

A Woman's Story

By Linda E. Wyman-Collins, BSN, RNC-NIC

My dream is that eventually the diagnosis for bleeding disorders will be based on substantiated factor levels rather than solely on gender. Although it is improving, the mind-set today is still that bleeding disorders are a male disease and that women, other than being carriers, are not affected.

"You are fair and a redhead," is what I heard for 35 years to explain my bleeding symptoms. As a child, I was regularly covered with bruises and most often did not remember how I got them. I bled with dental work and cleanings, had many nosebleeds, endured intestinal bleeding since age eleven, had undiagnosed muscle and joint bleeds, and of course, suffered from heavy menstrual cycles that would last for weeks. Doctors would inquire as to whether my mother and grandmother also had heavy cycles. Since they did, it was considered "normal" that I did too. However, the truth was that the heavy bleeding was not normal for all three generations!

Despite my family history of bleeding symptoms and the fact that my first son hemorrhaged with his circumcision and took weeks to heal, he was seventeen months old before he was diagnosed with severe hemophilia. Even then, it was not suspected that I too had an actual bleeding disorder. Many mothers of hemophiliac children that are labeled as symptomatic carriers never have their own clotting levels drawn. Yet when they are tested, many find that they have lower clotting rates, which correlate to the symptoms of a bleeding disorder. In some symptomatic carriers, a process called "lyonization" may be responsible for the lower clotting values. Lyonization is a process in which one X chromosome may shut down and not replicate its DNA. If a woman has only the X chromosome with the hemophilia gene replicating its DNA, she will display more symptoms and have lower factor levels, thus making her more than "just" a carrier.

Years after my two sons were diagnosed with severe hemophilia, I finally underwent genetic testing. Even then, I was labeled as a carrier and still did not receive treatment for my own bleeding problems. Finally at the age of 35,



I was properly diagnosed: Prior to an upcoming surgery, I met with an anesthesiologist who, given my family history, decided to request a consult from a hematologist. In addition to the hemophilia, it was revealed that I have a platelet disorder and a connective tissue disorder called Ehler's Danlos, which made me more susceptible to muscle and joint bleeds.

Since being properly diagnosed and subsequently being prescribed a treatment plan, my life has totally changed. I can clear up a gastrointestinal bleed in two days, treat prior to dental work, treat muscle and joint bleeds immediately to prevent further arthritis, and I am much better able to manage my menstrual cycles.

In light of my experiences, I would like to offer some advise... women, stand up for yourselves! Ask questions, be educated, and be empowered! Let's teach our daughters to do the same.



Making a Difference....

Linda Wyman-Collins, commonly referred to as "Lew," noted that it was through her involvement with such organizations as the Hemophilia Federation of America that "*I met more and more women that had bleeding disorders that were not having their needs met or identified.*" In 1999, Lew took a position on the HFA board of directors. Soon, with her close family connection to the community, coupled with a drive to "*empower people to get involved and be their own advocates...and helping women become properly diagnosed,*" Lew found herself becoming involved even further.

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Linda Eleanora Wyman-Collins, BSN, RNC-NIC
• National Hemophilia Foundation:
 Educator for Project Red Flag
• Hemophilia Federation of America:
 Medical Advisory Board
 Focus on the Feminine Committee
 Board of Directors representing the
 Texas Central Hemophilia Association
• Hemophilia A, Platelet Disorder, Ehler's Danlos
• Two sons with severe hemophilia A
 • Daughter with carrier status
 • Husband with severe hemophilia A
 • Stepdaughter with mild hemophilia A

Did you know... .

One sign of having a bleeding disorder is having endometriosis. Endometriosis is often given as a cause for women's heavy menstrual flow. Endometriosis is a condition that occurs when tissue, which should only be located inside the uterus, is found elsewhere in the abdomen. In recent years, according to data collected by the Center for Disease Control (CDC), it has been found that women with a bleeding disorder have a higher incidence of endometriosis. The theory is that affected women have a heavier flow. So heavy, that a backflow into the Fallopian tubes may occur. The backflow causes tissue and cells to move and implant themselves elsewhere in the abdomen.

In the United States, there are 2.8 million women who have von Willebrand Disease, a relatively common bleeding disorder. Although it is found equally in males and females, it is not diagnosed very readily in females. The most common symptom is a heavy menstrual cycle. Many women may not understand how much is too much. Especially when a woman's cycle has always been heavy, as have been her mother's or sisters, there most often is no readily available scale with which to measure or compare. In addition, something as private as a menstrual cycle may be something that is difficult or embarrassing to speak about.

A period that lasts longer than seven days, or produces more than 80 ml (about six tablespoons) of blood is considered abnormally heavy. Feminine products hold from 2.5 to 60 ml depending on the type. If you suspect that your cycles or those of your daughter's are not normal, keeping a diary of the cycles is advised. During each day of the cycle, write notes regarding the heaviness of the flow, what type of feminine products were used and how often a change was required. Note if the cycle kept you from enjoying an activity or going to school or work. Keep this diary daily for the full length of your cycle so that the number of days it lasts will also be recorded.

This diary will then provide concrete information when consulting with your physician. If you sense that the doctor is not taking you seriously specifically ask that he or she run tests to rule out a bleeding disorder as a cause for your heavy periods. If you are considering a hysterectomy as a treatment for heavy bleeding, insist on being screened for a bleeding disorder before consenting to surgery. 