National Vulvodynia Association

NVA News

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Differentiating Vulvodynia and Pudendal Neuralgia

By Richard P. Marvel, MD

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Chronic vulvar pain disorders are commonly underdiagnosed and according to the research, their prevalence is quite high. Goetsch's survey of a general gynecology practice estimated the prevalence of vulvar vestibulitis to be 15 percent. In a community-based survey, Harlow estimated the prevalence of chronic unexplained vulvar pain at seven percent.

The classic definition of vulvodynia is "vulvar pain, burning, rawness or irritation" present for more than six months, which cannot be attributed to any other cause. Vulvar vestibulitis is a subset of vulvodynia in which the burning or pain only occurs with light touch in the vestibule, the area immediately surrounding the vaginal opening. The International Society for the Study of Vulvovaginal Disease developed a new set of definitions for vulvodynia in 2003. They created two subgroups: (i) localized vulvodynia and (ii) generalized vulvodynia. Each subgroup was further subcategorized as provoked, unprovoked, or mixed pain. Although terms such as *localized provoked vulvodynia* are useful in research papers, they can be quite cumbersome in discussions with patients. The revised definitions were debated at a 2004 consensus meeting of national vulvodynia experts. At this meeting it was decided that the term vulvodynia be maintained and defined as '*vulvar pain of at least three to six months duration without a verifiable cause*.' It was further decided that descriptors such as generalized or localized be used with an accurate pain map, but that further sub-classification, such as provoked vs. unprovoked, was not warranted. For the remainder of this article, the terms *generalized vulvodynia* and *vulvar vestibulitis* will be utilized for simplicity.

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Multilevel Nerve Blocks in the Treatment of Vulvodynia

By Andrea J. Rapkin, MD and John S. McDonald, MD

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Many characteristics of neuropathic or nerve pain, such as burning and extreme sensitivity to both painful and nonpainful stimuli (hyperalgesia and allodynia, respectively), are also classic features of vulvodynia. Because there are no abnormal anatomic features associated with vulvodynia, the pain has been characterized as neuropathic in etiology, and in some cases, a variant of pudendal neuropathy or neuralgia. Neuropathic pain is a chronic abnormal state that evolves over time, ultimately leading to a number of changes in the central nervous system (brain and spinal cord) and peripheral (somatic and autonomic) nervous system.

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Diagnostic Precautions

A critical component of the definition of vulvodynia disorders, including the newer definitions, is that a physical exam reveals no sign of any other condition. In order to make an accurate diagnosis, a careful evaluation, including a limited sensory exam of the vulvar skin, is critical. A wet prep should be performed and cultures obtained for yeast, because vaginal inflammation can upregulate the pain fibers and lead to focal localized tenderness in the vestibule. In this case, it is not truly vestibulitis because treatment of the infection and/or inflammation can lead to resolution of the allodynia (hypersensitivity to non-painful stimuli) and pain with intercourse.

It is vital to understand that many chronic pain syndromes involve a combination of several distinct entities. It is quite common in clinical practice to find multiple clinical syndromes in women with chronic vulvar pain. As the etiology of vestibulitis is not currently known, it is not possible to rule it out despite other findings. Women who have a combination of several disorders causing vulvar pain are more complex to evaluate and manage. Each patient is unique and has a different mix of components related to her pain syndrome. Pain is interpreted in a context of an individual's past experiences and emotions. In order to maximize the effectiveness of treatments, all components need to be identified and managed concurrently. Patients commonly present with co-morbid conditions such as interstitial cystitis, endometriosis and irritable bowel syndrome. The existence of other conditions does not preclude the diagnosis of vulvodynia, and for a woman to reach maximum well-being, all identifiable conditions must be concurrently managed.

Some common vulvar diseases can exist with few clinical signs and mimic the symptoms of vulvodynia. An irritant or chemical dermatitis, chronic yeast vulvovaginitis, lichen sclerosus, inflammatory vaginitis, and pudendal neuralgia are some of the more common diagnoses. Careful evaluation can confirm or eliminate various conditions. The evaluation should always begin with a careful history. I always start my evaluation with a detailed pain questionnaire. An excellent questionnaire that can be downloaded and used by any practitioner can be obtained from the International Pelvic Pain Society (www.pelvicpain.org). This questionnaire is aimed at women with chronic pelvic pain, but is also very helpful for diagnosing vulvar pain conditions. An attempt should be made to obtain and review the patient's records from prior health evaluations. For vulvar pain, the most useful records are vaginal culture and wet smear results. I begin the interview by asking the patient to "tell her story" from the very beginning, when her vulvar pain first started. *Patience is a virtue*.

Diagnostic Procedures

A careful pain history is included in the evaluation. I use the mnemonic **SCORED** to remember the multiple aspects of the pain. **S**ite, or exactly where is the symptom located? Does the pain occur on the entire vulva, inner labia, vestibule, clitoral or perianal area? Is it on one side or bilateral? A unilateral complaint, or pain only on the right or left side of the vulva, is highly suggestive of neuropathy. **C**haracter

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of pain refers to pain quality such as burning, irritation, sharp, stabbing, aching or gnawing. **O**nset involves not only when the pain started, but whether it started suddenly or gradually. Also, was there some type of episode that preceded or triggered the pain? **R**adiation of the pain can occur and affect the anus, rectum, vagina or clitoris. **E**xacerbation refers to factors that elicit or worsen the pain. Finally, **D**uration takes into account how long the pain lasts and when it occurs, as well as the total number of months or years it has existed.

In some cases, the pain can be cyclical, varying with the menstrual cycle or even the seasons. The pain's association with sexual intercourse is very important. In the case of vulvar vestibulitis, the pain only occurs with some type of pressure on the vestibular tissue. Intercourse, gynecologic exam, Q-tip exam, or even clothing can elicit the pain. Taking a complete medical history, including psychological or psychiatric disorders, also can be helpful.

A careful gynecologic evaluation, including a brief sensory exam, is required. Speculum exam and evaluation of a wet mount is performed. If skin abnormalities are observed, a careful vulvoscopy is often very helpful. A single digit pain mapping pelvic exam also is performed. During this exam, tenderness of multiple sites can be determined and an attempt is made to reproduce the pain or dyspareunia. Palpation of the vestibule, pelvic floor, urethra, bladder, cervix, cul de sac, uterus and adnexa is performed. Upon rectal or vaginal exam, palpation of the sacrospinous ligament and the sciatic notch can reveal the tenderness of the pudendal nerve in cases of pudendal nerve entrapment. These women generally have significant tenderness to palpation of the lateral portion of the sacro-spinous ligament and the sciatic notch, which reproduces the pain they experience with sitting.

Although infrequently used by most clinicians, I highly recommend examination of cutaneous sensation to light touch with a Q-tip, not only in the vestibule, but across the skin of the entire vulva, mons pubis, inner thigh, and medial buttock. The results of the Q-tip test indicate whether there is normal sensation, paresthesia (tingling, prickling, or numbness), allodynia (pain from non-painful stimuli) or hypoesthesia (decreased sensitivity). Next, the skin is tested for pinprick sensation. During this part of the exam, I use a broken Q-tip across the inner thigh, buttock, outer vulva and inferior mons pubis. This is probably the most enlightening part of the exam, because it is one of the best ways to evaluate the function of the pudendal nerve. Side to side and different nerve distributions are tested repeatedly to check for consistency. The most common finding in women with pudendal nerve dysfunction is hyperalgesia (extreme sensitivity to painful stimulus) in the pudendal nerve distribution. The pudendal nerve pro-

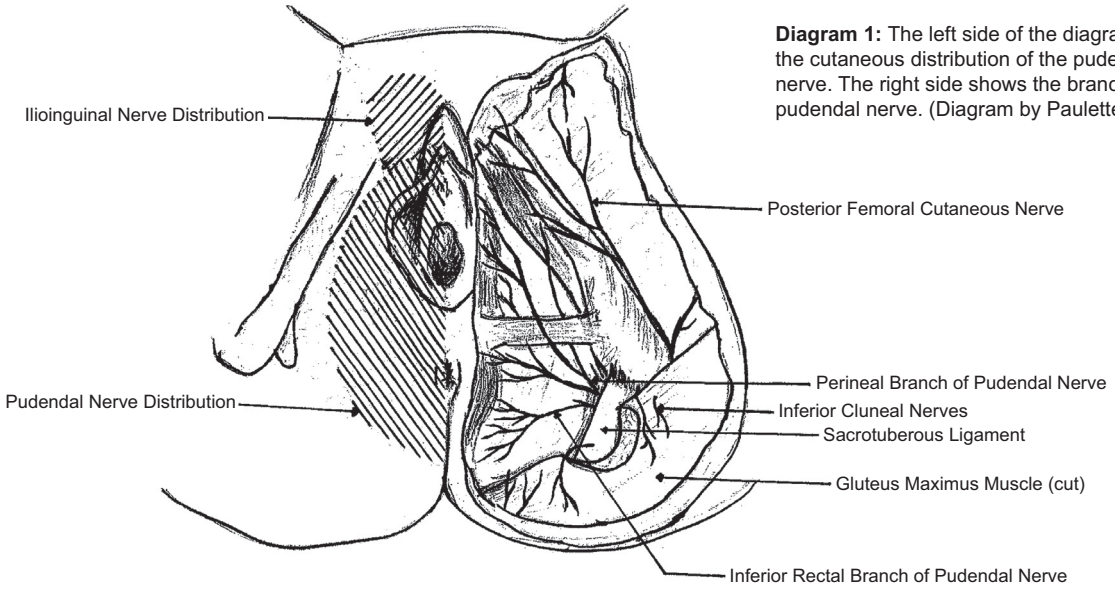

Diagram 1: The left side of the diagram shows the cutaneous distribution of the pudendal nerve. The right side shows the branches of the pudendal nerve. (Diagram by Paulette Painter)

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vides sensory innervation across the vulva up to a level somewhere between the urethra and clitoris, innervating the vulva, vestibule, perianal skin and clitoris. (See Diagram 1, previous page.) The motor branches of the pudendal nerve innervate the external anal and urethral sphincters.

A wet mount, plus vaginal and/or vulvar cultures, should be obtained. The most important aspect of the wet mount is to evaluate for inflammation and evidence of infection. Some women who present with vulvar burning and irritation may have inflammatory vaginitis as described by Thompson. These women have significant vaginal inflammation, but no evidence of infection on wet mount or cultures. The wet mount is critical for the evaluation. Keep in mind, according to the definition of vulvodynia, a wet mount with vaginal inflammation rules out the diagnosis.

Generalized, as opposed to localized, vulvodynia is characterized by diffuse, unprovoked burning or other type of vulvar pain. A thorough evaluation by a vulvovaginal specialist will typically separate women with generalized vulvodynia into one of several different categories. The three main categories are: (i) inflammatory disorders, such as lichen sclerosus, lichen planus, inflammatory vaginitis and desquamative inflammatory vaginitis; (ii) disorders of infectious origin, most commonly recurrent yeast vulvovaginitis; and (iii) neuropathic pain disorders, most likely pudendal neuralgia (pain along the distribution of the pudendal nerve).

In fact, the vast majority of women commonly diagnosed as having generalized vulvodynia exhibit symptoms characteristic of neuropathic pain. These symptoms include abnormal responses, such as extreme sensitivity to pinprick, during a sensory exam of the vulva. In my opinion, women with chronic vulvar pain who exhibit hyperalgesia and other neuropathic pain symptoms would be more appropriately classified as having pudendal neuralgia.

Pudendal Neuralgia

The pudendal nerve is located in the pelvis along the side of the pelvic cavity and exits just medial to the bony prominence felt by sitting on your hands. It has branches that then spread out and extend to the skin of the vulva and anal area. Pudendal neuralgia is a neuropathic pain syndrome in which the pain is generated by the nerve itself rather than by a receptor at the nerve ending. Pain can be generated at different locations along the nerve. Dysfunction of the pudendal nerve as a cause of chronic vulvar pain was first described by Robert (1989).

Women with pudendal neuralgia have diffuse vulvar pain, usually referred to as burning, but sometimes described as a deep aching or throbbing. It can be constant and quite severe. The symptoms are generally worsened by sitting and patients usually feel some relief with standing. Some patients can even be pain-free upon standing or lying down and only have pain when sitting. This combination suggests the possibility of pudendal nerve entrapment. Entrapment of the nerve involves scarring along the nerve or nearby structures that fixes the nerve in a position that makes it more likely to be compressed. The most common area of entrapment is located where the pudendal nerve runs between the sacrospinous and sacrotuberous ligaments. The nerve can also be entrapped at the falciform process of the sacrotuberous ligament or in Alcock's canal, which is a condensation of the fascia (fibrous tissue) of the obturator internus muscle. (See Diagram 2, next page.)

The main risk factors for the development of pudendal neuralgia or pudendal nerve entrapment are related to damage to the nerve, scarring along the nerve, or prolonged compression. Risk factors include: being thin, repetitive prolonged sitting, cycling, horseback riding, early excessive exercise, gymnastics, dance, excessive straining due to constipation, falls onto the buttock and sometimes surgical procedures.

The mainstay of therapy for women with pudendal neuralgia is a combination of medical therapy and self-care. The self-care program is initiated to prevent any further damage to the pudendal nerve. For sitting, a cushion that can easily be fashioned out of a gardener's knee pad is used to manually decompress the pudendal nerve. A cutout is made so the *ischial tuberosity* sits half on and half off the cushion's cutout. (The *ischial tuberosity* is the broadening of the bone in the frontal portion of the ischium, the lowest of the three major bones that make up each half of the pelvis, which bears the body's weight when sitting.) I have the patient keep a cushion in the car, at work and at home. Certain activities, such as cycling,

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horseback riding, and squatting, must be eliminated. More problematic for the woman, especially if her job requires long hours at a desk, is the need to eliminate prolonged periods of sitting.

Medical management primarily involves the use of medications that interfere with the transmission of pain impulses, e.g., antidepressants and/or anti-convulsants, such as amitriptyline, nortriptyline, gabapentin (Neurontin) and duloxetine (Cymbalta). Trial and error is necessary to find a medication and dosage that is beneficial in minimizing pain while avoiding troublesome side effects. Sometimes a combination of two medications at modest doses works better than a higher dose of one medication, because lower doses limit side effects. Sequential image guided nerve blocks, first with anesthetic and later combined with corticosteroid, are another treatment option. Anecdotal reports have shown some success, but no controlled studies on this treatment have been done. In cases of severe pain, chronic opioid analgesic therapy is often required to maintain a good quality of life. Local use of an anesthetic ointment, in addition to an oral antidepressant and/or anticonvulsant, also can be beneficial. For example, a 5% lidocaine ointment can be applied 30 minutes prior to intercourse to decrease introital discomfort. Other general recommendations are to use mild, unscented and dye-free soap and laundry detergent, and eliminate vulvar irritants such as fabric softeners, dryer sheets, bleach and Oxyclean. Chronic sanitary pad use for urinary incontinence or chronic discharge should be eliminated.

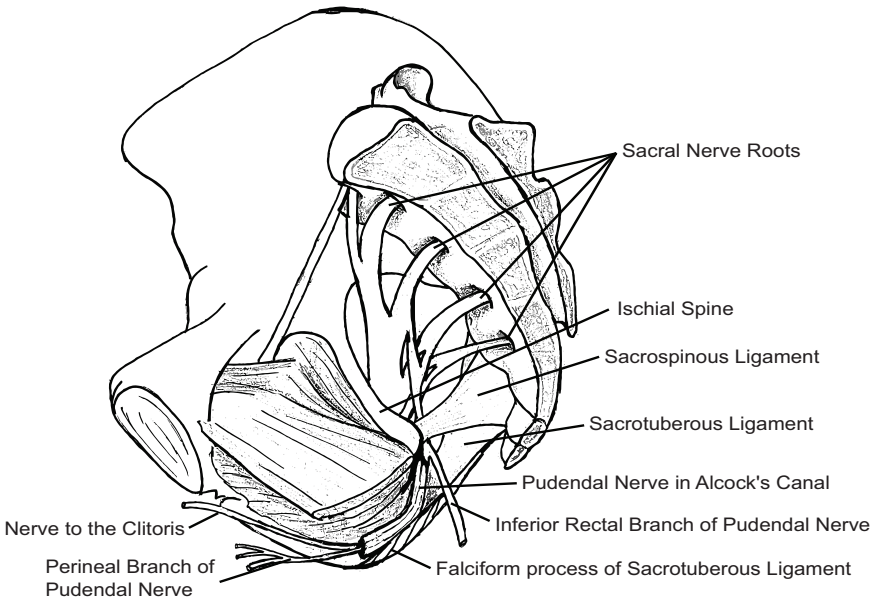

Diagram 2: The right hemipelvis from midsagittal section. Shows the pudendal nerve from the sacral roots, generally S3 and either S2 or S4. Areas of potential entrapment include the grip between the sacrospinous and sacrotuberous ligaments, falciform process of sacrotuberous ligament, and in Alcock's canal. (Diagram by Paulette Painter)

Pudendal Nerve Entrapment

Recently, in cases of severe pain with pudendal nerve entrapment, a surgical procedure to decompress the nerve has been utilized. Making the decision to undergo this type of surgical therapy is complex. There are no absolute criteria indicating the need for surgical intervention, nor are there distinct criteria to rule it out. One criterion that strongly indicates the need for a surgical procedure is pain that is brought on, or significantly worsened, by sitting, but relieved by standing or sitting on the toilet. In my opinion, the most significant reason to use surgical intervention with pudendal nerve entrapment is an inability to sit due to pain.

For those patients who do not achieve relief with medical therapy and self-care, surgical decompression of the pudendal nerve may be considered. The pre-operative evaluation should include some type of imaging test, generally MRI, to rule out compression of the nerve due to

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NIH Launches Vulvodynia Awareness Campaign

After years of urging US Senators and Representatives to help NVA educate the public about vulvodynia, Congress mandated the National Institutes of Health (NIH) to develop the first *National Vulvodynia Awareness Campaign*. This campaign targets primary health care professionals and the general public, as well as vulvodynia patients.

On October 24, 2007, after more than a year of preparation, Vivian Pinn, MD, director of the NIH Office of Research on Women's Health launched the campaign at the National Press Club in Washington, DC. The press conference was attended by representatives from more than 30 partnering organizations and government agencies. The diverse group of partnering organizations includes the National Women's Health Resource Center, the American College of Obstetricians and Gynecologists, the Society for Women's Health Research, the Center for Disease Control, the National Black Nurses Association and the National Hispanic Health Association.

Dr. Pinn outlined the goals of the outreach campaign and introduced the panel of eight speakers. Among the speakers were Hope Haefner, MD, director of the University of Michigan's Center for Vulvar Diseases; Bernard Harlow, PhD, chair of the University of Minnesota's Division of Epidemiology and Community Health; Candace Brown, PharmD, MSN, professor of pharmacy, psychiatry and obstetrics and gynecology at the University of Tennessee Medical School; and Christin Veasley, NVA's Associate Executive Director. Dr. Harlow presented the findings of the NIH-funded vulvodynia prevalence study, and Drs. Haefner and Brown described vulvodynia's symptoms, diagnosis and treatment. The emotional high point of the event was Christin Veasley's first-hand account of her eight year struggle with vulvodynia. (Read her speech on the next page.)

The NVA, the NIH Office of Research on Women's Health and the National Women's Health Resource Center have been leading the publicity campaign by contacting editors and writers at popular magazines, newspapers, and health and news websites. Following the launch event, for example, many internet sites, such as everydayhealth.com and earthtimes.org featured articles on vulvodynia and Dr. Laura Berman discussed chronic vulvar pain on her Yahoo health blog, *The Art of Intimacy*. Reporter Darla Carter wrote an article on vulvodynia for the Louisville Courier Journal and Denise Oliviera, a New York journalist and NVA member, wrote an excellent piece for the New York City Independent Media Center. One of NVA's strongest proponents for the past 10 years has been Phyllis Greenberger, MSW, president of the Society for Women's Health Research (SWHR). Shortly after the campaign launch, Dr. Jennifer Wider of the SWHR wrote an article on vulvodynia for newshealthdigest.com, which was subsequently picked up by numerous web sites, including Science Daily, AHN and MedHeadlines.

If you would like to receive a press kit on vulvodynia, please e-mail aprilb@esi-dc.com. You can order the Vulvodynia Awareness Campaign information packet by contacting the NIH Resource Center at 1-800-370-2943 or the National Women's Health Resource Center at www.healthywomen.org or 1-877-986-9472. ■

NVA Joins Forces with Gynecologic Cancer Activists

To raise Congressional awareness of gynecological cancer and pain disorders, the US House of Representatives' Cancer and Women's Issues Caucuses organized a briefing held September 25, 2007. The briefing was hosted by Representative Steve Israel (D-NY), co-chair of the Cancer Caucus.

Emmy-nominated actress Fran Drescher described her personal experience overcoming uterine cancer and the creation of the Cancer Schmancer Movement. Sherry Salway Black, executive director of the Ovarian Cancer National Alliance, discussed her battle with ovarian cancer and Dr. Richard Schlegal, chair of the pathology department at Georgetown University Medical Center, gave an overview of cervical cancer and his work on the new HPV vaccine. NVA's associate executive director, Christin Veasley, focused her presentation on vulvodynia, specifically addressing the problem of misdiagnosis, the stigma associated with having a chronic vulvovaginal disorder and the lack of research on treatments. She closed by outlining what Congress can do to help women with gynecologic pain disorders. To read NVA's presentation, please visit our home page at www.nva.org and click on the link in the second news article. ■

NVA's Christin Veasley Speaks at National Press Club

Below is her speech given at the launch of the NIH Vulvodynia Awareness Campaign.

On behalf of the millions of women who suffer from this life-altering pain condition, I would like to thank Dr. Vivian Pinn, director of the NIH Office of Research on Women's Health, for her exemplary effort in planning this long-deserved public awareness campaign. Thirty years ago, women reached a milestone when they started openly discussing menstrual issues; twenty years ago, it was breast cancer, and ten years ago, menopause. Sadly, however, women still feel too embarrassed to reveal they have vulvodynia or other vulvovaginal disorders, which is the reason why this campaign is so important.

I stand before you as both a representative of the National Vulvodynia Association and as a former vulvodynia sufferer. My vulvar pain came on suddenly when I was 18 years old. I thought, like most of us, that I would visit the doctor, get a prescription and feel better in a few days. I only wish that were the case! The pain was relentless and I kept going back… and going back… and when my provider finally told me that I had vulvodynia, my reply to her was very similar to that of HBO's Sex and the City character Carrie Bradshaw. When her friend Charlotte disclosed that she had vulvodynia, Carrie incredulously asked, "Vulvo-what-ia?" I thought, "What in the world is vulvodynia? Is that even a word?" I couldn't even pronounce it. What I learned about vulvodynia at 18 was that: (i) it is a chronic pain condition; (ii) the medical community didn't know what causes it; and (iii) there was no cure. I had absolutely NO idea what I was up against in the months and years ahead. At the time, I was a full-time pre-med college student and worked part-time at a restaurant. My genital area was burning all the time, like someone was pouring acid into an open cut on my skin. I couldn't wear pants or sit through a one-hour class. I vividly remember having pain so intense in the middle of my physics final that I had to get up and turn in a half-complete exam. I couldn't stay seated or concentrate because of the pain. Can you imagine having pain that severe and then your doctor dismisses it by saying, "Have a little wine before intercourse." Even today, women with vulvodynia hear this from some doctors!

Having a name for my condition was half the battle. I could focus on solving the problem instead of seeking a diagnosis. After my provider said she couldn't help me, I did what the majority of women still have to do today – I became my own educator. I went to the medical library and requested every vulvodynia article ever published. I searched the University hospital for a physician who was a little bit knowledgeable about the condition. By far the most valuable thing I did was contact the NVA. I scoured all of the back issues of their newsletter and volunteered to be a support leader. At a time when I was desperate and had no hope, NVA helped me regain control of my life and find the treatment that would enable me to have the family I dreamed of having someday. It took time, however. Because there were no studies on which treatments worked, it took years of trial and error until I found one that was successful. Even though it took seven years, I feel very fortunate, because the majority of women with vulvodynia live with some degree of pain their entire lives. The type of vulvodynia I had – vulvar vestibulitis – was treatable with surgery. It's been eight years since the surgery which eliminated my pain and afforded me the gift of two beautiful daughters.

When NVA surveyed 2000 women with vulvodynia, 75 percent reported discomfort discussing the condition with even their closest female friends. Feeling embarrassed keeps women silent. It took me years to confide in close friends and family. I still remember the very first time I spoke to another sufferer on the phone. The comfort that conversation provided me was immeasurable. To speak to another woman who knew what I was going through was life-changing for me. That is what a big part of this campaign is about – reaching out to women who don't know what's wrong with their bodies – to let them know they're not alone, there are treatments and there is hope.

In the NIH press kit, there are profiles of eight selfless women who have overcome their hesitation to speak publicly about having vulvodynia for a greater purpose – to raise awareness of this condition. They are of different ethnic backgrounds and range in age from 20 to 60. But they all share a common experience – every day they struggle to cope with vulvar pain and its consequences on their quality of life. With your help, their stories will be told. Ghandi said, "We must become the change we want to see." These courageous women are doing just that. (To read their stories, go to www.nva.org and click on the link in the *NIH Campaign* article.) ■

Pudendal Neuralgia

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some type of extrinsic mass. At least one, and sometimes a series of pudendal blocks, is administered to ensure that a pudendal nerve block provides at least temporary relief of the symptoms. Many surgeons perform a pudendal nerve terminal motor latency (PNTML) test, which evaluates conduction along the pudendal nerve. This measures conduction along the motor fibers, but is not necessarily abnormal in patients with pudendal neuralgia or nerve entrapment. It has been used most extensively in the evaluation of pudendal nerve function in cases of anal incontinence.

One of the first publications discussing pudendal nerve decompression was by Robert (1998). He identified three areas of possible entrapment: the clamp between the sacrotuberous and sacrospinous ligament, Alcock's canal, and at the falciform process of the sacrotuberous ligament. Robert reported on the outcomes of 170 procedures using the *transgluteal* approach. This procedure includes an oblique incision along the longitudinal axis of the sacrotuberous ligament. The sacrotuberous ligament is windowed over 2-3 cm and the neurovascular bundle is identified. The sacrospinous ligament is divided and the nerve is transposed anterior to the spine. The fascia of Alcock's canal is opened and the nerve is freed from the falciform process if needed. The entire nerve trunk is freed. In their series of 170 patients, 45 percent considered themselves cured, 22 percent improved, and 33 percent received no benefit, but suffered no exacerbation.

In this series, the surgical procedure was limited to patients who did not respond to serial nerve blocks, which reportedly cured 65 to 70 percent of patients. They subsequently reported a randomized controlled trial of 32 patients, comparing pudendal nerve decompression to nonsurgical treatment. Both groups received similar non-surgical therapies. At three months, 50 percent of the surgical arm reported improvement, while 6.2 percent of the control group improved (p=.0155). At 12 months, 71.4 percent of the surgery group reported improvement compared to 13.3 percent of the control group (p=.0025). At four years, 50 percent of the surgical group reported ongoing improvement, defined as a 30mm decrease on a visual analogue pain scale, plus the patient's report that pain did not restrict activities. The report notes that Robert evaluates approximately 700 patients with chronic perineal pain a year, of which about 40 (5.7%) proceed to surgical decompression.

Shafik's 1998 study reviewed 11 women with idiopathic vulvodynia and chronic constipation. All the women had prolonged PNTML testing showing slowed conduction along the pudendal nerve and underwent a *transperineal* pudendal nerve decompression at Alcock's canal. In this perineal (area between vulva and anus) surgical approach, a vertical incision is made lateral to the anus, the inferior rectal nerve is identified and then followed to find Alcock's canal. Once identified, the fascia of Alcock's canal is opened, adding length to the pudendal nerve. The patients were followed for a mean of 22 months. Nine of 11 patients (82%) were cured of their vulvar pain, constipation was alleviated in 8 of 11 and the PNTML was normalized in 9 of 11. Since the pudendal nerve innervates the external anal and urethral sphincters, improvement in incontinence can also occur.

The third decompression technique is the *trans-ischio rectal fossa* approach of Bautrant. This is a transvaginal technique in which the sacrospinous ligament and the falciform process of the sacrotuberous ligament are divided. In his series of 104 trans-ischio-rectal pudendal nerve decompressions, Bautrant reports an 86 percent success rate with patients experiencing either a significant reduction in pain or being pain-free at one year. This procedure divides the falciform process and part, or all, of the sacrospinous ligament. The nerve itself is not visualized. There is a higher risk of bleeding, hematoma and infection with this procedure.

To date, there have been no randomized trials comparing the efficacy of the different surgical techniques. The majority of surgeons currently use the *transgluteal* procedure. In this approach, the nerve can be more easily identified and all areas of entrapment observed and managed. Significant reduction in vulvar pain or total pain-relief occurs in approximately 66 percent of patients who undergo transgluteal surgical decompression. Transection of the ligament(s) is of concern as there are some reports of pelvic instability following the procedure. This can lead to a myofascial pain syndrome which, in and of itself, can be difficult to manage. In the largest published series, worsening of

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NVA Funds Record Number of Research Studies

In the early years, NVA was able to fund only one pilot research study each year. As the organization has grown, we have focused more and more on raising money specifically for research grants. The result is that we have been able to double the number of research grants awarded every year since 2004. *This past year, NVA was able to award nine research grants for studies on vulvar vestibulitis or generalized vulvodynia*. This article will describe all studies NVA funded between July and December 2007. Summaries of studies funded earlier in the year, and in previous years, can be viewed on our website, www.nva.org. (Click on 'NVA-Funded Research' in the left column of the home page.)

Multilevel Nerve Blocks in the Treatment of Generalized Vulvodynia

In the summer of 2007, a grant was awarded to a multidisciplinary team at the UCLA School of Medicine to study the efficacy of multilevel nerve blocks in women with generalized vulvodynia. With this grant, gynecologist Dr. Andrea Rapkin and anesthesiologist Dr. John McDonald will use the same series of nerve blocks that produced successful outcomes in their earlier study with vulvar vestibulitis patients. Their hypothesis is that generalized vulvodynia involves abnormalities in the nervous system that can be effectively treated with local anesthetic nerve blocks. The study requires multiple treatment sessions. During each visit, a patient receives three nerve blocks administered at different levels of the nervous system: a caudal (spinal) block, bilateral pudendal block and a vulvar block targeting the perineal branch of the pudendal nerve. Patients will receive up to five treatment sessions, two to three weeks apart, and be followed for 12 months after their last treatment. (See Multilevel Nerve Blocks article, page 1.)

Compounding Pharmacy Trends in Women's Health

Given the lack of consensus guidelines and specific medications for the treatment of vulvodynia, many practitioners rely on independent compounding pharmacies to formulate topical medications for their patients. Compounding pharmacies are in jeopardy because a bill recently introduced in Congress, The Safe Drug Compounding Act of 2007, would authorize federal regulation of their practices. Therefore, NVA provided modest funding to Denniz Zolnoun, MD, assistant professor at the University of North Carolina-Chapel Hill School of Medicine, who proposed to conduct and analyze a survey of the practice trends in compounding pharmacies. Although the importance of compounded medications in treating vulvodynia is commonly acknowledged by specialists in the field, this survey will provide the objective data needed to empower advocates representing women's health interests. One of the study's main goals is to gather information on medications made by these pharmacies that are critical to the treatment of women with vulvodynia. Zolnoun distributed a questionnaire to more than 450 compounding pharmacies and will analyze the survey data to: (1) demonstrate the importance of compounding pharmacies in the provision of women's health services; (2) establish the prevalence of medications compounded for vulvodynia, and (3) identify the types and combinations of medications these pharmacies make for the treatment of vulvodynia.

Hormonal Influences in the Etiology of Vulvar Vestibulitis

This past fall, NVA awarded a grant to Catherine Leclair, MD, director of the vulvar health program, and Terry Morgan, MD, PhD, assistant professor of pathology, both of Oregon Health and Science University. Dr. Leclair was the 2006 recipient of NVA's first *Dr. Stanley C. Marinoff Vulvodynia Career Development Award*. With this award, LeClair began investigating possible hormonal influences in the etiology of Vulvar Vestibulitis Syndrome (VVS).

With their current NVA grant, Drs. Leclair and Morgan will continue their study of the underlying mechanism responsible for the increase in nerve fiber density in the vestibules of women with VVS. They will also investigate whether a mild chronic inflammation involving mast cells (cells involved in inflammatory and allergic reactions) plays a role in the initiation and/or perpetuation of VVS.

Recent research has shown that women with VVS have a reduced number of estrogen receptors in their vestibular tissue. According to Leclair and Morgan, one consequence of this decrease may be an upregulation of epidermal growth factor receptor (EGFR). (Upregulation means that a cell increases the number of receptors to a certain hormone or neurotransmitter to improve its sensitivity to this molecule.) LeClair and Morgan hypothesize that abnormal estrogen receptor down-regulation and/or androgen receptor up-regulation may lead to an increase in EGFR expression and the cascade of events

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Pudendal Neuralgia

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the condition was not reported.

Surgical therapy for pudendal nerve entrapment is an option for patients with *severe pain*. It should be noted that only a small percentage of patients who present with pudendal neuralgia are candidates for surgical decompression. The vast majority can be managed with medications and alterations in activities, such as using a pudendal nerve cushion**.** Once again, the main indication for surgical decompression is pain with sitting, severe enough to almost preclude being able to sit, with significant relief upon standing or sitting on the toilet. In this subgroup of patients, the benefits of surgery almost certainly outweigh the risks, but the decision must remain with the individual patient.

Conclusion

Unfortunately, chronic vulvar pain is a significant problem in women that is not well managed by the majority of practitioners. It is still commonplace for women to remain undiagnosed and repetitively told there is nothing wrong and to "just relax." As the diagnoses of pudendal neuralgia and pudendal nerve entrapment become well known, some of the mystique of vulvodynia may be eliminated. A careful vulvar evaluation, including a sensory exam, is a necessary part of the diagnostic procedure in women with chronic vulvar pain. Hypersensitivity to a pinprick is a sign of neuropathy and helps confirm a diagnosis of pudendal neuralgia; once diagnosed, effective interventions and medical therapies are available. If severe pain with sitting is a significant component of the pain syndrome and medical management is not successful, the patient should be evaluated for pudendal nerve entrapment. If the patient is an appropriate candidate for surgical decompression, the procedure can lead to a significant improvement in quality of life.

References

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(*Editor's note: If you'd like a complete list of references for this article, email* ***chris@nva.org***.)

Nerve Blocks

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Our hypothesis regarding vulvodynia is that this pain experience has established adverse changes in both the somatic and autonomic nervous system. To reverse these changes, we must attempt to downgrade painful or noxious impulses at all levels. Recent experimental evidence suggests that intravenous infusions of lidocaine have salutary effects because they impact at multiple levels: the dorsal root and dorsal root ganglion associated with the spinal cord, as well as the involved peripheral nerve. Adequate exposure over time to local anesthetic agents can help the central and peripheral nervous system return to a more normalized state, by reversing the peripheral and central sensitization (hypersensitivity to painful sensations). This reversal relieves the pain. Local anesthetic agents are sodium channel blockers, which block those pore openings along the nerves controlled by sodium ions. Some clinical investigators propose that sodium channel blockade over an extended period of time can prevent abnormal conduction of pain impulses or signals and be effective in alleviating neuropathic pain. To achieve this clinically, low doses of local anesthetic agents, which effectively block sodium channels, but do not entirely block nerve impulse transmission, are administered.

Vulvar Vestibulitis Study

To test our hypothesis that multiple anesthetic blocks would relieve vulvodynia, we designed a pilot study to test the effectiveness of multilevel local anesthetic injections targeting three areas: the small nerve fibers that supply the vestibule; the pudendal nerve, which is the major peripheral nerve that innervates the vestibule; and the S2-4 nerve roots of the sacral

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region of the spinal cord. A multilevel approach is most effective because it addresses three levels of pain transmission: (i) at the small nerve fiber level in the vulvar area (at the site of pain); (ii) at the level of the main nerve that supplies the vulvar area, i.e., the pudendal nerve; and (iii) at the dorsal root ganglia just outside the sacral spinal cord, which receive impulses from the pudendal nerve.

We enrolled 27 women with well-defined vulvar vestibulitis syndrome, or vestibulodynia, who did not respond to medical and/or surgical therapy. The study required a total of six visits. There were five treatment sessions, spaced two to three weeks apart, and a follow-up visit at 8 to 12 weeks. During each treatment session, local anesthetic nerve blocks were performed in the following sequence: (1) caudal epidural block (10 ml of 0.2% ropivacaine through the sacral coccygeal hiatus); (2) transvaginal pudendal block (5 ml of 0.25 % bupivacaine for each side through an Iowa trumpet sheath); and (3) transperineal vestibular infiltration (10 ml of 0.25% bupivacaine delivered into the vestibule at the 6 o'clock position, then directed to the right and left).

Using a specialized measurement tool called a vulvalgesiometer, we measured both pain threshold and tolerance at the 3, 6, and 9 o'clock positions of the vestibule. *Pain threshold* was defined as the lowest level of pressure reported to be painful. Pain was rated on a verbal analog scale of 0 (no pain) to 10 (most severe pain imaginable). *Pain tolerance* was defined as the number of grams of pressure necessary to produce a pain rating of 6.

Compared to baseline measures, we found that our subjects' pain threshold and tolerance were significantly higher at visits 3, 4, 5, and 6. Median improvement (from baseline to final visit) was 51 percent for pain threshold and 45 percent for pain tolerance. A significant reduction in the average level of pain with intercourse or sexual contact occurred over the course of treatment. At the follow-up visit, we asked women to estimate the percent change in symptoms. Using the McGill Pain Questionnaire, patients estimated an average 54 percent improvement; four women reported 100 percent improvement, two reported no improvement, and no one reported worsening of symptoms. We also administered a questionnaire three to six months after the study's completion. At that time, more than 50 percent reported that they were able to engage in enjoyable intercourse. None of the women reported painless intercourse before the treatment, compared to 25 percent of women reporting painless intercourse after treatment. In general, patients reported an overall improvement in sexual function, in addition to reduced pain.

In conclusion, after local anesthetic injections were administered to three areas involved in maintaining vestibular pain, 57 percent of patients reported less pain and 52 percent were able to experience pleasurable intercourse. Furthermore, the impact of significantly improved sexual arousal cannot be underestimated, since it plays such an important role in reestablishing pleasurable intercourse. This study suggests that a series of local anesthetic nerve block procedures – caudal epidural, pudendal and vestibular – is a promising new treatment approach for vulvar vestibulitis.

Generalized Vulvodynia Study

Since we observed successful outcomes in our vulvar vestibulitis study, we decided to repeat this procedure with generalized vulvodynia patients. In summer 2007, we submitted a research proposal to the NVA which was approved, so we have begun to enroll 30 women with well-defined generalized vulvodynia for this study. The criteria for enrollment are that participants previously either refused, or failed to tolerate or benefit from, a range of medical therapies, including topical anesthetics, antidepressants and/or anticonvulsants. The study will include a total of six visits – five treatment sessions, spaced two to three weeks apart, and a follow-up visit four weeks after the final treatment session, at which time women will complete a questionnaire on pain and sexual functioning. To reassess pain, study satisfaction and functional status, additional questionnaires will be administered six and twelve months after the final treatment session.

At the first visit, we will take a thorough history and perform a physical examination. Women will also complete a series of questionnaires including the UCLA pelvic pain questionnaire, the McGill Pain questionnaire short form, the Female Health and Sexual Functioning Index, and the Hospital Anxiety and Depression Scale. At every session, study participants

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Research

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culminating in VVS. Their long term goal is to determine the underlying mechanisms responsible for the initiation of vestibulitis and develop treatment strategies that will eliminate the need for surgery.

Genetic Predisposition in Vestibulodynia (Vulvar Vestibulitis)

Longtime clinical researcher, Jacob Bornstein, MD, chief of the department of obstetrics and gynecology at Western Galilee Hospital, Nahariya, Israel, and associate professor, Rappaport Faculty of Medicine, Hatechnion, Haifa, received his first NVA research grant. In this study, Dr. Bornstein and genetics researcher, Dr. Tzipora Falik, are investigating associations between vestibulodynia and genes that transcribe proteins, which either have been found, or are thought to be involved in, the abnormal tissue changes seen in this disorder. Specifically, they will study a number of polymorphisms (variations) of three genes coding for molecules involved in the breakdown of vestibular mast cells and increased vestibular nerve fiber growth: heparanase, vanilloid receptor-1 (TRPV1), and nerve growth factor (NGF). The subjects for this pilot study are women suffering from severe vulvar vestibulitis who have experienced pain since their first episode of sexual intercourse. This study is an important exploratory component of a larger-scale study that will help delineate genetic susceptibility to vestibulodynia, or vulvar vestibulitis, ultimately paving the way for individualized treatment.

Research Grants Awarded in December 2007

Because the quality of last year's research proposals was outstanding, NVA made a special fundraising appeal to its donors in November 2007. The response was so successful that NVA was able to award two additional research grants in late December. Drs. Linda McLean and Caroline Pukall, of Queen's University in Kingston, Ontario, received a grant to study pelvic floor muscle function in women with vulvodynia, and Dr. William Ledger, a pioneer in the treatment of vulvodynia and chairman emeritus of the department of obstetrics and gynecology at New York Presbyterian Hospital, was awarded a grant to further his study of vulvar vestibulitis. Based on the findings of his collaborative work with Dr. Steven Witkin at Cornell University's Weill Medical College, Dr. Ledger will test a novel treatment for vulvar vestibulitis patients. We will include summaries of these studies in our next newsletter. ■

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will complete both daily pain ratings and the McGill short form questionnaire. All questionnaires will be repeated at the time of the post-treatment visit. At each treatment session, blocks will be given in the following order: (i) caudal (10 cc of 0.2% ropivacaine delivered via a 25 gauge needle through the sacral coccygeal hiatus for caudal epidural blockade); (ii) transvaginal pudendal (10 cc of 0.25 % bupivocaine -5cc for each side for the standard pudendal block delivered via a 22 gauge five inch needle through an Iowa trumpet sheath), and (iii) transperineal vulvar infiltration (10 cc of 0.25 % bupivocaine delivered via a 25 gauge 1 ½ inch long needle).

The objectives of this study are to assess the relationship among several factors: overall health, gastrointestinal and/or urologic symptoms, pelvic floor findings, questionnaire responses, pain levels, and pre- and post-treatment sexual functioning. We hope that analysis of the questionnaire responses will help us to determine which patients will be likely to respond to this therapeutic intervention in the future.

Summary

We are optimistic that there will be a positive response to multilevel local anesthetic nerve blocks in women suffering from generalized vulvodynia, similar to the pain relief experienced by women with vulvar vestibulitis who received the same treatment. ■

New CME/CE Online Tutorial On Chronic Vulvar Pain

The NVA is pleased to announce the release of the first continuing medical education (CME/CE) accredited online vulvodynia tutorial titled, *Vulvodynia: Integrating Current Knowledge into Clinical Practice*. This CME program was funded by a generous educational grant from The Patty Brisben Foundation and is jointly offered by the NVA and the Dannemiller Memorial Educational Foundation. It is free to all viewers and includes a self-guided presentation on the prevalence, differential diagnosis, treatment and proposed etiology of chronic vulvar pain. To access the tutorial, please visit **http://learn.nva.org**. The CME expiration date is October 31, 2009. ■