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## Understanding Vulvodynia

► *planning for future research*

### Overview

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 as “feminine pain.” The nature of the pain varies, but most women with this chronic pain condition describe it as a burning pain. Other common symptoms include stinging, irritation (rawness), or a pain sensation that may be constant or intermittent.

Researchers and health care providers do not know what causes vulvodynia. Typically, a diagnosis evolves by eliminating other possibilities, an expensive and time-consuming process.

Common treatment recommendations include dietary changes, avoiding irritants (such as perfumes or detergents), oral and/or topical medications, biofeedback, physical therapy exercises, or surgery. No single treatment is effective for all women with vulvodynia. Experts often tailor treatment combinations to improve the quality of life for women who suffer from vulvodynia.

### The Impact of Vulvodynia

Although it is difficult to determine exactly how many women vulvodynia affects, researchers have estimated that 9 to 18 percent of women between the ages of 18 and 64 may experience vulvar pain during their lifetimes. Vulvodynia affects women of all races and cultures and is especially common among women 20 to 50. The condition can make sexual intercourse, tampon insertion, and even wearing clothes painful. Many women

suffer in silence because they are uncomfortable discussing their symptoms with their health care providers or with family members.

Other chronic pain disorders such as fibromyalgia, irritable bowel syndrome, and interstitial cystitis can co-occur with vulvodynia. The Institute of Medicine’s report “Relieving Pain in America,” published in 2011, highlighted the prevalence of pain disorders in the United States and the significant impact pain disorders have on quality of life and on the nation’s economy.

### Vulvodynia Research at the National Institutes of Health

Research at the National Institutes of Health (NIH) continues to explore precise clinical definitions for vulvodynia, more effective methods of identifying conditions that coexist with vulvodynia, and more comprehensive clinical management tools.

NIH has released three program announcements designed to promote interdisciplinary research, reduce the burden of the disease, and ultimately improve the quality of life for women affected by vulvodynia.

Published by the *Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)* and cosponsored by the NIH Office of Research on Women’s Health (ORWH), these R01, R03, and R21 funding mechanisms share the title *Vulvodynia—Systematic Epidemiologic, Etiologic or Therapeutic Studies*. View the R01 program at <http://grants.nih.gov/grants/guide/pa-files/PAR-10-190.html>.

*The Office of Research on Women's Health (ORWH) promotes women's health and sex differences research within and beyond the NIH and works to ensure that women and minorities are included in clinical research. ORWH establishes the NIH research agenda for women's health, co-funds research in partnership with NIH Institutes and Centers, and supports women in biomedical careers and women's health researchers.*

## Resources

- **NIH Office of Research on Women's Health  
NIH Vulvodynia Awareness Program**

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

- **NIH Research Plan on Vulvodynia**

*Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)

[http://www.nichd.nih.gov/publications/pubs/upload/NIH\\_Vulvodynia\\_Plan\\_April2012.pdf](http://www.nichd.nih.gov/publications/pubs/upload/NIH_Vulvodynia_Plan_April2012.pdf)

- **MedlinePlus.** Vulvar Disorders. U.S. National Library of Medicine, NIH. <http://www.nlm.nih.gov/medlineplus/vulvardisorders.html>.

- **Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research.** Institute of Medicine of the National Academies. 2011. <http://iom.edu/Reports/2011/Relieving-Pain-in-America-A-Blueprint-for-Transforming-Prevention-Care-Education-Research.aspx>.

On behalf of the NIH Pain Consortium, the National Institute of Nursing Research has released other active program announcements for R01, R03, and R21 funding mechanisms to stimulate research in the field of pain, which would include research on vulvodynia. These program announcements share the title *Mechanisms, Models, Measurement, & Management in Pain Research*. View the R01 program at <http://grants.nih.gov/grants/guide/pa-files/PA-10-006.html>.

In addition to funding scientific research on this disorder, NIH has supported several workshops on vulvodynia. In July 2011, NIH sponsored a scientific meeting of interdisciplinary scientists, clinicians, and advocates to gather input for the development of a research agenda to guide the field of vulvodynia research. The research agenda focuses on building additional research capacity and addressing research gaps. The agenda follows other workshops where leading researchers met to identify key issues associated with conducting clinical research on vulvodynia and treating patients with the condition.

## Models for Future Research

NIH recently released the *Research Plan on Vulvodynia* (January 2012), which reflects the current state of research on the condition and outlines a plan for future research. The report, developed by NICHD, is based on

- a literature review and NIH-supported grants related to vulvodynia
- interviews with leading scientists
- the scientific meeting *Vulvodynia: A Chronic Pain Condition—Setting a Research Agenda*, convened in 2011.

The study of vulvodynia involves several different scientific disciplines, including gynecology, neurology, dermatology, and pain research. Investigators are needed to conduct high-quality, rigorous research (including randomized controlled trials) to explore almost every aspect of vulvodynia—from causes to cures. The report calls for a collaborative effort among federal, private, and nonprofit agencies and researchers in the field in order to better understand the etiology, diagnosis, and treatment of vulvodynia.

## Resolving Methodological and Other Issues

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, NIH is working with the National Vulvodynia Association, the American College of Obstetricians and Gynecologists, and other professional organizations to explore the development of a national educational program for primary health care providers, patients, and the public about symptoms, diagnosis, and treatment options for vulvodynia. 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 ORWH on these efforts to advance research and education on vulvodynia.

For more information, visit the NIH Vulvodynia Awareness Program at the ORWH web site:

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

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