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National Vulvodynia Association

PO Box 4491, Silver Spring, MD 20914-4491 301-299-0775 • 301-299-3999 (fax) • www.nva.org

How Can We Help?

The NVA, founded by five patients in 1994, is one of the only non-profit organizations in the world dedicated to improving the health and quality of life of women who suffer from chronic vulvar pain. The NVA has many excellent resources, including:

Educational Resources

The NVA maintains online teaching programs for patients (www.nva.org/learnpatient) and health care providers (www.nva.org/ce), and distributes newsletters to keep you up-to-date on the latest vulvodynia research findings and treatments. Our newsletter also contains helpful articles on emotional and sexual issues that are associated with vulvodynia.

Support Services

Women find speaking to others who have vulvodynia is both a good source of information and the best way to overcome the emotional isolation that often accompanies the disorder. To facilitate this, the NVA oversees a support network across the United States and Canada.

Health Care Provider Referrals

The NVA maintains a database of health care providers who are knowledgeable about the diagnosis and treatment of chronic vulvar pain disorders.

Research Funding

The NVA funds research studies on treatments for vulvodynia and promotes increased federal funding of vulvodynia research.

To Learn More

For further information on vulvodynia and the services the NVA provides, contact:

National Vulvodynia Association PO Box 4491 Silver Spring, MD 20914-4491 301-299-0775 (phone) • 301-299-3999 (fax) Website: www.nva.org NationalVulvodyniaA Association

Improving the health and quality of life of women with vulvodynia through education, research, support and advocacy

www.nva.org

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What is Vulvodynia?

Vulvodynia (pronounced VUL-vo-di-nee-a) is chronic vulvar pain without an identifiable cause. Symptoms include burning, stinging, stabbing, irritation and/or rawness; pain may be constant or intermittent, localized or diffuse. Upon examination, the vulvar tissue may appear inflamed and swollen or perfectly normal. The severity of the condition ranges from mild discomfort to excruciating pain.

Other gynecological and skin conditions that can cause chronic vulvar pain should be ruled out or treated before a diagnosis of vulvodynia is made. These conditions include, but are not limited to, yeast infections, bacterial infections, and dermatologic conditions such as dermatitis, lichen planus and lichen sclerosus. Many women with vulvodynia report visiting at least three health care providers before receiving an accurate diagnosis. The two main subtypes of vulvodynia (which sometimes coexist) are:

- Provoked Vestibulodynia (aka Vulvar Vestibulitis)
 Pain is localized in the vestibule (the area surrounding the vaginal opening) and occurs during or after touch or pressure is applied, e.g., with sexual intercourse, tampon insertion or prolonged sitting.
- Generalized Vulvodynia

Symptoms occur in several areas of the vulva, e.g., the labia, vestibule, and clitoris. Pain is relatively constant, but there may be some periods of relief. Pressure on the vulva usually exacerbates the symptoms.

Similar to other chronic pain conditions, vulvodynia often impacts quality of life. Most women with vulvodynia experience pain with sexual intercourse and sitting for long periods. Living with the pain and physical limitations may lead to anxiety and depression.

Who is Affected?

Millions of women of all ages, races and ethnic backgrounds experience chronic vulvar pain. The highest incidence of symptom onset is between the ages of 18 and 25.

What Causes Vulvodynia?

Vulvodynia is not caused by an active infection and is not a sexually transmitted disease. The precise cause of the condition is still undetermined. Researchers propose that one or more of the following may cause, or contribute to, vulvodynia:

- An injury to, or irritation of, the nerves that transmit pain from the vulva
- An increase in the number of "pain-sensing" nerve fibers in the vulva
- An abnormal response of certain cells to environmental factors such as infection or trauma, e.g., pelvic injury
- Genetic susceptibility to chronic vulvar inflammation, widespread body pain and/or an inability to combat infection
- Pelvic floor muscle weakness or spasm

How is Vulvodynia Diagnosed?

After taking a thorough medical history, including questions about your current symptoms, a gynecologist or other health care provider will examine the vulva, vagina and vaginal secretions to rule out an active infection or skin disease. Different areas of the vulva will be touched with a cotton-tipped applicator to determine the location and severity of pain. If an area of skin appears suspicious, it can be examined more closely with a magnifying instrument or a biopsy of the area may be taken.

How is Vulvodynia Treated?

Since vulvodynia is a chronic pain condition, affects the genital area, and often involves the pelvic muscles, experts recommend a multidisciplinary treatment regimen. Treatment may involve visiting a gynecologist or vulvovaginal specialist, dermatologist, neurologist, pain management specialist, and/or physical therapist.

Treatment is directed toward alleviating pain and typically provides some relief. No single treatment is effective for all women. Although some women may find substantial relief with a certain treatment, others may not respond or experience unacceptable side effects.

It can take months or longer to find a treatment or combination of treatments that adequately relieves your pain. Keep in mind that most women with vulvodynia find ways to control the pain and resume their lives, so don't lose hope. Some current treatments include:

- Discontinuation of irritants
- Topical medications applied to the vulva
- Tricyclic antidepressants (e.g., amitriptyline)
- Anticonvulsants (e.g., gabapentin)
- Nerve blocks
- Pelvic floor muscle therapy (physical therapy for pelvic floor muscle abnormalities)
- Surgery (for provoked vestibulodynia only)

For self-help tips on vulvar skin care, please visit www.nva.org/tips.

Medical Advisory Board

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The National Vulvodynia Association does not practice medicine. We recommend that you consult one or more health care providers regarding your treatment options.