

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>

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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

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

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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>

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

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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. Available 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

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.¹ 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.² 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.³

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), the American College of Obstetricians and Gynecologists (www.acog.org), the International Society for the Study of Vulvovaginal Disease (www.issvd.org), and the National Vulvodynia Association (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.

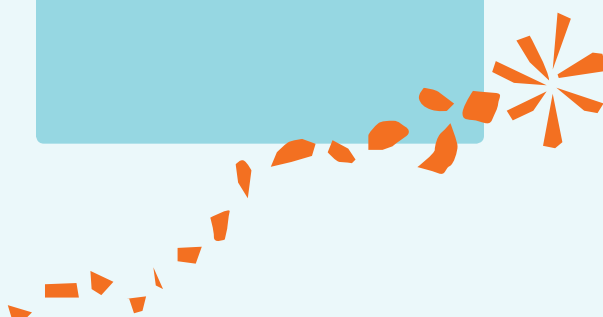
What research is being done about vulvodynia?

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
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Vulvodynia

WOMEN'S HEALTH INFORMATION ENCLOSED

