Title IX for Bleeding Disorders

By Alice Ma, MD,
and Jay Coghill, MD

Today at 2:00 p.m., a special symposium, "Bleeding Disorders in Women's Health" will be presented. Dr. Andra James will present the perspective of the OB-GYN practitioner, focusing on presenting symptoms which bring women with bleeding disorders to seek gynecologic care. She will also discuss barriers to diagnosing these women's bleeding disorders, as well as issues regarding management and referral of these patients. Dr. Margaret Ragni will present the hematologist's perspective on the care of women with bleeding disorders. She will discuss the diagnostic evaluation, genetics, and management of these patients, with a focus on von Willebrand's Disease (VWD). Lastly, Dr. Vincent Picozzi will discuss the impact that the unmet needs of these patients have on society. He will summarize the improvements in the public health approach that are necessary to improve health care outcomes for these women.

Premenopausal women with bleeding disorders comprise a major public health issue. It is estimated that 5 percent of all American women will present with menorrhagia at some point in their lives. Of these, up to 20 percent will have an underlying bleeding disorder which typically goes unrecognized by the health care provider. A survey of practicing gynecologists found that fewer than 4 percent of them considered any woman with menorrhagia as having the potential for having an underlying bleeding disorder. An average gynecologic practitioner seeing 50 patients per week will see 125 patients for menorrhagia yearly. If none of these women is considered to have a bleeding disorder, then 20 patients per practitioner per year will have an undiagnosed bleeding disorder. Consequently, the average woman with VWD waits 17 years after her first bleeding symptom for her diagnosis to be made. Many of these patients have been told that they do not have a bleeding disorder.

In addition to menorrhagia, these women may develop other bleeding symptoms and complications, including iron deficiency anemia, hemorrhagic ovarian cysts, endometriosis, post-partum hemorrhage, post-surgical bleeding, and hysterectomy. Women with VWD have more hysterectomies and have more bleeding complications with their operations. The care of these women is compromised, not only by poor recognition on the part of the provider of the potential existence of an underlying bleeding disorder, but also by poor recognition of the patient that her menorrhagia is excessive, by lack of screening tools for detection of pathologic bleeding, by limitations in testing for VWD and other bleeding disorders, by the lack of specialists with expertise in hemostasis, and by the need for improved therapeutic approaches for VWD and other bleeding disorders.

Women bleed. They bleed more frequently than do men, and have more barriers to adequate diagnosis and management. Today's symposium is but one of a number of steps needed to address this public health issue. Join us today to begin to meet the needs of this underserved population.