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Fall is in the Air

Great Lakes Hemophilia Foundation
Headline News - August 2011

Danielle Leitner-Baxter



As kids get ready to head back to school, here at GLHF we also feel an excitement for the “new year”. We are lucky that our “class” is made up of the entire bleeding disorders community and the learning opportunities are endless.

This Fall, we look forward to field trips to the Hemophilia Walks in Madison (Aug. 27), Fox Valley (Sept. 10) and Milwaukee (Sept. 24) and then learning the benefits of independence and fun at our new family camp (Sept. 30-Oct. 2).

We will be studying up on the successes of 2011 and planning our “lesson plans” of 2012. In November, we will network with families and colleagues at the NHF national conference in Chicago to set our curriculum for this year and beyond.

Even though most of us may have finished our official school days, we do want to continue to receive our report cards. We rely on you to let us know how we are doing. I welcome your feedback and am genuinely interested in how you feel we can improve or add to our programs or our contact and correspondence with you.

I was thrilled to have the opportunity to attend our Wisconsin Bleeding Disorders Conference in June. This event is a great example of GLHF, HTC's and families working together to provide relevant information and resources and build community. We had so many impressive teachers leading our sessions and eager students soaking up the information and making new friends (And, I heard recess in the water park was a lot of fun too!) Mark your calendars for our 2012 conference on June 8 and 9 and watch for exciting updates on the agenda and format.

Stay tuned for updates on upcoming events, new programs and lots of learning this year! We look forward to a great year!

THANK YOU to those who participated on the Wisconsin Bleeding Disorders planning committee for all your time and hard work throughout the process; Jeff Amond, Terry Brosig, Jessica Pindilli, Corbett Reinbold, Sheri Robbins, Stephanie Youngbauer, and Karin Daniels. A Special **THANK YOU SPEAKERS** for your commitment and expertise. Pulse on the Road, Laurie Kelley. Dental Program, Bonnie Des Jordins. Improving Adherence, Shannon Penica. Emergency Room Visits, Stephanie Youngbauer and Jessica Pindilli. Questions and Answer with the Doctor, Dr. Joan Gill. New Horizons for Older Adults, Ada Gonzalez. VWD and Women, Virginia Kraus. Physical Therapy, Tom Casey. Healthy Cooking, Carmen Gorniak. Additional **THANK YOU** to Volunteers.

Family Camp

Register Today

Great Lakes Hemophilia Foundation
Headline News - August 2011

Karin Daniels, Program Services Coordinator



Great Lakes Hemophilia Foundation is thrilled to offer a Family Camp for the first time on September 30 through October 2, 2011. Family Camp is designed to prepare families that have a child with a bleeding disorder (target age 5-9) for the summer camp experience.

ABOUT CAMP

Family Camp will take place at Camp Matawa in Campbellsport, WI. At Family Camp you will experience a variety of activities like canoeing, hiking, fishing, archery, campfires, and wagon rides among the beautiful fall colors. Families will stay in modern cabins with a common sitting area, screened in porch and private family sleeping arrangements. Cabins are comfortable and family friendly.

Family Camp is designed for:

- Children, ages 5-9 living with a bleeding disorder, and their family
- Families wishing to understand the benefits of summer camp programs
- Families looking to get away from the hustle and bustle of life and spend quality time as a family amongst their peers in the bleeding disorders community



REGISTRATION

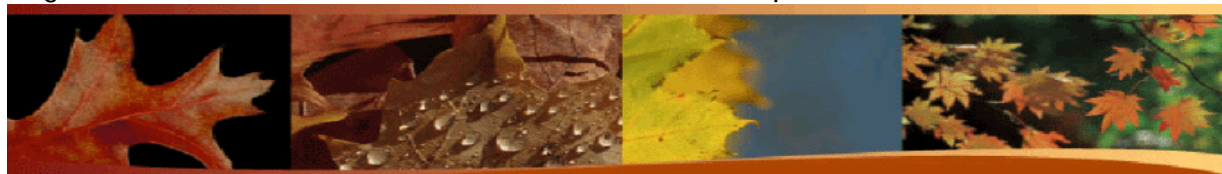
A small registration fee of \$35 per family includes; lodging, 6 meals per person, and programming for the weekend. Refunds will only be given if cancellation is made prior to September 12th. Call GLHF at 414.937.6782 to cancel. There will be a waiting list so please allow time to notify a replacement family.

A limited amount of space is available for this weekend. Priority will first be given to those families (immediate family) with children ages 5-9 with a bleeding disorder that have yet to attend summer camp. Families not meeting this specific criteria, yet wishing to attend, are welcome and will be placed on the secondary list.

REGISTER ONLINE by September 1, 2011.

Contact Karin at GLHF with questions at 414.937.6782 or kdaniels@glhf.org.

Registration confirmation will be sent the week of September 1st.



September is National Preparedness Month

Family Emergency Kit Checklist

Great Lakes Hemophilia Foundation
Headline News - August 2011



This informational resource was developed for families with bleeding disorders. Work was done by the National Hemophilia Foundation (NHF) Emergency Preparedness Task Force in collaboration with the Centers for Disease Control and Prevention. Adapted with permission from Freedom from Fear: A Guide for Safety, Preparedness and the Threat of Terrorism. Gregory A. Thomas, Random House Publishing, 2005.

For the full *Emergency Kit Checklist* for people with bleeding disorders visit:

<http://www.cdc.gov/ncbddd/hemophilia/documents/FamilyEmergencyKitChecklist.pdf>

Family Emergency Kit Checklist

Your family may not be together at the time of a disaster so it is important to develop an emergency plan before disaster strikes. The plan should include a communication plan, disaster supplies kit, and an evacuation plan. It is especially important for people with bleeding disorders to have a plan in place in order to ensure that the same level of care is maintained in the event of a disaster.

Bleeding Disorders - Specific Preparedness

GENERAL TIPS FOR PEOPLE WITH BLEEDING DISORDERS*

- *Be sure to consult your Hemophilia Treatment Center for a plan specific to your needs.
- Wear a medical alert bracelet or necklace that explains the family member's bleeding disorder.
- Place multiple ice packs in the freezer.
- Make sure you always have enough cash or change for parking at an HTC or hospital or for cab, bus, or subway fare to get you to the HTC or an ER, and make sure you always keep it in the same place.
- Make sure you always take factor and supplies with you when you leave home.
- Keep important telephone numbers in multiple locations for example, for your HTC, homecare company, physicians, insurance, and ER (for example, on the refrigerator, in your wallet, on your child's car seat, in school or work bags, with your car registration papers, and in your go-bag).
- Keep as much factor and supplies on hand as your insurance will allow.
- Teach extended family and friends how to mix the clotting factor into a syringe, put the needle into the vein and give the factor, as others might have to give the factor.
- Keep a family manual, or notebook, containing such things as up-to-date medical information, directions on mixing and infusing factor, maps of the area to the HTC and hospital, important telephone numbers, diagnosis and treatment regimens, and

the location of a backup HTC. See www.cdc.gov/bloodtreatmentcenters for a list of treatment centers in the U.S.

- Keep an infusion log and take it with you in case you have to leave your home.
- Keep a go-bag or small suitcase of factor and supplies packed at all times so it is easy to grab and go. Make sure you change out supplies regularly so they can be used before they expire.
- Program your emergency contact into your telephone under “ICE” (In Case of Emergency). Emergency medical services responders now look for such numbers in cell phones and call the number if need be.
- Program 1-800-42-HANDI into your cell phone in case you need information on available HTCs in areas to which you might have to evacuate.
- Contact your local emergency management office or public health department for information on sheltering in place and other safety procedures for your area.

In the Game

Managing Heavy Periods So You Can Remain Active

Great Lakes Hemophilia Foundation
Headline News - August 2011

By Heather Boerner

Originally Published in Hemaware, July 2011



When she was in high school, Meghan McDonald, 20, felt she could not tell her private dance instructor about her type 1 von Willebrand disease (VWD). It wasn't that she was embarrassed by the [nosebleeds](#) or muscle bleeds. It was that, for weeks at a time—clad only in a leotard and tights for up to three hours a day, five days a week—she had a [heavy period](#) that required frequent bathroom breaks.

McDonald was mortified talking about her period. “No girl wants to be thought of as the one with bad hygiene,” she says. “I was very self-conscious, always worrying if blood was running down my leg or whether I started to leak when I stretched. It made it hard to concentrate.” McDonald, a native of Louisville, Kentucky, is now a junior dance major at Smith College in Northampton, Massachusetts.

For many girls with bleeding disorders, physical education class, exercise and participating on sports teams are complicated not just by the risk of nosebleeds or joint or muscle bleeds, but also by menstrual cycles that are excessively long, heavy and painful. They can feel self-conscious changing in the school locker room or nervous about being required to wear gym clothes.

“The goal is to manage symptoms so girls aren't faced with the need to miss school,” says Danielle Nance, MD, a fellow in hemostasis and thrombosis at the Puget Sound Blood Center and University of Washington in Seattle. There are medications that can help control the bleeding so girls don't have to miss out on normal activities or feel embarrassed.

Controlling Your Period

A period that lasts for more than seven days, passes clots the size of a quarter, is linked to iron deficiency, or that causes you to bleed through protection more than once every two hours is not under control. Girls who experience these symptoms or miss school because of their periods should work with their hemophilia treatment center (HTC) to find a solution, Nance says. It's also imperative to [check with a gynecologist](#) to rule out any other conditions that might cause excess bleeding.

To get your bleeding under control, the first thing your doctor may prescribe is oral hormone therapy, [birth control pills](#). The hormones regulate bleeding and can often make periods lighter and less frequent. “These medications are known as birth control, but for girls with bleeding disorders, they're really bleeding control,” says [Lisa Perriera](#), MD, an assistant professor in the Department of Obstetrics and Gynecology at University Hospitals Case Medical Center in Cleveland.

Research is now under way on how the Mirena[®] hormonal intrauterine device (IUD) can help girls and women with bleeding disorders. The tiny T-shaped plastic device releases levonorgestrel, which, in addition to regulating fertility, regulates the buildup and release of the uterine lining, making women's periods shorter and lighter. Other hormonal contraceptive formulations give girls the option of having their periods four times a year or even once a year.

Hormonal contraception helped Callie Clark get her bleeding under control. Clark, 19, a Toledo native who attends Miami University in Oxford, Ohio, has moderate to severe type 1 VWD. She is an avid dancer and was a member of her high school's track team. Her periods sometimes lasted for three weeks, and she would sometimes bleed through her protection every hour.

Clark tried several types of hormonal birth control before settling on NuvaRing[®], a flexible, hormone-emitting contraceptive that fits inside the vagina. Now she gets her period every four months. "It's a godsend," says Clark. "By the time track season started up, I was in good shape. I didn't have to miss it ever."

Other options are medications such as [Stimate Nasal Spray](#),[®] a highly concentrated form of desmopressin (DDAVP), or [Lysteda](#),[™] an oral form of tranexamic acid. For women with type 3 VWD, the most severe type, daily infusions of plasma-derived von Willebrand factor containing factor VIII concentrate are another option.

Creating a 504 Plan at School

Regardless of how well controlled a girl's bleeding disorder usually is, it's still a good idea to have a 504 plan for gym class, Nance says. (See "[Learn More](#).") Under the Rehabilitation Act of 1973, [a 504 plan provides accommodations](#) for students who need them. Unlike an Individualized Education Program (IEP), which addresses a variety of disabilities, the 504 may be used for students with medical issues.

The 504 plan outlines a student's health condition and treatment. In the case of heavy periods, the plan may spell out that a girl is allowed to leave class frequently to go to the restroom, do alternate exercises in physical education class or opt out of sports when her bleeding is at its worst.

Today, McDonald uses NuvaRing to keep her periods well controlled. She's outgrown her fear of talking about her period. "If I could go back and redo high school, I would have better communication with my dance instructor and my teachers," McDonald says. "It's all about advocating for yourself and voicing what you need so you can continue what you want to do on a daily basis."

The Universal Data Collection (UDC) System

Lessons Learned and Future Directions

Hemophilia and other bleeding disorders can cause lifelong problems and complications. The Centers for Disease Control and Prevention (CDC) established the Universal Data Collection (UDC) system to gather information about complications that occur among patients receiving care in hemophilia treatment centers (HTCs) throughout the United States. Researchers are using this information to learn more about why some people with bleeding disorders develop complications while others do not.

What have we learned from UDC?

The UDC system was designed to monitor trends and changes over time, so some of the analyses are just beginning. However, many articles have been published describing the findings to date. Following are a few of the areas in which some of these findings are detailed:

Joint Health

Joint infections are a rare complication of hemophilia and occur mostly in target joints or in joints that have undergone joint surgery.

Males with hemophilia who are overweight are more likely to have less mobility in their joints than those who are not overweight.

Inhibitors

The rate of new inhibitors among previously treated patients with hemophilia is very low, but more study is needed to determine why they occur.

People with inhibitors are at higher risk for joint disease and other complications from bleeding, resulting in reduced quality of life.

Treatment Practice

Treatment practices (such as prophylaxis, which is regularly scheduled treatment using clotting factor to prevent bleeding) differ among HTCs. Further study is needed to understand why these differences exist.

Prophylaxis appears to decrease bleeding inside the head (which is known as intracranial hemorrhage)

among patients with severe hemophilia who do not have an inhibitor or human immunodeficiency virus (HIV).

Babies

The most common sites of bleeding among babies are the circumcision site and the head (either inside or outside the skull). Bleeding inside the head (intracranial hemorrhage) is a serious complication and results in serious brain injury among 20% of patients.

More than 70% of the 580 babies with hemophilia enrolled in UDC from 2003 to 2007 reported having a bleeding episode before 2 years of age, and one in five of these bleeds involved the head.

In the United States, most people with hemophilia are diagnosed at a very young age. Half of those people with mild hemophilia are diagnosed by 3 years of age, half of those with moderate hemophilia by 8 months of age, and half of those with severe hemophilia by 1 month of age.

Academic Achievement

Men with hemophilia A graduate from high school at a similar or higher rate than the national population of men.

The UDC system monitors major complications of bleeding disorders, such as:

- Developing or worsening joint disease, or both
- Developing inhibitors (a substance in the body that inhibits—that is, stops—bleeding disorder treatments from working)
- Acquiring diseases such as hepatitis and acquired immune deficiency syndrome (AIDS) through blood products





Overweight and Obesity

Youth with hemophilia are just as likely to be overweight as youth among the general population; however, the extra weight puts them at increased risk for long-term damage to their joints.

Males with hemophilia who are overweight are more likely to have less joint mobility than those who are not overweight.

Blood Safety

Since 1998, no new infections of hepatitis A, hepatitis B, hepatitis C, or HIV have been linked to using blood products to treat bleeding disorders.

Samples of stored blood from UDC system participants from the early days of the West Nile virus epidemic (2002–2003; before the virus

spread across the country) showed no evidence of spread of the virus through clotting factor products.

In 2004, a study of stored blood showed that very young children who used plasma-derived clotting factor products were more likely to have been exposed to parvovirus B19 infection. This led to increased testing as part of the manufacture of these products.

Changes in Causes of Mortality

Among deaths of people with bleeding disorders reported to CDC during the period 1997–2007, the most common causes were related to HIV (19%) and liver disease (22%). Hemophilia-related (bleeding) causes were less common (12%).

What studies currently are being conducted using UDC system data?

HTC investigators are busy looking at the UDC system data to find out more about:

- Inhibitors and ways to find and measure them.
- Links (if any) between the type of genes a person has and if the person will develop an inhibitor.
- Joint disease among people with severe von Willebrand disease.
- Hereditary bleeding disorders among women.
- Causes and consequences of bleeding in or around the brain.
- Use of routine preventive treatment.
- Use of devices that allow health care providers access to a patient's vein to provide treatment or draw blood.
- Joint disease and how it progresses among people who already have damaged joints.
- Parvovirus B19 and whether the testing the manufacturing companies are doing has decreased the risk of this infection from clotting factor.
- The extent of vaccination among the community with bleeding disorders and the effectiveness of prevention messages.

What future studies are planned?

Researchers plan to study:

- Reasons why some children with hemophilia have more loss of joint mobility than others, even though they do not bleed more often.
- Bleeding symptoms and other signs of severe von Willebrand disease.
- Complications among children with hemophilia who are younger than 2 years of age.



Win an iPad 2 in the 10 for 10 Challenge

Great Lakes Hemophilia Foundation
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Great Lakes Hemophilia Foundation wants you to take part in the 10 for 10 Challenge. The challenge is simple and the payoff is big. When we say "big" we mean iPad 2 big! Are you up for the challenge?

10 for 10 Challenge:

What if all 500 Wisconsin walkers talked to 10 people about the Hemophilia Walk?

- 5,000 more people would know what hemophilia is.
- 5,000 more people would know that ANYONE can have a bleeding disorder.
- 5,000 more people would know about an organization you support.



What if we asked those 5,000 people for only \$10 each?

- We could raise an additional \$50,000 for the Wisconsin bleeding disorders community.
- Think about how many kids could go to summer camp or attend the new family camp in Wisconsin with an extra \$50,000.
- The Wisconsin Bleeding Disorders Conference could accommodate addition families and enhance the education and networking programs with an extra \$50,000.
- \$50,000 could go a long way when assisting families with insurance premiums and medical bill expenses.
- With \$50,000 think of how many scholarships we could award, and so much more.



If we all take a simple step, we could make a huge impact on the bleeding disorders community.

We challenge you to take the 10 for 10 challenge. Ask 10 people for \$10!
For every \$100 you raise by September 16th you'll be entered to win an iPad 2.

We challenge you to make a difference for the Wisconsin bleeding disorders community!

Take a step and walk with us.

Saturday, August 27, 2011
[Henry Vilas Park in Madison, WI](#)

Saturday, September 10, 2011
[Schildt Park in Neenah, WI](#)

Saturday, September 24, 2011
[Harvest Fair at Wisconsin State Fair Park in West Allis, WI](#)



National Prevention Strategy Released

Great Lakes Hemophilia Foundation
Headline News - August 2011

National Hemophilia Foundation
E-notes July 2011



On June 16, the Obama Administration released the National Prevention and Health Promotion Strategy. Created by the National Prevention, Health Promotion, and Public Health Council, a group of 17 federal agencies, in consultation with the public and an advisory group of outside experts, the strategy is a comprehensive plan to promote better health and healthy lifestyles on a national scale. It recognizes that good health comes from quality medical care along with clean air and water, safe workplaces and healthy foods.

“The National Prevention Strategy, called for under the Affordable Care Act, will help us transform our health care system away from a focus on sickness and disease to a focus on prevention and wellness,” said Kathleen Sebelius, Secretary of the US Department of Health and Human Services. It includes actions that the government, the public, and private partners can take to improve health and fitness, reducing the demand placed on the healthcare system.

The strategy outlines four strategic directions for improving the nation’s health:

- Building Healthy and Safe Community Environments
- Empowering People to Make Healthy Choices
- Eliminating Health Disparities
- Expanding Quality Preventive Services in Both Clinical and Community Settings, which includes supporting and implementing coordinated care models, such as hemophilia treatment centers.

Within these strategic areas, the strategy focuses on seven priorities that are most likely to reduce the causes of preventable death and major illness:

- Tobacco-free living
- Preventing drug abuse and excessive alcohol use
- Healthy eating
- Active living
- Injury- and violence-free living
- Reproductive and sexual health
- Mental and emotional well-being

In the future, the strategy will guide how resources are allocated and how programs are funded.

More information on the National Prevention Strategy can be found at:
<http://www.healthcare.gov/center/councils/nphpphc/index.html>.

GLHF's Campers & Scholars Say Thank You!

Great Lakes Hemophilia Foundation
Headline News - August 2011



For over 20 years Great Lakes Hemophilia Foundation has sent youth to summer camp with the help of "Camperships" funded by our donors and friends. This year's campers and parents share the joy of the camp experience and what it means for a child with a bleeding disorder.

"My 2 children came home without worrying about the bleeding disorder stopping them from being able to join their friends. This was the first year I didn't have to worry about getting a phone call when they got hurt or anything else because they were able to take care of it themselves."

- Mother of two children with bleeding disorders, aged 11 and 9

"Camp was helpful for my son to better understand what activities he can do with no dangers. God bless you for your generosity, and there be more people like you who care for others.'

- Parents of 13-year-old child with a bleeding disorder

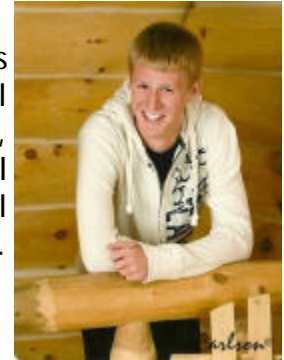
"Eagle outpost helped me become more independent in my infusions. Going to camp is the big reason I want to become a counselor so I can help kids with their condition like I was helped when I first started to go to camp."

- Happy camper, Age 16



Another service Great Lakes Hemophilia Foundation is proud to provide is annual scholarships that help students with bleeding disorders earn a degree that will help them get a job with essential health insurance. Our recipients share their story:

"Opening the letter about the scholarship was the biggest highlight of my entire summer. Once I earn my degree I hope to get a career marketing in the fishing and hunting industry, something I am very passionate about. I know with a job like that, I will not have to worry about my bleeding disorder while I am working and I know I could do it the rest of my life with no real health concerns."
-Alex J. Ostrowski



"This scholarship will help me in my career at Notre Dame, and in my goal of becoming a hematologist in the future. This summer I was able to learn more about blood disorders through my internship with the Platelet Neutrophil Immunology Lab ... this job and this scholarship will help me significantly in my educational journey. Thank you so much for helping me in my educational and career goals."
-Maureen Riegert

Thank you to the donors that have made these services possible:

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Michael & Sara Ottenberg

Special Giving Opportunity

Great Lakes Hemophilia Foundation
Headline News - August 2011

Maripat Monahan, Director of Resource Development



As we approach the fall season, many of us have a special opportunity to support Great Lakes Hemophilia Foundation. If your employer offers a workplace giving campaign, such as United Way or a Combined Federal Campaign, you can pledge a gift through the campaign and designate your donation to Great Lakes Hemophilia Foundation. This method of giving offers the convenience of payroll deduction so your payment can be spread out over the whole year.

United Way Campaigns usually take place in the months of October, November and December. In order to designate your gift to Great Lakes Hemophilia Foundation you may have to ask for information about the Donor Choice program. Through Donor Choice, you have the option to select from many specific charities. GLHF is listed under Community Health Charities. Whether your employer participates in Donor Choice or not, you may be able to enter GLHF as a write-in designee.

Please consider making a generous gift to support the programs and services GLHF provides to the bleeding disorders community, and encourage your friends and family to designate Great Lakes Hemophilia Foundation through their workplace giving campaigns also. We greatly appreciate every donation - large or small - that supports the GLHF mission.

If you have questions about giving to Great Lakes Hemophilia Foundation through a workplace giving campaign, please contact Maripat Monahan at 414-937-6783 / mmonahan@glhf.org. Thank You!