

Hemophilia Services

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Women “Carriers” At Risk For Mild to Severe Bleeding Disorders

In the United States, 1.5 to 4 million women have a bleeding disorder. And up to 2 million American women have a bleeding disorder and don't know it, according to the National Women's Health Information Center.¹

The two most common bleeding disorders are von Willebrand disease (VWD) and hemophilia.¹ VWD and most cases of hemophilia are inherited. Women who pass on the genes that cause hemophilia are called “carriers.”

If you are a carrier, you are at risk for a mild to severe bleeding disorder, according to the Canadian Hemophilia Society. Many carriers have a clotting level averaging from 30 to 70 percent of normal and do not suffer from excessive bleeding. Some, however, have a clotting level of less than 30 percent of normal.

These women are considered to have mild hemophilia. In any case, all carriers should pay close attention to abnormal bleeding, such as prolonged menstrual cycles, known as menorrhagia, as well as easy bruising and frequent nose bleeds.²

If excessive bleeding is making you feel miserable through your menstrual period, you should talk with your doctor about potential causes and treatment options.

If your doctor suspects you may have a bleeding disorder, it's important to then receive a definitive diagnosis from a hematologist, the National Women's Health Information Center says. The cause and severity of your bleeding will determine the best treatment. For example, women experiencing mild bleeding problems may need treatment only before or after surgery and dental work or after an injury.

With treatment and regular visits to the doctor, women with bleeding disorders can lead full and active lives.

References

Bleeding disorders: frequently asked questions. The National Women's Health Information Center. <http://womenshealth.gov/faq/bleeding-disorders.cfm>. Content last updated March 4, 2009. Accessed April 16, 2009.

Heredity of hemophilia. Canadian Hemophilia Society. <http://www.hemophilia.ca/en/bleeding-disorders/hemophilia-a-and-b/heredity-of-hemophilia/#c171>. Accessed April 16, 2009



Top Ten Reasons for Kids to Attend Camp

10. Learn how to infuse themselves
9. Have fun away from home
8. Swim, swim, swim!
7. Become more self reliant
6. Give mom and dad a breather
5. Learn about outdoor activities that are safe and fun
4. Catch a BIG FISH!!!!
3. Hang out with cool counselors
2. Helps boost their self-esteem
1. Get to meet other kids just as special as them

Sending Your Child to Summer Camp: What It Can Accomplish

Across the nation, summer camps for children with bleeding disorders give kids the chance to enjoy themselves while learning how to manage their condition.

These camps also give kids the chance to meet other children with bleeding disorders, allowing them to build new friendships and share a great educational experience.

Operated by local chapters of the National Hemophilia Foundation (NHF), as well as by children's hospitals and other organizations, camps are located in most states. Children usually do not have to travel too far to participate.

According to the NHF's Web site (www.hemophilia.org), most camps are free and open to children age 7-17. They usually last a week. Some camps also include parents and siblings.

The camps offered by NHF chapters have educational programs that follow the NHF's "Do the 5!" campaign, says NHF camp directory coordinator Renee LaBrew. The five steps are:

- Treat bleeds early and adequately
- Exercise regularly
- Visit a treatment center annually
- Get checked for blood-borne viruses
- Get vaccinated for hepatitis A and B

To learn more about camps, contact your local NHF chapter, the NHF national headquarters, ask your doctor or search "camps for children with bleeding disorders" on the Internet. Once you have gathered basic information, you and your child can choose a camp that fits your goals and needs.

Walgreens-OptionCare's Hemophilia Team
Provides 24/7 Support! Call toll-free at **866-436-4376**.

Rehabilitation After a Bleed: A Matter of Critical Importance

Muscles and joints suffer greatly from bleeds, even from a child's first bleed. It is important for parents and healthcare providers to recognize the critical nature of bleeds and assure proper physical and occupational therapy.

According to M. Eileen San Juan, PT, MS, a physical therapist in the Department of Rehabilitation at St. Michael's Medical Center in Newark, New Jersey, a bleed into muscles, subcutaneous tissues and joints can cause a good deal of damage.



“When bleeding occurs in a joint, the blood pools in the joint space. Our body then produces enzymes to remove the blood. The excessive increase of these enzymes over time may cause erosion of cartilage and bone resulting in permanent joint damage,” explains San Juan, who has worked with hemophilia patients for more than three years. “A bleed also can lead to fibrosis of the synovium and may be coupled with pain and loss of range of motion at the joint,” she adds.

If a bleed is improperly treated, the following symptoms can occur:

Swelling/Edema: Swelling, or edema, can cause temporary or permanent nerve and muscle impairment due to compressed muscles, nerves and blood vessels. Parents should monitor a child for loss of sensation or muscle strength at the area of the bleed and throughout the limb where the bleed is located, San Juan says.

Joint and muscle mobility: Loss of muscle strength and joint range of motion also is an area of great concern. Disuse of muscle tissue can cause atrophy (muscle wasting), which can lead to limited and painful muscle movement. If a patient does not receive proper therapy they may experience permanent changes in muscle length and strength, joint and muscle integrity, and in joint stability. These adverse changes can lead to poor posture, loss of mobility and the need for surgery, she explains.

Upon the first bleed, parents should find a physical or occupational therapist trained by a hemophilia treatment center to identify the location of the bleed. The therapist also should have the expertise to advise how and when to progress into exercise, activities and sports, San Juan says.

Along with regular medical care and factor replacement, proper therapy can help children maintain active and healthy lifestyles and reduce the risk of long-term musculoskeletal damage caused by bleeding, she adds.

For information on physical and/or occupational therapy relating to blood disorders, contact your hemophilia treatment center or Walgreens-OptionCare at **866-436-4376**.

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Save a Few Bucks (And Maybe the Planet While You're At It)

These days, everyone is talking about belt-tightening and how to reduce our carbon footprint. Here at *The Infusion Inquirer*, we're no different. What can you do this summer to both save money and go green?

Think back to how your parents and grandparents got through tough economic times. For example, they used a tea bag more than once, used a piece of aluminum foil over and over again and saved their coffee cans.

You might consider the following ideas relating to caring for your child's hemophilia, both to save money and to make an important environmental statement.

1. With summer around the corner, you will begin to use your ice chest quite a bit. Save the ice packs that come with your factor shipment and use the packs throughout the summer. If you get a regular factor order each month and accumulate quite a few ice packs, share them with family and friends.
2. If you have gauze left over from a dressing kit, use it to clean your jewelry or remove nail polish.
3. Save the large plastic zip bags that the factor and/or supplies come in. There are so many ways to use plastic zip bags. They come in especially handy when packing for travel or when organizing household supplies and items.

Can you think of any other ways to save and go extra green this summer? Share your ideas with our readers and receive a free "green bag." Send your comments to cazandra.macdonald@walgreens.com

Has Your Child Learned to Self Infuse?

If your child has recently learned to self infuse, we'd love to hear his or her story and share it with our readers. Was it scary? Easy? What helped your child learn? What role did you play in helping your child? Contact Natalie Russo at natalie.russo@walgreens.com to share your story.