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NVA News

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# Predictors of PVD Treatment Outcome

## *Questions and Answers with Nina Bohm-Starke, MD, PhD, and Ulrika Heddini, MD*

*Dr. Bohm-Starke is an associate professor in the division of obstetrics and gynecology, department of clinical sciences, at the Karolinka Institutet in Stockholm, Sweden. She is also a senior consultant in the department of obstetrics and gynecology at Danderyds Hospital, where she directs the vulvar open care unit. Dr. Heddini is a specialist within the unit, as well as a senior resident in the department of clinial sciences at the Karolinska Institutet. She is currently completing her PhD and her thesis research is focused on vulvodynia.*

Recent studies demonstrate that women with Provoked Vestibulodynia (PVD, aka vulvar vestibulitis syndrome) have reduced pain thresholds in extra-genital body sites such as the arms and legs, suggesting that abnormal pain processing mechanisms in the brain and/or spinal cord may be responsible. Additionally, mounting evidence suggests that PVD patients frequently suffer from other pain conditions such as interstitial cystitis, fibromyalgia and temporomandibular disorders. This has led scientists to propose that a subgroup of women with PVD may be genetically predisposed to developing chronic pain in general. To better understand the factors associated with these preliminary findings, in 2009, the NVA awarded a four-year grant to Dr. Bohm-Starke to investigate alterations in several genes involved in pain modulation and inflammation in PVD patients and controls. Her findings will be published in a series of five journal articles, the first of which is summarized in this article and was recently published in the *Journal of Sexual Medicine*.

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# NVA Director Testifies at Landmark Senate Hearing

On February 14, 2012, the U.S. Senate Committee on Health, Education, Labor and Pensions (HELP) convened its first hearing on our nation's chronic pain epidemic, *Pain in America: Exploring Challenges to Relief*. This landmark hearing brought together legislators, physicians, scientists, patients and advocates in an effort to begin to address this major public health concern that costs our country $635 billion per year and affects one in three American adults – more than those affected by cancer, diabetes and heart disease combined. "Chronic pain is a significant public health challenge that has yet to receive adequate attention," said Senator Tom Harkin (D-IA), HELP Committee Chair, in his introductory statement. "It remains one of the most challenging conditions to

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## Senate Hearing

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assess and effectively treat, even though it's one of the top reasons for doctors' visits." The senator continued, "Because of its pervasive impact, we've convened this hearing to: explore the current state of pain care research and education; examine barriers to treatment; and discuss opportunities for future research and prevention strategies."

HELP Committee member Sheldon Whitehouse (D-RI), who has a longstanding record of advancing pain initiatives in Rhode Island, introduced his constituent Christin Veasley, Executive Director of the NVA. As the only witness invited to share the patient advocacy perspective, Christin described some of her experiences as a chronic pain sufferer and vulvodynia advocate of nearly 20 years. "My story echoes the experiences of millions in our country. Pain exhausts, depletes, dehumanizes and drains you in *every* capacity – physically, emotionally, spiritually and financially." Further, she highlighted how the lack of federal research funding for chronic pain disorders affects the millions who suffer. "Due to this inadequate research effort, doctors don't have the training or scientific information they need to effectively manage pain. As patients, we are left completely disillusioned, forced to navigate the health care system on our own and implement a trial-and-error process, which can easily take months to years, to find a treatment(s) to lessen the pain." She further described the experiences of women with vulvodynia: "When you have pain in an area of your body that is still not openly discussed in our country, suffering is further compounded with embarrassment, stigma and isolation." Because conditions that solely or predominantly affect women have historically been neglected, she contended that future pain initiatives must include a long-overdue and appropriate inclusion of these disorders. She concluded, "It is only through research that we will better understand the mechanisms of pain and delineate effective treatments, and that medical professionals will have the scientifically proven information they need to make appropriate diagnostic and treatment recommendations. Then, and only then, will the haphazard treatment of pain, as well as costly and wasteful health care spending, come to an end, giving the millions of American pain sufferers and their families the one thing we desperately want returned to us – and that is our lives."

Lawrence Tabak, DDS, PhD, Deputy Director of the National Institutes of Health (NIH), echoed Senator Harkin's statements on the seriousness

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The National Vulvodynia Association is a nonprofit organization that strives to improve women's lives through education, support, advocacy and research funding. The NVA is not a medical authority and strongly recommends that you consult your own health care provider regarding any course of treatment or medication.

# Senate Hearing

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of this issue: "Chronic pain is one of the most important public health problems facing our nation … and an increasing problem for the future." He continued, "The most important modern day insight on chronic pain is that, however it begins, pain can become a disease in and of itself." This recognition has important implications for how we study and treat pain, as well as structure our health care system to care for the afflicted. "Congress took steps towards advancing research, education and care for people with pain through specific provisions in The Affordable Care Act of 2010," Tabak explained. The Act directed the Secretary of Health and Human Services to establish the Interagency Pain Research Coordinating Committee, whose responsibilities include summarizing advances in pain care, identifying gaps and duplication of effort across the federal pain research portfolio, and recommending how to disseminate information about pain care. (The NVA is serving on this committee.) The Secretary also engaged the Institute of Medicine (IOM) to delineate the magnitude of this public health problem, survey the adequacy of pain diagnosis and treatment, identify barriers to pain care, and make recommendations on how to reduce these barriers. He concluded by highlighting several important pain-specific initiatives underway at the NIH such as the Pain Consortium, Neuroscience Blueprint and the Multidisciplinary Approach to the Study of Pelvic Pain Research Network. As a result of advocacy efforts led by the NVA and partnering organizations through the Chronic Pain Research Alliance, for the first time in history, neglected pain disorders such as vulvodynia are now being included in these initiatives.

Philip Pizzo, MD, Dean of the Stanford University School of Medicine and Chair of the IOM pain committee, outlined the main goals of the IOM study and the resultant June 2011 report, *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research*. These included

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*Witnesses speaking with Senator Harkin (D-IA) following the hearing. From left to right, Senator Harkin, Dr. Pizzo, Dr. Maixner and NVA Director Christin Veasley.*

# Senate Hearing

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assessing the magnitude of this public health issue, reviewing impediments and barriers to accessing medical care, better delineating special populations that are at higher risk of developing pain, identifying scientific tools and technologies that can be used to advance pain research and care, and discussing better ways to conduct research through public-private partnerships. He explained that their work was guided by several overarching principles, one of which was that "pain management is a moral imperative."

The IOM report included 19 recommendations, assigning tasks to all levels of government, patient advocacy and medical organizations, as well as public and private institutions. Dr. Pizzo reviewed a few high-priority recommendations to be carried out by the end of 2012, including directing the Secretary of Health and Human Services to create a comprehensive population-level strategy for pain prevention, treatment, management and research. He concluded, "The scope of the pain management issue is truly daunting, and the limitations in knowledge and education for pain health care professionals are glaring. The medical community *must* engage in the necessary cultural transformation to reduce pain suffering of Americans and work collaboratively with the public and private sectors."

William Maixner, DDS, PhD, Director of the Center for Neurosensory Disorders at the University of North Carolina in Chapel Hill, stated that "we are on the verge of being able to make massive progress on this issue" and discussed the barriers to pain research, education and patient care that must first be addressed. Currently, there is a significant mismatch between the societal cost of pain and the amount of federal funding allocated to pain research. Only 1.3 percent of the NIH's budget is allocated to pain research, an inadequate amount to address our gaps in knowledge and the large societal costs associated with pain. Further, medical school curricula do not spend an appropriate amount of time addressing pain biology and pain management strategies, leaving many clinicians ill-equipped to adequately treat pain. He stated, "The average medical student receives nine sessions related to pain - a woefully inadequate amount to develop competent individuals who are able to diagnose, assess and treat patients with chronic pain." Mechanisms and incentives to improve the continuing medical education of front-line providers such as primary care physicians must be put in place to expand their pain management skills. He continued, "Barriers to patient care are substantial. There is a great need for the development of advanced pain management centers, and *now* is the time for these advanced centers to become a reality."

The testimony of the final witness, John Sarno, MD, professor of clinical rehabilitation medicine at the New York University School of Medicine in New York, was controversial and insulting to many of those who suffer from chronic pain. As a pain practitioner of 40 years, he believes pain can be categorized into two groups – pain that results from injury, surgery or infection, or pain that is of psychophysical or emotional origin." Fellow witnesses were quick to respond, including Dr. Pizzo, who said, "We need to be very sensitive to the words we use and the way they are perceived. One of the challenges in medicine is that when we don't know an answer, we often assign it to something else. Those assignments are often emotional and are attributed back to the individual … and now the individual becomes a victim of his or her own suffering. This speaks to why we need

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# Results of First Cost Study on Vulvodynia Published

## By Cristina Shea

*Cristina Shea, the newest member of the NVA's staff, is a senior at Stanford University majoring in biological chemistry. She plans to pursue a medical degree and dedicate her career to caring for those with chronic pain, particularly vulvodynia.*

Multiple studies have shown that vulvodynia poses a significant physical and emotional burden on the afflicted. Women visit multiple clinicians and a delay in diagnosis is common. In a population-based study funded by the National Institutes of Health, Harlow and colleagues (2003) found that 60 percent of women consulted at least three clinicians while seeking a diagnosis, 40 percent of whom remained undiagnosed after three medical consults. These findings suggest that vulvodynia may also pose a significant financial burden on vulvodynia sufferers, as well as our nation's health care system and economy. No studies, however, have been conducted to delineate the economic and societal impact of vulvodynia. This information is critical to improving awareness of this life-altering condition and to help guide decision makers as they allocate resources for scientific research and awareness efforts.

For these reasons, the NVA collaborated with Lizheng Shi, PhD, adjunct professor of medicine in the department of global health systems and development, and Yiqiong Xie, MD, a doctoral candidate in the department of epidemiology, both of Tulane University in New Orleans, and Eric Wu, PhD, a health economist at the Analysis Group, Inc., in Boston, to conduct the first economic impact study on vulvodynia. The results were recently published in *Current Medical Research and Opinion* and presented at the 17th Annual Maternal and Child Health Epidemiology Conference of the Centers for Disease Control and Prevention.

Three hundred patients tracked their costs pertaining to office visits, lab work, diagnostic tests, surgical procedures, prescriptions, hospitalizations and transportation, as well as lost wages and inability to perform household chores due to vulvodynia for up to six months. Dr. Shi and his team also extracted the average insurance payments for direct health care services from a commercial insurance database. The expenditures were separated into three categories: i) direct health care costs, ii) direct non-health care costs, e.g., transportation expenses, and iii) indirect costs, e.g., financial loss due to an inability to work or perform household chores. The team also utilized a web-based survey to measure participants' quality of life.

Thirty-two percent of women who participated in the study reported a diagnosis of generalized vulvodynia, 40 percent had provoked vestibulodynia and 28 reported suffering from both subtypes. On average, women experienced vulvar pain for seven years since symptom onset and three years since diagnosis. The majority of participants reported excessive pain on contact to the genital area (86%), burning in the genital area for three months or more (75%), greater than 10 episodes of pain on contact (90%) and limitation in intercourse (95%). These screening questions were included in the study because they've previously been shown to be highly predictive of an in-office vulvodynia diagnosis (Harlow 2009). Common co-morbidities reported by women included irritable bowel syndrome, migraine headache, temporomandibular disorders, interstitial cystitis, endometriosis, depression and anxiety.

Based on the reported prevalence range of 3 to 7 percent in the U.S. and the proportion of women

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## Economic Impact

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seeking treatment (54%), the investigators' analysis yielded an annual national burden ranging from $31 to $72 billion (Arnold 2007, Harlow 2003, Reed 2004, Reed 2006, Reed 2008). Sixty-eight percent of this amount was attributable to direct health care costs, 6 percent to non-health care costs and 26 percent to indirect costs. Women reported being unable to participate in social activities due to vulvodynia an average of three times per month. Similar to prior studies, women reported a significant decrease in quality of life, which was lower than that reported by kidney transplant patients and those with osteoporosis-related fractures (McDonough 2011, Neri 2011).

The findings suggest that vulvodynia is a costly disorder with a significant impact on quality of life. Due to the historic lack of research on vulvodynia, identification and diagnosis of the condition remains challenging for the majority of clinicians. Additionally, pain disorders like vulvodynia typically require a multidisciplinary approach to treatment, utilizing many therapies in combination. As a result, the process of seeking a correct diagnosis for women is long and arduous, and they often obtain treatment from many different specialists, e.g., pain specialists, gynecologists, physical therapists. Additionally, many women with vulvodynia suffer from coexisting conditions, and together, they pose an enormous burden. The study's findings highlight the urgent need for an expanded research effort to determine causes and mechanisms of vulvodynia, as well as effective therapies. Additionally, a timely and appropriate assessment of multiple disorders among women with vulvodynia is essential.

The investigators did point out some limitations of the study and the need for more expansive follow-up studies to be conducted. Participants were mostly highly educated and insured Caucasian Americans, nearly half of whom had an annual household income above $70,000. Additionally, patient disease severity, subtype and health awareness could have influenced their decision to participate. Thus, this group may not be representative of all women with vulvodynia, and the estimated costs determined by the study may overestimate the actual cost of the disorder. Larger studies are needed to confirm the findings of this preliminary investigation, as well as examine methods of reducing the individual and societal costs of vulvodynia.

*[Editor's Note: This article summarizes: Xie Y, Shi L, Xiong X, Wu E, Veasley C, Dade C. Economic burden and quality of life of vulvodynia in the United States. Curr Med Res Opin. 2012 Apr:28(4):601-8.]*

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# Understanding Clitoral Pain

## By Deborah Coady, MD, and Nancy Fish, MSW, MPH

*Dr. Deborah Coady is a clinical assistant professor of obstetrics and gynecology at NYU Langone Medical Center. Her medical practice, Soho Obstetrics and Gynecology, is located in New York City. Ms. Fish is a licensed social worker with a master's degree in public health. She works part-time at Soho OB-GYN and her private practice is located in Bergen County, New Jersey. This article was adapted from the authors' book,* Healing Painful Sex: A Woman's Guide to Confronting, Diagnosing, and Treating Sexual Pain*, with permission from Seal Press, a member of the Perseus Books Group. Copyright November 2011.*

Pain in the clitoris, or clitorodynia, is probably one of the most severe and emotionally disruptive types of sexual pain there is. It is also less common than other types of sexual pain, but that fact is of no comfort if you are suffering from it. Because of the silence surrounding this condition—both among women and in the medical community—there aren't many reliable statistics about it. But we have noticed (and our fellow clinicians confirm this impression) that more women seem to be reporting this type of pain.

**How Clitoral Pain Affects You**

While you have clitoral pain, you might feel the condition has taken over your life. Rest assured that treatments are available and they offer good prospects for long-term freedom from pain. While you're waiting for the treatments to work, you'll need plenty of patience, fortitude and support.

Even when sex isn't involved, clitoral pain can play havoc with your life. Jessie told us that when her pain was at its worst, she hurt all the time, no matter what she was doing. She couldn't find a comfortable seated position or even wear underwear.

"The pain covers the clitoris, labia and the very top part where the pubic bone is. Light touch is irritating and sets the pain off like a fire alarm," she says. "What makes my pain worse is wearing tight clothes, sitting—sitting in cars especially—and certain exercises, like the treadmill and elliptical," she says. Beyond the physical accommodations, Jessie frequently feels both depressed and anxious. "It affects my life all day and pretty much every day."

**What's Going On: The Biology**

Because the clitoris plays a major role in female arousal and orgasm, it is well endowed with nerve endings, making this tiny area highly sensitive to touch, pressure, temperature, vibration and chemicals. The primary nerve connecting the clitoris to the central nervous system is the pudendal nerve, however, fibers from a host of others including the ilioinguinal, iliohypogastric, and genitofemoral nerves, as well as autonomic nerves from the sacral plexus, heighten its sensitivity further (see figure on page 9). The clitoris is also connected to the uterus and other pelvic organs by connective tissue and the round ligament. With the use of magnetic resonance imaging (MRI), we are learning more about the complex anatomical details of this relatively unstudied organ, including how it functions during sexual arousal.

The clitoris has its own muscles, which are connected to the pubic bone and large muscles of the pelvic floor (see figure on page 10). Within the superficial layers of muscles at the vaginal

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opening, is a plexus (interwoven network) of blood vessels, which become engorged and enlarged with sexual stimulation and deflate and return to normal size after orgasm. This is key to sexual arousal and orgasm. The clitoris is actually composed of several active structures under the skin and hidden from view, which wrap around the urethra and lower vagina and surround the vaginal opening, as seen in the figure on page 9. The corpora cavernosa are two large erectile chambers that underlie the labia and vestibule. The corpus spongiosum is composed of hidden spongy elastic structures around the urethra and oval bulbs of tissue located under the vestibule. The portions of the clitoris surrounding the urethra and extending under the lower vagina correspond to what some researchers have previously called the Grafenberg Spot (G-spot), which contributes to arousal and orgasm with vaginal penetration. These components form the clitoris, a complex functional organ that's up to six inches long, almost as large as the penis and much more than the tiny "button" it has long thought to be.

### Symptoms of Clitoral Conditions

If you are suffering from pain in your clitoris, you are likely to have at least some of the following symptoms:

- Exquisite tenderness with touch;
- A feeling of uncomfortable constant or intermittent swelling or sexual arousal, sometimes relieved by self-stimulation and orgasm;
- Pain in the clitoris triggered by certain leg movements, sitting, driving, or tight clothing; or
- Burning pain after touch or orgasm that sometimes lasts for hours or days.

The extraordinary sensitivity, connectedness, size and complexity of these structures mean that clitoral pain can be excruciating. Pain may be momentarily provoked by something as casual as the touch of clothing, or it can be continuous, radiating and unremitting. For a variety of reasons, the nerves in this sensitive organ can become irritated, leading to inappropriate random engorgement and muscle tension. For many women, along with the pain comes an uncomfortable feeling of being aroused, which is made all the more disturbing if actually touching the clitoris (to relieve the arousal) is also painful.

Clitorodynia isn't the name of a specific disease—the suffix "odynia" simply means "pain." The pain can have a variety of causes and a woman might be suffering from one, two or many of them. In some cases altered nerve functioning is to blame. Examples include overgrowth and/or extreme sensitization of the nerve fibers in or around the clitoris, or nerve disorders that cause pain during or after viral infections such as recurrent herpes simplex virus infection or postherpetic neuralgia. Pain can also result from compression or dysfunction of the pudendal, ilioinguinal, iliohypogastric or genitofemoral nerves anywhere along their paths from the lumbosacral spine to the vulva; a small anatomical problem such as a cyst or neuroma; spasm/tension in the pelvic floor muscles that surround the pudendal nerve's clitoral branch; or hip disorders that cause groin pain. Decreased blood supply to the clitoral nerves due to blockage of blood vessels (especially the pudendal artery), or inappropriate filling of erectile tissues with blood due to abnormalities in blood vessels such as a varicose vein or an arteriovenous malformation may also be responsible. Skin conditions, especially lichen sclerosus and chronic

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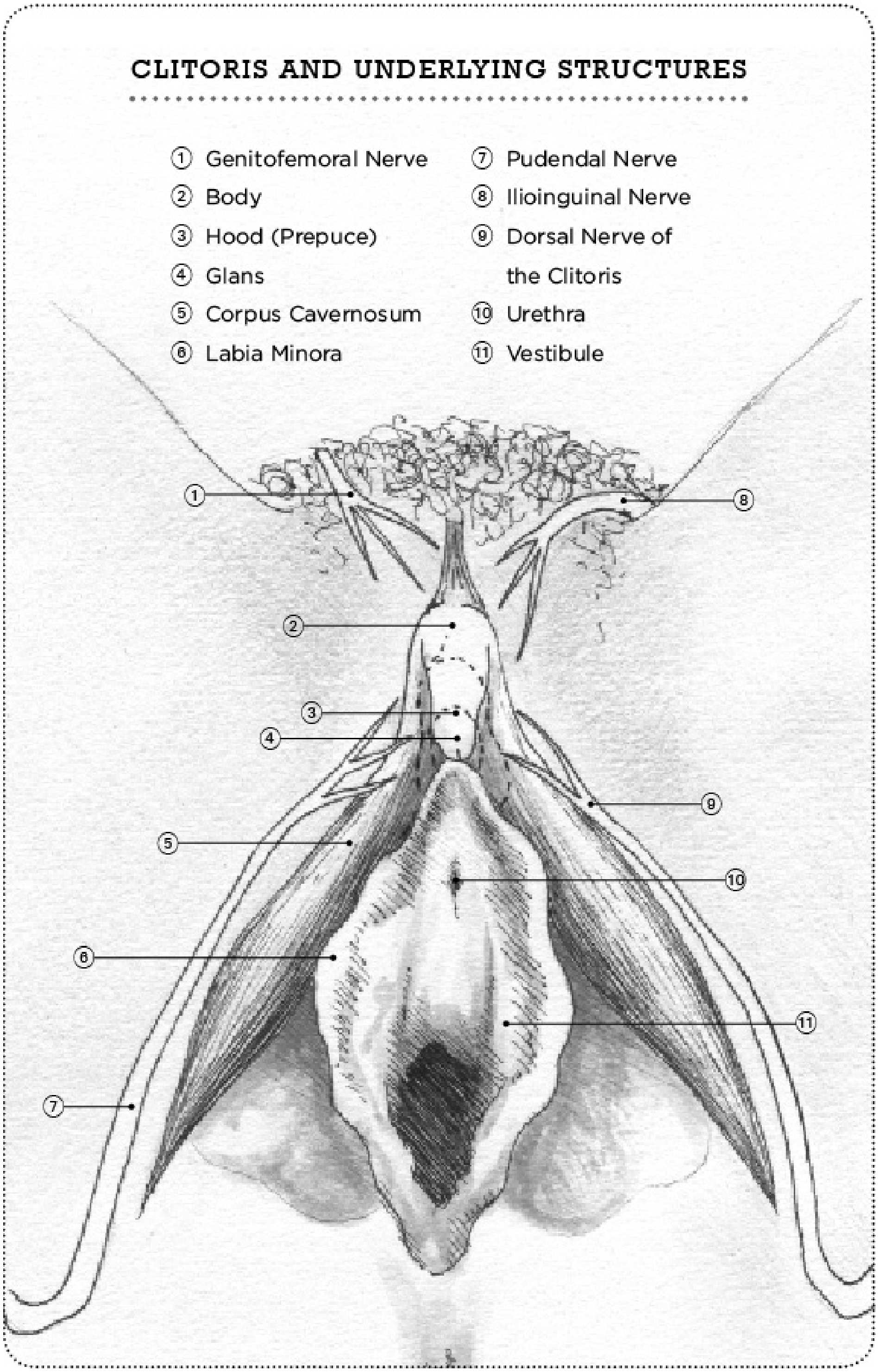

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## Clitoral Pain

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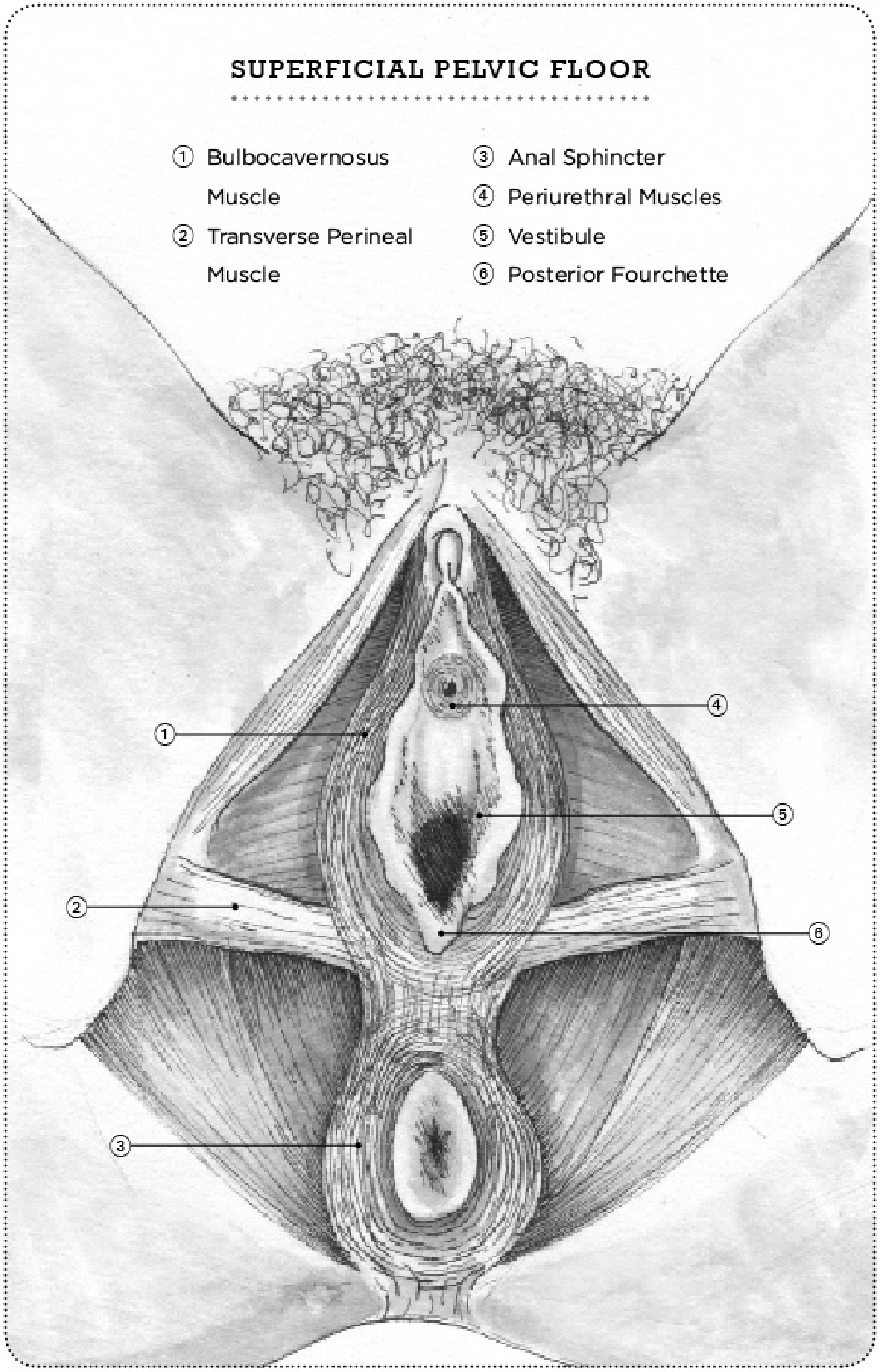

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# Clitoral Pain

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skin yeast infections, may be hidden under the clitoral hood or deep within a skin fold. The pain could also be a side effect of medication, especially antidepressants such as trazodone and duloxetine (Cymbalta), which increase the brain's dopamine levels. Finally, a chemical imbalance in the brain marked by high dopamine levels can lead to a distressing condition called Persistent Genital Arousal Disorder, in which a woman feels perpetually and painfully aroused.

**Diagnosis: The Tests You Need**

Chronic sexual pain is one of the most commonly misdiagnosed and mistreated conditions in all of medicine. This information should help you ensure that your health care provider is ordering the right tests to properly diagnose your condition and develop an appropriate treatment plan. First and foremost, your clinician needs to conduct a comprehensive physical exam to delineate the areas of tenderness, rule out small abnormalities in the clitoris and evaluate muscle and nerve problems that might be the source of pain. The exam should include a detailed skin evaluation, during which your clinician will closely look (with magnification) at all the folds in your genitals, pulling back the clitoral hood for good exposure of all the surfaces. He or she will look for white areas, inflammation, ulceration and/or injury, and should also take cultures to test for infection.

Your health care provider should also evaluate other parts of your pelvis and lower back to look for muscle spasm, hip disorders and scarring of fascia and other connective tissue. Since abnormal discharge might also affect your clitoris, your clinician should also perform a vaginal exam to rule out irritating vaginitis and culture vaginal fluid for yeast, bacteria and viruses.

Depending on your history and the results of your physical exam, your health care provider might order imaging tests such as an MRI to evaluate any abnormalities in blood vessels, muscles or other structures in the pelvis. We strongly believe that pelvic floor muscle therapy is a crucial part of treatment for this type of pain, as well as diagnosing possible orthopedic or muscular causes of the problem. In most cases, a referral to a physical therapist is needed to determine whether a muscle imbalance or movement disorder might be affecting your clitoral nerves. Your clinician may also schedule a neurology evaluation to identify possible nerve compression or small-fiber neuropathy.

**Treatments: What You Can Expect**

Many cases of clitorodynia can be cured, so please do not give up hope. Yes, the pain is excruciating and the condition often seems as though it has taken over your life, but you can be helped and the pain can go away. Rally your support system and keep the ultimate goal in mind.

**How *Not* to Treat Clitoral Pain**

Do *not* . . .

- Pretend it does not really exist;
- Listen to the opinions of people who aren't well informed or educated about the condition;
- Allow yourself to believe it's just in your head;
- Use topical steroids without your physician's approval;
- Decide that nothing could be worse than this and give up hope; or
- Avoid counseling to cope with this tough condition.

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Effective treatment begins with identifying the underlying cause, which as we have seen, might be anything from a skin condition to a muscular problem to a vascular issue to a nerve disorder, or some combination of many causes. Once the underlying causes have been addressed, your clinician should then move on to treat the nerve sensitization that has almost certainly resulted from the pain itself.

The selection of appropriate treatment(s) will depend on the fundamental diagnosis, but the following are likely possibilities. If your skin has been infected, you'll be given oral (or topical) antifungal or antibacterial medication to use for at least one month. Your nerves may be desensitized with topical nerve-sedating medications such as lidocaine, bupivacaine, gabapentin (Neurontin) or amitriptyline (Elavil), to be applied several times daily for three months. If the regional nerves are to blame, you may be given a series of local anti-inflammatory and anesthetizing injections alongside the clitoris (at the clitoral branches of the pudendal nerve), the pudendal nerve itself or at one or more of the three neighboring nerve pathways. Because the nerves may become further irritated by pelvic tightening (a response to pain), physical therapy is utilized as a mainstay treatment to address tension in the pelvic floor muscles and fascia. If a blood vessel abnormality is suspected, imaging and interventions to close off the culprit vessel are available. If your problem lies in the central nervous system or results from a peripheral nerve injury, i.e., is neuropathic, you may be given oral medications. If in rare cases, an injured nerve(s) is the problem, you might be treated with pulsed radiofrequency (a method to "stun" the nerves) or sacral neuromodulation. In severe cases, where the nerves do not respond to other treatments, nerve release surgery may be needed. [*Editor's note: Many of these treatments are discussed in greater detail in NVA's online tutorial for women with vulvodynia, available at http://learnpatient.nva.org/understanding_vulvodynia_4.php*.]

**Potential Breakthroughs: Looking Forward**

We're happy to report that there is a great deal of promising research being conducted that will help us better understand both nerve-related pain and the biology of pain. As new approaches are developed and made available, clinicians will become more used to treating clitoral pain. The medical silence surrounding this condition will be broken once and for all. Meanwhile, if you're seeking or receiving treatment for this condition, be assured that things can and do get better. "After I started taking medication, I haven't had one moment with the thought that I can't live with this," Jessie says. Although she is still trying to determine whether she must resign herself to a certain degree of pain, she is far from hopeless. "I now know I can do things to help myself."

*[Editor's Note: Help the NVA raise funds for medical research by ordering* Healing Painful Sex: A Woman's Guide to Confronting, Diagnosing, and Treating Sexual Pain *from Amazon through NVA's web site. Just click on the book cover located at www.nva.org/book_list.html, proceed with your purchase and Amazon will donate a percentage of your purchase price to the NVA. Additionally, the authors are generously donating a percentage of the book sale proceeds to the NVA.]* ■

**Moving? New E-mail address?**

Please send any changes in your contact information to NVA's administrator, Gigi Brecheen, at gigi@nva.org or call 301-949-5114. Thank you.

# In Her Own Words

*In this new column women with vulvodynia share their journies in obtaining diagnoses and treatment to provide hope and encouragement to others.*

My name is Katie Conrad. I was 24 when I was diagnosed with what I now call "The Big V" and I thought my life was over. The journey of procuring what seemed like a life sentence of a diagnosis was certainly wrought with pain, confusion and financial expense, and finding an effective, liveable treatment plan was definitely a longer, more painful road paved with as many disappointments as triumphs. However, when you are so young, your life is full of promise (I had just gotten my first job and was engaged) and a doctor hands down a verdict of chronic pain, you learn one thing: you cannot *ever* give up!

My vulvodynia began with a rash that occurred after intercourse with my then fiancé, Kevin, who is now my wonderfully supportive and loving husband. I woke up the morning after with a burning sensation, took a peek with my hand mirror and proceeded to freak out when I saw unusual redness. I made an appointment with my gynecologist who examined and tested me for herpes, gonorrhea, the whole gambit. It's a very strange thing in life when you look back on a situation and say to yourself, 'Man, I wish I had herpes,' because at least there is a clear treatment plan for that. It's something thousands of doctors have diagnosed and treated with confidence in young women who could at least, when armed with a Valtrex script, wait out a resolution.

Katie and her husband, Kevin

This was not the case for me. After about my 12th pelvic exam, two rounds of herpes medication and many cold baths, my regular gynecologist was smart enough to realize this was out of his league. Unlike many women in my situation, I was lucky enough to not be strung along on the false hope of infection medications for very long. He sent me to a vulvovaginal specialist to figure out why, even when the rash was gone, my pain was not.

I saw the very best vulvovaginal specialists in the country and some local doctors along the way. At first, just having a doctor give my horrific problem a name – vulvodynia and pelvic floor muscle dysfunction – was a relief. But after this brief feeling of relief passed, I began my quest to find some kind of respite from the constant pain. Could I dare think that I might find a cure?

I am a relentless person and all I wanted to do was find someone who was cured – that one woman who could honestly say that she had been there and came out on the other side. I felt that if I could just meet her or even hear her story that something must be out there for me too. I joined several support groups and read everything I could get my hands on. I talked to as many women as I could and tried absolutely everything. And you must. You must try absolutely everything within your means, and never stop thinking positively that this treatment

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might be your cure. One thing that is frustrating about vulvodynia, or any chronic pain problem, is that there isn't one true treatment protocol that works for everyone and some of the therapies are experimental. Instead of viewing this as negative, I considered it a collection of possibilities. As long as there were more treatments to try, there was still hope for me.

Eventually I took a medical leave from my awesome new job. Two months later, I was taking an antidepressant and undergoing physical therapy. I was about 75 percent pain-free most of the time and very thankful for this progress. But again, I didn't stop there. You cannot ever give up. I decided to take the advice of a woman in my support group and obtain another opinion from a local doctor who took my insurance. Her treatment recommendation tipped the scales and I returned to work at the end of my leave 90-95 percent pain-free on most days.

In the end, I had seen nine doctors and two physical therapists. I tried almost every medication and diet suggested to me. What helped me return to work and back to being a bit of myself was a combination of an antidepressant medication, physical therapy and topical cream that I still consider magical in nature.

I wish I could say that I remained in that nearly pain-free place forever, but life changes. Stress wreaks havoc on your body. You forget you have a "chronic pain problem" and you don't keep up with your maintenance therapy. I can say that I now possess the tools to get myself back to that place, and I often do.

In addition to never giving up, I've learned many lessons. I have learned that my husband loves me for so many other reasons besides sex and that we can get through anything together. I have learned how to say 'no' to overextending myself and 'yes' to taking care of myself. I have learned empathy towards others who are suffering that I honestly didn't have before this happened to me. Mostly, I have learned that you can really live your life with chronic pain when you use the resources you have available, lean on the people who really love you and approach everything with hope.

Sometimes I do still cry to my husband and ask him why this happened to me. He often answers: "I think this happened because you have a strong voice and maybe you can help other women. Maybe you were meant to help others." I hope I have here by sharing my story today. ■

## New Clinical Trial Enrolling Participants

The University of Tennessee is conducting a double-blind placebo-controlled research study sponsored by the National Institutes of Health to determine the effectiveness of gabapentin (compared to placebo) in reducing intercourse pain. Participants will receive gabapentin one-half of the time and placebo (inactive treatment) one-half of the time, study-related care at no cost, and $50 per visit, or a total of $300 if all six visits are completed. Patients will be enrolled in three states at the University of Tennessee, University of Medicine and Dentistry of New Jersey and the University of Rochester. For more information, please call Leslie Rawlinson at 901-448-6693 or email lrawlins@uthsc.edu.

## Treatment Outcome

*(from page 1)*

**NVA: What were the goals of this first part of your study?**

**Drs. Bohm-Starke and Heddini**: Very few publications have examined predictors of treatment success or failure in women with PVD. Our first goal was to examine a group of women who had previously completed treatment at our clinic to identify factors that may predict treatment outcome. We investigated many factors that may be associated with treatment success or failure including body-wide pain, duration of vulvar pain symptoms and hormonal contraceptive use, levels of anxiety and depression, pain sensitivity in extra-genital body sites and PVD subtype. (Women with primary PVD have had pain since their first attempt at vaginal penetration, compared to those with secondary PVD, in which pain begins after a period of pain-free vaginal penetration.)

**NVA: What did the study involve?**

**Drs. Bohm-Starke and Heddini**: Our study included 70 premenopausal women who had previously undergone treatment for PVD at our clinic, two-thirds of whom suffered from the secondary subtype. Participants had concluded their treatment regimens between two months and 11 years prior to the commencement of this study, with a median of five years. Women completed comprehensive questionnaires regarding their medical, gynecological and psychosocial histories. We also collected information on the intensity of pain with intercourse, duration of symptoms, PVD subtype, treatments received and perceived treatment outcome (e.g., no change, improvement, major improvement or complete recovery). We assigned women a bodily pain score (0-5) after identifying the number of pain disorders they reported in different parts of the body (e.g., headache, muscle pain, gastrointestinal pain, back pain and other). To test for pain sensitivity, during the follicular phase of the menstrual cycle, we used a device that exerts increasing levels of pressure on the skin (pressure algometer) to obtain pressure pain threshold levels for the arm, leg and two sites in the vulvar vestibule (anterior next to the urethral opening and posterior next to the Bartholin's glands). Finally, we assessed levels of anxiety and depression with a validated questionnaire.

**NVA: What treatments did women receive at your clinic?**

**Table 1: Most Common Treatments**

| Treatments | All Patients (N=70) |
|---|---|
| Lidocaine gel (2% topical application 3-5 times/day) | 58 (83%) |
| Pelvic floor rehabilitation (physical therapy and/or EMG biofeedback) | 41 (59%) |
| Cognitive behavioral therapy (average of 10 sessions) | 38 (54%) |
| Posterior vestibulectomy | 22 (31%) |
| Botulinum toxin A (25E injected into the bulbocavernosus muscle bilaterally) | 13 (12%) |
| Amitryptiline (30-50 mg daily for at least two months) | 5 (7%) |

EMG = electromyography

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## Treatment Outcome

*(from page 15)*

**Drs. Bohm-Starke and Heddini**: Our multidisciplinary treatment protocols include different combinations of therapies tailored to the meet the specific needs of each patient. Women most commonly utilized the treatments listed in Table 1. Although treatment duration varied greatly, those who received more extensive care using a multidisciplinary approach usually attended the clinic for a period of approximately one year, with less frequent visits as time progressed. Twelve percent reported the use of other therapies – most commonly acupuncture and estrogen replacement – in the period between treatment cessation at our clinic and the commencement of this study. *[Editor's note: For additional information on these treatments, please visit: http://learnpatient.nva.org/understanding_vulvodynia_4.php.]*

**NVA: What percentage of women improved with treatment?**

**Drs. Bohm-Starke and Heddini**: Table 2 summarizes our findings. Although women with secondary PVD reported significantly better treatment outcomes compared to those with primary PVD, the majority of women in the study, irrespective of their subtype, improved with treatment. Those who reported 'major improvement' or 'complete recovery' also reported significantly lower pain scores with intercourse compared to those who reported 'no change' or 'improvement' with treatment.

**NVA: Did you identify any predictors of treatment outcome?**

**Drs. Bohm-Starke and Heddini**: In agreement with previous reports, we found that treatment outcome was statistically better among women with secondary PVD than those with the primary subtype. The most significant predictor of treatment outcome, however, was the presence of multiple concurrent pain disorders. Many study participants suffered from multiple pain disorders, one-third of whom had a bodily pain score of at least three. Sixty percent reported headache, 51 percent experienced gastrointestinal pain, 43 percent had back pain, 29 percent experienced muscle pain and 29 percent reported

**Table 2: Treatment Outcome**

| Treatment Outcome | All Patients (N=70) | Primary PVD (N=23) | Secondary PVD (N=47) |
|---|---|---|---|
| No change | 13 (19%) | 8 (35%) | 5 (11%) |
| Improvement | 25 (36%) | 8 (35%) | 17 (36%) |
| Major improvement | 26 (37%) | 5 (22%) | 21 (45%) |
| Complete recovery | 6 (9%) | 2 (9%) | 4 (9%) |

*See TREATMENT OUTCOME, page 17*

## Treatment Outcome

*(from page 16)*

additional pain disorders such as fibromyalgia or temporomandibular disorders. We did not find a significant difference in the number of coexisting pain disorders reported by women with the primary vs. secondary subtype. The likelihood of a treatment outcome of 'much better' to 'complete recovery' was significantly higher among participants with no more than one coexisting pain condition. We speculate that greater endogenous pain hypersensitivity in those with several pain disorders could explain these differences in treatment outcome. Contrary to this hypothesis, we did not find a significant difference in vestibular or extra-genital pressure pain threshold levels between patients who reported a treatment outcome of no change/improvement and those who reported major improvement/complete recovery. These somewhat contradictory findings may suggest that pain modulation and/or psychological traits influence the development of multiple pain disorders and experimental pain differently. While we did not conduct an extensive psychological evaluation in this study, anxiety and depression levels did not predict treatment outcome.

> ***Although women with secondary PVD reported significantly better treatment outcomes compared to those with primary PVD, the majority of women in the study, irrespective of their subtype, improved with treatment.***

When examining intercourse-related pain scores, we found that women who had previously received counseling due to depression, as well as those with multiple pain conditions and the primary PVD subtype, reported greater pain with intercourse following treatment. Other factors, including duration of PVD symptoms, anxiety/depression levels and pressure pain thresholds in the arm, leg and even the vestibule, were not associated with greater pain with intercourse following treatment.

**NVA: What were the study's limitations?**
**Drs. Bohm-Starke and Heddini:** We do recognize a few limitations in our study design. Although a bodily pain score has been used in an earlier vulvodynia study (Granot et al, J Pain 2004), it has not yet been validated in this patient population. We also asked the participants to report other frequent pain problems without defining the word *frequent* or the intensity of these conditions, which could have resulted in inter-individual differences. Finally, due to the large time gap between many patients' PVD treatment and this study, the risk of recall bias exists.

**NVA: What conclusions can you draw?**
**Drs. Bohm-Starke and Heddini**: PVD appears to be related to an increase in the number and activity of nociceptors (pain receptors) in the vulvar vestibule. Moreover, some studies have shown that women with PVD have higher pain levels and/or lower pain thresholds in other areas of their bodies, suggesting that some part of their pain may result from abnormal central nervous system pain processing. Amplified pain pathways in the central nervous system could be responsible for this overall increase in pain sensitivity. Part of our larger research project is to examine whether variations in genes related to pain modulation can be found in women with PVD. This will bring us closer to understanding the underlying factors that contribute to the development and maintenance of different PVD subtypes. Our hope is that this will lead to improved treatment strategies, as well as the identification of women who may be at risk for developing chronic pain.

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## Treatment Outcome

*(from page 17)*

**NVA: How can we use these findings to improve PVD treatment?**

**Drs. Bohm-Starke and Heddini**: In this study we looked at whether we could correlate treatment outcome with factors such as PVD subtype (primary vs. secondary), duration of PVD symptoms, levels of anxiety and depression and the presence of coexisting pain disorders. We believe that linking such factors to treatment outcome will allow clinicians to identify women who may need more intensive care and would benefit from early referrals to specialized vulvar pain clinics. Since there is not yet standardized treatment for PVD, and there are few clinical trials on available treatments, it is important to try to link health factors to treatment outcome in order to better understand which patient subgroups will respond favorably to a given treatment. This will enable women to work with their health care providers to make evidence-based decisions on their medical care.

**NVA: What is the next step of your larger research project?**

**Drs. Bohm-Starke and Heddini**: Next, we will analyze and report on correlations between the diagnosis of PVD and variations in specific genes related to endogenous pain modulation. Prior studies demonstrate that genetic variations are associated with both the development of, and protection from, chronic pain, although this has not yet been studied in women with vulvodynia. In our studies we also investigate the influence of genetics on vulvar and extra-genital pain sensitivity in women with PVD and healthy controls.

*[Editor's Note: This article summarizes the authors' recent publication: Heddini U, Bohm-Starke N, Nilsson KW, Johannesson U. Provoked Vestibulodynia-Medical Factors and Comorbidity Associated with Treatment Outcome.* J Sex Med. *2012 Feb 29. doi: 10.1111/j.1743-6109.2012.02665.x.]*

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## Senate Hearing

*(from page 4)*

a social and cultural transformation in the way that we look at pain in its vast manifestations."

Following up on Dr. Pizzo's statement, Christin said that while she is the first to admit that her emotional health impacts how she's able to cope with pain, there are numerous examples in medical history where conditions have been labeled "psychological" because we don't yet understand the underlying physical mechanisms. She cited stomach ulcers as an example of a condition believed to result from anxiety and stress, until research discovered that bacteria is the cause. She said, "Just because we don't yet understand the mechanisms and risks of chronic pain due to an inadequate research effort, does not mean that pain isn't real."

Upon conclusion of the witness' testimonies, several rounds of questions from committee members continued for another hour, addressing topics such as prevention and the need for medical professional education, although the majority of the discussion centered around the imperative need to increase collaborative research efforts. In his concluding statement, Senator Harkin concurred, "We have to do more research and I look forward to working with [the witnesses] and the HELP Committee to approach this issue of pain in a thorough holistic comprehensive way."

The publication of the IOM report and Senate hearing on chronic pain represent a growing national effort to address the health of millions of suffering Americans. The NVA will continue to work cooperatively with other patient advocacy and medical organizations to ensure that the recommendations from the IOM report are implemented, and we look forward to keeping our readers updated on our progress.

To view an archived video of the hearing, please visit www.help.senate.gov/hearings/ and click on 'Pain in America: Exploring Challenges to Relief – 2/14/2012.' To read the IOM report, please visit www.nap.edu/catalog.php?record_id=13172. ■

*Senator Harkin speaking with NVA Director Christin Veasley following the hearing.*

# Definitions and Types of Vulvodynia

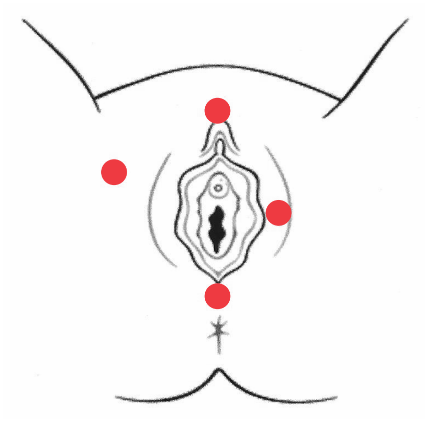
Many different terms have been used to describe vulvodynia. As a result, confusion among patients and medical professionals is common. To encourage consensus and clarify terms used in this newsletter, we have provided a brief summary of the most current definitions and classification.

For more detailed information, please visit http://learnprovider.nva.org/historical_overview.htm and http://learnprovider.nva.org/terminology_classification.html.

Vulvodynia is *chronic (more than three to six months) vulvar pain without an identifiable cause*. The location, constancy and severity of the pain vary among women. The two main subtypes of vulvodynia, which sometimes co-exist, are:

**Provoked Vestibulodynia (PVD)**
*(Previously: Vulvar Vestibulitis Syndrome)*

Women with PVD have pain limited to the vestibule, the area surrounding the opening of the vagina, that occurs during/after touch or pressure, e.g., with intercourse, tampon insertion and/or prolonged sitting. PVD is further classified as *primary (pain since the first attempt at vaginal penetration)* or *secondary (pain that starts after a period of pain-free vaginal penetration)*.



**Generalized Unprovoked Vulvodynia (GV)**
*(Previously: Dysesthetic or Essential Vulvodynia)*

Women with GV have spontaneous pain in multiple areas of the vulva. It is relatively constant, but there can be some periods of symptom relief. Activities that apply touch or pressure to the vulva, such as prolonged sitting or simply wearing pants, typically exacerbate symptoms. ■

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## Economic Impact

*(from page 6)*

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