

# Vulvodynia

RESEARCH, RESOURCES, TREATMENT, HOPE





## NATIONAL INSTITUTES OF HEALTH (NIH), U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS)

Office of Research on Women's Health  
*Vulvodynia*  
<http://orwh.od.nih.gov/health/vulvodynia.html>

National Institute of Child Health  
and Human Development  
*Vulvodynia*  
<http://www.nichd.nih.gov/health/topics/Vulvodynia.cfm>

National Institute of Neurological  
Disorders and Stroke  
<http://www.ninds.nih.gov>

The NIH Pain Consortium  
<http://painconsortium.nih.gov>

National Library of Medicine  
*Vaginal Diseases*  
<http://www.nlm.nih.gov/medlineplus/vaginaldiseases.html>

### ADDITIONAL HHS RESOURCES

Agency for Healthcare Research and Quality  
<http://www.ahrq.gov>

Centers for Disease Control and Prevention  
<http://www.cdc.gov>

Health Resources and Services Administration  
<http://www.hrsa.gov>

Office of Disease Prevention and  
Health Promotion  
<http://odphp.osophs.dhhs.gov>

Office of Minority Health  
<http://www.omhrc.gov>

Office of Women's Health, U.S. Department  
of Health and Human Services  
<http://www.womenshealth.gov>  
Tel: 1-800-884-9662 for an  
*information specialist in English and Spanish*

U.S. Food and Drug Administration  
<http://www.fda.gov>

### NON-FEDERAL RESOURCES AND PARTNERS

American College of Nurse-Midwives  
8403 Colesville Road, Suite 1550  
Silver Spring, MD 20910-6374  
Tel: (240) 485-1800  
<http://www.midwife.org>

American College of Obstetricians  
and Gynecologists  
409 12th Street, SW  
P.O. Box 96920  
Washington, DC 20090-6920  
Tel: (202) 863-2518  
<http://www.acog.org>

American Medical Women's Association  
211 N. Union Street, Suite 100  
Alexandria, VA 22314  
Tel: (703) 838-0500  
<http://www.amwa-doc.org>

American Society for Colposcopy  
and Cervical Pathology  
152 West Washington Street  
Hagerstown, MD 21740  
Tel: (301) 733-3640  
<http://www.asccp.org>

Association of American Indian Physicians  
1225 Sovereign Row, Suite 103  
Oklahoma City, OK 73108  
Tel: (405) 946-7072  
<http://www.aaip.org>

*With gratitude to Christin Veasley, National Vulvodynia Association, and Gloria A. Bachmann, M.D., University of Medicine and Dentistry of New Jersey, Robert Wood Johnson Medical School, for their assistance in the development of these materials.*

Black Women's Health Imperative  
1420 K Street, NW, Suite 1000  
Washington, DC 20005  
Tel: (202) 548-4000  
<http://www.blackwomenshealth.org>

International Society for the  
Study of Vulvovaginal Disease  
8814 Peppergrass Lane  
Waxhaw, NC 28173  
Tel: (704) 814-9493  
<http://www.issvd.org>

National Alliance for Hispanic Health  
1501 16th Street, NW  
Washington, DC 20036-1401  
Tel: (202) 797-4322  
<http://www.hispanichealth.org>

National Hispanic Medical Association  
1411 K Street, NW, Suite 1100  
Washington, DC 20005  
Tel: (202) 628-5895  
<http://www.nhmamd.org>

National Medical Association  
1012 Tenth Street, NW  
Washington, DC 20001  
Tel: (202) 347-1895  
<http://www.nmanet.org>

National Research Center  
for Women & Families  
1701 K Street, NW, Suite 700  
Washington, DC 20006  
Tel: (202) 223-4000  
<http://www.center4research.org>

National Vulvodynia Association  
P.O. Box 4491  
Silver Spring, MD 20914-4491  
Tel: (301) 299-0775  
<http://www.nva.org>

National Women's Health Network  
514 Tenth Street, NW, Suite 400  
Washington, DC 20004  
Tel: (202) 347-1140  
<http://www.nwhn.org>

National Women's Health Resource Center  
157 Broad Street, Suite 315  
Red Bank, NJ 07701  
Tel: 1 (877) 986-9472  
<http://www.healthywomen.org>

North American Menopause Society  
5900 Landerbrook Drive, Suite 390  
Mayfield Heights, OH 44124  
Tel: (440) 442-7680  
<http://www.menopause.org>

Our Bodies Ourselves  
34 Plympton Street  
Boston, MA 02118  
Tel: (617) 451-3666  
<http://www.ourbodiesourselves.org>

Society for Women's Health Research  
1025 Connecticut Avenue, NW, Suite 701  
Washington, DC 20036  
Tel: (202) 347-1140  
<http://www.womenshealthresearch.org>

University of Michigan Center  
for Vulvar Diseases  
c/o Hope K. Haefner, M.D., Director  
1500 East Medical Center Drive,  
Room L4000  
Ann Arbor, MI 48109-0276  
Tel: (734) 763-6925  
<http://www.med.umich.edu/obgyn/>

WebMD  
1175 Peachtree Street, NE, Suite 2400  
Atlanta, GA 30361  
<http://www.webmd.com>

Women's Health Specialists  
7800 Wolf Trail Cove  
Germantown, TN 38138  
Tel: (901) 682-9222  
[csbrown@utm.edu](mailto:csbrown@utm.edu)

### ADDITIONAL RESOURCES

American College of Obstetricians and  
Gynecologists. Vulvodynia. ACOG Patient  
Education Pamphlet AP127. Washington,  
DC: ACOG; 2007. Available from:  
[http://www.acog.org/publications/patient\\_education/bp127.cfm](http://www.acog.org/publications/patient_education/bp127.cfm)

American College of Obstetricians and  
Gynecologists. Vulvodynia. ACOG Patient  
Education Pamphlet SP127 [In Spanish].  
Washington, DC: ACOG; 2007. Available  
from: [http://www.acog.org/publications/patient\\_education/sp127.cfm](http://www.acog.org/publications/patient_education/sp127.cfm)

Bachmann GA, Rosen R, Pinn VP, et al.  
Vulvodynia: a state-of-the-art consensus  
on definitions, diagnosis and manage-  
ment. *Journal of Reproductive Medicine*.  
2006; 51(6): 447-56. Contact the NIH  
ORWH at: (301) 402-1770

Haefner HK, Collins ME, Davis GD, et al.  
The vulvodynia guideline. *Journal of Lower  
Genital Tract Disease*. 2005; 9(1):40-51.  
Available from: [http://www.nva.org/about\\_nva/Haefner%20-%20Vulvodynia%20Guideline%20-%202005.pdf](http://www.nva.org/about_nva/Haefner%20-%20Vulvodynia%20Guideline%20-%202005.pdf)

Harlow BL, Stewart EG. A population-  
based assessment of chronic unexplained  
vulvar pain: have we underestimated  
the prevalence of vulvodynia? *Journal  
of the American Medical Women's  
Association*. 2003; 58:82-88. Available  
from: <http://jamwa.amwa-doc.org/index.cfm?objectid=EF8F5FFC-D567-0B25-5A8A601C45B539AB>

National Vulvodynia Association. I have  
vulvodynia—what do I need to know? A  
self-help guide for women diagnosed with  
vulvodynia [article on the Internet]. 2004.  
Available from: [http://www.nva.org/new\\_patient\\_guide/index.html](http://www.nva.org/new_patient_guide/index.html)

National Vulvodynia Association. Vulvo-  
dynia: integrating current knowledge into  
clinical practice [tutorial with CME/CE  
accreditation on the Internet]. 2005.  
Available from: <http://learn.nva.org/>

U.S. Department of Health and Human  
Services, National Institutes of Health,  
National Institute of Child Health and  
Human Development. Vulvodynia:  
towards understanding a pain syndrome.  
*Proceedings of the workshop*; 2003 April  
14-15; Bethesda, MD. Available from:  
[http://www.nichd.nih.gov/publications/pubs/upload/vulvodynia\\_report.pdf](http://www.nichd.nih.gov/publications/pubs/upload/vulvodynia_report.pdf)

WebMD. Does sex hurt? [article on the  
Internet]. Available from: <http://www.webmd.com/sexual-conditions/features/sex-pain>

WebMD. Many women suffer from vulvar  
pain [article on the Internet]. 2003 April  
15. Available from: <http://women.webmd.com/news/20030415/many-women-suffer-from-vulvar-pain>

WebMD. Vulvar pain isn't so rare [article  
on the Internet]. 2004 Jan 13. Avail-  
able from: <http://women.webmd.com/news/20040113/vulvar-pain-isnt-so-rare>

WebMD. Vulvodynia: causes, symptoms,  
and treatments [article on the Internet].  
Available from: <http://women.webmd.com/Women-Medical-Reference/vulvodynia>



# Vulvodynia

<http://orwh.od.nih.gov/health/vulvodynia.html>

## UNDERSTANDING VULVODYNIA AND PLANNING FOR FUTURE RESEARCH **An Overview of Vulvodynia**

Vulvodynia is chronic discomfort or pain of the vulva, which is the area around the outside of the vagina. This discomfort has been referred to as “the pain down there” or also as “feminine pain.” Burning is the most common symptom, with stinging, irritation, and stabbing pain reported by many women. There is no apparent infection or skin disease that could cause these symptoms. Treatment can include advice on vulvar skin care, oral and/or topical medications, biofeedback, physical therapy exercises, or even surgery in specific cases. No single treatment is effective for all women with vulvodynia; experts often recommend an individualized combination of treatments to improve the quality of life for vulvodynia sufferers.

### **Why Is Vulvodynia a Problem?**

Results from research on the epidemiology (the study of the distribution and causes) of vulvodynia have helped to clarify the magnitude of the problem. A large, population-based study in ethnically diverse Boston neighborhoods, by Harlow and Stewart, revealed that chronic burning, knifelike pain, or pain on contact that lasted at least 3 months or longer in the lower genital tract occurred frequently.<sup>1</sup> These symptoms were reported by White, African American, and Hispanic women of all ages, and nearly 40 percent of these women chose not to seek treatment. Of the women who sought treatment, 60 percent saw three or more doctors. These researchers estimate that up to 18 percent of women will experience symptoms consistent with vulvodynia in their lifetimes.<sup>2</sup> In addition, the incidence of symptom onset is highest between the ages of 18 and 25, and lowest after age 35. These findings highlight the reality that vulvodynia may affect many women in the U.S. Anecdotal evidence suggests that vulvodynia may in many cases make sexual intercourse, tampon insertion, or even wearing clothing, such as undergarments or trousers, difficult or impossible. When women do choose to seek care, the lack of health care provider education about the diagnosis and treatment of vulvodynia may lead to multiple office visits with different providers before a correct diagnosis and the appropriate intervention are determined.

### **What Is the NIH Doing about Vulvodynia?**

Research today continues to explore better clinical definitions of vulvodynia, better methods of identifying conditions that coexist with vulvodynia, and more comprehensive clinical management tools. Findings from NIH-funded research have led to several active research program announcements.

One program announcement, published by the National Institute of Child Health and Human Development (NICHD) and co-sponsored by the NIH Office of Research on Women's Health (ORWH), *Vulvodynia—Systematic Epidemiologic, Etiologic or Therapeutic Studies (R01)* (<http://grants.nih.gov/grants/guide/pa-files/PA-07-182.html>), is designed to promote interdisciplinary research, with the goal of reducing the burden of this disease and ultimately improving the quality of life for women affected by this disorder. Other active program announcements have been released by the National Institute of Nursing Research on behalf of the NIH Pain Consortium for R01, R03, and R21 funding mechanisms to stimulate research in the field of pain and share the title, *Mechanisms, Models, Measurement, & Management in Pain Research*. The Web site for the R01 program is <http://grants.nih.gov/grants/guide/pa-files/PA-07-282.html>.

In addition to funding scientific research on this disorder, the NIH has supported several workshops on vulvodynia. A recent publication, *Vulvodynia: A State-of-the-Art Consensus on Definitions, Diagnosis and Management*, from a workshop in which NIH participated, describes findings and recommendations, such as key topics and issues needing further study, including the role of inflammatory mechanisms and genetic factors.<sup>3</sup>

## Models for Future Research

For research on vulvodynia to progress, definitions should be standardized for the terms that describe vulvodynia and the conditions that are associated with it. The terms and procedures used to characterize the pain associated with vulvodynia should also be standardized. Many biologic mechanisms are currently being investigated, including inflammatory and infectious disease processes, stress factors, neurologic and genetic factors, and the relationships between these processes and hormonal and immune system changes. Establishing the natural progression of vulvodynia will contribute toward a better understanding of the role of etiologic factors (causes).

## Methodological and Other Issues To Be Resolved

The NIH will continue to foster and support research focusing on basic, clinical, translational, and/or behavioral studies that expand our knowledge of vulvodynia, and to coordinate educational efforts for patients and physicians based on research and scientific evidence. To further outreach efforts, the NIH is working with the National Vulvodynia Association, the American College of Obstetricians and Gynecologists, and other professional organizations to develop a national educational program for primary health care providers, patients, and the general public regarding vulvodynia's symptoms, diagnosis, and treatment options. The NICHD, the National Institute of Neurological Disorders and Stroke, the NIH Pain Consortium, and other agencies in the U.S. Department of Health and Human Services are collaborating with the ORWH on these efforts aimed at advancing research and education on vulvodynia.

### REFERENCES

1 Harlow BL, Stewart EG. A population-based assessment of chronic unexplained vulvar pain: have we underestimated the prevalence of vulvodynia? *J Am Med Womens Assoc.* 2003;58:82-88.

2,3 Bachmann GA, Rosen R, Pinn VW, et al. Vulvodynia: a state-of-the-art consensus on definitions, diagnosis and management. *J Reprod Med.* 2006;51(6):447-56.

# Frequently Asked Questions (FAQs) about Vulvodynia

## *What is vulvodynia?*

Vulvodynia is chronic unexplained pain or discomfort of the vulva. The vulva is the area of the female genitals surrounding the vaginal opening and includes the labia, the vestibule, and the perineum. Some women refer to it as “the pain down there” or as “feminine pain.” It affects all women, including racial and ethnic minorities, women with disabilities, sexual minorities, and those in rural and urban areas.

## *What are the symptoms of vulvodynia?*

Women with vulvodynia often experience burning, stinging, irritation, rawness or stabbing pain in their genitals, with no apparent explanation. The pain or discomfort can be chronic or intermittent, and generalized or localized to one area of the vulva. Some women also report itching. For many women, sexual intercourse, and even tampon insertion or wearing clothes (such as underwear or trousers) is very uncomfortable or painful.

## *What causes vulvodynia?*

### *Do I have an infection or a disease?*

While a number of causes have been proposed, researchers still don't know why vulvodynia happens to some women. Most likely, there is no single cause. Because of this, vulvodynia remains difficult to assess and diagnose. Many health care providers are not aware of the existence of vulvodynia, so aren't always able to diagnose it. As a result, many women may go for a long period of time without diagnosis.

## *How is vulvodynia diagnosed?*

You should share with your health care provider information about your symptoms and related problems you are experiencing. In turn, your health care provider should talk to you about these symptoms and raise questions about your lifestyle, medications you may be taking, and your sexual and family history, in order to better understand the possible causes of your pain. Your health care provider should also do an examination of your pelvic area, including your vulva and vagina, and laboratory tests to rule out other causes of your pain and discomfort. These causes could include endometriosis, a yeast infection, a sexually transmitted infection, or dermatitis. The diagnosis of vulvodynia can be established after ruling out other causes of your pain and discomfort.



### ***Is there a treatment or cure for vulvodynia?***

While there is no cure, there are a number of treatment options for vulvodynia. These can include advice on general vulvar care, topical and/or oral medications, physical therapy exercises, injections, biofeedback, or even surgery in some specific cases. Although no single treatment is effective for all cases, a multi-faceted approach to prevent and reduce symptoms can improve quality of life. You and your health care provider should work together to develop a strategy of treatment that works best for you. Many women find that wearing only cotton underwear, not wearing panty hose, or tight-fitting jeans or other clothes around their pelvic area; using only white, unbleached toilet tissue and 100% cotton sanitary products (tampons and pads); washing their genitals frequently with water; and avoiding using creams, soaps, douches, or deodorants on your vulva also helps. What is important is to find a low stress strategy for you that reduces the pain and discomfort.

### ***How may vulvodynia affect my personal relationships?***

For many women, vulvodynia may result in sexual activity being very uncomfortable and even painful. Because of this, vulvodynia may also cause emotional stress for women whose intimate partners may not fully understand the effects of this condition. Women should be encouraged to discuss vulvodynia openly and honestly with their partner and should not feel obligated to engage in sexual activity if it is painful. More information on this issue is available from our partners, including the American College of Nurse-Midwives ([www.acnm.org](http://www.acnm.org)), the American College of Obstetricians and Gynecologists ([www.acog.org](http://www.acog.org)), the International Society for the Study of Vulvovaginal Disease ([www.issvd.org](http://www.issvd.org)), and the National Vulvodynia Association ([www.nva.org](http://www.nva.org)).

### ***Did my partner give this to me? Can I give this to my partner?***

There does not appear to be a link between sexually transmitted infections and vulvodynia; thus it cannot be shared among sexual partners. However, because vulvodynia can interfere with a woman's enjoyment of sexual activity, a woman with vulvodynia should discuss it openly and honestly with her partner.

### ***Is there something a woman can do to prevent it?***

This is still unknown. Further research is needed to assess the causes and underlying factors that contribute to vulvodynia.

### ***How do I talk to my health care provider about vulvodynia?***

For many women, talking about pain or discomfort that occurs in or around their genitals can be very uncomfortable and difficult. Women may feel embarrassed, or worry that they might have a sexually transmitted infection. Others may worry that their health care provider won't take them seriously and dismiss their concerns as unimportant. Some may have raised this with other providers, and felt frustrated by their responses. Nevertheless, it is very important that women tell their health care providers about any pain and discomfort they are experiencing, being specific about where the pain and discomfort occurs, when it started, and whether or not the pain or discomfort is episodic in nature. Be open about what sort of home remedies you may have tried, and whether or not there have been other changes in your medical history. While you may indeed have vulvodynia, it is entirely possible that there may be another cause for your pain and discomfort, and you and your health care provider will want to determine that as well. If your health care provider does not respond to your concerns, you should raise the possibility of vulvodynia with them, or seek another opinion.

### ***Why did it take so long for my health care provider to diagnose it?***

Many health care providers are unaware that vulvodynia is a diagnosis. Further, most health care providers will want to make sure that your vulvar pain doesn't have another organic cause.

### ***How many other women have vulvodynia?***

Because many women are reluctant to report symptoms of vulvodynia to their health care providers, and because many health care providers don't always quickly diagnose vulvodynia, assessing how many women have vulvodynia is difficult. Nevertheless, researchers conservatively estimate that over their lifetime, as many as 18% of women will experience symptoms

consistent with vulvodynia. Symptom onset appears to be highest among women between the ages of 18 and 25, and lowest for women older than 35. As noted before, vulvodynia knows no ethnic or socio-economic boundaries, including women with disabilities, sexual minorities, and rural and urban women. Once considered a condition that affects primarily Caucasian women, several recent studies have shown that African American and Hispanic women are equally likely to develop vulvodynia. More studies are needed to understand the risk factors, etiology, diagnosis, and clinical management of vulvodynia.

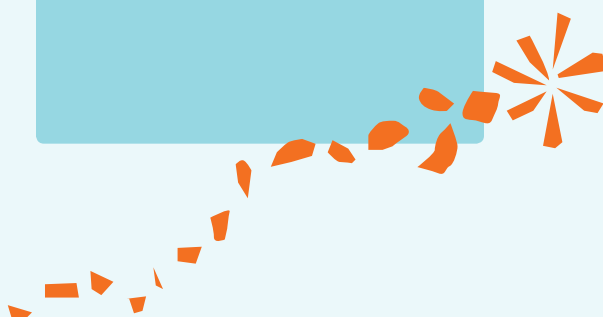
### ***What research is being done about vulvodynia?***

Researchers continue to explore better clinical definitions of vulvodynia, better methods of identifying conditions that co-exist with vulvodynia, the etiology of the condition, risk factors associated with its development and more comprehensive clinical management tools for vulvodynia. NIH encourages investigators to submit qualified applications for further studies on vulvodynia to appropriate program announcements.

### ***Where can I go for more information about vulvodynia?***

The Web site of the Office of Research on Women's Health, the National Institutes of Health, U.S. Department of Health and Human Services (<http://orwh.od.nih.gov/health/vulvodynia.html>) has additional information on electronic and print resources regarding vulvodynia.

Other resources are also listed in this brochure.



Office of Research on Women's Health  
National Institutes of Health  
U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES  
6707 Democracy Blvd. Suite 400  
Bethesda, MD 20892-5484

OFFICIAL PENALTY FOR PRIVATE USE, \$300

PRST STD  
POSTAGE & FEES PAID  
NIH/OD  
PERMIT NO. G-802



The Vulvodynia Campaign is brought to you by the Office of Research on Women's Health, National Institutes of Health, U.S. Department of Health and Human Services, in partnership with other federal and non-federal agencies and organizations.

# Vulvodynia

WOMEN'S HEALTH INFORMATION ENCLOSED

