

## JOIN THE NVA

For a \$45 tax-deductible contribution you receive:

- One-year newsletter subscription plus current issue
- Contact information for your local support leader
- Health care provider referral list
- Online access to patient booklets: Self-Help Guide, Pregnancy and Childbirth, and Advice for Partners

You can either submit this form (by fax or mail) or join immediately online at [www.nva.org](http://www.nva.org) by clicking 'Join Now' on the upper right side of the home page.

If a \$45 contribution presents a financial hardship, please email [gigi@nva.org](mailto:gigi@nva.org) or call 301-949-5114.

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

E-mail \_\_\_\_\_

- U.S. Resident (\$45)
- Non-U.S. Resident (\$50)  
(US money order/credit card only)
- Health Care Provider (\$100)  
(For information on NVA services for health care providers, visit [www.nva.org/join](http://www.nva.org/join).)

### Please send me:

(will be e-mailed unless e-mail address is not provided above)

- 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 \$10)  
\_\_\_\_\_ Disability (pdf only)

\* \$5 added for international shipping

### Method of Payment:

- Check or Money Order (enclosed) \_\_\_\_\_
- Visa or MasterCard

Credit Card Number \_\_\_\_\_

Exp. Date \_\_\_\_\_

**National Vulvodynia Association**  
PO Box 4491, Silver Spring, MD 20914-4491  
301-299-0775 ▪ 301-299-3999 (fax) ▪ [www.nva.org](http://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 valuable resources including:

### Educational Resources

The NVA maintains online learning programs for patients ([www.nva.org/learnpatient](http://www.nva.org/learnpatient)) and health care providers ([www.nva.org/ce](http://www.nva.org/ce)), 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 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 and collaborates with the National Institutes of Health and members of Congress to promote 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](http://www.nva.org)**

© 2016 by the NVA



National



Vulvodynia



Association

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

[www.nva.org](http://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 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 impairs quality of life, limiting one's ability to work, engage in sexual intercourse and participate in daily activities. Living with the pain and these limitations may lead to depression and anxiety.

## Who is Affected?

Studies indicate that millions of women of all ages, races and ethnic backgrounds experience vulvar pain. A recent study indicates that it is 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 multidisciplinary 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 toward 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., gabapentin)
- Nerve blocks
- Pelvic floor muscle therapy (physical therapy 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/tips](http://www.nva.org/tips).

## What women have said about the NVA:

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

## Medical Advisory Board

Libby Edwards, MD *Southeast Vulvar Clinic*

David Foster, MD *University of Rochester Medical Center*

Andrew Goldstein, MD *Centers for Vulvovaginal Disorders*

Bernard Harlow, PhD *University of Minnesota*

Stanley Marinoff, MD *George Washington University*

Paul Nyirjesy, MD *Drexel University Medical College*

Elizabeth Stewart, MD *Harvard Medical School*

Justin Wasserman, MD *Pain Treatment Center*

Jerome Weiss, MD *Pacific Center for Pelvic Pain*

Ursula Wesselmann, MD *University of Alabama*

Steven Witkin, PhD *Cornell University Medical College*

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.