AANP Survey Reveals Lack Of Dialogue Regarding Bleeding Disorder

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The American Academy of Nurse Practitioners has issued a statement calling for women to have more dialogue about von Willebrand disease, a common but often undiagnosed bleeding disorder.

The AANP commissioned an online survey to gauge whether women experience, recognize and seek treatment for the five signs and symptoms of von Willebrand disease, one of the most common hereditary bleeding disorders.

In VWD, a potentially life-threatening condition, a protein necessary for clotting either is missing in the blood or does not function properly. The five signs and symptoms of VWD are easy bruising, frequent or prolonged nosebleeds, heavy and prolonged menstruation, prolonged bleeding during dental procedures and prolonged bleeding following injury, childbirth or surgery.

According to the survey of more than 1,000 women, close to 40% have experienced one or more of the potential symptoms, but nearly half of that group have not discussed the symptoms with their healthcare provider.

The majority of women who reported having one or more symptoms do not recall their healthcare provider mentioning that the symptom could be a sign of a bleeding disorder. Approximately three out of four respondents said they did not recall their provider asking questions about the severity or duration of menstruation, key questions in screening for VWD.

The Centers for Disease Control and Prevention (CDC) estimates up to 1% of the U.S. population — 3 million people — have VWD. While the disorder affects men and women equally, according to the CDC, women who are undiagnosed have a greater risk for serious complications such as miscarriage, life-threatening bleeding following childbirth and undergoing unnecessary hysterectomies.

“VWD symptoms may be something that many women dismiss as normal or do not feel comfortable discussing, but the survey showed that healthcare providers may not be broaching the subject, either,” said, Josie Weiss, PhD, FNP-BC, associate professor, Christine E. Lynn College of Nursing at Florida Atlantic University and a fellow of the AANP.

“Our findings are a wake-up call, underscoring the importance of more meaningful discussions about VWD between healthcare providers and patients.”

The AANP’s VWD Young Women’s Education Campaign includes educational materials developed for both healthcare professionals and patients. These materials include VWD fact sheets, a screening questionnaire and links to hemophilia treatment centers that specialize in treating bleeding disorders.

The virtual toolkit can be found in the AANP Toolkits section of the organization’s website: http://bit.ly/jTkElU.
The survey, conducted by Harris Interactive, is part of an ongoing VWD awareness campaign by the AANP to help educate women experiencing the five signs and symptoms, as well as their healthcare providers, about the condition.