NVA Resources and Services

Founded in 1994, the NVA is the only non-profit in the world funding research on promising new treatments for vulvodynia. On our website, **www.nva.org**, you will find excellent resources and services for vulvodynia patients.

Educational Resources

The NVA maintains online teaching programs for patients (www.nva.org/learnpatient) and health care providers (www.nva.org/ce). In addition, you can access over 60 newsletters containing vulvo-dynia experts' advice on various treatments and maintaining sexual intimacy. You can also learn how to cope with vulvodynia by reading the following NVA booklets:

Vulvodynia: A Self-Help Guide Vulvodynia, Pregnancy and Childbirth My Partner Has Vulvodynia - What Do I Need To Know?

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. To access our referral list, go to the U.S. map near the top of NVA's website and click on Find a U.S. health care provider. On the next page, enter your zip code to view the list of gynecologists, physical therapists, nurse practitioners, psychologists and other health care providers in your area.

Support Services

Women find that 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 condition. On our website, there is a list of women with vulvodynia that you can contact or you can visit our Facebook or Instagram pages.

E-mail Updates

Three times a year, we distribute medical journal abstracts on vulvodynia to keep patients and health care providers informed about treatment effectiveness and other developments. We also e-mail announcements of upcoming events, research grants and book publications. Many researchers use this service to find women to participate in vulvodynia studies or surveys.

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You Can Help Us Find Effective Treatments

The NVA is the only non-profit in the world committed to funding research on vulvodynia. Many NVA-funded studies have furthered our understanding of what causes chronic vulvar pain. Currently, we are encouraging researchers to test promising new treatments for vulvodynia.

Since the NVA doesn't require a membership fee, we can only afford to fund research by keeping our overhead costs low. Many supporters are surprised to learn that the NVA's work is done by two part-time employees and one long-term volunteer.

We hope you will take advantage of the patient services and educational resources on our website. If you share our goal of alleviating pain and restoring quality of life to millions of women with vulvodynia, please donate to our Medical Research Fund. 100% of your donation will be spent on direct research costs. You can donate online at www.nva.org/donate or by mail using the form below.

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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?

Treatment typically involves a gynecologist, pelvic floor physical therapist, and in some cases, a psychologist. When the diagnosis is Generalized Vulvodynia, referral to a pain management specialist is recommended.

Treatment is directed toward alleviating pain, but **no** single treatment is effective for all women. It can take months, or sometimes years, to find a combination of treatments that provide maximum relief.

The initial treatment advice is to discontinue everything that can be irritating to the vulva. Most clinicians prescribe 5% topical Lidocaine, which provides

temporary relief. Many women apply it a few minutes before sexual intercourse.

Your health care provider may prescribe an oral antidepressant or anticonvulsant used for other chronic pain conditions. If your symptoms don't improve after 10 weeks, tell your provider. They may suggest a different oral medication plus a topical medication. If oral and topical medications aren't effective, your provider may then recommend a nerve block.

Over the same period, a women's health physical therapist should evaluate the pelvic floor muscles and start treatment, if warranted. If you don't experience relief after many months of trying medical treatment and physical therapy, surgery may be recommended if your diagnosis is provoked vestibulodynia.

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

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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.