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## **13 Million US Women Suffer Pain with Sex Nearly Half are Misdiagnosed**

### *Prominent Medical Groups Take Steps to Educate Physicians*

WASHINGTON – A frequently overlooked and under-researched chronic pain disorder, which affects 16% of women (one in six) in the United States, is gaining the attention it has long warranted. In the past few months, two prominent medical organizations, the American College of Obstetricians and Gynecologists (ACOG) and the American Academy of Family Physicians (AAFP), have disseminated important documents on vulvodynia to their 150,000 cumulative members, alerting them to this often misdiagnosed and inappropriately treated women's health condition.

"This neglected women's health problem is finally getting some of the attention it deserves," says Phyllis E. Greenberger, MSW, President and CEO of the Society for Women's Health Research. "Every woman's health care provider should know about this condition and I applaud ACOG and AAFP for taking this important step to help make that happen," she adds.

*Vulvodynia is vulvar pain without an identifiable cause that persists for three months or longer.* The most commonly reported symptoms are burning, stinging and/or rawness in the vulva (the area surrounding the vaginal opening). Some women describe the pain as a feeling of "acid being poured into an open wound." Vulvodynia has a profound negative impact on a woman's quality of life and ability to perform basic daily activities. Affected women are unable to engage in sexual activity, hold a job requiring extended periods of sitting and participate in physical exercise or even social activities. In severe cases, women with vulvodynia are bedridden with unrelenting pain.

"Data from a recent study funded by the National Institutes of Health (NIH) and conducted by Dr. Bernard Harlow at Harvard University show that 13 million women may suffer from vulvodynia during their lifetime and that six percent have symptoms before age 25," says Dr. Vivian W. Pinn, Director of the NIH Office of Research on Women's Health. "Almost 60% of patients consulted three or more doctors in seeking a diagnosis and 40% remained undiagnosed, even after this many visits. The data clearly demonstrate the need for continuing research on vulvodynia and for increasing awareness about this condition among both women and their health care providers," adds Dr. Pinn.

Women experiencing any of the following symptoms may be suffering from vulvodynia and should contact their health care provider promptly:

- Pain or any discomfort with sexual intercourse, tampon insertion, or while sitting;
- Burning or other painful sensations in the vulva;
- Red patches of skin in the vulvar area (indicating inflammation).

While research has shown that vulvodynia is *not* caused by an active infection, sexually transmitted disease or cancer, and is not a psychological condition, conclusive studies on its exact causes are lacking. Current research suggests that there are likely different causes for the pain, including nerve damage, genetic factors and/or abnormal nerve growth leading to increased skin sensitivity. Current treatments are limited in their effectiveness and aimed solely at managing symptoms; these include topical anesthetics, oral pain-relieving medications such as anticonvulsants and antidepressants, nerve blocks and physical therapy, as well as surgery for a very select sub-group of patients.

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The American College of Obstetricians and Gynecologists (ACOG), with over 51,000 members, is the nation's leading group of women's health care professionals. The October issue of ACOG's clinical journal, *Obstetrics & Gynecology*, contains a specialized document on vulvodynia called a Committee Opinion, a brief consensus document addressing an urgent or emergent clinical issue. All Committee Opinions are included in the annual ACOG Compendium, the premier desk reference for obstetrician-gynecologists.

The American Academy of Family Physicians (AAFP), a national association of more than 94,000 family doctors, is one of the largest medical organizations in the US. An article entitled, *Vulvodynia: Diagnosis and Management*, appeared in the April 2006 issue of AAFP's clinical journal, *American Family Physician*, which circulates to 156,000 medical practitioners. The article and an accompanying patient handout can be viewed online at <http://www.aafp.org/afp/20060401/1231.html>

The National Vulvodynia Association ([www.nva.org](http://www.nva.org)), a non-profit organization established in 1994, began as a small local support group. Today, more than 25,000 patients and health care providers have joined the organization. The NVA educates the medical and patient communities through its educational materials and symposia, provides physician referrals and support groups, and both directly funds, and lobbies for, medical research. NVA's medical advisory board is comprised of clinicians and scientists from diverse medical specialties.