hemophilia compared with the general population, but the cause is unclear. "One question that was raised in the past was whether high blood pressure is related to the factor concentrates, particularly when they were not as pure as they are now," says Konkle. If that were the cause, purer plasma-derived and recombinant factor products should reduce the rate, she says.

Some of the drugs prescribed to treat strokes, heart attacks and arrhythmias may disrupt blood clotting, says Konkle. "Someone with hemophilia is going to bleed more on those medications," she says. That can make management tricky. "Bob's got a boatload of stuff to keep his blood pressure and pulse regulated," says Marla. His heart conditions surfaced after he took a long bike ride in 95-degree heat. "My pulse, which usually runs in the high 40s or low 50s, was in the 90s. I knew at that time I had messed up," he says.

Cancer Risk

People with hemophilia are not at increased risk for cancer overall, but are for some specific cancers caused by viruses and their treatments. Chronic hepatitis C infection can lead to hepatocellular carcinoma, or liver cancer. "As we have a larger population of older individuals with cirrhosis from hepatitis C, we're seeing more liver cancer," Konkle says. Biopsies and blood tests can provide pertinent information on the liver's deterioration. Liver transplant is sometimes the only option. (See "[In for the Long Haul](#)," *HemAware* May/June 2009.)

Colon cancer is another concern. Baseline colonoscopies are generally recommended beginning at age 50. However, people with hemophilia might put them off because factor concentrate is needed. But procrastination is not your friend. Neither is overlooking symptoms. "There could be a delayed diagnosis because of some blood in the stool that would be ignored," Konkle says.

Bob found out the hard way that cancer biopsies need adequate factor coverage. A skin cancer biopsy in his dermatologist's office led to problems. "I didn't have any pre-op for that," Bob says. "We didn't think it would bleed, but it really did." His wife infused him at home afterward.

Kidney Concerns

Konkle's review noted the finding from a [Centers for Disease Control and Prevention](#) study that older people with hemophilia have a 50-fold increased risk of dying from kidney disease than their nonhemophilic peers. HIV was an important factor contributing to that increase, but hypertension (high blood pressure) and kidney bleeding also appeared to contribute, Konkle says. "The role of kidney bleeding is unclear," she says. "We don't know if changing our treatment approach is needed."

Liver Damage

Virtually all patients with hemophilia who used plasma-derived products before the early 1990s were infected with HCV. Because the virus slowly destroys the liver, symptoms can be mild and easily disregarded for years. The current treatment regimen is rough—side effects abound and less than half of patients clear the virus. Improvements, however, are on the horizon. "There are new drugs coming on the market as early as this year that will increase the response rate and decrease the time of treatment," Konkle says.

Achy Joints

Prophylactic treatment, in which clotting factor product is infused to prevent bleeds, was not routinely prescribed to older men with hemophilia in the US during their youth. Consequently, [arthritic, achy joints are common in most men with severe hemophilia over 40](#).

"When I was growing up, I wanted to be a Major League baseball pitcher. That's how I screwed up my right elbow," says Larry Maddox, 51, of St. Paul, Minnesota. He has stiff ankles and severe arthritis in his knees. Maddox uses crutches to get around his apartment and a walker when he's out in public. Due to complications from his severe hemophilia A, Maddox retired from clerical work 14 years ago. He receives [Social Security disability benefits](#) through Medicare.

Bob also has bad joints. "In my left elbow, I have synovium buildup. I have very little, if any, usage of it," he says. As a lefty, that's a problem. "It creates a lot of pain in the evening," he says. He takes hydrocodone on the bad days. Bob's right knee also bothers him. "I have a hard time walking down steps. I can't walk long distances either."

Prophylaxis is used in some older patients. "Secondary prophylaxis, where we start factor after someone has established joint disease doesn't reverse it, but it may slow the progression," Konkle says. Still, more data are needed, she says.

Older people with impaired leg joints tend to be more sedentary, have weaker muscles and are more prone to falls. "I always worry about falling because I have poor balance, largely due to my knees not being able to bend," Maddox

says. In January 2010 he fell twice in his apartment and could not get up. Wearing a wireless medical alert device allowed him to summon help. "The paramedics were out here in a flash, so it does work."

Where there is osteoporosis, or bone thinning, falls can result in fractures. Viruses may also play a role. "Hepatitis C may be a slight risk factor for increased risk of osteoporosis," says Konkle. "Those who are HIV-positive are definitely at risk," she says. The cause may be the virus and/or its treatment. (See "[Vitamin D and Hemophilia](#).")

HTC's Expanding Role

Ellen Kachalsky, LMSW, ACSW, and Angela Lambing, MSN, NP-C, of the Hemophilia and Thrombosis Treatment Center, Henry Ford Health System, in Detroit, are spreading the word that HTC staff are positioned to meet aging patients' multifaceted needs. They co-authored the 2009 Haemophilia article "The New Age of Haemophilia." In 2010 Kachalsky co-wrote "Aging with Hemophilia: Implications for Social Work Practice," published in [Social Work in Health Care](#).



"We're providing much more advocacy for our patients with other services," Lambing says. One day she may act as the liaison with the cardiac catheterization lab, another she may accompany an older patient to a urology appointment. Lambing troubleshoots with staff from other departments, discussing how procedures and tests should be done for a patient with hemophilia. "The patients appreciate the fact that we're there putting it all together for them."

Your HTC visit can supplement or kick-start your visits to specialists, says Lambing. "We are looking at those other co-morbidities—the hypertension, the diabetes, being overweight," she says. She has sent a patient with angina to the cardiology department and recommended a specialist to a diabetic patient being followed by a primary care physician. With her background in geriatrics, Lambing is proactive on timely issues, such as sluggish thyroid glands. "When they're over 60, I'm starting to check their thyroid levels. If we can catch that, it will improve their health."

[Pain management](#) is another area your HTC can coordinate. "We look at multimodal pain management therapy," Lambing says. That can range from using topical nonsteroidal medications to physical therapy and TENS (transcutaneous electrical nerve stimulation) units that block pain signals. "We're not just using pills," says Lambing. Patients with chronic pain can also experience depression. "I will frequently add anti-depressants to the treatment plan," Lambing says.

Your HTC may also provide routine screenings. “A lot of our patients are deficient in vitamin D, so we’re now screening for it,” Lambing says. “We make sure their immunizations are up-to-date, and that everybody gets their flu vaccine and has an up-to-date tetanus shot.”

The annual HTC visit is not a substitute for having a primary care physician, though. “Ideally, adults with hemophilia should have an internist—someone who is up-to-date on what needs to be addressed and what needs to be treated,” Konkle says. The internist should collaborate with the HTC team, she says. “If the patient has a primary care physician, he is getting the benefit of two views,” Lambing adds.

Social workers on the HTC team advocate for patients in many ways. “We’re now assessing issues for applying for Social Security disability, if they’ve been working and have been having problems,” Kachalsky says. They also assess patient’s living arrangements and physical limitations. “We want to get the tools and social supports in place so they can be more independent.”

Modifications for Maddox to continue living alone include replacing his bathtub with a shower, having Meals on Wheels deliver food and hiring a housekeeper. The Metro Mobility bus provides the door-to-door transportation Maddox needs to go places.

Kachalsky links people with resources in their local community, from [nutrition and healthy cooking classes](#) at the library to senior centers or community centers with exercise classes. “We also help them explore their hobbies, interests and spirituality that they might have put on hold when they were working,” she says.

With the help of your HTC staff, remaining active and enjoying life as you age with hemophilia are not wishful thinking—they are realities. Asking for help as you age is crucial to staying healthy and independent. “People really need to be more assertive if they have a situation like ours,” Maddox says.

Learn More

- Konkle, BA et al. Emerging clinical concerns in the ageing haemophilia patient, [Haemophilia](#) 2009; 15(6) 1197-1209.
- Lambing, A, and Kachalsky, E. The new age of haemophilia, [Haemophilia](#) 2009; 15(6): 1330-1331.
- Neuman, KA, and Kachalsky, E. Aging with Hemophilia: Implications for Social Work Practice, [Social Work in Health Care](#) 2010; 49(4): 327-344.
- To order the video “Hemophilia: Healthy Aging,” e-mail [Inalex Communications](#) or visit the [Web site](#).
- For recommended health screenings, go to the [US Preventive Services Task Force](#) Web site.
- Federal report: ["Enhancing Use of Clinical Preventive Services Among Older Adults: Closing the Gap."](#)

Volunteer Spotlight

Meet GLHF's new board president

Great Lakes Hemophilia Foundation
Headline News - May 2011

Maripat Monahan, Director of Resource Development



Michael Kohler joined the Great Lakes Hemophilia Foundation Board in 2006. "Volunteering has always been important to me and when the opportunity to serve on GLHF's board presented itself, I thought it was an ideal way to use my skill sets to make a difference in our community," Michael reminisces of his initial decision to serve on the board.

In his role at The Marcus Corporation, Michael is Senior Counsel, representing the company's hotels and theatres before federal and state administrative agencies throughout the country in all areas of employment law. Michael also counsels and trains the Corporation's managers and human resource directors on all subjects concerning employee relations and human resources. In addition to his work at The Marcus Corporation, Michael teaches as an adjunct professor at Marquette University's College of Business and frequently provides lectures on employment and labor law topics to classes and professional groups.

As a board member, Michael has served on several committees, including Board Development, Resource Development, and the Human Resource Committee. He has always been willing to roll up his sleeves, and has served as the Chair of the Resource Development Committee, encouraging his fellow board members to join in the fun of fundraising for GLHF. In 2007 Michael shared his professional expertise with members of the bleeding disorders community by leading a presentation about employee rights.

In 2010, Michael accepted the role as GLHF's Board President. He will serve as Board President for a minimum term of three years, at which point he will stand for re-election to another three-year term.

"I am honored to serve Wisconsin's bleeding disorder community and have enjoyed meeting GLHF's clients at our programs, galas and walks. I look forward to working with the talented members of our board and staff to ensure that we continue to meet the ever-changing needs of the bleeding disorder community," Michael says of his nomination to Board President for GLHF. In this new role with GLHF, Michael immediately rose to the challenge to replace vacant board seats and conduct a search for GLHF's new Executive Director.

Michael originally hails from Chicago which explains his allegiance to the Chicago Bears and the friendly ribbing he received after this year's Super Bowl. If you come to the Milwaukee Hemophilia Walk on September 24, there's a good chance you will have the opportunity to meet our new Board President as he has been known to bring his wife Laurie and young daughters, Abby and Maddie, to our annual Walk event.

Please join GLHF in welcoming our new Board President, and if you have any comments or recommendations to share with him, please send them along to info@glhf.org.

Michigan Researchers Develop Disease-Specific Stem Cell Lines

National Hemophilia Foundation's E-Notes, May 2011

Great Lakes Hemophilia Foundation
Headline News - May 2011



Researchers from the University of Michigan (U-M) in Ann Arbor have developed the state's first embryonic stem cell lines that carry genes linked to specific inherited diseases, including hemophilia.

On April 4, U-M announced the creation of two stem cell lines: one carries the gene for hemophilia B (factor IX deficiency) and the other for Charcot-Marie-Tooth disease, a neurological disorder that causes progressive degeneration of the foot, lower leg and hand muscles.

Stem cells are unspecialized cells that can renew themselves for prolonged periods. They can also develop into many different cell types, making them a potentially renewable source of replacement cells that could be used in the future to treat many conditions. The creation of such stem cell lines will open the door to an enhanced understanding of the origin and progression of congenital disorders, and hopefully to new treatments based on those findings. "These stem cell lines hold so much promise for medical science, and for this reason, they will be of tremendous interest to researchers around the world," said Eva L. Feldman, MD, PhD, director of U-M's A. Alfred Taubman Medical Research Institute.

Access to embryonic stem cells was first made possible in Michigan in November 2008, when voters approved Proposal 2, a state constitutional amendment. The law allows investigators to generate new lines from unused embryos donated by fertility clinics. Instead of discarding the embryos, which in some instances carry the genes responsible for congenital disorders, scientists now have a new approach for advancing research.

The amendment led to a partnership between U-M's Consortium for Stem Cell Therapies (CSCT) and Detroit-based Genesis Genetics, a company specializing in pre-implantation genetic diagnosis (PGD), a test used to identify days-old embryos carrying disease-causing genetic mutations. This partnership now gives patients the option of donating embryos that test positive for a genetic disorder to the CSCT.

While the use of disease-specific embryonic stem cell lines looks promising, scientists are still in the relatively early stages of investigation. It will take years of preclinical and clinical research before actual treatments for diseases, such as hemophilia, become available.

"We are producing tools that can be of immeasurable aid to scientists studying such disorders as hemophilia and Huntington's disease. And we are just beginning to scratch the surface of this new scientific frontier," said A. Alfred Taubman, founder and chair of the A. Alfred Taubman Medical Research Institute.

Source: University of Michigan news release dated April 4, 2011

Meet Us in the Windy City at NHF's Annual Meeting

National Hemophilia Foundation's E-Notes

Great Lakes Hemophilia Foundation
Headline News - May 2011



Chicago, dubbed the "city of broad shoulders" by the poet Carl Sandburg, will open its arms to the National Hemophilia Foundation for its 63rd Annual Meeting, November 10-12, 2011.

"Inspiration in the Windy City" is this year's theme for the three-day conference, which offers educational sessions, networking opportunities and social events for all ages. Individuals and families come with questions and concerns, but leave with answers, encouragement and hope.

Sessions tentatively planned for consumers include: "Super Dad—How to be a Real Man"; "What's My Name? Dealing with the Diagnosis of 'Symptomatic Carrier'"; and "Your Ailing Liver."

The two-day Medical Track for Researchers and Physicians includes a poster abstracts presentation and reception.

Check [NHF's Web site](#), for updated information on Annual Meeting registration and how to book your hotel room later this spring.

Apply Now for Annual Meeting Grants for First-Timers

The National Hemophilia Foundation is pleased to offer Educational Participation Grants for first-time attendees of its 63rd Annual Meeting, "Inspiration in the Windy City" in Chicago, November 10-12, 2011. The grants are given to individuals and families with bleeding disorders who have never attended an annual meeting. They cover such costs as airfare, hotel, expenses and/or registration fees. Awards are based on several factors, including financial need.

[Download and print your application form](#) to apply for a 2011 NHF Educational Participation Grant. Applications are due by mail to NHF's office in New York City. They must be postmarked no later than Friday, June 24, 2011.

For more information, e-mail: sroger@hemophilia.org.

Programs & Services Updates

Stay up to date with the latest programs and services happenings at GLHF.

Great Lakes Hemophilia Foundation
Headline News - May 2011

Karin Daniels, program Services Coordinator



Stay up to date with the latest programs and services happenings at GLHF. We have exciting program opportunities this year including: **The Wisconsin Bleeding Disorders Conference** with expanded programming, a **Family Camp**, and **Advocacy Programs**, along with **Education Scholarships, Camperships** and the **Patient Financial Assistance Program**.

Wisconsin Legislative Day

On Wednesday, April 20th the bleeding disorders community gathered in Madison, Wisconsin for the Wisconsin Legislative Day at the Capitol. Clients met with their State Representatives after a morning training focusing on the key issues we are facing in the state and the importance of advocacy.

[Read More](#)

Wisconsin Bleeding Disorders Conference

Each year families from the Wisconsin bleeding disorders community attend the Annual Wisconsin Bleeding Disorders Conference (formerly the Fun & Education Weekend). The weekend provides families with an opportunity to gather information through educational sessions, meet with healthcare and industry professionals and form important connections with other Wisconsin bleeding disorders families. By doing so, Great Lakes Hemophilia Foundation hopes that families can find ways to ease the challenges of living with a bleeding disorder. Join GLHF at the Kalahari Resort in Wisconsin Dells this June 11-12, 2011. The registration deadline has passed. Please contact Karin at 414.937.6782 to inquire about possible space.

Family Camp

GLHF is thrilled to offer a Family Camp for the first time this fall! The family camp is designed to prepare families and their child for the summer camp experience by easing their comfort levels, getting a feel for the true camp experience and understanding the importance of camp goals to gain independence through self infusions and care, learn new skills, engage in healthy lifestyle activities and bond with other children facing the same issues they do. This exciting new camp program will take place on September 30th through October 2nd at Camp Matawa in Campbellsport, Wisconsin. Please contact Karin at the Foundation at 414.937.6782 or kdaniels@glhf.org for more information.

Patient Financial Assistance (PFA) Program

GLHF offers patient financial assistance to individuals and families needing funding assistance with medical bills, insurance premiums and emergency basic living expenses. GLHF also assists with payment of medical alert bracelets and membership renewals. Please contact Karin at the Foundation at 414.937.6782 if you would like more information on the GLHF Patient Financial Assistance Program.

Scholarship Program

Each year GLHF awards educational and career development scholarships to students with bleeding disorders. New this year, GLHF will be providing funding for youth interested in attending college bound preparatory programs, like College for Kids. Please visit <http://www.glhf.org/scholar.htm> for an up to date list of both GLHF scholarships and other bleeding disorder specific scholarships offered across the country. Contact Karin at the Foundation for further details at kdaniels@glhf.org or 414.937.6782.

Campership Program

GLHF provides camp scholarships (Camperships) to Wisconsin youth, underwriting the costs of attending a week-long summer camp which is designed and staffed especially for those who have bleeding disorders. Campers apply to the GLHF Campership program and can select the camp of their choice from three Midwest camps in Illinois, Michigan or Minnesota. At these summer camps, campers are encouraged to learn self-infusion with training, and practice with medical professionals and with the support of their peers and teen mentors. At camp, lifelong friendships are formed with peers and children are given the opportunity to have a safe and fun week without limitations related to their bleeding disorder. Contact your Hemophilia Treatment Center or Karin at the Foundation for more information on GLHF Camperships at kdaniels@glhf.org or 414.937.6782.

Upcoming Programs:

June 11-12, 2011	Wisconsin Bleeding Disorders Conference
July 10-16, 2011	Camp Courage South, Minnesota
July 10-14, 2011 (Session I)	Camp Bold Eagle, Michigan
July 16-23, 2011 (Session II)	
July 24-30, 2011	Camp Warren Jyrch, Illinois
September 30-October 2, 2011	GLHF Family Camp

If you have an idea for a program or topic please feel free to call Karin at the Foundation at 414.937.6782 to discuss. We appreciate your input!

Teeing Up Charity

Celebrating 20 Years

Great Lakes Hemophilia Foundation
Headline News - May 2011

Jessica Kveen, Special Events Coordinator

Golfers enjoyed a windy day at The Bog on Monday, May 16th. This year marked the 20th anniversary of Teeing up for Charity® presented by Harleys: The Store for Men. Tim Ryan has been a dedicated volunteer putting this event together for the past twenty years, and has raised over \$480,000 for the Wisconsin bleeding disorders community. A huge thank you to Tim, and all our volunteers and sponsors that made this event possible.



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- The Moxom/Stoka Group of Wells Fargo Advisors
- Thomson Reuters

Hemophilia Treatment Centers (HTCs): Five Fast Facts

Great Lakes Hemophilia Foundation
Headline News - May 2011

Kathryn Reese, Regional Coordinator



1. There are four HTCs in Wisconsin serving 1,840 patients and growing, plus countless other family community members.
2. HTCs use a model of care that has federal standards and has been proven effective by the Centers for Disease Control and Prevention (CDC).
3. Income from factor purchased through HTC 340b programs goes directly back toward patient care and HTC programs.
4. The Universal Data Collection (UDC) study that HTCs participate in monitors blood safety to protect patients in case of a blood-borne illness.
5. HTCs maximize the effectiveness and efficiency of health care by providing access to multiple disciplines, preventative care, individual treatment plans, and hemophilia experts.

Wisconsin Hemophilia Treatment Centers

**BloodCenter of Wisconsin
Comprehensive Center for
Bleeding Disorders**
P.O. Box 2178
Milwaukee, WI 53201-2178
414.257.2424
[www.bcw.edu/bcw/blood
products/ccbd/index.htm](http://www.bcw.edu/bcw/bloodproducts/ccbd/index.htm)

**Gundersen Lutheran
Pediatric Hematology/
Oncology**
1900 South Avenue EB2-002
La Crosse, WI 54601
608.782.7300

Hemophilia Outreach Center
2060 Bellevue Street
Green Bay, WI 54311
920.965.0606
www.hemophiliaoutreach.org

**University of Wisconsin
Hospital and Clinics Comprehensive
Program for Bleeding Disorders**
5105 University Avenue
Madison, WI 53705
608.890.9495

Thank You Novo Nordisk

Your support improves the lives of those living with bleeding disorders in Wisconsin.

Great Lakes Hemophilia Foundation
Headline News - May 2011

Maripat Monahan, Director of Resource Development



Without funding from our donors and friends, including corporations, foundations and individuals, Great Lakes Hemophilia Foundation simply could not provide the programs and services we offer to the bleeding disorders community of Wisconsin. We want to thank one of our long term generous donors -- Novo Nordisk - for all it has done to ensure that GLHF programs are supported and the bleeding disorders community is well served in Wisconsin.

Novo Nordisk has supported Great Lakes Hemophilia Foundation since 2000, and has been our Title Event Sponsor for the past four years. The significant financial investment Novo Nordisk has made in these past eleven years has helped sustain all GLHF programs and services, touching the lives all those we serve in Wisconsin.

Thank you, Novo Nordisk, for your strong, ongoing commitment to improve the lives of people affected by bleeding disorders throughout Wisconsin! If you get a chance this year, please join us in extending a warm thank to our friends at Novo Nordisk.

Raising Money for the Hemophilia Walk

Is it hard? The answer - NO!

Great Lakes Hemophilia Foundation
Headline News - May 2011

Jessica Kveen, Special Events Coordinator



Asking for money can be difficult and intimidating, but here are a few secrets from the pros. Test them out, it's easier than you think.

Here are four easy steps to get you started:

1. **Start early.** The earlier you start the more money you can raise.
2. **Contact everyone you know.** Don't just post it on Facebook or send an e-mail to everyone in your e-mail address book (however those are great places to start!). Think of people you interact with regularly. Develop a list! Think of your church congregation, your book club, boy scouts, and your Holiday card list. Make sure they know why you give, and how to donate.
3. **Ask at work.** First ask your employer about policies related to soliciting donations in the workplace. Then send an e-mail around work, start a penny jar, or sell fresh baked goods during lunch.
4. **Follow up with your list!** Give your list a call, and ask. "Give people a chance to donate, but leave the ultimate decision up to them. Just don't take it personally if they don't give. 'Fundraising professionals are often told 'no' but they don't stop asking,'" (nonprofit)

Still need some help? Follow these steps and you'll **Raise \$500 in 7 Days!**

- #1 Sponsor yourself first \$50.00
- #2 Ask 4 family members to sponsor you for \$25 each \$100.00
- #3 Ask 5 co-workers to contribute \$15 each \$75.00
- #4 Ask 5 friends to contribute \$15 each \$75.00
- #5 Ask 5 neighbors to sponsor you for \$15 each \$75.00
- #6 Ask your boss for a company contribution of \$50 \$50.00
- #7 Ask 3 businesses you frequent for a donation of \$25 each \$75.00

AND YOU'VE DONE IT!

This article has been adapted from NPT Instant Fundraising, a publication of The NonProfit Times.

Walk with Us

The summer is a perfect time to get outside, get moving, and support a great cause all at the same time. With this in mind, GLHF is hosting three walks across the state for you to enjoy!

Get started by registering online at hemophilia.org/walk.

Walk with us!

Pick your date, pick your place and join us for a Walk in 2011.

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The Unfamiliar Bleed

Recognizing joint bleeds in people on prophylaxis

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By Laura Putre

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As a toddler, Andrew Morado experienced many bleeds in his left ankle due to his severe **hemophilia A**. But at age 4, when he started a three-day-a-week prophylaxis regimen, the bleeds subsided and so did the attentiveness of [his mother, Alicia](#). No longer was she constantly monitoring his gait and sizing up his ankles for the slightest sign of pain or swelling that might indicate a joint bleed.

“For the most part, he was in really great shape because of the prophylaxis,” says Alicia. Andrew has two brothers, one who has mild hemophilia and one who is not affected.

Andrew, now 15, is an active sophomore in high school. In the winter of 2009, Alicia noticed his right elbow was very stiff and swollen a few days after he slipped and fell in their Joliet, Illinois, driveway. She can’t recall whether he infused immediately after the fall. It wasn’t a priority, she says, because she figured his regular infusions would take care of any bleeding. “At the time I didn’t think it would be a recurring thing,” she recalls. She thought: “It will swell, we’ll treat him, it’ll go away.”

But the damage was serious enough that Andrew experienced repeated bleeds in his elbow. “The family’s focus has changed. “Before, we were concerned about his ankles. Now, it’s a different joint. I’m not really sure what to look for a lot of times,” Alicia says.

The Morados are part of the generation of families that has benefited from prophylaxis. However, for many of them, joint bleeds are so infrequent, they may not recognize them. Or, they may not know how to treat them properly when they do occur.

“One of the things that is wonderful about the prophylaxis is it decreases the anxiety or the likelihood of having a spontaneous joint bleed,” says Carol Diamond, MD, a pediatric hematologist and oncologist at the University of Wisconsin Hospital in Madison. “But the other part of it is if somebody has never had a joint bleed, he is not as vigilant.”

Susan Hunter, RN, the senior hemophilia clinical nurse at University Hospitals of Cleveland, says that occasionally a parent of a school-age child will call her

and say, "I don't know what this is." "If the child has been on prophylaxis, he may not have had a knee bleed. The family is not familiar with the treatment or the follow-up," she says.

Because joint bleeds can lead to permanent damage, parents and kids should know the signs and what to do next.

Know the Signs

The most common sites for joint bleeds are the knees, elbows or ankles; less often, the shoulders or hips. Bleeds can happen as a result of trauma, but they also frequently occur spontaneously. The joint and surrounding area become swollen, which can result in irritation or pain. "Often people will complain of a sensation of heat and bubbling," Diamond says. "They will not want to move the joint."

Bleeds into the joint cavity can cause synovitis. Iron in the blood irritates the synovium, the tissue that lines the joint. When damaged, the synovium becomes inflamed and thickened, and has increased blood flow. This makes the joint incapable of normal function, explains Diamond. The synovial lining is fragile and at higher risk of repeated bleeding. "Once you have one joint bleed, you're very likely to have another one," says Diamond. Target joints are those that have had repeated bleeds, or at least four bleeds within six months.

By the time a joint bleed causes pain, decreased range of motion and obvious swelling, it's likely the damage has already occurred. That's why it's important to notice subtler signs. Infants rarely get joint bleeds because they aren't mobile yet. Parents of toddlers should look for changes in function.

"Toddlers with a bleed will limp or refuse to bear weight, or they won't want to get up," says Diamond. "Or, they'll hold their knee or their ankle where it hurts." Any change in the way a child walks or unwillingness to use or bend a limb should be taken seriously and addressed immediately, she says.

Hunter suggests that parents with small children routinely compare joints during bathtime or diaper changing. "Sometimes one leg does look different than the other." If that happens, she says, make a small ink mark on the suspect area and measure the circumference with measuring tape. Measure it again after a few hours—the time should be determined by your doctor, nurse or treatment plan—to see whether the size has changed.

Sometimes, it's simply a matter of noticing that your child is acting out of character. "There might be no signs of illness, but maybe he's uncomfortable," says Joann Deutsche, RN, FNP-C. As a family nurse practitioner at the Hemophilia Center at Oregon Health and Sciences University in Portland, she has fielded calls from plenty of worried parents. "It's very hard for parents initially, but they have to be alert. We don't want them to wait to come in until after the joint is terribly swollen."

The signs may vary even among siblings, says Deutsche. “Parents have to be really keyed into their child,” she says. “They really are the baby’s eyes and ears.”

Don’t Wait to Treat

Wendy Dean’s son, Cole, 2, has severe hemophilia A. The family from Charleston, South Carolina, has already had several scares, including a muscle bleed after a round of immunizations, that resulted in calls to their hemophilia treatment center (HTC) at MUSC Children’s Hospital in Charleston. Wendy, who considers herself well informed in recognizing bleeds, has advice for other parents: “If you think something’s wrong with how your child’s acting, sit down and take a look.”

If Wendy sees something amiss, she’ll give Cole a dose of factor. But less experienced parents should call their HTC first, says Diamond. “Call any hour of the day or night. That’s why we have 24-hour services,” she says. “Whatever we can do to minimize joint bleeding is the best thing for the child.” Joint bleeds that aren’t treated quickly could lead to frozen joints, which can’t fully flex or extend.

Hunter says too often parents watch the joint for a day or two and then call the HTC. “We nurses would like to see a big campaign: Make the Call,” she says. Because time matters, Hunter advises families to carry at least one dose of factor with them at all times and follow the manufacturer’s storage guidelines for the medication when traveling. Ask your HTC about travel cases for factor. If a family’s headed for a daylong event, such as a picnic or family reunion, Hunter advises administering a preventive dose of factor before leaving home.

Follow Up With RICE

When a joint bleed happens, infusing with factor isn’t enough. To prevent joint bleeds from recurring, stick to the RICE treatment plan—Rest, Ice, Compression, Elevation. RICE is crucial in the 24 to 48 hours after infusion, Hunter says.

Rest involves staying off the joint for at least a day, depending on how severe the bleed is, then slowly returning to activities. Older children and teenagers tend to re-bleed because they’re up and moving too soon after they treat. “The more you bleed, the more likely you’re going to bleed,” Hunter says. “It becomes a very vicious cycle, and the healing takes longer. You end up needing more and more factor.”

Ice means applying a cold compress for 15 minutes, every couple of hours, to reduce swelling.

Compression involves wrapping the joint in an Ace™ wrap. Make sure you've been taught by the staff at your HTC on the proper wrapping technique so the bandage doesn't constrict the limb. "The compression helps reduce the bleed," Hunter explains. "It also can serve as a reminder to the child to be careful of that joint."

HTCs may give older kids a Cryo Cuff,® a gravity-driven type of icepack that gradually provides ice and compression to the joint, minimizing the need to change wraps and ice packs.

Elevation can be as simple as using pillows to prop up the joint above the rest of the body. This keeps the blood flowing away from the joint, and reduces swelling and discomfort.

Exercise Makes a Difference

Once the joint has healed, children can return to safe physical activities. The National Hemophilia Foundation's *Playing It Safe* booklet assigns safety ratings to various sports and activities (see "[Learn More](#)").

Diamond highly recommends swimming because it builds strength and endurance. Besides, it is easy on the joints. "Being strong and active, having good nutrition, and avoiding obesity are extremely helpful for hemophilia patients," says Diamond.

Active children with hemophilia tend to have stronger muscles and connective tissue than their counterparts who don't exercise regularly, according to a November 2009 study published in the journal *Pediatrics*. The study was conducted by Marilyn Manco-Johnson, MD, and colleagues at the Mountain States Regional Hemophilia and Thrombosis Center at the University of Colorado in Denver.

The researchers found that some higher-impact sports may be beneficial for children with severe hemophilia with the proper protective gear. They found that the impact from playing basketball and baseball, as well as running, actually helped move calcium through the bones to build up bone density. Target joint bleeds were no more common than in children who swam and cycled. (See "[Jump Start](#)," *HemAware* Spring 2010.) It's still important, though, to talk with your HTC team if you are considering allowing your child to play a high-contact sport.

After a bleed, parents may want to try to protect their children from everything in sight. "We don't want our children with hemophilia to be couch potatoes," Diamond says. "Early on, you can start talking about sports that are safe and encourage your child to participate in them."

Now that Andrew is an active teenager, Alicia worries that he doesn't pay attention to the signs that he's having a bleed. "Sometimes it's not a big deal to him unless it's stopping him from doing the things he wants to do," she says.

Andrew's elbow is still giving him trouble, so Alicia often finds herself spot-checking for signs of swelling. She has been imploring Andrew to infuse as soon as he feels the telltale bubbling and tingling in his joints. "I'm trying to get him to be more diligent, because when he gets older, that's when the problems are going to manifest the most. He thinks because he's 15, he's OK, but he's got to think of the future."

Learn More

- For a copy of NHF's *Caring for Your Child With Hemophilia* or *Playing It Safe: Bleeding Disorders, Sports and Exercise*, e-mail [HANDI](#), NHF's information resource center, or call 800.42.HANDI.
- Read MASAC document #179, "[MASAC Recommendation Concerning Prophylaxis](#)."
- Ross C, et al. Athletic participation in severe hemophilia: Bleeding and joint outcomes in children on prophylaxis. *Pediatrics* November 2009; 124 (5):1267-1272.