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Let Your Voice Be Heard

Great Lakes Hemophilia Foundation
Headline News - February 2011

Mary Anne Schall, Interim Executive Director



For over 30 years, Great Lakes Hemophilia Foundation (GLHF) has dedicated itself to advocating on behalf of the bleeding disorder community. In the fall of 2010, the GLHF Board of Directors and staff created a strategic plan that recommitted advocacy as one of the Foundation's top three priorities over the next several years.

An important part of this commitment is the revitalization of the advocacy committee. This group of consumers, board members, and staff will develop strategies to address key issues at the state and national levels. With health care reform in flux and anticipated state and national budgetary shortfalls on the horizon, this moment is crucial for the bleeding disorders community. It is critical that we come together and let our voice be heard. The advocacy committee, with the assistance of our lobbyist, will be closely monitoring state budgetary allocations. Staff and members of the advocacy committee will be contacting and meeting with Wisconsin legislators. Plans are underway for our Wisconsin Legislative Day in Madison on April 20.

To make this happen, WE NEED YOUR HELP! We need you there, we need your voice, we need you to tell your story so the bleeding disorders community will be heard and not forgotten. Please consider joining the GLHF Advocacy committee by contacting Karin Daniels at 414.937.6782 or emailing kdaniels@glhf.org. Let us know if you have an existing relationship with a Wisconsin legislator. We can help you tap into that relationship to share your story. Mark your calendar for April 20 and join us for Legislative Day. You can register for Legislative Day online at glhf.org or calling 414.937.6781.

Change doesn't just happen. Whether it is a bill to direct the way Wisconsin regulates or finances bleeding disorder care, or assuring the continuation of the Wisconsin Chronic Disease Home Care Program, change is driven by people and organizations who are committed to making a difference and who help to persuade others. If policymakers are going to take action to preserve and expand access to quality care for people with bleeding disorders, they need to hear directly from YOU. By taking action you can assure that your child, a friend, a co-worker, a loved one, and you have access to high quality care when it's needed.

Advocacy is really very simple:

- **Don't' be intimidated.** Advocating for a cause is as American as baseball and apple pie. It is how we get important laws passed and how we change society.
- **Learn the issues.** GLHF will provide you with updates on bleeding disorder issues, an understanding of the issues, and the tools to engage in advocating for them.
- **Relax.** Although communicating with policy makers may seem intimidating, you can do it! Remember that Legislators were elected to represent you.
Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has. -Margaret Mead

Become a part of GLHF's advocacy efforts on behalf of families with bleeding disorders. Join us with your voice. No experience needed.

MASAC RECOMMENDATION

ON USE OF EMERGENCY MEDICAL IDENTIFICATION DEVICES FOR CHILDREN

Great Lakes Hemophilia Foundation
Headline News - February 2011

MASAC Document #201

The following recommendations were approved by the Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation on November 13, 2010, and adopted by the NHF Board of Directors on November 14, 2010.



The Nursing Working Group conducted a survey of use of Emergency Medical Identification (EMI) devices available for children and found that there are no devices appropriate for infants and young children under 3 years of age. In addition, the number of children wearing these devices is low in all age groups. Based on their study, the NWG has established the following guidelines for use of EMI devices in children:

- For all age groups, EMI should be worn on the body instead of externally such as in a wallet, on a car seat, or in a caregiver's purse or diaper bag. An emergency medical identification card placed in one of those locations can accompany the child, but this should not replace EMI on the child.
- The EMI should be identified with a medical symbol (i.e. Caduceus) and look like an EMI so it will not be mistaken for a piece of jewelry.
- The EMI should be fastened securely but not tightly and should be assessed frequently to insure that the fit is snug but not tight.
- Presently there is no ideal EMI for infants under 1 year of age.
- All EMIs placed on a child <3 years old which have emblems or clasps <1 3/4 inches should carry the warning: "Not intended for children <3 years old due to choking hazard."
- These are general guideline to be adapted to meet the needs of each child.

NHF does not endorse any specific brand of EMI, however being affiliated with a 24 hour on-call nonprofit program is encouraged.

Great Lakes Hemophilia Foundation (GLHF) will pay for a Medic Alert stainless steel bracelet, pendant or dog tag for individuals with a bleeding disorder needing financial assistance. The initial Medic Alert membership and the annual renewal will also be provided by GLHF when applicable.



You must contact your Wisconsin Hemophilia Treatment Center to arrange order and payment by GLHF.

"If I had a world of my own everything would be nonsense,"
and that's exactly what you'll find at
GLHF's Mad Hatter's Reception.

Let the Magic Begin at 5:30pm on Friday, March 25, 2011.



We are flipping this event on its head. Our traditional Gala is moving: time, place, and style. Join us on Friday, March 25, 2011 for a pasta bar, drinks, desserts, live and silent auction and raffles. No sit down dinner, but a chance to mix and mingle while raising money for the Wisconsin bleeding disorders community.

For more information or to RSVP visit glhf.org or, call 414-937-6780 or 888-797-GLHF

Help out the Reception Auction It's Fun and Easy!

Gather a group of friends, or maybe everyone in your office wants to chip in and create a splendid basket.

Try an Italian Themed basket- someone can buy a pasta pot, another person a romantic Italian movie, and a third can buy a few packages of pasta and sauce.

Or maybe a Family Fun night basket someone brings Monopoly, another Checkers, and someone else the popcorn and snacks.

There are endless possibilities if you use your imagination or [check out our website](#) for some more ideas.

Thanks for your help!

We need your help on the Acquisition team!

GLHF is looking for help securing the following Live or Silent Auction or Raffles packages. How you can help?

1. Take a peak at our [Auction/ raffle list](#) to spur some ideas.
2. Download or copy the attached letter and donation form.
3. Send them to businesses you have contacts at or utilize frequently, or to individuals that would be able to help secure items.
4. After you mail or e-mail out a letter, follow up with a phone call.
5. Let GLHF know who you are contacting, we can help you ask.
6. Say thank you! GLHF will send the donor an official thank you letter for tax purposes (yes all donations are tax deductible), but it's always nice to get an extra thank you!

Volunteer at the Reception!

We are looking for volunteers during the day on Friday, March 25th to help us set up the event, and during the evening to help run the event, if you are interested please [Click here to sign up](#).

Auction Spotlight!

Enjoy four tickets to see the Super Bowl Champion Green Bay Packers, head off to Walt Disney World, or enjoy Miller Beer for a year. Visit the [Auction Spotlight](#) online for more information.

Taking the “PAIN” out of “GAIN” in 2011

This article has been adapted from the Institute of Health website “We Can!”

Great Lakes Hemophilia Foundation
Headline News - February 2011

Mary Anne Schall, Interim Executive Director



You cannot open a magazine, walk through a store, or watch television without hearing about the benefits of healthy eating and exercise. Yet, many of us are overwhelmed by the thought of changing our life style even though we know it’s important. If you are interested in jump-starting your family on a healthy life style here are few strategies to make change easier and take some of the “pain” out of “gain” in 2011.

Pick Something Small to Adjust

Make small, easy changes over time. Suggesting that your family take a run together will probably get a lot of eye-rolling. It’s easier to start more modestly with something that the whole family is willing to try. You might suggest taking a walk after dinner a couple of nights a week. Avoid diets; instead make small manageable changes to your eating habits. For example, try putting a lighter cream cheese on your bagel. Eat two cookies instead of three. Small changes can have a big impact.

Focus on Family

As families, we can more successfully adopt healthy choices and make changes. It’s hard to make changes on your own. Creating family habits around smart eating and physical activity can make it easier for everyone to maintain a healthy weight. For example:

- Planning regular family time that involves physical activity means that everyone is supported and encouraged to be active.
- Putting a bowl of fruit on the kitchen counter and making a family agreement not to have chips or other high-calorie snacks in the house can change everyone’s snacking habits.
- Eating one family meal together every day has been shown to protect against obesity. Trying a new food will add a little adventure and helps picky eaters to expand their tastes.

Keep Moving

Limit video, TV, and computer time. Advances in medical therapy have given people with bleeding disorders freedom to enjoy activities that may once have been “off limits”. Studies have shown that in general, persons with toned muscles and strong joints experience fewer bleeds than inactive individuals. Keep in mind the three “Es” - start early, educate yourself, and chose activities that you enjoy.

Actively Choose

This means not doing things by default. When we are tired, we sometimes come home and automatically turn on the TV. Recognize that you have more control than you

might think. You can turn off the TV and limit computer games. You can give your family more vegetables for dinner. Stop and savor the moment and be conscious of your choices.

Making the decision to help your family eat well and get more physically active is the first step. For additional ideas, talk to your hemophilia treatment center staff, visit the "We Can!" website at www.nhlbi.nih.gov/health/public/heart/obesity/wecan/, or contact the National Hemophilia Foundation at 800-42-HANDI and request information about maintaining healthy weight, nutrition, and physical activity. Make a commitment to a healthier lifestyle for you and for your family.

Programs & Services Updates

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

Great Lakes Hemophilia Foundation
Headline News - February 2011

Karin Daniels, Program Services Coordinator



Wisconsin Legislative Day

Join GLHF in Madison, Wisconsin on Wednesday, April 20th for the Wisconsin Legislative Day at the Capitol. Meet with your State Representatives, learn how state government impacts health care and bleeding disorder policy issues and how YOU can make a difference through government advocacy. Register for the Wisconsin Legislative Day by March 28th by going to glhf.org, or by calling Karin at 414.937.6782.

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.

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.

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 glhf.org for an up to date list of GLHF scholarships and other bleeding disorder specific scholarships offered across the country. Mark your calendar, May 1st, GLHF scholarships are due! Contact Karin at the Foundation for further details at kdaniels@glhf.org or 414.937.6782 apply online at glhf.org.

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. The deadline is May 20, 2011.

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.

Upcoming Programs:

[Madison Legislative Day](#), April 20, 2011

[GLHF Scholarship](#) Deadline, May 1, 2011

[GLHF Campership](#) Application Deadline, May 20, 2011

[Wisconsin Bleeding Disorders Conference](#), June 11-12, 2011 in Wisconsin Dells

Family Camp, September 30-October 2, 2011 in Campbellsport, WI

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!

GLHF Welcomes Kathryn Reese the New Regional Coordinator

Great Lakes Hemophilia Foundation
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Kathryn Reese joined GLHF staff as Regional Coordinator on January 31st. Kathryn was selected to succeed Mary Anne Schall, who will retire in April after serving at GLHF in various capacities over the past 20 years.

Kathryn holds a Master of Public Health degree from Case Western Reserve University with a concentration in Management and Policy. Prior to joining GLHF, Kathryn held the position of assistant researcher at the Center for Urban Population Health (Milwaukee). She also brings three years of experience as a Public Health Program Manager within the Columbus Public Health Department. Among other distinctions, Kathryn is the recipient of the 2006 Case Western University Excellence in Public Health Award. Kathryn's skills and experience will be invaluable in assisting GLHF implement public health initiatives on the state and regional levels. Please join the GLHF staff in welcoming Kathryn Reese.

Factor XIII Deficiency One of Rarest Bleeding Disorders

Factor XIII needed to stabilize clots

Great Lakes Hemophilia Foundation
Headline News - February 2011

By Kurt Ullman | 02.05.2011
Published on hemaware.org



Update: [The Food and Drug Administration \(FDA\) approved Corifact](#), the first factor treatment for factor XIII deficiency available in the US, on February 17, 2011. Corifact is already available in 12 other countries under the name [Fibrogammin P[®]](#).

Kathy Stewart, co-president of the [Central Ohio Hemophilia Foundation](#) of Worthington, Ohio, is the mother of three grown children with factor XIII deficiency. - Factor XIII, also known as **fibrin stabilizing factor**, stabilizes the clot that forms when a person bleeds. A clot, made up of many clotting proteins and platelets, acts like a patch to stop bleeding. When some of the clotting proteins, called coagulants, are missing or not properly formed, the patch may not work effectively and the bleeding may continue. Without factor XIII, the clot will still form but it will be easily broken down, causing the bleeding to start again.

Factor XIII deficiency is one of the rarest bleeding disorders, affecting one in 5 million live births in the world, according to the [National Hemophilia Foundation](#). In contrast, **hemophilia A** affects one out of every 5,000 male births and **hemophilia B**, one out of 25,000 male births.

Kathy knows firsthand the difficulties of getting a proper diagnosis. "My son Nelson was not diagnosed until after his sister, Vanessa, was born," she says. "He had bleeding from a circumcision for more than a week that resulted in his being admitted to the hospital. All the tests they did showed no evidence of hemophilia. Finally, they gave him whole blood, which stopped the bleeding."

"Factor XIII stabilizes blood clots after they have already formed," says Bernard Silver, MD, staff physician in the hematology department at the Cleveland Clinic in Ohio. "This makes them durable and solid."

This is one major difference from the more common **bleeding disorders**. In hemophilia A and B, problems occur earlier in clot formation, and clots are not able to form at all.

"This deficiency is genetic, and both parents must have the gene to pass it along to the baby," says Diane Nugent, MD, medical director of [Hematology and Blood Donor Services](#) at the Children's Hospital of Orange County in Orange, California. "Unlike hemophilia A and B, which are passed along via the X sex gene to boys, factor XIII deficiency is seen equally in both boys and girls."

Umbilical Cord Bleeding May Be the First Clue

Bleeding from the umbilical cord is often the first symptom of **factor XIII deficiency**. Others include excessive bruising, nose and mouth bleeds, bleeding under the skin and bleeding into muscles. The bleeding is often delayed—that is, it occurs several days after surgery or trauma because clots still form normally, but the lack of factor XIII prevents clots from strengthening. A frequent and often devastating symptom is bleeding into the brain, also known as **intracranial hemorrhage**. Female carriers may have frequent miscarriages.

Because factor XIII holds a clot together after formation, most standard laboratory tests for clotting show normal results in a factor XIII-deficient person. The diagnosis is often made by the presence of symptoms and by eliminating other potential causes of bleeding. Specific tests for factor XIII and clot stability confirm the diagnosis.

When Kathy brought Nelson to the hospital after he had been bleeding for more than a week, the doctors told her it was a freak occurrence and that there was nothing to worry about. When Vanessa was born two years later, she bled from the umbilical cord, and an important part of the puzzle fell into place.

“This deficiency is unique in that virtually all of affected newborns have umbilical cord bleeding,” says Marilyn Manco-Johnson, MD, director of [Mountain States Regional Hemophilia and Thrombosis Center](#) in Denver. “One patient in four with the disorder will experience bleeding into the brain. This is much higher than rates seen in hemophilia A or B.”

Establishing the severity of the deficiency can be difficult. “One of the challenges to diagnosing this deficiency is that we don’t yet have a good test for those with 10% factor or less,” says Nugent. “This means there is not an exact number that we can link severity to, so we usually do that based on presentation. Those with frequent bruising and bleeding, especially into the brain, are considered severe while less bruising and bleeding only following a trauma like surgery are considered moderate. People who seldom bleed are considered mild.”

Factor XIII Deficiency Treatments Available

Two treatments for factor XIII deficiency are available in the US. Both are made from plasma, the liquid part of the blood. Although only factor XIII is needed, all the factors and proteins in plasma are included.

In the first treatment, fresh plasma is collected, frozen and stored until used. The second treatment, **cryoprecipitate**, requires that the plasma be frozen and then slowly thawed. This slow thaw causes the factor to separate from the plasma and is generally more concentrated than **fresh frozen plasma**. Unlike other forms of treatment, cryoprecipitate does not go through processes that can kill viruses in the blood and reduce the risk of transmitting these types of diseases. Because the treatments are considered blood transfusions, patients or their family members cannot infuse at home. Trips to the doctor or the emergency room are necessary.

“With both of these treatments, there are some concerns that patients should know about,” says Silver. “All products that come from plasma contain proteins and factors that are different from those naturally produced by the person receiving the treatment. This can cause an allergic, or what we call a hypersensitivity, reaction in some people.”

In addition, there is a small chance that viruses, such as those that cause hepatitis and AIDS, could be inadvertently transmitted in the plasma, along with the factors. All three medical experts interviewed for this story said that donors are screened, but that there is still what they called a “low, but not zero” risk of contamination.

A third treatment, Fibrogammin P[®], is available in Europe, Canada and Japan. It is still in the final stages of clinical trials in the United States and is only available through doctors participating in the Investigational New Drug study. This means the medication can only be given at larger medical centers and other places that have experience with the patient safeguards required by the [FDA](#). *Update: On February 17, 2011, the FDA approved Fibrogammin P[®], known as Corifact, for use in the US.*

This treatment is also made from plasma. Unlike the other treatments, only factor XIII remains and the medication undergoes an additional cleaning step, further reducing the chance of virus transmission. There is also a recombinant form of factor XIII undergoing study; that formulation carries no real risk of viral transmission.

“My children have also been prescribed Fibrogammin P[®], and it is much easier to use,” says Kathy. “It is easily stored in the refrigerator and can be given in the home without having to involve a doctor or nurses, so it saves trips to the emergency department.”

The available treatments are all used prophylactically to prevent bleeding episodes. “It is very important that both physicians and patients understand that prophylaxis is very feasible in this disorder and that it can prevent intracranial hemorrhage or other life-threatening events,” says Manco-Johnson. “Because factor XIII lasts so long in the bloodstream, treatment is usually monthly. Also, as little as 5% of normal can still prevent bleeding.”

Factor XIII Deficiency Research and Support Difficult

Because so few people have factor XIII deficiency, it is difficult to find information on it and doctors who specialize in treating it. Silver, for example, only knows of two families with the disorder in Northeastern Ohio. Nugent treats three patients—out of the 5 million people who live in Orange County, California.

“Any hemophilia treatment center [HTC] or the hematology department of a major medical center with a specialist in coagulation disorders will be able to treat factor XIII deficiency,” says Silver.

However, treatment for the disorder may not always be well understood by healthcare workers outside the HTCs. When Kathy’s youngest son, Mark, fell and had bleeding inside his head, treatment was delayed. The pediatrician, who was unfamiliar with factor XIII deficiency and its risk of intracranial hemorrhage, looked for an ear infection and the flu.

“Problems continued while the kids grew up,” says Kathy. “I have gotten several articles on this that I give to new doctors. I also have a list made up by the HTC that tells emergency room or other doctors how much fresh, frozen plasma is needed over what time period.”

Individuals with the disorder are spread out across the US, making information and support specific to the disease hard to find. HTCs are generally not able to provide support groups for these patients and their families, who typically end up being placed in more general groups.

Still, much of the networking and education about this deficiency fall to those most affected by it. Kathy gathered information on other medical treatments for factor XIII deficiency from a person she contacted through the [National Organization for Rare Disorders](#) (NORD). She also wrote letters to HTCs and NHF chapters asking if they knew of any families with the deficiency and asking them to pass her name along.

Rare Bleeding Disorders Database

To more efficiently gather information on patients with factor XIII deficiency and other rare bleeding disorders, the [Centers for Disease Control and Prevention](#) (CDC) is working with HTCs in the US on a patient registry. The registry may also be linked with a similar database in Europe to further increase the information flow on these rare disorders.

“This will help us accurately assess the number of persons with factor XIII deficiency and enable researchers to more effectively estimate the number of patients for treatment trials, new tests and other important research,” says Manco-Johnson. “The cataloging of gene mutations may help develop gene therapies.”

Nugent says, “No one can step up and develop treatments if they can’t even know how many patients there are and what kind of bleeding events we are trying to prevent.”

The database will collect information on patient demographics, family histories, treatments and patient responses. Other details of interest include incidence of complications, such as what triggers bleeding episodes.

This work may soon result in changes to a major data collection tool used at HTCs nationwide. The Universal Data Collection Tool (UDCT) is a standardized questionnaire developed in conjunction with the CDC that is used at all HTCs. Started as a method to gather information on the joint problems associated with hemophilia A and B, the UDCT has broadened the understanding of these diseases. Researchers hope it eventually will do the same for rare bleeding disorders.

“The UDCT has been incredibly useful in finding what things can impact outcomes in our patients,” says Nugent. “Now we may be able to develop hard information on how well treatments work and what other things may help or interfere with treatments.”

Learn More ...

- Visit the [factor XIII deficiency](#) section of the NHF Web site. You can also find a report on the [NORD](#) Web site.
- Other sources include the [Canadian Hemophilia Society](#), which has a publication that can be downloaded free.
- International [Factor XIII Registry Database](#).

Tests for Factor XIII Deficiencies

Factor XIII does not affect the early parts of the clotting process; it is responsible for the strength of the clot after it is formed. Because of this, most standard tests for blood clotting cannot be used because they produce normal results that do not indicate factor XIII deficiency.

Tests include:

- A test of **clot stability** is the most common screening method for factor XIII deficiency. In this test, a blood sample is taken and allowed to clot; the formed clot is suspended in a solution. If factor XIII is present, the clot will remain stable after 24 hours. If not, the clot will dissolve quickly, sometimes within minutes.

This test result is positive when no factor XIII is present. However, factor XIII levels as low as 1% to 3% may be enough to stabilize the clot. Therefore, in patients with milder deficiencies or in those with recent transfusions, the results of the test may still be normal.

- The next step is usually an **assay test for factor XIII**. Two tests measure the activity of factor XIII by measuring the amount of certain chemicals that are produced when the factor is working correctly.
- **Enzyme-linked immunosorbent assay (ELISA)** is another test often used to find levels of factor XIII in the blood. When the factor is present in the sample, the test solution changes color, indicating a positive test result.

Making Better Food Choices

Nutrition advice for people with bleeding disorders

Great Lakes Hemophilia Foundation
Headline News - February 2011

By Jennifer LaFranco RN, BSN, and Diane Delorm, RD | 12.29.2010
Originally Published January 2007



Eating healthy is easier said than done, especially for people who are managing a chronic condition like a bleeding disorder. The stress of trying to keep up with a busy schedule can often lead to overeating, eating on the run and/or poor food choices. In our hurry-up lifestyle, zipping to a fast-food restaurant is often more convenient and less expensive than preparing a home-cooked meal. But when we eat out for lunch or dinner we have a tendency to consume larger portions and foods with more calories than we would normally eat.

So how do these choices affect your health if you have hemophilia? Increased weight strains your joints and muscles, and can lead to further complications, including increased bleeds in susceptible joints. And during times of bleeds you are often more sedentary and not able to participate in appropriate exercise to burn those excess calories.

If you have a tendency to increase food consumption when you are inactive, this can add to the dilemma if you are already overweight or obese. The Centers for Disease Control and Prevention report teens and children with hemophilia are almost twice as likely to become overweight as the general population.

This means it's more important than ever for patients with hemophilia to be eating a balanced diet and controlling portion size.

In addition, of particular concern is the predisposition of osteoarthritis (arthritis where there is loss of cartilage) in people with hemophilia after repeated episodes of bleeding into a joint.

Obesity causes and complicates osteoarthritis by increasing the mechanical stress on the cartilage within the joint. In fact, next to aging, obesity is the most powerful risk factor for osteoarthritis of the knees.

Gentle exercise usually does not aggravate osteoarthritis when it's done at a level that does not cause joint pain.

And if those problems aren't enough for people with bleeding disorders, the complications associated with obesity alone are serious.

According to the World Health Organization, there are 300 million obese adults worldwide and 18 million children are classified as overweight.

Obesity causes more than 300,000 potentially avoidable deaths each year. It contributes to heart disease, osteoarthritis, diabetes, stroke, hypertension, cancer and sleep apnea.

So what can you do to ensure that you are as healthy as you can be?

Exercise and proper nutrition must be incorporated into a healthy lifestyle plan in order for you to maintain a healthy weight.

Improving your nutrition and physical exercise program should begin with a visit to your physician to make sure you are able to endure physical activity with no health risks. Appropriate exercise should then be performed. Thirty minutes of exercise daily is recommended to maintain weight; 60 minutes per day to lose weight.

Gradual changes in eating habits, such as the ones mentioned here, are most likely to yield long-term results:

Be aware of portion sizes, read labels and avoid snack foods. Steer clear of foods that are high in fat and calories and offer little in the way of nutritional value. Be mindful of “hidden” or overlooked sources of excess calories, such as large glasses of juice and soft drinks.

Increase your consumption of fruits and vegetables. Dark, leafy greens and orange fruits and vegetables are excellent sources of vitamins and minerals. They are also a rich source of fiber, which helps you to “fill up” and maintain intestinal health.

Try to eat at least half of your grains from whole grain products. Try oats, barley, whole wheat, flax seed, bran, brown rice and pasta. Whole grains help to satiate the appetite, lower cholesterol and stabilize blood glucose levels to avoid an afternoon “slump.” Eat baked snack items instead of fried.

Use low-fat dairy sources such as 1% or skim milk and low-fat cheeses. These contain plenty of vitamins and minerals without the fats that have been linked to heart disease. (If you cannot consume milk, look for other sources of calcium, such as calcium-fortified orange juice.)

Bake, broil or grill lean meats, poultry and fish. Avoid heavy gravies, sauces and toppings that are often full of calories from fat. Include some meatless meals during the week by incorporating dried beans, nuts and seeds into your menus. Dried beans provide an excellent source of protein, and are high in fiber and low in fat, with no cholesterol. (Cholesterol is found only in animal-derived food sources, such as meats, eggs and milk.)

Reduce fat intake and increase the use of “good fats.” These include olive and canola oils. Limit the use of butter, stick margarine, shortening and lard.

A few other nutritional suggestions are especially important for people with hemophilia.

In addition to maintaining healthy weight, people with bleeding disorders need to maintain normal blood volume and blood cell production. There are several nutrients involved in blood cell production, such as: iron, protein, copper, vitamin C, vitamin B12, vitamin B6, vitamin E and folic acid.

But it would be wise for patients to avoid vitamin E supplements since they may increase the risk of bleeding. A diet that incorporates all of the food groups should provide nutrients adequately.

During a bleed, it is estimated that a miniscule amount of iron—roughly .75 micrograms—is lost with each tablespoon (15 ml) of blood. Maintain your iron levels by eating naturally iron-rich foods such as liver, lean red meat and poultry, all of which provide the best and most readily absorbed iron sources.

Other excellent sources of iron are leafy green vegetables, broccoli, dried beans, grains and raisins. Combining iron-rich foods with good sources of vitamin C (such as orange juice) can enhance iron absorption.

Being realistic, you know that you're not going to make perfect choices at every meal, but it is important to make the effort to try to improve your diet.

It's OK to indulge in a piece of cake at a birthday party, but don't forget to eat lots of fresh vegetables at the next meal.

In other words, "Spend your calories as wisely as you would your money."

Editor's Note: Jennifer LaFranco is director of clinical programs at The Mary M. Gooley Hemophilia Center in Rochester, New York. Diane Delorm is the consulting clinical dietitian at the center.

When you eat out...

- Keep portions small. Large portions are the biggest assault on good diet intentions, especially when ordering out. Avoid "biggie" combos or meal packages that entice you to overeat.
- Avoid fried side dishes or order a small size. Baked snacks such as pretzels are low in fat and calories.
- Take half of your meal home and make another meal out of it later.
- Watch out for "hidden" calories in smoothies and coffee drinks. Some have as many as 400 calories per 12 oz. serving.
- Cut the calories in your order by avoiding high-fat, high-calorie condiments such as mayonnaise. Mustard has no calories.
- Opt for whole grain choices if available. These will help fill you up and give you the benefits of whole grain nutrients and fiber.
- Ask for your salad dressing on the side so YOU control the amount used. The nutritional value of a salad is lost if it's loaded with high-fat, high-calorie dressings.
- Opt for lean meats such as turkey vs. higher-fat cold cuts. Skip the cheese or opt for a low-fat cheese if available.



Leave an important legacy for children with bleeding disorders...

Great Lakes Hemophilia Foundation's (GLHF's) Legacy Circle

Great Lakes Hemophilia Foundation
Headline News - February 2011

Maripat Monahan, Director of Resource Development

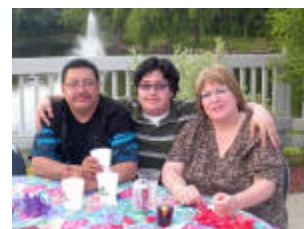


We all know good health insurance is imperative for people with chronic health conditions such as bleeding disorders. GLHF's Legacy Circle provides the ultimate "insurance" for the bleeding disorders community of Wisconsin. When you become a member of the GLHF Legacy Circle by arranging for a planned gift, you help ensure that individuals and families coping with bleeding disorders will have access to important resources throughout a lifetime.

"It's been 16 years since we got on this roller-coaster ride and it's comforting to know that GLHF will be there with us as long as the ride takes!" Terri S.

Planned gifts strengthen GLHF's financial base, allowing continued service to the bleeding disorders community into the future. A planned gift could include:

- A bequest - name GLHF as beneficiary of your will or living trust
- A stock gift - contribute appreciated stock or other securities
- An Insurance policy - name GLHF as beneficiary of your life insurance policy or retirement fund



All contributions and bequests made to GLHF are tax deductible. There are many tax benefits available through planned giving options. GLHF suggests you seek advice from your lawyer, accountant or other investment advisor when preparing to make a planned gift. Please contact GLHF with any questions you have about planned giving opportunities, and to let us know that you have included Great Lakes Hemophilia Foundation in your estate plans. (You can contact Maripat Monahan, mmonahan@glhf.org / 414.937.6783).

"Over the years the foundation has developed many programs to help hemophiliacs and their families deal with the disease. Knowing we were not alone and sharing stories, treatment tips and ideas helped our entire family cope with the problems of hemophilia."
Ed B.

Annual Wisconsin Bleeding Disorders Conference

Life's A Stage, Act Two: Building Self Advocacy Across the Community

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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 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.

Programs in 2011 will include Laurie Kelley's Pulse on the Road, Dental Care, A Healthy Cooking class, New Horizons for Older Adults, Doctor Q & A's, VWD & Women, Transitioning for 17-24 year olds, and ER Visits to name a few. Please contact Karin at the Foundation at 414.937.6782 if you would like to register or have any questions. Registration and a full agenda will be coming out in spring!

2010
Annual
Weekend

