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NVA News

Volume VII, Issue I

Summer 2001

Treating Generalized Vulvar Dysesthesia

By Elizabeth Gunther Stewart, M.D.

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Vulvodynia is defined as chronic vulvar itching, burning, and/or pain that causes physical, sexual, and psychological distress. Over the years, the term has been applied to a wide variety of vulvar conditions because specific diagnostic criteria were not established.

Although the prevalence of chronic vulvar pain in the U.S. is unknown, for the past decade estimates have ranged from the low to mid-hundred thousands. While it was previously thought that chronic vulvar pain is a rare complaint, it may simply have been under-recognized by the medical profession; in fact, the disorder only received a diagnostic code about five years ago. Last fall, the National Institute of Child Health and Human Development funded a 5-year prevalence study on vulvodynia in the general population. According to epidemiologist Bernard Harlow, Ph.D., associate professor of Obstetrics, Gynecology, and Reproductive Epidemiology, Harvard Medical School, "the preliminary data suggests that possibly millions of women may be affected at some point during their lifetime."

After a 1997 workshop at the National Institutes of Health, practitioners began to conceptualize vulvodynia as a pain problem. In 1999, at the annual meeting of the International Society for the Study of Vulvovaginal Disease, a two-year trial of specific pain terminology was proposed. This new terminology includes generalized vulvar dysesthesia (VDY), formerly known as dysesthetic or essential vulvodynia, burning vulva syndrome, pudendal neuralgia, or perineal pain syndrome. It is characterized by pain that may be located anywhere on the vulva. Localized vulvar dysesthesia refers to pain that can be consistently localized by point-pressure mapping

See DYSESTHESIA, page 3

NVA Meets With Congressional Leaders

NVA representatives, seeking Congressional support for an increase in vulvodynia research funding, attended two important meetings on Capitol Hill in the past six months. In late July, NVA executive director Phyllis Mate and executive board members Jeanmarie Dunn and Maurice Kreindler met with Rep. Bill Young (R-FL), chairman of the House Appropriations committee, and Rep. Ralph Regula (R-OH), chairman of the House subcommittee on Labor, Health and Human Services. Both congressmen were supportive of the NVA's request for the National Institutes of Health (NIH) to allocate more funds for vulvodynia research and Chairman Regula committed to including such language in the House of Representatives' next NIH appropriations report.

Earlier this year, Phyllis Mate and Christin Veasley, the NVA's director of research and development, discussed future vulvodynia research funding with Peter Reinecke, Legislative Director to Senator Tom Harkin (D-IA), and Phyllis Leppert, M.D.,Ph.D., chief of the Reproductive Sciences Branch, National Institute of Child Health and Human Development (NICHD). In her summary of the NICHD's funding to date, Dr. Leppert stated that 3 of the17 proposals submitted under last year's Request for Applications were funded, in addition to a fourth proposal that was funded under

See CAPITOL HILL, page 5

NVA Presents at Major Health Conference

Stanley Marinoff, M.D., a member of the NVA medical advisory board, and Christin Veasley, the NVA's director of research and development, gave a presentation emphasizing the importance of developing improved treatments for vulvodynia at a major women's health conference this past March in Washington, D.C. Organized by the Drug Information Association (DIA), the conference focused on the need for drug discovery and development in areas of unmet women's health needs. Musculoskeletal disorders, chronic pain conditions, sleep disorders, gynecologic cancers and incontinence were among the women's health issues discussed. In addition to presentations on current research developments, Vivian Pinn, M.D., director of the Office of Research on Women's Health of the National Institutes of Health (NIH), summarized the conclusions of the NIH's 2001 report on women's health policy.

Attending the DIA conference were clinical directors from major pharmaceutical companies, including Johnson and Johnson, Pfizer, Merck, Bristol-Myers Squibb and Pharmacia. Among the other attendees were government representatives from the Department of Health and Human Services (HHS) and Food and Drug Administration (FDA), who also gave updates on women's health policy at their respective agencies.

Dr. Marinoff's presentation covered the different types of chronic vulvar pain, preliminary prevalence data, diagnostic procedures, and available treatments. Christin Veasley presented dysesthetic vulvodynia and vulvar vestibulitis case studies and discussed the impact of these disorders on quality of life. Immediately following her presentation, Christin was approached by Ruth Merkatz, M.D., Pfizer's director of women's health, who expressed interest in learning more about chronic vulvar pain disorders and their prevalence. Brinda Wiita, M.D., director of clinical affairs in the Personal Care Products division of Johnson and Johnson, also attended the DIA conference. A few weeks later, she met with Christin to further discuss vulvodynia and the NVA's role in promoting awareness of the disorder. In June, on behalf of Johnson and Johnson, Dr. Wiita presented the NVA with a substantial grant to be used for educational programs. ■

NVA Exhibits at ACOG Annual Meeting

For the first time, the NVA exhibited at the annual meeting of the American College of Obstetricians and Gynecologists (ACOG), one of the largest medical professional associations in the United States. The three-day ACOG 50th anniversary meeting took place in late April 2001 in Chicago and was attended by more than 5,000 obstetricians and gynecologists from the United States and many foreign countries. The NVA was one of the only non-profit, patient advocacy organizations present among the hundreds of exhibitors, the majority of which were major pharmaceutical companies and medical equipment manufacturers.

By exhibiting at ACOG, the NVA was able to distribute educational materials to more than one thousand medical professionals and stimulate their interest in learning more about treatments for the disorder. Hundreds of physicians visited the NVA booth to ask questions and obtain samples of our patient brochure and newsletter. At least five hundred doctors were added to our mailing list on site and requested that patient brochures be mailed to their offices. The most common reply doctors gave to being asked whether or not they treat vulvodynia was, "I try, but it's a difficult condition to treat."

Many vulvodynia experts, including some who have written articles for our newsletter, stopped by the booth as well. They pointed out that it is important for the NVA to continue exhibiting at medical conferences to raise the profile of chronic vulvar pain conditions among medical professionals, particularly gynecologists. After receiving such a positive response at this year's meeting, the NVA plans to attend ACOG's annual meeting in Los Angeles next May. ■

Dysesthesia

(from page 1)

within specific areas of the vulva, and mixed dysesthesia describes pain on touch in the vulvar vestibule as well as pain in other areas of the vulva.

NVA News
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The *NVA News* is published three times per year.

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Essential characteristics

VDY can take the form of burning or any combination of stinging, irritation, itching, pain, or rawness anywhere from the mons pubis (bony protrusion where the pubic hairline begins) to the anus. It may be diffuse or focal, unilateral or bilateral, constant or sporadic. Women with VDY frequently have difficulty describing and localizing their pain. Many feel that they have a constant yeast infection. Others mention constant irritation, a feeling of continual swelling, a raw sensation, or the sense that they are sitting on a hard knot or ball. Brief paresthesias (abnormal sensations such as burning, prickling or tingling) also are characteristic. Involvement of the urethral meatus (opening of the urethra) leads to symptoms resembling those of a urinary tract infection —i.e., frequency, urgency, and dysuria— with negative urine cultures.

Dyspareunia (painful sexual intercourse) may or may not be a feature of VDY, although intercourse may trigger pain. Tight pants or undergarments or even the movement of pubic hair also may provoke discomfort. At the same time, it is not unusual for women to report symptom-free periods lasting days or weeks.

The pain of VDY may be neuropathic in nature. Neuropathic pain states originate with an injury to the sensory nervous system itself, which continues to transmit pain signals even when acute injury is absent. Neuropathic pain is most commonly a result of peripheral neuropathy, nerve or root compressions, trauma, or other injuries to the peripheral nervous system. Any surgical incision damages sensory nerves and can cause chronic neuropathic pain, even when the original neural injury is insignificant or unapparent.

"The preliminary data suggests that possibly millions of women may be affected at some point during their lifetime."

As it crosses the sacrospinous ligament and courses along the pelvic sidewall, the pudendal nerve is vulnerable to traction (pulling), pressure, and injury from a wide variety of insults. Injuries from unicycles or horseback riding are documented examples of sports trauma leading to vulvar pain. Injury from descent of the presenting part of the fetus during vaginal delivery, recognized in the pathophysiology of prolapse and incontinence, also is a possible etiology of VDY. Some types of vaginal surgery may injure the pudendal nerve, resulting in VDY.

The pinformis, pubococcygeus, and obturator internus and externus

See DYSESTHESIA, page 4

Dysesthesia

(from page 3)

muscles (pelvic floor muscles) as well as the sacroiliac joint, commonly refer pain to the perineum, vagina, and rectal areas. Branches of the pudendal nerve lie directly over the belly of the obturator internus muscle. Any injury or orthopedic condition affecting these muscles and joints—e.g., injury to the back, hips, or knees, or repetitive musculoskeletal or postural stressors—can result in vulvar pain.

Pain also may be referred to the vulva from a ruptured disc or scarring around sacral nerve roots after disc surgery, spinal stenosis, or significant spinal arthritis. In addition, neurologic disease such as multiple sclerosis may lead to vulvar pain, as may a solitary neurofibroma (benign nerve tumor).

The neuropathic viruses varicella zoster and herpes simplex may lead to post-herpetic neuralgia manifesting as VDY. When a lesion thought to be herpes simplex turns out to be culture-negative, herpes zoster may be present. VDY should be considered when a woman with a history of herpes is successfully suppressed on acyclovir but continues to complain of irritative symptoms or pain.

Diagnosis

Since irritation, burning, and sometimes an increase in discharge are features of VDY, many women believe they have yeast or another type of vaginitis. Patients often are treated for bacterial and/or yeast infections, but multiple antifungals and antibiotics fail to resolve irritative symptoms. Women whose VDY mimics a urinary tract infection will have negative urine cultures, fail to respond to antibiotics, and have a negative urologic workup. Many women are sent to dermatologists to determine whether there is a skin etiology for the chronic symptoms, especially since VDY sometimes involves fissuring with sexual activity. Topical steroids usually are of no benefit. In the postpartum and menopausal periods, estrogen cream may be soothing for a short time, but will not dispel discomfort or dyspareunia.

The diagnosis of VDY is largely a diagnosis of exclusion. A careful history is essential to ascertain the type of pain as well as its manifestation and location. The clinician should inquire about any initiating factors or associated events such as medical illness, pelvic or vulvovaginal surgery, childbirth, injury to the back or hips, or development of a vulvar lesion that may provide clues to etiology. Any history of sports injury, back surgery, herniated disc, arthritis, spinal stenosis, and hip dislocation also is important. In addition, the clinician should ask about occupational and leisure-time activities that might affect the back or pelvis.

During the physical, it is important to look for skin or oral lesions suggestive of disease or dermatosis. Labial and anal muscle reflexes should be tested, and the patient should be asked to point out areas of pain and identify areas tender to the touch.

To look for evidence of VDY, the clinician can untwist the end of a cotton swab to create a cotton wisp and move it across the vulva and vestibule to assess the patient's response to light touch. If the cotton wisp feels like a pinch, knife, sandpaper, or other irritant, allodynia (a stimulus that is ordinarily not painful produces pain) is present. The stick of the cotton swab may then be broken—forming a sharp point—to test for areas of hypo- or hyperesthesia (decreased or increased intensity of feeling). These abnormal findings are easily missed without proper testing. When findings are abnormal inside as well as outside the vestibule, both VDY and vestibulodynia (VBY) may be present. However, even with careful testing, there may be no significant findings.

To rule out vulvar dermatitis or dermatosis, colposcopy and biopsy may be necessary. Any suspicious lesions should be cultured for both herpes simplex and varicella zoster viruses. To rule out a tumor, herniated disc, severe arthritis, spinal stenosis, or arachnoiditis, x-ray or magnetic resonance imaging (MRI) may be useful. A loss of urinary or bowel control and/or the anal wink reflex requires a workup for a spinal cord lesion.

Treatment

Once VDY is diagnosed, the clinician should provide education and support and refer the patient for evaluation if depression is present. Most patients experience a huge sense of relief once a concrete diagnosis is made, feeling reassured that their pain is real and that the condition is neither malignant nor communicable. Couples and sexual counseling are valuable when dyspareunia is present, but sexual

See DYSESTHESIA, page 8

Dermatological Conditions of the Vulva

by Gordon Davis, M.D.

Dr. Davis is immediate past president of the American Society of Colposcopy, a member of the International Society for the Study of Vulvovaginal Diseases and director of the Arizona Vulva Clinic in Phoenix, Arizona.

Before a physician can be confident in making a diagnosis of dysesthetic vulvodynia or vulvar vestibulitis, it is important to rule out other medical conditions that may be less difficult to treat. This article covers some dermatological conditions of the vulva that cause discomfort and pain: dermatitis, dermatosis, and atrophy.

Dermatitis

Dermatitis simply means inflammation of the skin, and at one time or another everyone experiences it. Dermatitis may occur anywhere on the body including the vulva and the vestibule. The characteristic sign of vulvar dermatitis is a red, tender vulva. There may be some short episodes of itching, occasionally intense, but most often vulvar dermatitis causes burning and pain with sexual activity, explaining why it may be mistaken for vestibulitis.

Contact Dermatitis: Fact and Fiction

Contact or primary irritant dermatitis is a common cause of vulvar burning. This condition is often puzzling to the clinician and its course of treatment varies among practitioners. When irritant dermatitis is suspected, many clinicians caution their patients to avoid exposing the genital area to dyes and perfumes, since they are often irritants or allergens that can cause dermatitis. Whether dyes in toilet paper or clothing actually contribute to vulvar dermatitis is unknown. However, it is reasonable for highly allergic patients (those with hay fever and seasonal allergies) to avoid certain hair dyes, perfumes and the usual list of so-called "allergic" but more often "irritant" substances. Although an occasional patient may find nylon undergarments irritating, they do not appear to

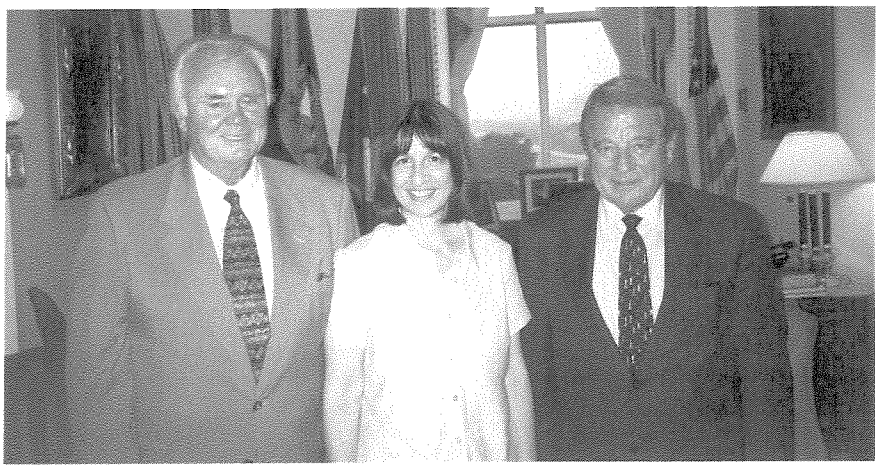
See DERMATOLOGY, page 6

Capitol Hill

(from page 1)

the ongoing vulvodynia Program Announcement. She also mentioned that a fifth study would be funded by the fall. (Subsequently, we have learned that a sixth study will receive funding as well.)

The meeting in Senator Harkin's office produced two important outcomes. First, the NICHD agreed to fund a second vulvodynia medical conference tentatively scheduled for spring 2003 (the first was in April 1997). The eight member planning committee for the conference includes Maria Turner, M.D., chairperson of the 1997 vulvodynia workshop, NVA medical advisory board member Ursula Wesselmann, M.D., and Phyllis Mate. The second important outcome of the meeting was a commitment by the NICHD to develop educational materials on vulvodynia for the public, as well as the medical community. The first publication, directed at patients, will summarize the steps involved in obtaining an accurate diagnosis. The NVA will assist the NICHD's communications department in the development of these materials. ■



Pictured from left to right are Rep. Bill Young, NVA Executive Director Phyllis Mate, and Rep. Ralph Regula.

Dermatology

(from page 5)

constitute a problem for most women, except by increasing moisture in the vulvar area.

Irritant reactions either occur immediately upon exposure ("the medicine burned me") or after a short duration of use. Most irritant reactions at the vestibule subside within days, but some take several weeks. Allergic reactions require prior exposure, i.e., the substance has been used before; in this instance, a reaction occurs after 48 to 96 hours of use. The patient will report a vulvar "flare-up" or worsening of vestibulitis or vaginitis when using the substance. Generalized itching may also occur with true allergic episodes. The most common sources of irritants are antifungal (anti-yeast), antibacterial and steroid creams. Specific irritating agents in these compounds have been identified and it is also reasonable to think that the drug in the cream or ointment (such as metronidazole) may damage the vulvar and vaginal surface as well. Vulvar and vaginal creams and ointments contain various preservatives, stabilizers, and delivery vehicles, to which many people react. Propylene glycol, a vehicle commonly used in topical and oral preparations, has been shown to be an irritant and an allergen in up to 12.5 percent of patients. Allergic sensitization has been demonstrated by controlled oral provocation studies. For example, when propylene glycol was ingested, a recurrence of dermatitis in previously affected areas was seen in close to 50 percent of patch-test positive patients.

Skin or mucosal inflammation caused by irritants in creams usually takes the form of redness, swelling of the labia minora, and superficial fissures (splits) in the skin around the vestibule. Irritative symptoms consist of pain and burning at rest as well as introital dyspareunia (painful sexual intercourse). Repeated irritant exposure can lead to allergic sensitization. Both irritant and allergic dermatitis are frequent causes of recurrent burning and are possible predisposing factors for recurrent vaginal infections or vestibulitis.

The first step in treating local reactions is to attempt to identify the causative agent and eliminate its use. If the specific agent cannot be identified, all known irritant agents must be stopped and, if needed, replaced by hypoallergenic nonirritating moisturizing preparations, such as Crisco and hydrophilic (water-holding) preparations. The behavior of self-treatment with over-the-counter anti-yeast products is believed to contribute to the development of vulvar dermatitis or vestibulitis. The treatment of suspected or confirmed irritant reaction symptoms includes local measures. Oatmeal colloidal soaks used several times daily are soothing. Treating with sitz baths and soaks argues the old adage "dilution is the solution to pollution." Ice packs may be used liberally. Frozen peas come in packages that can be placed on the vulva, providing a safe, convenient form of ice pack. Milk compresses are sometimes used with success. A mild steroid (1%) ointment in petroleum may be used sparingly. An aqueous, 4% Xylocaine solution (not viscous) also may be used to numb the area. The Xylocaine solution is not irritating and the patient does not become sensitized to it.

Dermatosis

All vulvar diseases that are chronic skin conditions, whether or not they cause symptoms, are grouped into the category of non-neoplastic vulvar diseases called dermatoses. These include ulcerative conditions, abscesses, hair follicle disorders and myriad others. Vulvar dermatoses do not include new growths such as cancer, pre-cancer, warts, and tumors. Dermatoses that affect the vulva may be found elsewhere on the body as well; for example, lichen sclerosus, which has a predilection for the vulva, is found on the back or arms thirty percent of the time. Similarly, lichen planus is a vulvovaginal dermatosis that also may be found on the arms and legs, or in the mouth and vagina.

Lichen Sclerosus

Lichen Sclerosus (LS) is the most common vulvar dermatosis. LS is not a new growth, but an epithelial or skin disease. LS may affect children and young adults, but most commonly affects post-menopausal women. I have treated LS in children as young as five months and in women in their late eighties and nineties. Regardless of age, patients who have LS will show some or all of the following signs: atrophy (thinning of the skin), white patches of skin, thickened areas and red-dark areas that appear to be a bruise. The vulvar skin typically exhibits marks indicating that skin has been scratched away (excoriation) or thickened areas resulting from rubbing. The most common complaints of LS patients are itching, burning, and painful sexual intercourse.

LS patients may have introital dyspareunia when the midline structures of the introitus (opening of the vagina) fuse, or if the introitus has lost its elasticity. Superficial mucosal

See DERMATOLOGY, page 7

Dermatology

(from page 6)

erosion and frequent fissuring occur with sexual intercourse or other physical activities and produce burning or outright pain when the area is touched. Fifteen percent of patients with LS have vulvodynia symptoms at initial examination. If left untreated, LS can result in fusion of the skin around the clitoris; atrophy and splitting of the vestibule; severe narrowing of the vaginal opening; and, rarely, cancer of the vulva.

The patient examination must include a thorough search for islands of thickened skin or ulcers. Such areas within skin affected with LS may harbor coexisting abnormal cells that may be the first sign that cancer is developing. These areas must be biopsied. Even though LS is classified as a dermatosis, any of the vulvar dermatoses that cause chronic irritation may predispose to the development of vulvar cancer, but the risk is small with proper care.

The treatment of LS no longer requires testosterone. Testosterone propionate, the mainstay of therapy for 30 years, has been replaced by clobetasol dipropionate. Clobetasol is clearly the drug of choice for patients with LS. This very potent corticosteroid is used in thin applications twice daily for one month, then daily for two weeks. Clobetasol ointment is used for maintenance therapy after symptoms are under control. This medicine is so effective in treating LS that failure of Clobetasol to stop LS occurs in only 10 percent of patients. Flare-ups may signal overuse of the medicine, yeast overgrowth or areas of abnormal cells (mentioned above). Failure of Clobetasol to control LS may necessitate the injection of cortisone-like medicines into the LS skin. Surgery and laser are not acceptable treatments unless sexual intercourse is painful due to LS, or if the patient begins to develop abnormal cells in areas of LS. The outlook for control of symptoms in patients with LS is excellent, but the condition must be treated over time (as with any dermatosis), until a cure is found.

Lichen Planus

Lichen planus (LP), another dermatosis, can appear in several forms, the most distressing of which for women are erosions in the mouth, vestibule and vagina. LP may appear as a red tender spot on the inner labia minora or vestibule, a visible white lesion, a small rash, or a purple rash. Vulvovaginal LP rarely presents as the typical violet color, as it does on the flexor surfaces of upper extremities, or on the penile shaft. When it involves the hair-bearing skin of the vulva, the condition causes itching and a lesion that forms plaques. LP is likely when accompanied by "sore spots" of the mouth and a violet rash on the wrists or legs. The diagnosis of LP is often not even considered by clinicians if no oral or skin lesions accompany other vestibular and vaginal symptoms such as painful intercourse or a persistent yellow vaginal discharge. Over 70 percent of our patients with LP are between 30 and 60 years of age, but it can occur at any age.

LP is a cell-mediated immune response of unknown origin, i.e., an autoimmune disease. Vulvovaginal lichen planus, either on the hairy areas of the vulva (where it causes itching) or in the vestibule or vagina (where it causes burning and pain with sex), is seen in approximately one percent of all new patients at our clinic. Approximately five percent of our patients between 30 and 60 years of age who are seen for a persistent yellow-sticky discharge have vulvovaginal lichen planus. LP may also be subtle and easily mistaken for vestibulitis. LP is suspected when white, "lace-like"

See DERMATOLOGY, page 8

Johnson & Johnson Awards Educational Grant to NVA

The NVA Executive Board expresses its appreciation to Johnson & Johnson for its generous grant to support programs designed to educate the public and medical community regarding the diagnosis and treatment of vulvodynia. Among other programs, this grant will enable the NVA to exhibit at more medical conferences next year. We would especially like to thank Dr. Brinda Wiita, director of clinical affairs, Johnson and Johnson's Personal Care Products Division, for her commitment to our efforts.

Dermatology

(from page 7)

changes on the labial surface at Hart's line are seen with the colposcopy. In advanced cases, the vagina closes completely.

Topical and sometimes oral corticosteroids are used to treat vulvar LP. If marked erosion is present, clobetasol dipropionate or other high potency steroids may be used. Long-term maintenance with a low or mid-potency topical corticosteroid cream is required. Vaginal dilation and vaginal cortisone suppositories are used to keep the vagina open. Sometimes surgery is required to open the vestibule or uncover the clitoris. Supplemental estrogen, although seemingly indicated by the presence of thin vaginal tissue is not an essential ingredient of LP therapy unless estrogen-related atrophy coexists. Dapsone, griseofulvin, and cyclosporine may be useful in some cases of LP, but results are variable and these drugs can be dangerous. Persistence of the vaginal disease is the rule. With both lichen planus and lichen sclerosus, any thickened area or ulcer in the vestibule or vagina should be biopsied, because of the small risk of malignancy if the conditions are not adequately treated.

Atrophy

Vaginal or vulvar atrophy is a condition that primarily affects perimenopausal and postmenopausal women, but it can occur in women of all age groups. Atrophic vulvar and vaginal tissue is thinner, drier and less elastic than normal tissue. During menopause, atrophy is caused by the decreased amount of estrogens circulating in the body. Surgical removal of the ovaries, Lupron, Depo-Provera, eating and weight disorders, the postpartum period and lactation also may cause a decrease in estrogen and lead to vaginal atrophy with symptoms similar to vestibulitis. All of these produce regressive functional changes in the minor vestibular glands and vestibular mucosa (just as they do at the cervix and endometrium), resulting in painful sexual intercourse identical to "pure" vestibulitis.

During a pelvic examination, the physician must examine the walls of the patient's vagina to diagnose atrophy. A sample of vaginal cells or discharge that contains cells may be examined under a microscope to confirm the diagnosis. No blood tests are needed. Signals that atrophy may be present include thinning of vaginal lining; a pale, smooth or shiny appearance of vaginal lining; loss of elasticity of skin and vaginal walls; loss of fullness of labia and vulva; dryness of labia; and loss of vaginal moisture.

Because low estrogen levels cause vaginal atrophy, the most common treatment is supplemental estrogen, either as a cream, pill or patch. Lubricants or moisturizers may also be helpful. In some cases, another medical condition (e.g., bulimia) has caused atrophy and must be addressed.

Conclusion

Careful differential diagnosis of vulvar symptoms is the key to successful treatment. Dermatitis reactions, vulvar skin dermatoses and atrophy are the main dermatological conditions that should be ruled out before a diagnosis of dysesthetic vulvodynia or vestibulitis is considered. ■

Dysesthesia

(from page 4)

relations should be limited until pain is controlled. The patient also should be counseled to avoid known sources of inflammation such as scents, dyes, chemicals, and other substances that might cause irritation when in contact with the skin; to wear loose, comfortable clothes; and to avoid thong underwear and biking. The daily use of mini-pads should be curtailed for both chemical and mechanical reasons. (If secretions are a problem, women should be advised to change their underwear as often as necessary.) Hydration through sitz baths in comfortably warm water is a mainstay of any vulvar care.

If any orthopedic, neurologic, dermatologic, or urologic findings are contributing to the pain, the patient should be treated or referred, as appropriate. Physical therapy with a focus on the back or pelvic floor also may be helpful. Topical anesthetics such as EMLA cream or lidocaine may be of value. If the patient experiences frequent recurrences of herpes simplex or an active outbreak of the varicella zoster virus, herpes suppression is important. However, acyclovir alone will not relieve vulvar dysesthesia. Any vaginal atrophy should be treated with topical estrogen; even breast cancer patients are now permitted to use the vaginal estrogen ring by many oncologists.

The tricyclic antidepressants have proven useful in managing VDY. Whereas amitriptyline was the tricyclic originally used for neuropathic pain, nortriptyline appears to offer equal efficacy, is less

See DYSESTHESIA, page 9

Dysesthesia

(from page 8)

sedating and has fewer anticholinergic side effects such as dry mouth, constipation, and palpitations. However, if one tricyclic is not helpful, others should be tried, e.g., desipramine, imipramine, doxepin. The dosages are the same for all tricyclics (20 to 150 mg daily).

Unfortunately, besides taking weeks to work, tricyclics work unevenly, so that "good days" and "bad days" are common. The leading reasons for failure are an inadequate dosage over too short a period of time or an intolerance of side effects. If the patient fails to improve after three months of therapy at a daily dosage of 100 to 150 mg, another agent should be tried. Tricyclics are contraindicated in patients with urinary retention and glaucoma. Caution is advised in patients with cardiac arrhythmias. Tricyclics potentiate selective serotonin reuptake inhibitors (SSRIs) such as Prozac and Paxil; when a patient takes both an SSRI and more than 50 mg. daily of a tricyclic, monitoring of drug levels may be necessary. Tricyclics also are sun sensitizers, so patients should be advised to avoid prolonged exposure to sunlight.

When the tricyclics are not helpful, anticonvulsants may be tried instead. Although carbamazepine and Dilantin originally were used for VDY, the drug levels and monitoring of blood chemistries that are required make them less attractive alternatives than the newer anticonvulsant, gabapentin (Neurontin). The preferable initial dosage of gabapentin is 100 mg daily at bedtime and it may be increased by 100 mg every two days. Side effects can be minimized by beginning with a low dosage and increasing the amount gradually. If the drug is well-tolerated, doses as high as 3600 mg daily may be used if necessary. Gabapentin lacks the anticholinergic side effects of the tricyclics and is preferred by physicians because of its favorable side-effect profile. It may produce sedation, dizziness, and ataxia in certain patients, but some of the side effects, e.g., sedation, may be transient.

Once an effective dose of either the tricyclic or anticonvulsant is achieved, it usually is maintained for several months, then gradually tapered in weekly decrements. Some women are not able to remain comfortable off the medications, most of which are safe for long-term use. However, gabapentin must be discontinued during pregnancy. While the tricyclics have not been linked to birth defects, the avoidance of all medications during the first trimester is advised. Consequently, many women taper their medication once they begin trying to conceive.

Acupuncture, massage therapy, and stress management often are helpful adjuncts in managing vulvar pain. Pain clinics also may provide valuable consultation, although few are experienced with VDY. Contrary to popular belief, opioids may be helpful in the management of neuropathic pain. The risk of drug addiction in a general medical population without a history of drug abuse is likely to be very low.

Conclusion

The diagnosis of VDY is largely a diagnosis of exclusion, complicated by the fact that the condition often mimics other entities such as vaginitis and urinary tract infections. Management consists of education and counseling, the elimination of chemical and other irritants, treatment of any underlying disorders, and medical therapy with tricyclics or anticonvulsants when necessary. VDY should be regarded as a chronic pain syndrome and treated accordingly, with an emphasis on a multidisciplinary approach and improvement in symptoms rather than single interventions and a "cure."

References

Harlow, B. Prevalence and predictors of chronic lower genital tract discomfort. *Am J Obstet Gynecol.* 2001 (in press).

King PM. Musculoskeletal origins of chronic pelvic pain. In: Obstetrics and Gynecology Clinics of North America. Philadelphia, Pa: WB Saunders; 1993:718.

Masheb RM, Nash JM, Brondolo E, Kerns RD. Vulvodynia: an introduction and critical review of a chronic pain condition. *Pain.* 2000;86:3.

Oaklander AL. The pathology of pain. *Neuroscientist.* 1999; 5:302.

Paavonen J. Vulvodynia—a complex syndrome of vulvar pain. *Acta Obstet Gynecol Scand.* 1995;74:243.

Portenoy RK. Opioid and adjuvant analgesics [syllabus]. New York: Beth Israel Medical Center, Department of Pain Medicine; September 23, 2000.

Travell JG, Simons DG. Myofascial Pain and Dysfunction: The Trigger Point Manual. Baltimore, MD: Williams & Wilkins; 1983. ■

News From The Support Corner

Illinois

In June, 11 women attended the first meeting of the new Chicagoland area support group. On August 1st, Dee Hartmann, P.T., a member of the NVA's medical advisory board, spoke to the group about the role of physical therapy in the treatment of vulvodynia. Going forward, meetings will take place on the first Wednesday of every other month at 7p.m. There is a suggestion box at every meeting and future topics will include sexual intimacy, among others. The goal of the group is twofold: to share information and to provide emotional support. For more information, please e-mail pampatfish@aol.com.

Maryland

A support group will begin meeting in late September 2001 in the Baltimore area. For more information, please e-mail Chris@nva.org.

North Carolina

A new NVA support group is currently being formed in Central/Eastern North Carolina. Meetings will take place in Raleigh on a weeknight once a month. If you would like to receive e-mail notices about this group, please e-mail annesiegel@cs.com.

Wisconsin

Members of the Wisconsin Vulvodynia Support Group contacted a health team reporter in Madison, Wisconsin, who subsequently featured vulvodynia on the local television news. It was a very effective piece and generated more calls to the station than they had ever experienced. The reporter also did a follow-up article in the publication *Wisconsin Woman*. Many thanks to Caroline More and Jane Elmer for coordinating this publicity effort! ■

LETTERS TO THE EDITOR

Dear Editor:

I have been coping with moderate to severe dysesthetic vulvodynia for 10 years. After trying a few antidepressant medications (e.g., Desipramine, Effexor) that did not provide relief, I found some relief with the anticonvulsant Tegretol (900 mg. daily).

For reasons that I do not understand, the degree of pain fluctuates. Most days I still have discomfort but am able to "distract myself," but some days the pain is so severe I can't sit or even concentrate enough to read. For those days, my pain specialist prescribed Dilaudid (2 mg.), an opioid that is rarely used by most physicians because of its reputation for being addictive. Within 40 minutes of taking the medication, the pain disappears and I feel like a normal person again. The main side effects are drowsiness (I would not recommend driving!), constipation and urinary retention. When I've decided to "tough it out," instead of taking Dilaudid, I've regretted it. Properly used, Dilaudid breaks the pain cycle and after a few days, I'm happy not to need it anymore.

My advice to others whose physicians have not adequately addressed their pain is to find a chronic pain specialist. To paraphrase the wonderful pain specialist that I've been seeing, "No one should have to live with pain."

Sincerely,
Bethany Maxwell

Dear Editor:
I've had some type of vulvodynia since my late teens and underwent several surgeries for endometriosis and vulvar vestibulitis as well. My vulvodynia became much worse five years ago when I had a bacterial infection that was misdiagnosed. The infection went untreated for almost four weeks, and left my vulvar area raw. The pain was so bad I couldn't sit or sleep at night for three months. Unfortunately, I was in a city that did not offer good health care, so I tried acupuncture to relieve the pain. It actually helped me through the worst of it. Fortunately, we moved to another city and I found a doctor who was dedicated and willing to work with me. He discovered that some of my vulvar tissue had actually fused together and was able to correct it without surgery.

The reason I'm writing now is to tell your readers that in the past four years I've had two babies. I was afraid that being pregnant would make things worse, but it actually made me feel better. I never had any vulvar pain with my pregnancies, and even felt fine after two vaginal deliveries. When I'm not pregnant, I still have minor burning every once in a while, but it is very mild. Five years ago I thought I would never be able to have sex, yet alone have children, and now I'm thinking about having my third child. After going through the suffering that I went through, I believe that there is hope for everyone!

Sincerely,
Elaine Jefferson

Vulvodynia Receives National Coverage

In the past six months, vulvodynia has been a topic on several television shows such as *Oprah, Sex and the C*ity (HBO), and *Strong Medicine* (Lifetime), and received coverage in at least six major newspapers across the country. The response to this publicity has been overwhelming. Following the discussion of vulvodynia by Drs. Jennifer and Laura Berman on *Oprah*, the NVA's Website received an unprecedented 10,000 "hits" within one month. This occurred in spite of the fact that the NVA's information and Website address were not provided on the show; thousands of viewers managed to find us even though they weren't sure how to spell the word!

A few months later, we were taken by surprise when the season premiere of HBO's *Sex and the City* dealt with vulvodynia. In keeping with the show's typical lighthearted approach to serious subjects, the disorder was treated frivolously, but the episode still managed to spread the word. The next morning, vulvodynia was one of the main subjects discussed around the water coolers of America. People wanted to know if it was a real condition and how it was treated. In the episode, a gynecologist suggests to one of the main characters (Charlotte, played by Kristin Davis) that she might have vulvodynia and that she should "take an antidepressant for her vagina" and "keep a vaginal journal." Of course, at lunch the next day her friends are incredulous at the notion that her "vagina is depressed."

When contacted by the NVA, *Sex and the City's* publicist said that Charlotte's condition was not vulvodynia and consequently would not be a continuous storyline. The huge number of inquiries the NVA received after the episode supports the position that any publicity, accurate or not, can help to spread awareness. Within two weeks, newspapers across the country reported on what it's really like to have vulvodynia, as opposed to *Sex and the City's* portrayal of the condition; these newspapers included the New York Daily News, Chicago Sun-Times, Chicago Tribune, and Pittsburgh Post Gazette. The NVA is grateful to volunteer publicist Laura Newman for writing the NVA's press release and capturing the interest of so many newspaper reporters.

On the local level, this past March a television station in Madison, Wisconsin covered vulvodynia in the health portion of its evening news. A vulvar pain sufferer was interviewed and viewers were directed to contact the NVA for further information. The Channel 15 reporter, Karyn Odway, followed up the coverage with an article in the July 2001 issue of *Wisconsin Woman* magazine. The NVA thanks volunteer Caroline More for spearheading the Wisconsin campaign.

On the heels of this national and local publicity, the NVA is soliciting the help of volunteers to continue approaching newspapers, magazines, and television shows to feature stories on vulvodynia sufferers. At this time, we have been informed that vulvodynia will be covered in Redbook magazine's November issue and Marie Claire's December issue. If you have any media contacts that could help with this effort, please send an e-mail to mate@nva.org. ■

A SPECIAL THANK YOU

Since its inception in 1994, the NVA has relied on private donations. We are grateful to all our donors, but are especially indebted to Mona Schlossberg, who always understood the need for patient advocacy organizations. When Mona heard that we wanted to exhibit at the American College of Obstetricians and Gynecologists' annual meeting in Chicago this year, she stepped forward to help fund our booth. Once again this summer, she made yet another generous donation to the NVA for both research and operating expenses. On behalf of all women who have benefited from our services, we express appreciation to this compassionate woman.

THE NVA NEEDS YOUR CONTRIBUTION

I WANT TO SUPPORT THE NVA AND RECEIVE MORE INFORMATION ON VULVODYNIA.

Name _____

Address _____

_____

Phone (H) _____ (O) _____

The NVA needs the support of everyone: patients, families, and health care providers.

❑ $35 ❑ $50 ❑ $100 ❑ Other $ _____

❑ $60 Health Care Professional

❑ Yes, I would like to be contacted by other NVA supporters in my area.

❑ No, I do not want to be contacted. Please keep my name confidential.

Please send your check or money order, payable to NVA, together with your name, address and telephone number to: NVA, P.O. Box 4491, Silver Spring, Md. 20914-4491.

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NATIONAL VULVODYNIA ASSOCIATION

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