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A Shared Responsibility – A Shared Opportunity

Great Lakes Hemophilia Foundation
Headline News - April 2010

Sandy Lampman, Executive Director



Over the next few months we at GLHF will be focusing on building community. Building community. You've heard the phrase used over and over again, but have you given much thought to what it really means?

The dictionary defines community as a group of people with a common background or with shared interests within society.

The communities in which we belong help define, support, teach and engage us. We find strength in community and it can give us a sense of belonging and purpose.

Our reasons for being a part of a community are different, but there is a common thread of understanding and responsibility among each of us within a community. You are reading this newsletter because one of the communities in your life is the bleeding disorders community-as a patient, parent, sibling, healthcare provider, sponsor, friend or volunteer.

Being a part of a community is a little like being a part of a family – it can feel warm, fun, and embracing, but it can also be frustrating at times because of our different views, opinions and priorities. It is, however, these very differences, interests and roles that strengthen the fabric of the community.

Each of us gains something from being a member of a community; in return we have a responsibility and an opportunity to contribute to the community to ensure future generations will also benefit. Contributing takes many forms: sharing ideas, providing feedback, participating in events, volunteering, and offering financial support.

Challenge yourself and challenge us here at GLHF. Let us know how we can work together, in what direction you would like us to move and how you can contribute.

Great Lakes Hemophilia Foundation exists to advance the interests of the bleeding disorders community. Your positive contributions toward building GLHF will ensure our common goals as a community are achieved. Be a part of the solution. We would like to hear your ideas of how to build community. Please email us at info@glhf.org.

Navigating the Emergency Department

Anticipate, Educate, and Advocate

This article is adapted with permission from the CDC workbook, Basic Concepts of Hemophilia. This workbook is intended to help families and young adults learn the fundamentals of hemophilia and serve as a catalyst for dialogue with treatment center staff.

Great Lakes Hemophilia Foundation Headline News - April 2010

Mary Anne Schall, Regional Coordinator



While the vast majority of individuals with a bleeding disorder manage their routine infusions of factor at home, there may be times when you or your child may require an emergency department visit. Stories abound about long waits, repeated sticks, and medical staff who do not believe a bleed they cannot see. However, a visit to the emergency department (ED) can be a more positive experience if you -- anticipate, educate, advocate.

Anticipate- Have a Plan

Emergency rooms can be busy and stressful. If possible, try to have a plan in place before you visit the emergency department. Talk to your treatment center staff about their recommendations which might include:

- A modified treatment plan in place in the ED (how much factor, what type of factor concentrate, etc.)
- A letter from your treatment center physician with details of your treatment that you can give to the staff of the emergency department
- A recommended emergency department in your local community
- A phone number where you can reach a member of your treatment center team after business hours (on-call number)

Educate

Even if you have a plan, you may encounter difficulties. It is important to understand that health care providers in an emergency room cannot be experts in everything and thus may not be experts in the care of bleeding disorders. It is important that you let them know that you or your child has a bleeding disorder and that it needs to be treated quickly. Physicians are accustomed to running tests before they prescribe treatment. Thus, it is critical to stress that when children with bleeding disorders are seen in the ED for a suspected bleed, they should be given factor before any diagnostic tests are administered. In an emergency situation, time is a critical element. If the staff do not seem to know how best to treat, let them know that you or your child is seen by a local treatment center. Give them your center's after-hours (on-call) number so they can talk to your physician. Sometimes you may have to ask more than once. Do not give up. If you feel uncomfortable, insist that someone contact the treatment center, or make the call yourself.

Educate the staff. Stress the importance of having a skilled phlebotomist. A child in an emergency situation, especially a child with a bleeding disorder, is not the patient on whom medical students and residents should learn intravenous techniques. Repeated needle sticks can cause bruising around the vein and soft tissue hematomas—conditions that may cause further trauma and make future attempts at intravenous access problematic.

Advocate

Effective advocacy has two key elements: 1) Getting the information you need about your condition and treatment; and 2) interacting with providers to obtain the best care possible. Both of these elements can be achieved through good communication. Good communication does not mean that everyone always agrees. Sometimes conflict can occur. At times, you may feel that the providers are not treating you or your child appropriately (for example, having to wait for treatment in an emergency room). There are times when you need to speak up about the problem and your concerns.

This can be difficult. However, if you do not speak up about your concerns you will not get the problem solved. The best way to handle conflict is to use assertive statements -- state clearly and specifically what is causing the problem, how you feel about the problem, and what you would like to see happen. For instance, in an emergency department conflict you might say, “When you refuse to give my child factor right away, it worries me because factor is important to immediately stop bleeding in a child with hemophilia. I need you to call my child’s hemophilia physician. Here is the number.”

You will find that most providers want to work with you to resolve problems. Sometimes you may have to state your problem more than once. That’s okay. Be persistent. No one else will be as interested in solving your problem as you are. On those rare occasions when problems are difficult to solve, it can help to involve staff from your center. They can help you find the resources you need or help negotiate an acceptable solution. After an emergency department visit, follow-up with the emergency department director if there are things about your visit that you would like to see changed in the future. Bleeds may be an inevitable part of having a bleeding disorder, but a bad experience in an emergency department doesn’t have to occur. Remember things will not change for the better unless you stand up for yourself or your child. Advocacy is giving a voice to your questions and concerns and following up responsibly.

Health Reform Prioritizes Creating National High-Risk Pool

National Hemophilia Foundation e-notes

Great Lakes Hemophilia Foundation
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Last month, President Obama signed sweeping healthcare reform legislation into law. Read a [summary of the health reform legislation](#). Some provisions of the law will become effective as early as the end of June and many others by September.

One of the first provisions taking effect is the creation of a temporary national high-risk pool to provide coverage to adults who have been uninsured for six months as a result of pre-existing conditions. The health reform bill provides \$5 billion to create a network of risk pools by July 1, which will exist until 2014, after which insurance companies will no longer be able to deny coverage to adults with pre-existing conditions. Unlike current high-risk pools, the new high-risk pool program will require plans to keep their premiums at “standard rates” that are no higher than what the average person of that age would pay for insurance in the private market.

Many aspects of the new program are still unclear, such as how the \$5 billion will be distributed to states. Last week, the Secretary of the U.S. Department of Health and Human Services sent a letter to states outlining several options for implementing the new high-risk pool program. Our current understanding is that states with existing pools will maintain them and create new pools to satisfy the new law.

The implementation of the new high-risk pool program is just one example of how quickly some provisions of the bill will be implemented and the need to monitor this process closely. NHF’s state and federal advocacy teams are working together to closely monitor the implementation of the new laws. We will keep you informed via articles in eNotes, HemAware and on the NHF Web site. Another good Web site to track progress of the implementation is: www.healthreform.gov. Please feel free to contact NHF’s advocacy team if you have questions by visiting www.hemophilia.org.

Advocating in Wisconsin

Great Lakes Hemophilia Foundation
Headline News - April 2010

Shelly Mattson, Community Member



Advocacy efforts have been in full swing at Great Lakes Hemophilia Foundation. To date, 16 individuals and their family members have committed to meeting with their local legislator in-district to tell their story, educate and inform them about bleeding disorders, and discuss important issues concerning the bleeding disorders community. The senators include: Sen. Jon Erpenbach (D-Middleton), Sen. Mary Lazich (R-New Berlin), Sen. Fred Risser (D-Madison), Sen. Judy Robson (D-Beloit), Sen. Russ Decker (D-Weston), Sen. Scott Fitzgerald (R-Juneau), Sen. Tim Carpenter (D-Milwaukee), Sen. Alberta Darling (R-River Hills), Sen. Robert Wirch (D-Salem), Sen. Pat Kreitlow (D-Chippewa Falls), and Sen. Joseph Leibham (R-Sheboygan). The representatives include: Rep. Sandy Pasch (D-Whitefish Bay), Rep. James Soletski (D-Green Bay), Rep. Steve Kestell (R-Elkhart Lake), and Rep. Joan Ballweg (R-Markesan).

The goal of the meetings is to develop and/or strengthen relationships with legislators in the event legislation is presented in the future that may positively or negatively affect individuals with bleeding disorders. The meetings will also provide an opportunity to remind legislators about the importance of the following issues:

- ♦ Health Insurance Risk Sharing Plan (HIRSP), which offers health insurance to Wisconsin residents who either are unable to find adequate health insurance coverage in the private market due to their medical conditions or who have lost their employer-sponsored group health insurance.
- ♦ Wisconsin Chronic Disease Program (WCDP), funded entirely by state dollars, which offers assistance to Wisconsin residents with chronic renal disease, hemophilia, and adult cystic fibrosis. The WCDP pays health care providers for disease-related services and supplies provided to certified participants after all other sources of payment have been exhausted.
- ♦ Prophylaxis, or the preventive measure against spontaneous bleeds by infusing factor product on a consistent and proactive basis may appear to be expensive, but actually proves to be more cost-effective in the long-run by minimizing long-term joint damage and the ensuing disability of patients with bleeding disorders that treat on an episodic basis.

Advocates will also inform legislators about the bleeding disorders community's position regarding a Sole Source Pharmacy Provider, that is a designation of a pharmacy contracted without competition to be the sole supplier of factor product. Although a sole source pharmacy provider may be appealing for its administrative ease, in the long run an inability for patients to choose among various clotting factor products may cause a variety of negative consequences. These include reducing market competition, elevating the cost of factor, and potentially increasing the likelihood of expensive and even life-threatening complications, such as inhibitors.

If you are interested in meeting with your local legislator, Great Lakes Hemophilia Foundation will help you set up a meeting. Even if you have had no prior experience in advocacy—not to worry. If you have a story to share, then you are already an advocate! GLHF is happy to help you out with the rest.

Advocating En Masse at Washington Days

National Hemophilia Foundation

Great Lakes Hemophilia Foundation
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National Hemophilia Foundation e-notes



Wisconsin Advocates: Stacy Brault, Sandy Lampman, Congresswoman Tammy Baldwin, Kimberly Haugstad and Michael O'Connor

Approximately 300 people traveled to Washington, D.C. on February 24-25, 2010 to participate in the National Hemophilia Foundation's Washington Days annual advocacy event. When meeting with their senators and representatives participants focused on two key issues: maintaining federal funding for the U.S. Centers for Disease Control and Prevention's (CDC) hemophilia program and garnering support for the private insurance reforms included in health reform.

Washington Days provides the bleeding disorders community the opportunity to educate Congress about the issues affecting us and to spotlight the importance of the hemophilia treatment center (HTC) network. This year's effort is particularly important because President Obama's FY 2011 proposed budget for the CDC zeroes out the hemophilia program, reallocating the money for a "public health approach to blood disorders." It is not clear what the CDC intends to do with this new approach and there is no guarantee that existing hemophilia program activities will be adequately supported. Participants this year advocated for the reinstatement of the CDC's hemophilia program to ensure that access to care at HTCs is not jeopardized.

Efforts on the health reform front were directed at advocating for key private insurance market reforms to be included in the final reform legislation, which will benefit individuals with bleeding disorders and other high-cost, chronic and rare conditions. Participants requested that the final health reform legislation have the strongest possible patient protections and ensure access to health insurance plans for individuals with high medical costs. We respectfully requested that the final health reform legislation be applicable to all insurance plans--existing and new plans--and that it include the immediate elimination of lifetime and annual caps, and other key reforms such as the elimination of pre-existing conditions exclusions.

For more information on the funding issue regarding the CDC's hemophilia program be on the lookout for e-mail blasts from NHF's policy department. To stay up to date on health reform and opportunities to get involved, please visit the Advocacy section at www.hemophilia.org.

One Boy's Journey

Incorporating sports into life with a bleeding disorder

Great Lakes Hemophilia Foundation
Headline News - April 2010

Maripat Monahan, Director of Resource Development



The Haas family discovered son, Briar, was born with von Willebrand disease when he was three years old. Briar is now an energetic nine year old who loves football and wrestling. In fact, Briar is a wrestling champion. At six years old he won first place in a national wrestling tournament, and is a three-time state qualifier in the sport. But Briar's sports participation was a deliberate decision he and his parents reached together. Not all children with bleeding disorders are given free rein to play sports. Doctors and parents have varying views about the wisdom of sports play for kids with bleeding disorders. This is among the many decisions that face families affected by bleeding disorders, and why it's so important for families to feel part of a greater community.

Carmen Hass recalls that staff at the Hemophilia Outreach Center in Green Bay suggested that their family could benefit from becoming involved with Great Lakes Hemophilia Foundation. Carmen has since appreciated that Briar has been able to make friends with other children with bleeding disorders, something he desperately needs for normal social development.

"At GLHF events, he gets to hang out with kids who have bleeding disorders too, and he learns from them," says Carmen. At school, the Hass family tries to spread awareness of Briar's condition to the children in his classes, but older children still refuse to let him play football. According to Carmen, the older children tell Briar "You have a disease, you can't play," but she hopes that the children his age who have been educated about vWd will defend him. The need to fit in has led the Hass family to become more involved with Great Lakes Hemophilia Foundation events, where Carmen says most of Briar's friends forget that he even has vWd.

GLHF provides its clients access to a wide range of events, such as the annual Wisconsin Bleeding Disorders Conference (formerly the Fun & Education Weekend), and summer camp. These events provide the Hass family and many other Wisconsin families affected by bleeding disorders a chance for children like Briar to be with other children who share their unique experience and to feel normal, one of Carmen's primary concerns for her son. "I just hope that he can grow up and lead a happy and healthy life," she says.

Briar, like so many other youth with a bleeding disorder, has had transformative experiences at summer camp. He first attended a special bleeding disorders summer camp in 2008 with a GLHF

campership. This experience helped him turn a corner his mom had hoped he could. Prior to attending camp, Briar felt isolated and lamented being different from the other kids at school. Once at camp, Briar was in his element. Not only did he have access to sports activities, he celebrated his new experience, saying “I had fun meeting new friends. Now I know I’m not the only one with vWD.”

During Briar’s second year at summer camp, again through a GLHF campership, Briar gained confidence and an improved self image. After returning home, Carmen observed her son relating to those kids at school who gave him a hard time about his disorder. Briar no longer looked to his mother for support in these situations, but handled them with greater ease and confidence than ever before.

When Briar lost his medic alert bracelet last year and GLHF replaced it through our Patient Financial Assistance Program, Carmen thanked GLHF, saying, “the memories and self esteem that Briar gains through his involvement with GLHF are much more precious and difficult to replace.”

The Hass family genuinely appreciates the support they receive through participation in GLHF events, and embraces being engaged members of the bleeding disorders community. This year, the Hasses are leading the planning committee for a fundraiser walk event scheduled to take place in Neenah in the fall. Keep an eye out for more information about this event.

You can help Briar and his family, and many other families throughout Wisconsin who face the challenges that accompany a bleeding disorder. Here’s how:

- Visit our website to make a donation glhf.org
- Sign up at Pick ‘N Save or Copps to have GLHF benefit every time you shop. GLHF’s ID # is 293550.
- Use GoodSearch (powered by Yahoo) to surf the net – be sure you designate GLHF as your charity of choice.

Get involved! Attend a GLHF event, join a committee, hold a Party with a Purpose...give us a call to talk about any creative way you can think of to garner resources for GLHF so we can keep supporting families with bleeding disorders.

A Note from the Executive Director

...And the survey says!

Great Lakes Hemophilia Foundation
Headline News - April 2010

Sandy Lampman



As you know, over the last few months the staff and Board of Directors of Great Lakes Hemophilia Foundation have been engaged in a process to hear from a number of individuals about their perspectives on the role of GLHF. We spoke with current and inactive clients, individuals with bleeding disorders who have never engaged with GLHF, the four Wisconsin hemophilia treatment centers, pharmaceutical industry representatives, and Chapter executives and healthcare leaders from around the country.

We will be using the information to cast the future direction of Great Lakes Hemophilia Foundation. As you would expect, the community has differing views on the future role of the organization, but common threads exist.

Over the upcoming months, we will share some of the information we learned from the market research firm, The Mosaic Group, who interviewed 62 individuals with bleeding disorders (or parents of children with bleeding disorders) – 25 active clients, 25 inactive clients and 12 individuals who have never engaged with GLHF. Individuals from all four hemophilia treatment centers were represented. Both males and females were represented as well as individuals from a broad range of diagnoses and severity of hemophilia, von Willebrand and platelet function disorder.

Here are some of the results...more to come in upcoming newsletters!

What sources do you use to educate you/your family about your bleeding disorder? All that apply.

- ◆ 60 of 62 respondents listed their hemophilia treatment center (HTC) as their primary source for information.
- ◆ 56 of 62 respondents listed newsletters from various sources as their secondary source.
- ◆ 47 of 62 respondents mentioned hemophilia foundations (NHF, GLHF, HFA, Hemophilia of Georgia and Hemophilia Foundation of Illinois)
- ◆ 36 of 62 respondents listed word of mouth/networking as a source of information
- ◆ 33 of 62 respondents listed the internet as a source of education (favorite sites included webMD, MedicalNews.com, nhf.org, glhf.org and the Baxter site)

Do/did you receive information about GLHF from your HTC?

- ♦ 33 of the 62 respondents recall receiving information from the HTC about GLHF.
- ♦ 22 of the 33 took the next step and contacted GLHF about services, camp and other specific events.
- ♦ The 11 who did not contact GLHF did not feel the need to reach out.

How important is it that GLHF arm individuals with bleeding disorders with the knowledge and skills to grow and develop to optimum levels?

- ♦ 60 of the 62 respondents felt it was important or very important that GLHF arm individuals with knowledge and skills, however some respondents remarked it's not the responsibility of the organization and individuals need to take initiative.
- ♦ One respondent said, "Help educate the patients to be pro-active with the doctors", another respondent remarked, "By educating yourself, you are better able to cope with the disorder."
- ♦ Still another thought this was the role of the treatment center to arm patients with knowledge and skills.

Would you like to weigh-in on these three questions? Email your comments to info@glhf.org!

Thanks for helping us cast the future!

Annual Wisconsin Bleeding Disorders Conference

Life's A Stage, Act One: Building Community

Great Lakes Hemophilia Foundation
Headline News - April 2010

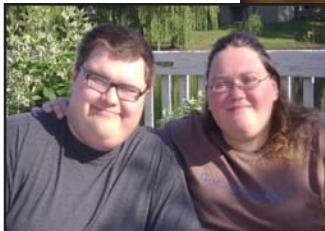
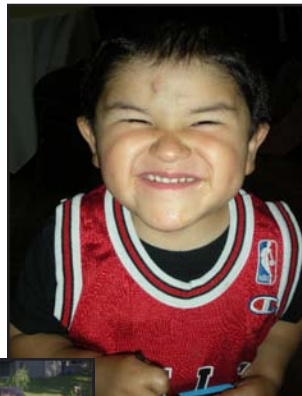
Karin Daniels, Program Services Coordinator



Each year families from the Wisconsin bleeding disorder 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 those 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 12-13, 2010.

Registration materials and a tentative agenda, including programs on *healthcare reform, dealing with stress and chronic illness, cooking and wii olympics to name a few*, are now available at glhf.org. Please contact Karin at the Foundation if you would like to register or have any questions.

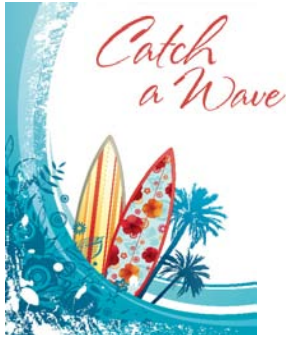
2009 Annual Weekend



Catch A Wave Gala

Great Lakes Hemophilia Foundation
Headline News - April 2010

Jessica Kveen, Special Events Coordinator



Gala guests enjoyed a beach party at this year's "Catch a Wave" gala on Saturday, March 20th. Guests bid on exciting auction items, had the chance to dig for gems thanks to a generous donation by Jewels Jewelry Design, and sipped on our signature drink provided by Badger Liquor.

A special thank you to the evening's sponsors, our honored guests, and all the volunteers who put in long hours coordinating the event!

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Save the Date



May 14, 2010
Campership Application
Deadline



May 17, 2010
Teeing Up for Charity
The Bog, Saukville, WI



June 12-13, 2010
Annual Wisconsin Bleeding
Disorders Conference
Life's A Stage, Act One:
Building Community
Kalahari Resort
Wisconsin Dells, WI



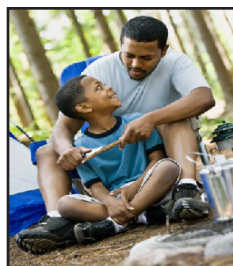
August 7, 2010
Walk with the Animals
Vilas Park
Madison, WI



September 18, 2010
Walk Event
Neenah, WI



September 25, 2010
Hemophilia Walk
Harvest Fair, Wisconsin State
Fair Park
West Allis, WI



October 2-3, 2010
Father - Son Weekend
Location TBA

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