

It takes more than medicine..

Red Hot Mamas

By Cathy Hulbert , LCSW, Social Worker

Businesswoman Karen Giblin, a spokesperson for menopause-related health issues, was well into adulthood when she was diagnosed with von Willebrand Disease. But her shortage of the blood protein called "von Willebrand factor" impacted her life in many ways before she learned three years ago that she had a bleeding disorder.

At age 40, while living in Ridgefield, Connecticut, she underwent a hysterectomy to stop abnormal and heavy bleeding during menstrual cycles. Before that, she had two complicated but successful pregnancies and one miscarriage, all involving irregular bleeding. Blood and platelet transfusions, hormone therapy and bed rest all were prescribed at different points. Members of the fire department in her community, concerned about their town leader (she was a "selectman" for three terms), donated their platelets to help her. She was diagnosed with thalassemia minor in response to severe anemia during pregnancy. But the subject of a bleeding disorder just didn't come up, she said.

"I had a good doctor and I was getting care at a world-renowned medical center at Yale University," she said. "But at the time the right questions weren't being asked. I never had extensive testing until I came to Georgia and went to Emory."

Realizing that other women still face similar challenges – despite what is now known about VWD and other bleeding disorders – Ms. Giblin is telling her story nationally as she is interviewed by broadcast and print journalists on the subject closest to her heart: women and menopause. She is the founder of "Red Hot Mamas," a national menopause education program. And she already has established a format to stimulate discussion about these issues. She has been interviewed on ABC's "Good Morning America", NBC's "Today" and CNN. Since starting her education program in 1991, she has had articles on menopause published in *Fortune, Family Circle, Good Housekeeping, TIME* and *Harper's Bazaar* magazines. *Newsday, USA Today* and the *Chicago Tribune* also have interviewed her on the subject of menopause.

This spring she is scheduled to participate in the first international summit on menopause in Zurich, Switzerland, where she will weave her passion for the concerns of aging women with her new cause: getting the word out about bleeding disorders and how they affect women of all ages. "I want to guide women to educate themselves so that they can help educate their doctors if they have to," said the Roswell resident. "Sometimes women can be very passive patients. They assume their doctors know it all or they're afraid that their concerns will be dismissed. I want women to know that they can contact organizations like Hemophilia of Georgia or the National Hemophilia Foundation for help in speaking about their bleeding symptoms.

"Maybe they are bleeding from their gums or have trouble with easy bruising," she added. "Not everyone's symptoms are the same. The key for women is that if you suspect you might need to be tested, become your own healthcare advocate. There is still the idea out there that only men have bleeding disorders. If you

need to go back and speak with your doctor again, make sure you take along reliable information. Get the specialists involved to help you."

In many ways, her story is similar to the many women who long went undiagnosed with a bleeding disorder. Her grandmother was always known as "a bleeder," she said. Her mother and father tended to be quiet about their health issues, rarely seeking a doctor's advice. Heavy menstrual periods were considered a simple fact of life, not something to seek treatment for. Bruises on her leg were shrugged off as a consequence of "lazy platelets," a term given by one of her doctors.

Even in this day and age, when so much more is known about bleeding disorders, the pressures that many doctors face to move quickly from patient to patient can hinder discussions about such family and personal histories, said Ms. Giblin, a newlywed whose husband is a physician. "And the insurance companies might balk if there is an increase in the number of women being tested. But testing and proper diagnosis result in better health outcomes—and that is the key. Why should women face hysterectomies to address bleeding, when the consequences of such surgery without a proper diagnosis could be so severe?"

She advises women who have questions about their health "to face the issues head on." And she adds, "The first time I bought a book about menopause years ago, I was embarrassed. I hid it under the other books I was buying because there was such a stigma. It seems that everyone has an 'Aunt Tillie' that supposedly went crazy when menopause came on. I didn't want to be associated with that. Now I'm talking about it everywhere and it feels great. Today, women are often seen as just coming into their power at the age of menopause. It's a great time of life. I want to see the same thing happen to the subject of bleeding disorders in women. My goal is to open up healthy discussions so that women aren't embarrassed to talk about what's going on with their bodies."

Ms. Giblin's website is <u>www.redhotmamas.org</u>.