National Vulvodynia Association

NVA News

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Chronic Vulvar Pain and Tarlov Cysts

Questions and Answers with Anne Louise Oaklander, MD, PhD

Dr. Oaklander is associate professor of neurology at Harvard Medical School and assistant in neuropathology at the Massachusetts General Hospital. She is a senior attending physician in the hospital's neurology service and the director of the neurodiagnostic skin biopsy service. This past August, Dr. Oaklander presented a poster at the International Association for the Study of Pain's World Congress summarizing the results of the first study investigating the relationship between Tarlov cysts and chronic vulvar or pelvic pain.

NVA: What are Tarlov cysts?
Dr. Oaklander: Tarlov cysts, also known as perineural cysts, are fluid-filled sacs that can damage sensory nerves as they exit the spine. They are most common in the sacrum, the thick triangular bone at the base of the spine, where the nerves that supply sensation to the pelvis originate. In 1938, American neurosurgeon Isidore Tarlov was the first to identify these cysts in a cadaver study. Tarlov later learned that in some patients, the cysts are associated with symptoms of chronic vulvar and/or pelvic pain that radiate from the nerve root (Tarlov 1952).

NVA: Why aren't the majority of medical providers knowledgeable about Tarlov cysts?
Dr. Oaklander: Tarlov's early publication is the only one that has been widely read and cited, and his first impression that these cysts were clinically irrelevant persists to this day. Additionally, about 75 percent of patients with Tarlov cysts are women and most spine surgeons are men. Both groups are mutually reluctant to discuss urogenital problems and sexual difficulties. Furthermore, most women with chronic vulvar, pelvic or urogenital pain consult their gynecologists, who do

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The Medical Management of Vulvodynia

Since vulvodynia is not simply a gynecological condition, many experts favor a multi-disciplinary approach to its management. Treatment may involve visiting a gynecologist or vulvovaginal specialist, dermatologist, neurologist, pain management specialist, urogynecologist, and/or physical therapist. Also, because vulvodynia often affects a woman's sexual relationships and emotional well-being, health care providers sometimes recommend consulting a psychologist or sex therapist.

Because we don't know what causes vulvodynia, treatment is directed towards alleviating symptoms and usually provides partial or complete pain relief. Some women experience relief with a particular treatment, while others do not respond to it or experience unacceptable side effects. No single treatment is appropriate for all women with vulvodynia and it may take time for a woman to find a treatment, or

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not usually test for neurological lesions as part of their evaluation.

NVA: What sparked your interest in Tarlov cysts?
Dr. Oaklander: In 2005, a woman in her forties who had suffered tremendously with vulvodynia since her teens came to me for help. I sent her for magnetic resonance imaging (MRI) of her spine, which showed multiple large Tarlov cysts. I wasn't sure if, or more importantly how, the cysts related to her symptoms, so I searched the medical literature. I found a paper by van de Kelft (1993) stating that 75 percent of 20 patients with unexplained chronic perineal pain had sacral cysts visible on MRI. Further, of the 12 patients who agreed to surgical treatment, all but two were symptom-free after 18 months. Van de Kelft wrote, "This evidence suggests that MRI of the lumbosacral spine should be one of the early investigations in a patient with chronic perineal pain." To this day, however, spine MRIs are not widely offered to women with unexplained chronic vulvar pain. I found this figure stunning and hard to believe, so we are now conducting the first large population-based epidemiological study of Tarlov cysts at Massachusetts General Hospital (MGH) to learn more about their prevalence and clinical significance.

NVA: Please tell us more about your study and preliminary findings.
Dr. Oaklander: We electronically searched reports of lumbar MRI or CT imaging performed at MGH between 1992 and 2009 to identify 1,305 records in which the terms "Tarlov" or "perineural" appeared. We found that almost two percent of patients undergoing lumbosacral MRIs had Tarlov cysts, 75 percent of whom were female. Prevalence of Tarlov cysts was also highly age-correlated; patients 65 years or older were 12 times more likely to have them compared to those under age 35.

NVA: Do we know how common chronic vulvar pain is in women with Tarlov cysts?
Dr. Oaklander: Unfortunately this has yet to be studied. Tarlov cysts are most commonly located at the second and third sacral nerve roots. When symptomatic, these cysts cause pain anywhere between the waist and the knees. Depending on their exact location and size, some women only experience vulvar pain, but it is more common for women to experience both vulvar and buttock pain. Some also report painful sex and many are unable to wear pants or even underwear. Because the spinal cord is so small at the sacral level, the

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side of the spine where the cysts reside does not always predict the side of pain. Affected women may have pain on both sides of the vulva, buttocks or other affected areas of the body. Most have difficulty with sitting and their pain is not significantly altered by standing. Some may experience relief after lying down, because this position reduces the fluid pressure in the cyst.

NVA: What other symptoms do women experience?
Dr. Oaklander: If the cysts increase in size over time, patients may also report sciatica, pain that radiates down the back of the leg. They may also experience difficulty with urination and defecation, as well as sexual problems. When the cysts become very large, women may experience leg weakness that interferes with their ability to walk, and the cysts begin to erode the bones of the sacrum, predisposing them to fractures. If the cysts leak spinal fluid, patients may experience headaches and/or low back pain.

NVA: Which test(s) can be done to determine if a woman has Tarlov cysts?
Dr. Oaklander: An MRI is the preferred diagnostic test. Comparison studies show that MRI is more sensitive than CT scan and that x-rays can only detect very large cysts that are eroding bone. A correct diagnosis is essential to avoid unnecessary procedures. Once a diagnosis is made, we are able to put women on a logical treatment path to prevent worsening of symptoms, and in some cases, eliminate the cysts.

I would like to clarify that MRIs should not be the first test ordered for women with chronic vulvar pain. Routine tests for known causes of vulvar disease, such as infection and dermatoses, should always be performed first; however, if a woman has otherwise unexplained chronic vulvar, pelvic and/or urogenital pain after numerous tests, she should probably have MRI of her lumbar and sacral spinal cord. An MRI is not only non-invasive and safe (because it does not involve radiation), it is indicated for *any* unexplained focal neurological problem in which a structural lesion is suspected.

NVA: How are Tarlov cysts treated? How effective are the treatments?
Dr. Oaklander: There are two classes of disease-modifying treatment for Tarlov cysts. Due to a lack of research, we don't know which treatment is best for which patients, but small studies and clinical experience have demonstrated the efficacy and safety of both procedures. Patients can have their cysts surgically removed, which typically involves complex surgery, or the cysts can be drained using CT-guided imaging to ensure the correct placement of the needle. Draining alone does not work for most patients, because the fluid re-accumulates. Once we verify that the main fluid compartment around the spinal cord and nerve roots is not leaking fluid into the cyst, we recommend that draining be combined with the injection of a tissue sealant. The advantage of surgery is that it is more likely to resolve the condition, but it is also more invasive because it involves an open-back procedure, with a longer recovery time. Injection of sealant is clearly less invasive, but less likely to be a permanent solution. Additionally, if a patient first has the fluid drained and then needs to have surgery, the surgery may be more difficult and less effective. These treatments are not widely available, forcing many patients to travel out of state to find a practitioner experienced in these procedures.

Following treatment, symptoms may either improve substantially, go away entirely, or if the

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patient has had long-standing cysts and the associated nerve damage is too severe, symptoms may persist. At that point, treatment is palliative and involves the use of medications with demonstrated efficacy for treating neuropathic pain (e.g., anticonvulsants, tricyclic antidepressants, selective serotonin norepinephrine reuptake inhibitors). There is no evidence suggesting that alternative medicine or physical therapy does any good for patients with Tarlov cysts, but implantation of small electrical stimulators near the nerve roots, spinal cord, and perhaps the brain, may be worth considering.

NVA: What general advice do you have for women with vulvodynia who suspect they may have Tarlov cysts?

Dr. Oaklander: The bottom line is that MRI is indicated for any woman with long-standing vulvar pain of unknown cause. Women with vulvodynia deserve the same standard of care as those with neurological problems affecting other areas of the body! This is mainstream medicine and there is nothing experimental about it. For these reasons, women should not have any problem obtaining insurance coverage for the test.

Additionally, it is essential for women whose imaging shows Tarlov cysts (or any other type of spinal or nerve root lesion) to obtain a neurological or orthopedic evaluation. They should know, however, that the vast majority of spine specialists are unfamiliar with Tarlov cysts and, as a result, may not be able to offer sound advice. In this case, patients must be their own advocates. They should print medical literature on Tarlov cysts and take it with them to their appointments. If women are unsatisfied with the quality of their medical care, they should seek help from a knowledgeable specialist. Additional information can be found on the Tarlov Cyst Disease Foundation's web site: www.tarlovcystfoundation.org.

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NVA Year in Review: 2010

As proud as we are of our accomplishments, we recognize that none of them would be possible without the support of our committed donors. The following is a summary of the NVA's most significant achievements of the past year.

Expansion of Vulvodynia Treatment Registry
In fall 2009, thanks to the generosity of a longtime donor, NVA funded the first national multi-center *Vulvodynia Treatment Registry.* With continued support from this donor and a generous complementary grant from The Patty Brisben Foundation, we have now expanded the Registry project to five data collection sites in Florida, Arkansas, Colorado and Washington, DC, and continue to work on adding three more sites in Ohio, Maryland and California by spring 2011. We funded this extensive groundbreaking study because it is unacceptable for women to have no scientific information on which to base their treatment choices. In addition to gathering preliminary data on which treatments are most effective for vulvodynia, the Registry aims to identify factors that predict treatment success and will guide the development of large controlled trials of promising therapies. Additional information on the Registry project and its investigators can be viewed on NVA's web site: www.nva.org/treatmentregistry.html.

NVA Accelerates Vulvodynia Research
Since the creation of our Medical Research Fund in 1997, we have awarded almost $700,000 to more than 40 vulvodynia research projects. Many investigators have used data collected with NVA grants to secure multi-million dollar funding from institutions such as the National Institutes of Health. As a result of our donors' generous support, NVA was able to allocate 50 percent of our 2010 budget to funding medical research. In addition to supporting the Vulvodynia Treatment Registry, NVA is currently supporting 16 studies. In 2010, our Executive Board approved grants for the two projects described below. Additionally, because of our commitment to accelerating vulvodynia research, NVA will now solicit research applications twice a year. The next group of grant recipients will be announced in April 2011.

University of North Carolina – Chapel Hill
Drs. Mark Tommerdahl and Denniz Zolnoun of the University of North Carolina – Chapel Hill, will use their NVA grant to conduct the first large-scale study investigating the underlying mechanisms of Generalized Vulvodynia. They will compare peripheral and central nervous system pain processing in three groups: (i) women with Generalized Vulvodynia, (ii) women with Provoked Vestibulodynia (PVD, aka vulvar vestibulitis), and (iii) women with both vulvodynia subtypes. Understanding the mechanisms that initiate and maintain abnormal pain processing at all levels of the nervous system – the brain, spinal cord and peripheral nerves – will help to determine which therapeutic agents are likely to be effective in the treatment of women with Generalized Vulvodynia.

Cornell University
Drs. Steven Witkin and William Ledger of Cornell University received an NVA grant to analyze the types of bacterial organisms found in the vagina and vulva of women with PVD. They are investigating the relationship between specific bacterial organisms, genetic makeup and degree of vestibular inflammation, helping to clarify how the interaction of these three factors affects susceptibility to developing PVD. To read summaries of other NVA-funded projects, please visit www.nva.org/research_fund.html.

NVA Encourages Careers in Vulvodynia
In 2006, NVA established the *Dr. Stanley C. Marinoff Vulvodynia Career Development Award* to

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encourage medical professionals to pursue a clinical and/or academic interest in vulvodynia. The purpose of the award is to provide seed money for medical research, the establishment or enhancement of a vulvar pain clinic, or a written publication on vulvodynia. The NVA's intent is to encourage a medical professional's interest in this field and enable him/her to pursue further clinical or academic opportunities.

The 2010 recipient of the Career Award was Dr. Ruby Nguyen, an epidemiologist at the University of Minnesota, who is conducting the *first* prospective study of pregnant women with vulvodynia. For many years, women with vulvodynia have asked health care providers and NVA about the effect of pregnancy and childbirth on vulvodynia and the answers have been based on anecdotal evidence. Finally, Dr. Nguyen is now investigating whether there is a change in the severity of vulvar pain during pregnancy and the postpartum period.

NVA's Executive Board recently selected the 2011 Career Award recipients. Ahinoam Lev-Sagie, MD, an obstetrician-gynecologist at Hadassah University Hospital in Israel, spent several years in the United States training as a specialist in vulvovaginal disorders under Drs. Paul Nyirjesy, Steven Witkin and Lynette Margesson. Currently, she directs a Vulvar Pain Clinic at Hadassah. She will use her NVA award to conduct a randomized placebo-controlled trial to investigate the efficacy of low-level laser therapy in the treatment of PVD.

The second recipient, Stéphanie Thibault-Gagnon, PT, is a physical therapist and clinical researcher at Queen's University in Canada. In preparation for the development of a large controlled trial to investigate the efficacy of physical therapy treatment in women with PVD, she will test the validity and reliability of 3D transperineal ultrasound (a new imaging device) to measure pelvic floor muscle function in women with the disorder. To read summaries of all NVA-funded Career Development Awards, visit: www.nva.org/career_development_award.html.

NVA Funds New Vulvodynia Clinic

Over the past four years, NVA has funded the creation of vulvar pain clinics in New Jersey, Tennessee and Michigan. In early 2010, we awarded a grant to Danielle Tonelli, DO, to start a vulvar pain clinic in Milwaukee, Wisconsin. Dr. Tonelli is a fellowship-trained women's health specialist with board certification in family medicine and currently serves as co-clinical director of the Center for Optimal Health and Wellness at the Aurora Women's Pavilion (AWP) in Milwaukee. AWP demonstrated its support of her work by matching the NVA's grant. Dr. Tonelli will develop and implement educational programs for women with vulvodynia and medical professionals. "With the establishment of the AWP Vulvar Pain Clinic, women in our community and their providers will now have a local center with a full range of services, from outreach and education to compassionate patient care," says Dr. Tonelli.

Updated Tutorial Educates Medical Professionals

Thanks again to the generous support of The Patty Brisben Foundation, thousands of health care providers have now viewed the updated version of NVA's online course, *Vulvodynia: Integrating Current Knowledge into Clinical Practice,* which offers them Continuing Medical Education credits. We also attended several national health care conferences this year, distributing thousands of educational packets to health care providers specializing in vulvovaginal disorders, gynecology and women's health.

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New Booklets for Women with Vulvodynia
Since July, NVA has disseminated thousands of our new patient booklets to women with vulvodynia and to health care professionals who specialize in its treatment. Written from both the gynecological and chronic pain perspectives, our updated patient self-help guide, *I Have Vulvodynia – What Do I Need to Know?*, features important self-help strategies for alleviating vulvar pain and maintaining sexual intimacy, while helping women with vulvodynia to make educated decisions about their health care. The first of three new publications, *Vulvodynia, Pregnancy and Childbirth*, is the only resource of its kind for women with vulvodynia who are pregnant or want to conceive. This booklet covers conception through the postpartum period, dealing with issues such as alleviating vulvar pain during pregnancy and minimizing vulvar trauma during childbirth. Another booklet, *My Partner Has Vulvodynia – What Do I Need to Know?,* gives partners a better understanding of the challenges a woman with vulvodynia faces and discusses how they can show their support. Lastly, *How to Apply for Disability Benefits***,** guides women with vulvodynia who are unable to work through the process of applying to the Social Security Administration for disability benefits.

In November, NVA received a grant from Purdue Pharma, L.P., to support the translation into Spanish of our introductory brochure and several sections of our web site. Both projects will be completed by summer 2011.

First Economic Impact Study on Vulvodynia
In cooperation with Wendy Max, PhD, adjunct professor of medical economics at the University of California, San Francisco, and Lizheng Shi, PhD, assistant professor in the department of health system management at Tulane University School of Public Health, NVA conducted the first economic impact study on vulvodynia. From an economic impact survey, analysts can calculate the extent to which a particular health condition impacts the nation's economy. The information gathering portion of this study ended in December, and Dr. Shi's research team is currently analyzing the data, which will be published in a medical journal in 2011. NVA will be able to use this information in our continued effort to persuade Congress and federal health agencies to increase vulvodynia research.

Progress in NIH Research Funding
The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) is responsible for funding the majority of vulvodynia research at the NIH. In early August, NVA met with NICHD's new director, Dr. Alan Guttmacher, to discuss a strategic plan for increasing NICHD-funded vulvodynia research next year. Because few investigators familiar with vulvodynia have been included in prior NIH review committees, Dr. Guttmacher committed to organizing a special study section to review vulvodynia research applications during the next three years, and asked NVA to submit for consideration as reviewers the names of basic and clinical scientists, as well as members of the public. Since NICHD has not held a vulvodynia conference in six years, Dr. Guttmacher also committed to organizing a vulvodynia conference to be held in spring/summer 2011. NVA will serve as a member of the planning committee. In preparation for the NIH workshop, the NVA collaborated with Drs. David Foster, Gloria Bachmann and Candace Brown, and held a meeting of vulvodynia researchers funded by the NVA, NIH and the Canadian Institutes of Health Research. At the meeting, 13 scientists presented data from their research projects and the group identified critical knowledge gaps.

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At NICHD's request, we will submit the proceedings for their consideration in planning the 2011 conference, in addition to publishing them in a medical journal.

Campaign to End Chronic Pain in Women

In May, the NVA and other organizations of the Overlapping Conditions Alliance (OCA) launched the *Campaign to End Chronic Pain in Women* at a Capitol Hill briefing attended by more than 30 congressional staffers. The campaign's aim is to increase federal funds allocated to both disorder-specific and collaborative scientific research on six chronic pain conditions that often co-exist and either solely or disproportionately impact women: vulvodynia, fibromyalgia, temporomandibular disorders, endometriosis, interstitial cystitis and chronic fatigue syndrome.

At the briefing, held in cooperation with the Congressional Caucus for Women's Issues, the OCA released a groundbreaking report, *Chronic Pain in Women: Neglect, Dismissal and Discrimination (*see www.endwomenspain.org), which details the staggering human and financial toll of these pain disorders and offers policy solutions to improve the quality of medical care for affected women. The report's key findings are: (i) up to 50 million American women suffer from one or more of these chronic pain disorders; (ii) our country's failure to support an adequate research effort and train medical professionals in the appropriate diagnosis and treatment of these six conditions adds as much as $80 billion a year in direct and indirect costs to America's annual health care bill, and (iii) despite this enormous burden, the NIH's research investment in the six conditions averaged only $1.33 per affected woman in 2009!

The report's remarkable findings enabled us to make significant progress in the past six months. In August, U.S. Representatives Lois Capps (D-CA) and Tammy Baldwin (D-WI) requested a congressional hearing to address these overlapping pain conditions. We were also successful in including strong language in the FY2011 Appropriations Bill and the NIH responded that it will assemble the first Trans-Institute Working Group on this topic. Next year, the group will bring together a diverse cross-section of clinical and basic science researchers and convene a scientific meeting on the disorders, with the aim of developing a strategic research plan to identify both unique and shared underlying mechanisms. ■

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combination of treatments, that alleviates her pain.

Self-Help Strategies

Utilizing self-help strategies, such as the elimination of potential irritants, is typically the first step in treatment. This may include wearing all-white cotton underwear, loose-fitting pants or skirts and thigh-high or knee-high stockings instead of pantyhose. Women should use a dermatologically-approved detergent and avoid the use of fabric softener on undergarments. Double-rinsing underwear and other clothing that comes into contact with the vulva may also be helpful. Discontinuing the use of bubble bath, feminine hygiene products and perfumed creams or soaps is strongly recommended. The use of lukewarm or cool sitz baths and/or applying ice or a frozen blue gel pack wrapped in a hand towel can help relieve burn-

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ing and irritation. Some women find sitting on a donut-shaped cushion to be helpful, as well as interspersing periods of standing and sitting during the day. For additional self-help strategies, please visit www.nva.org/Self_Help_Tips.html.

Most Common Treatments

Oral "Pain-Blocking" Medications

Medications that are effective in alleviating other chronic pain conditions, such as Tricyclic Antidepressants (TCAs), are often used in the treatment of vulvodynia. Although TCAs were developed to treat depression, many controlled studies have demonstrated their effectiveness in treating chronic pain conditions. For women with vulvodynia or other chronic pain, the dosage is usually much lower than that used for the treatment of depression. To minimize side effects, it is best to start at a very low dose and increase the amount gradually; consequently, it can take several weeks to achieve a therapeutic level. Common side effects, which can usually be managed, include drowsiness, dry mouth, constipation and dizziness. The severity of the side effects depends on which TCA you take, e.g., amitriptyline causes stronger side effects than nortriptyline or desipramine. Before discontinuing a TCA, a woman should discuss how to taper it gradually with her health care provider.

Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs), a relatively new type of antidepressant, work differently than the TCAs. These medications are FDA-approved to treat depression and anxiety disorders, as well as certain types of pain, such as fibromyalgia and peripheral neuropathy. SNRIs are also used "off-label" to treat other chronic pain disorders. Three SNRIs, venlafaxine, duloxetine and milnacipran, have been used to treat vulvodynia, but their effectiveness has not been tested in large controlled studies. The most common side effects, some of which improve over time, include headache, nausea, insomnia, sexual dysfunction, dry mouth and dizziness. It is important to understand that it can take many weeks to months to reach a dose that will alleviate pain. If you decide to stop taking a SNRI, it should be discontinued slowly with the advice of your health care provider.

Anticonvulsants (medications intended to inhibit seizures) can also be effective in controlling some chronic pain syndromes. For example, the anticonvulsant pregabalin is FDA-approved to treat postherpetic neuralgia, diabetic neuropathy and fibromyalgia. Anticonvulsants are often prescribed for women with vulvodynia, especially when pain is described as having a "shooting, burning, stabbing or knife-like" component. Unfortunately, the effectiveness of pregabalin, gabapentin, and oxcarbazepine in the treatment of vulvodynia has not been tested in large controlled studies. As with TCAs, it is best to start at a very low dose and increase the amount gradually. If you decide to discontinue an anticonvulsant, you should not stop it abruptly.

Pain-relieving opioids, such as oxycodone and hydrocodone, can be very helpful for short-term use during vulvodynia flares. They can also be used to relieve moderate to severe pain early in treatment, while a woman gradually increases the dosage of an antidepressant or anticonvulsant to a therapeutic level. In severe cases, when more conservative therapies fail to provide relief, long-acting opioids may be used on an ongoing basis. Common side effects, which can usually be managed, include constipation, nausea and drowsiness. Opioids should not be discontinued abruptly, because it is likely that you will experience withdrawal symptoms.

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Topical Medications

Medications applied directly to the vulva may help to alleviate pain, but some preparations contain additive substances that are irritating to the skin. Therefore, many vulvodynia experts use compounding pharmacies to make individualized topical creams and ointments without irritating additives. Some examples include topical hormonal creams, anesthetics and specially formulated compounded creams. Topical estrogen cream can improve the health of vulvar tissue, particularly when the tissue is thin or dry because of a lack of estrogen. Recently, some experts have also emphasized the role of the hormone testosterone for women's sexual health and recommend combining estrogen and testosterone in a topical cream. Topical anesthetic cream or ointment provides temporary pain relief and is applied directly to the vulva prior to intercourse. Typically, the numbing effect lasts 15 to 30 minutes. One study found that long-term nightly use of lidocaine resulted in sustained pain relief, but in another clinical trial, women reported increased vestibular sensitivity with daily use. Medications that are normally prescribed for oral use, such as antidepressants and anticonvulsants, can also be formulated into a cream or ointment. Topical preparations either contain a single active ingredient or a combination of ingredients, e.g., an anesthetic and antidepressant. Compounded topical formulations may be used in conjunction with oral medications and other treatments.

Pelvic Floor Muscle Therapy

Some women with vulvodynia also have pelvic floor muscle weakness, spasm and/or instability. In addition to evaluating pelvic floor muscles, a physical therapist should assess joints, muscles and nerves in the lower half of the body to determine if they play a role in vulvar pain. Treatments include exercise, education and manual therapies, such as massage, soft-tissue work and joint mobilization. Modalities such as heat/cold, ultrasound and electrical stimulation may also be helpful. In addition, rehabilitation of the pelvic floor muscles may include insertion of a vaginal sensor and the use of a biofeedback machine. The machine provides visual feedback on the strength of pelvic floor muscles while performing exercises to normalize their function. This type of biofeedback is conducted by specially trained providers and some physical therapists.

Nerve Blocks

The pudendal nerve carries pain signals from the vulva to the spinal cord. A nerve block is an injection of anesthetic, often combined with anti-inflammatory medication, which 'breaks up' the transmission of the pain signal. In some cases, a series of injections, spaced days or weeks apart, is administered intravaginally or in the epidural space in the lower back (as done during childbirth). Most women experience short-term relief with this procedure and some experience long-term relief. One recent study found that women with vulvodynia who underwent a series of different nerve blocks (vulvar, pudendal and spinal) experienced sustained pain relief.

Surgery (for women with Provoked Vestibulodynia)

Surgery is contraindicated for women with Generalized Vulvodynia. Two surgical procedures are used for women with Provoked Vestibulodynia (PVD, aka vulvar vestibulitis). *Vestibulectomy with vaginal advancement* involves the removal of a portion (or all) of the vestibule, including the hymen, followed by advancement of internal vaginal tissue. In a *modified vestibulectomy*, only the superficial painful tissue is removed and there is no vaginal advancement. Most published outcome studies are based on vestibulectomy with

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vaginal advancement. It is difficult to compare the results of surgery studies, however, because different outcome measures are used and the length of follow-up time differs. Overall success rates for both procedures range from 60 to 96 percent. After surgery, physical therapy and the use of dilators are often recommended to improve any remaining pelvic floor muscle abnormalities. Careful patient selection for surgical treatment is essential because it increases the likelihood of success. Researchers are studying factors that may predict success or failure with surgery, but no conclusions can be drawn at this time. (For additional information on the two procedures, please see http://o.b5z.net/i/u/10023334/i/Goldstein-_vestibulectomy_JSM.pdf, and http://learnprovider.nva.org/pdf/Modified_Vestibulectomy_Diagram.pdf.)

Neurostimulation or Spinal Infusion Pump
In severe cases, when more conservative forms of treatment have not provided relief, neurostimulation or implantation of a spinal infusion pump may be recommended. Neurostimulation involves the implantation of an electronic device that delivers low voltage electrical stimulation to the spinal cord, or a targeted peripheral nerve, with the intent of substituting a tingling sensation for pain. Spinal infusion pumps continually administer very small amounts of medication to the spinal cord and nerve roots. For additional information on these treatment methods, please visit: www.cumc.columbia.edu/dept/pelvic/treat/neuromodulation.html.

Diet Modification
Some women find that eating a certain food increases their pain and that elimination of the food alleviates it. For example, some women eliminate acidic or high-sugar foods. If you want to test for food sensitivity, you should eliminate one item or food group at a time to determine which ones, if any, are affecting you. With the use of a food diary, women may begin to notice an association that they would not otherwise suspect.

Counseling
Since living with chronic vulvar pain often affects a woman's sexual relationship and may lead to anxiety and/or depression, some women find it helps to consult a psychologist or a sex/couples therapist.

Complementary or Alternative Medicine
Women with vulvodynia, as with all forms of chronic pain, may benefit from using alternative therapies in conjunction with traditional medical treatments. There are many complementary therapies available, including acupuncture, massage therapy, relaxation techniques and cognitive behavior therapy. To learn about complementary treatments, visit the National Center for Complementary and Alternative Medicine's web site, www.nccam.gov.

Additional Treatments
The treatments described above are, by far, the most common ones, but your provider may recommend one or more of the following therapies in your specific case.

Topical Steroids
Topical steroids are used to reduce inflammation in the vulvar tissue. If your provider thinks that inflammation is a factor, he/she may recommend steroids, which are generally used for short periods of time.

Topical Cromolyn
Cromolyn, commonly used to treat asthma due to allergy, is a synthetic compound that prevents mast cells, which are immune system mediators

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of inflammatory reactions, from releasing certain chemicals. In recent years, some researchers have implicated mast cells in the etiology of PVD. Cromolyn can be compounded into a topical preparation and applied directly to the vulva. An initial study showed little efficacy, but patients in this study had suffered from vulvodynia for a long time and tried many other treatments that were not successful. At this time, there is no information on the efficacy of cromolyn in newly diagnosed patients.

Subcutaneous Steroid/Anesthetic Injections
In a few publications, women have reported symptom improvement after undergoing a series of steroid/anesthetic injections into the vestibule or other vulvar tissue. These injections are usually administered one week apart for several weeks.

Botox Injections
Botox, a toxic protein produced by a certain bacteria, is sometimes used to treat muscle spasm. Recent studies have indicated that it may also interfere with pain transmission. For women with vulvodynia and pelvic floor muscle spasm, Botox is injected directly into the area(s) of spasm.

Topical Capsaicin
Capsaicin, a component of chili peppers that causes skin irritation, is currently used in topical ointments to relieve neuropathic and other types of pain. With repeated application of capsaicin, neurotransmitter levels in nerve cells diminish, leading to a reduction in pain transmission. Initial reports of capsaicin use in women with vulvodynia indicated moderate pain relief and less pain during intercourse.

Low-Oxalate Diet/Calcium Citrate Supplements
The recommendation that women follow a low-oxalate diet and take calcium citrate is controversial. Controlled studies have shown that a small percentage of women report some relief with this regimen, but that there is no difference in the amount of urinary oxalates excreted by women with vulvodynia and healthy controls. Some practitioners have noted that the low oxalate diet is detrimental to one's overall health because it eliminates many healthy foods.

Interferon Injections
Interferon is a substance produced by the body that helps to fight infection. In some cases, a series of injections of manufactured interferon have been injected into the vulva. Although initial studies of interferon appeared promising, recent studies indicate that interferon is not effective.

Managing Breakthrough Pain
Sometimes a relatively brief 'pain flare' escalates suddenly and breaks through a woman's regular pain management regimen. In addition to a long-term treatment strategy, it is important for women to discuss with their provider how to handle a pain flare *ahead of time*. Some providers will write a prescription for a fast-acting narcotic, such as hydrocodone, or prescribe another medication to use in this circumstance.

Looking Ahead
It is important to remain hopeful and positive, in spite of the fact that you may have to try several different treatments before achieving significant pain relief. There is more vulvodynia research being conducted now than ever before, including the first Vulvodynia Treatment Registry, which provides preliminary data on the long-term effectiveness of the most commonly used vulvodynia treatments. (See *NVA Year in Review* on page 5.)
In addition to the Registry Project, you can read summaries of treatments studies that are currently enrolling participants on NVA's web site, www.nva.org/participate.html. ■