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- Health care provider referral list
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Please send me:

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- Health care provider referral list for my state
- Contact information for my local support leader
- Printed Booklets: _____ Self-Help (add \$10)
_____ Pregnancy (add \$10)
_____ Partner (add \$6)
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I would also like to donate an additional amount of:

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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 the NVA Help You?

The NVA, founded by five patients in 1994, is one of the only non-profit organizations in the world dedicated to improving the lives of women who suffer from vulvodynia. NVA has established many programs including:

Educational Resources

The NVA maintains online learning programs for patients and health care providers (<http://learn.nva.org>), and disseminates newsletters that will keep you up-to-date on the latest vulvodynia research findings and treatments. Our newsletter also contains valuable articles on emotional and sexual issues related to 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 this disorder. To facilitate this, the NVA oversees a support network across the US and foreign countries.

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 directly funds pilot research studies and collaborates with members of Congress and the National Institutes of Health (NIH) to promote increased federal funding of vulvodynia research.

To Learn More

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

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Website: www.nva.org

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National
Vulvodynia
Association

*Improving the lives of women with
vulvar pain through education,
research, support and advocacy.*

www.nva.org

This brochure is published by the National Vulvodynia Association, Inc., a non-profit organization funded through private donations, grants and contributions.

What is Vulvodynia?

Vulvodynia (pronounced VUL-vo-DIN-nee-ah) 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 it may look perfectly normal. The severity of the condition ranges from mild discomfort to excruciating disabling pain.

Other gynecological and skin conditions that 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 sclerosus and lichen planus. Many women with vulvodynia report visiting at least three health care providers before receiving a diagnosis.

The two main subtypes of vulvodynia (which may co-exist) 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 to the area, 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, clitoris, and perineum. Pain is relatively constant, but there may be some periods of relief. Pressure on the vulva typically exacerbates the symptoms.

As with most chronic pain conditions, vulvodynia can have a profound impact on quality of life, limiting one's ability to work, engage in sexual activity and participate in daily activities. These limitations may lead to depression.

Who is Affected?

Studies indicate that millions of women of all ages and ethnic backgrounds experience vulvar pain. A recent study indicates that it may be quite prevalent among adolescents as well.

What Causes Vulvodynia?

Vulvodynia is not caused by an active infection and is not a sexually transmitted disease. The causes are still undetermined due to a lack of research on the disorder. Current studies are investigating possible causes and delineating risk factors for developing vulvodynia. Researchers speculate 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 medical history and asking questions about your symptoms, your provider should carefully examine the vulva, vagina and vaginal secretions to rule out an active infection or skin disorder. Different areas of the vulva may be touched with a cotton-tipped applicator to determine the location and severity of pain. If an area of skin appears suspicious, your provider may examine it more closely with a special instrument or take a biopsy of the area.

How is Vulvodynia Treated?

Since vulvodynia is a pain condition affecting the genital area, and often involves the pelvic muscles, experts favor a multi-disciplinary approach to its treatment. Treatment may involve visiting a gynecologist or vulvovaginal specialist, dermatologist, neurologist, pain management specialist and/or physical therapist.

Treatment is directed towards alleviating symptoms and may provide partial or complete relief. While some women experience relief with a particular treatment, others may experience unacceptable side effects or not respond to it.

No single treatment is appropriate for every woman and it can take a considerable amount of time to find a treatment or combination of treatments that will alleviate the pain. Some of the current treatments (not listed in order of efficacy) include:

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

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

What other women have said about NVA:

"I am so grateful to you. I was misdiagnosed for 7 years, but now I have some answers and hope!"

Medical-Scientific Advisory Board

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The National Vulvodynia Association does not engage in the practice of medicine and is not a medical authority. In all cases, the NVA recommends that you consult your own health care provider regarding any course of treatment or medication.