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NVA News

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Observations on Patients With Vulvar Vestibulitis

By William Ledger, M.D.

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As an obstetrician-gynecologist interested in infectious disease, I have had the good fortune to work with the brilliant laboratory investigator, Dr. Steven S. Witkin. This was a fortunate pairing because, over the years, he has provided up-to-date laboratory technology to determine the infectious, immunologic, and hereditary etiology of vulvar vestibulitis, a poorly understood syndrome which negatively impacts the quality of life of so many American women. As we have assessed individual patients and reviewed the literature over the past two decades, we have been struck with the resemblance of the published clinical studies of this syndrome to the description of the assessments in the Asian Indian legend of The Seven Blind Men and the Elephant. (In the legend, each blind man describes the elephant differently.) A wide variety of etiologies and treatments have been advanced, all partly right, but none that encompasses all aspects of this syndrome. Vulvar vestibulitis is a complex, multifaceted syndrome. Because the key to successful treatment of any disease requires exact knowledge of its pathophysiology, it is little wonder that there currently are a wide variety of nostrums prescribed, all with high failure rates. Further scientific understanding of the syndrome should lead to better treatment outcomes.

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NIH Allocates $5 Million for Vulvodynia Research

On February 7, 2000, the National Institute of Child Health and Human Development and the Office of Research on Women's Health issued a request for research proposals on vulvodynia, stating that organizations may apply for grants of up to $200,000 per year for the next five years. Depending on how many proposals are approved, up to $1 million dollars could be awarded as soon as this fall. This request for proposals is titled, "*Pathophysiology, Epidemiology and Treatment of Vulvodynia,*" and can be viewed at http://grants.nih.gov/grants/guide/rfa-files/RFA-HD-00-008.html.

In response to this long-awaited announcement, the NVA contacted researchers currently engaged in the study of vulvodynia, and urged them to submit a letter of intent to the NIH prior to the March 15 deadline. Completed proposals are due by May 5, 2000 and actual funding of selected proposals could begin as early as September 29, 2000. The NVA appreciates Senator Tom Harkin's longstanding dedication to women's health issues and recognizes him for the critical role he has played in promoting federal funding of vulvodynia research.

LETTER FROM THE EXECUTIVE DIRECTOR

Dear Friend:

In recent months, there have been several exciting developments that promise to have a significant impact on the lives of women with vulvodynia. In February, the NVA was contacted by Dr. Estella Parrott of the National Institute of Child Health and Human Development (NICHD), with the wonderful news that NICHD and the Office of Research on Women's Health had jointly announced a request for proposals on vulvodynia (see article, page 1). At long last, the NVA has attained one of its majors goals, *federal funding for vulvodynia research.*

Following the celebration of this news, the NVA received an important phone call from Donna Leyens, a past leader of the New York City support group. She informed us that there had been a segment on New York City's ABC-TV local evening news featuring breakthrough research on vulvar vestibulitis by Drs. William Ledger and Steven Witkin. Briefly, this is the first research to find that vulvar vestibulitis in some women may be genetically caused (see article, page 1). This finding may lead to an entirely new avenue of treatment for these patients.

The NVA is pleased to welcome Howard Glazer, Ph.D., and Justin Wasserman, M.D., to our medical advisory board. Dr. Glazer, a neurophysiologist and clinical psychologist, developed surface electromyography-assisted pelvic floor muscle rehabilitation for the treatment of vulvovaginal pain disorders. He practices at the New York City Center for Vulvovaginal Disorders and is a clinical associate professor in the Department of Obstetrics and Gynecology at New York Presbyterian Hospital. Dr. Justin Wasserman is board certified in physical medicine and rehabilitation, and specializes in the treatment of chronic pain conditions. He is associate medical director of Pain and Rehabilitation Medicine, a private practice in Bethesda, Maryland. Both Drs. Glazer and Wasserman, in addition to writing articles for the last edition of the *NVA News,* recently volunteered their time to speak to our Washington, D.C. area support group. They bring valuable areas of expertise to our medical advisory board and we look forward to working with them.

Harriet O'Connor, director of support services, and I want to express our deep appreciation to the 90 compassionate women who currently serve as volunteer contact leaders in their geographic regions. These leaders are located all across the United States and Canada, and six other countries. With few exceptions, they have volunteered to help others at a time when they too have been in distress and pain. We are impressed by the large number of women who have indicated their willingness to fill these positions should a replacement be needed. As a source of information, contact leaders are unequaled. In addition to providing emotional support to individuals, they have helped the NVA develop an ongoing list of health care providers who treat vulvodynia. Many leaders also keep us informed by sending in local newspaper and health newsletter clippings on vulvodynia and related topics. Our heartfelt thanks to all past, present, and future contact leaders!

Finally, I would like to offer a personal thank you to Christin Sanders, our Baltimore area contact leader. In the midst of planning her July wedding, she has taken on the task of fund-raising for the NVA. Chris has written three excellent project proposals which we will be submitting to foundations and corporations that are specifically interested in women's health.

With best wishes for a healthy summer,

Phyllis Mate

Vestibulitis

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As infectious disease observers and novices in the complexities of vulvar disease, Dr. Witkin and I began to evaluate patients with this disorder in the early 1980s. There was no shortage of patients. New patients were desperate for relief and were, in fact, experienced seekers of care who had migrated from one doctor's office to another, from one specialty to another, with visits to gynecologists, infectious disease specialists, urologists, dermatologists, and psychiatrists. These were then and remain now frustrated women. They had been misinformed by doctors in most cases, mistreated in many, and dismissed by some as having no vulvar disease, because the physicians did not recognize this syndrome. In my initial interview encounters, a number of common historical themes became apparent. The patient's symptoms usually began with a specific event, often local, such as a severe Candida vulvovaginitis. The difference for this population was that the vulvar symptoms did not disappear. There were interesting variations. A number of patients related the onset of vulvar inflammation and pain to distant events, such as cesarean section, abdominal hysterectomy, liposuction of the thighs, or colonoscopy. In these women as well, symptoms persisted. Seventy-five per cent of the first 220 patients evaluated with this syndrome exhibited excessive and persistent vaginal discharge.[1] All had been informed in prior physician encounters that they had a chronic vaginal yeast or bacterial infection, and all had been treated with scores of local vaginal creams and suppositories as well as systemic antibiotics and antifungal agents. Many had urinary frequency and urgency, but rarely had a positive urine culture.

For the past two decades, I have been perplexed by referring physicians' inability to make the diagnosis of vulvar vestibulitis. I never found this to be a difficult task if one is willing to examine the vulva. These patients have vestibular gland and vulvar point tenderness, easily elicited by the pressure of a cotton-tipped applicator. When I first began seeing these patients, I assumed the vulvar inflammation must be due to an infectious vulvovaginitis, and I did a compulsive infectious disease work-up that included a vaginal pH, a microscopic examination of vaginal secretions in saline and potassium hydroxide, and a vaginal secretion specimen dispatched to the laboratory for a culture to detect Candida and aerobic bacteria. The results of this simple office testing were surprising. All of these women had an inflamed tender vulva and 75

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For physicians to properly treat this condition, an understanding of its pathophysiology is essential.

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percent had an excessive vaginal discharge. Despite this, bacterial vaginosis was diagnosed in only one instance, trichomonas in none, and only 11.4 percent of the patients who had been told by physicians that they had a chronic vaginitis due to Candida were culture positive.[1]

This was our first exposure to the reality that the specificity of the diagnosis of Candida vaginitis by most practicing physicians is unacceptably low. This poor physician performance in diagnosis was confirmed again in a recent clinical study from Cornell, published in *Infectious Diseases in Clinical Practice*.[2] More important than this discovery, these culture findings made us disinclined to accept an underlying chronic Candida, bacterial, or protozoal infection as the cause of the vulvar inflammation and associated symptomatology. The results were particularly unequivocal with regard to Candida. A persistent vaginal yeast infection was not the cause of the unremitting symptomatology, because 88.6 percent of new patients were culture negative.

The absence of a major role for Candida in this patient population's symptomatology was further confirmed in the minority of women who were culture positive for yeast. Despite successful antifungal treatment, manifested by a negative post-treatment culture, only 16 percent had any symptom relief. (I might add that a 16 percent success rate is an acceptable figure for a placebo effect in clinical trials. Unfortunately, a 16 percent success rate has been posted for many vestibulitis treatment regimens over the years.) As a result, Dr. Witkin and I were soon convinced that longer and more intensive treatments for yeast or bacterial infections were not the answer.

In desperation, I sought out Dr. Witkin's advice regarding a non-infectious etiology of this disease. His next testing innovation was brilliant. Could a vaginal allergic reaction be involved?[3] The vaginal fluid of these patients was tested for IgE, the antibody associated with allergic responses, and positive test results confirmed a vaginal allergy in 19.5 percent of the patients tested.[1] This discovery of a vaginal allergic reaction modified my own history taking and subsequent therapeutic strategies in vulvar vestibulitis patients. As I added a new line of questioning, I became impressed with the frequency of patient descriptions of episodes of severe burning when antifungal creams or suppositories were introduced into the vagina, or steroid or hormonal creams were applied to the vulva. After careful assessment, we came to the conclusion that the common denominator in many of these cases was the presence of the preservative propylene glycol in these locally applied medications. For women with this history, I developed a philosophy of *less is better* and had the patient discontinue the use of local agents and added to the therapeutic mix, the prescription of an antihistamine. This did help many patients, but the complexity of vulvar vestibulitis continued to plague us because the treatment success with antihistamines was no greater in women who were vaginal IgE positive than in those who were vaginal IgE negative.[1] With mounting frustration, we continued our search for more specific etiologies.

At about this time, some of our patients had heard about the excessive urinary oxalate excretion theory of Dr. Solomons [4] and indeed, one patient reported complete remission of symptoms with diet and the use of a calcium citrate supplement. A number of women were tested, all but one had a positive test for urinary oxalates, and they were started on Dr. Solomons' regimen. Our experience with this therapeutic intervention was disappointing. I'll be the first to admit that I was not an enthusiastic proponent of this dietary intervention. I observed that patients hated the diet and lost weight, but not their vulvar pain. Most patients stopped the regimen after two or three months, with persisting vulvar symptoms. Our success rate (14.3 percent) would have been consistent with a placebo arm of any therapeutic intervention study.

Our next treatment option was operative care. For me, this was always the choice of last resort, because I don't believe any operation is minor, especially when it is impossible for me, the surgeon, to predict the outcome and I have seen in consultation, operative failures from other

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Osteoporosis: Prevention, Diagnosis and Therapy

In the United States today, 10 million people suffer from osteoporosis and an additional 18 million exhibit low bone mass, placing them at increased risk of developing the disorder. Of the 10 million already diagnosed, 80 percent are women. In response to growing concern about the prevalence of osteoporosis, in March 2000 the National Institutes of Health sponsored a conference which reviewed the latest research on osteoporosis and formulated future research directions.

What is Osteoporosis?

Osteoporosis is defined as "a disease characterized by low bone mass and structural deterioration of bone tissue, leading to bone fragility and increased susceptibility to fractures of the hip, spine and wrist." Primary osteoporosis refers to the form of the disease resulting from the human aging process, such as the bone loss that accompanies natural menopause or normal aging. Secondary osteoporosis refers to cases which have a cause other than the expected bone loss associated with aging. These causes include specific genetic, endocrine, gastrointestinal, connective tissue and bone marrow disorders, as well as long-term use of certain medications such as corticosteroids (e.g., Prednisone).

Risk Factors

There are many factors that increase the likelihood of developing osteoporosis. Even though the disorder is most prevalent among Caucasian post-menopausal women, it also occurs in other racial groups, younger women, and men. Risk factors include family history of osteoporosis, early menopause, malnutrition, sedentary lifestyle, small body build, smoking, and the long-term use of certain medications such as corticosteroids, anticonvulsants, and thyroxine.

Prevention

The average woman has acquired almost all of her bone mass by the age of 20. In addition to genetic factors, nutrition and exercise determine the amount of bone mass acquired. Vigorous, high-impact exercises such as gymnastics produce the greatest skeletal benefits. Nutrients required to build strong, healthy bones include protein, vitamins C, D, and K, calcium, magnesium, copper, zinc, phosphorous, and manganese. Unfortunately, surveys indicate that the majority of American children are not even receiving the recommended daily allowance of 1300 mg. of calcium.

To deliver long-term skeletal benefits, adequate nutrition and exercise must be sustained over the life span of the individual. Because many adult Americans live sedentary lifestyles, physical fitness levels have declined over the past few decades, contributing to the incidence of osteoporosis. Additionally, only 50 percent of American women currently meet the daily recommended intake of 1200 mg. of calcium and 400 I.U. of vitamin D.

According to medical experts, women experience the greatest bone loss five to seven years following menopause. During this time period, women can lose as much as 20 percent of bone mass. It is important to monitor bone mass and hormonal levels closely during this time period so that corrective steps can be taken before excessive bone loss occurs. Because of the accelerated rate of bone loss after menopause, many experts recommend that postmenopausal women increase their daily intake of calcium to 1500 mg.

Diagnosis

Often referred to as the "silent disease," osteoporosis does not usually produce physical symptoms until the bones have become so frail that they can fracture. There are currently no guidelines for bone density testing in the general population. The only group for whom testing is universally recommended are patients using corticosteroids for more than two months.

Bone density tests are non-invasive, painless, and take about five minutes. The most common body sites assessed are the hip, spine, and wrist. The hip is a preferred site of measurement because

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hip fracture can be a devastating outcome for many individuals with osteoporosis. The score on a bone density test is the number of standard deviations between a person's bone density and that of a normal thirty-five year old of the same sex. The World Health Organization has established the criteria for osteoporosis as at least 2.5 standard deviations below the bone density of a normal thirty-five year old of the same sex. (Osteopenia, or low bone mass, is 1 standard deviation below.) This score is widely used by physicians to decide whether intervention is necessary, but experts suggest that the diagnosis and treatment of osteoporosis should depend on risk-based assessments rather than solely on this test score.

Treatment

The first line of defense against osteoporosis is proper nutrition and weight-bearing exercise. In addition to total nutrition, 1200-1500 mg. of calcium and 400-600 I.U. of vitamin D are recommended. The preferred source of calcium is dietary, but if a supplement is necessary, calcium citrate is the easiest to absorb and less likely to cause constipation. For maximum absorption, calcium supplements should be divided into 2 or 3 daily doses and taken with a full glass of water. Calcium absorption is also facilitated by adequate intake of vitamins C and K, and the mineral boron.

For exercise to build bone mass, it must be weight-bearing. Whereas walking and swimming benefit general fitness, they do not combat osteoporosis and the resulting risk of fracture. Experts recommend weight-lifting exercises which build bone mass and strength, and improve balance as well. (A popular weight-training program is described in Dr. Miriam Nelson's book *Strong Women Stay Young*.)

Because estrogen replacement prevents further bone loss, the most well-established intervention for postmenopausal women with osteoporosis has been hormone replacement therapy. The protective effect of estrogen on bone mass lasts as long as hormone replacement is continued. Concern about the increased risk of breast and endometrial cancer associated with long-term hormone replacement therapy, however, has led to the development of other therapeutic alternatives.

The development of the selective estrogen receptor modulators (SERMs) is an important new area of osteoporosis research. The goal of these agents is to maximize the beneficial effects of estrogen on bone and to minimize or antagonize the harmful effects on the breast and endometrium. Raloxifene, a SERM approved by the FDA for the treatment and prevention of osteoporosis, has been shown to maintain bone mass and reduce the risk of vertebral fracture by 36 percent in clinical trials.

There is a great deal of public interest in natural estrogens, particularly the plant-derived phytoestrogens such as soy isoflavones. These compounds have weak estrogen-like effects and may be effective in maintaining bone density, although they have not been shown to reduce fracture risk. Before any conclusions can be drawn regarding phytoestrogen use in the treatment of osteoporosis, clinical trials with larger sample size and longer follow-up are needed to assess the efficacy and safety of these compounds.

The bisphosphonates represent an important nonhormonal approach to osteoporosis prevention and therapy. There is strong evidence that these drugs increase bone mass at most skeletal sites and significantly reduce vertebral fracture risk. Alendronate, a potent bisphosphonate marketed as Fosamax, has been shown to increase bone mineral density at the spine and hip, and reduce the risk of vertebral fractures by 30 to 50 percent. Fosamax was approved by the FDA five years ago for osteoporosis prevention and treatment. For prevention, 5 mg. daily is recommended; once a person has been diagnosed with osteoporosis, 10 mg. is the usual prescribed dose. To be effective, Fosamax must be taken first thing in the morning with a full glass of water, 30 minutes before eating or taking any other medication.

Psychosocial Impact

While there has been significant

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improvement in the clinical management of osteoporosis in recent years, little attention has been paid to the disorder's impact on quality of life. The existing literature is limited, but studies suggest that osteoporosis produces negative social and psychological consequences, especially in individuals with more than one significant fracture. These fractures often result in deformity and chronic pain, compromising physical activity and restricting participation in activities such as work and parenting. These limitations may lead to feelings of anxiety and depression, as well as low self-esteem.

Future Research

Research on osteoporosis prevention and treatment continues to proliferate. Maximizing bone mass in children, identifying genetic causes, developing assessments of fracture risk, and measuring the effectiveness of combination therapies are only a few of the major research areas currently under investigation. A promising new treatment for osteoporosis, parathyroid hormone, is also the subject of ongoing research. Unlike current therapies which work by reducing the rate of bone loss, parathyroid hormone actually stimulates bone formation.

Several researchers are investigating whether multiple therapeutic approaches provide an additive effect in the treatment of osteoporosis. For example, one study has shown that postmenopausal women on hormone replacement therapy who take 1200 mg of calcium daily experience less bone loss than women on hormone replacement therapy who take only 600 mg of calcium. Presently, studies are under way examining the combined effect of bisphosphonates and hormone replacement therapy. The goal of combination therapy is to obtain the best therapeutic outcome while minimizing both the dosage and adverse side effects of the individual medications.

With the aging of the baby boomers and heightened interest in medical disorders that disproportionately affect women, osteoporosis has become a major national health concern. Substantial amounts of money are being spent by the federal government and pharmaceutical companies on osteoporosis prevention and treatment. This research will likely lead to more effective therapeutic regimens within the next five to ten years.

DONATING STOCK TO THE NVA

Did you know that you can make a donation to the NVA using appreciated securities, including publicly traded or privately held stock and mutual funds?

The appeal of this method of giving is that the donor is entitled to take a charitable deduction for the full current value of appreciated securities held longer than one year, and is able to avoid paying the capital gains tax that would be due if the securities were sold.

If you have any questions about making this type of donation, please contact NVA Executive Director Phyllis Mate at 301-299-0775 or via e-mail at mate@nva.org.

PLANNING A MOVE?

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physicians. Over the years, a number of pre-operative, intraoperative and post-operative care components seemed to help these patients. After early failure, we did not select patients with constant vulvar burning, but only those who had pain with attempts at intercourse. Careful operative dissection, the use of thin hyporeactive sutures, and graduated use of vaginal dilators post-operatively after the sutures had been absorbed and before intercourse was attempted, all helped. These maneuvers in combination added up to 10 to 12 weeks of care. Although our success rate was high (83 percent) in this carefully selected group of patients, I found the failures resulted in inconsolable patients and this result was very disturbing to me. My own enthusiasm for operative intervention will be guarded until it is possible to scientifically identify candidates for successful operative care.

In the midst of these therapeutic meanderings, I began to do vulvar biopsies on women suspected of having an active vulvar Human Papilloma Virus (HPV) infection on the basis of staining the vulva with a dilute acetic acid solution. If the microscopic picture suggested an HPV infection, a DNA probe of the tissue was carried out to confirm the presence of HPV. If positive, treatment with vulvar injections of Interferon alpha 2 beta was performed with a technique described by Kent and Wisniewski.[5] For Infectious Disease afficionados, this therapeutic approach had all sorts of appeal. Our initial success rate, judged eight weeks after the last injection, was high, 10 of 13 (77 percent). It was a medical, not an operative approach, and more important, the vulvar anatomy in these young women after treatment, whether success or failure, was not altered. There were, however, problems with this approach. There was no patient who expressed enthusiasm at the prospect of 12 vulvar injections over a four-week period. In addition, a vulvar biopsy after the application of an irritating acetic acid solution in a young woman with an irritated vaginal entrance is no joy, particularly when the biopsy shows inflammation, but no evidence of an HPV infection. Another approach was needed. Once again, Dr. Witkin came to the rescue.

We were enthused about the interferon treatment approach, for it followed a more traditional infectious disease approach. A pathogen (HPV) was identified and then treated with interferon, a specific immuno-enhancing agent, to enable women to eliminate the virus and hopefully the vulvar inflammation. The problem was the necessity to use an invasive operative technique, an uncomfortable vulvar biopsy, to make the diagnosis. Dr. Witkin and his laboratory associates made available to me, a polymerase chain reaction (PCR) test for HPV. This was much more sensitive than the DNA probe tests then available and meant that I could detect the presence of HPV by applying a sterile swab to the vulva and placing the specimen in a solution to be evaluated in Dr. Witkin's laboratory. Candidates for interferon therapy could be identified without pain and as an added benefit, the PCR test could be employed post-treatment to test for virus elimination.

The therapeutic results were unexpected. The interferon treatment was highly successful in eliminating any traces of the virus by PCR testing of vulvar samples. Of the first 13 patients tested, 12 (92.3 percent) were PCR test negative for HPV eight weeks after the last injection. Unfortunately, the clinical response was much less dramatic. Only 5 of 13 (38.5 percent) were clinically improved. The large discrepancy from the 77 percent cure rate in the first study [1] was confusing.

At the same time, Dr. Witkin's laboratory was examining the role of genetics in HPV infection. Specifically, they were searching for polymorphisms (small changes) in genes that regulated the extent of inflammation. Our vulvar vestibulitis patients became part of this study, and to our great surprise, gave results very different from those of other women. The gene coding for the protein, interleukin-1 receptor antagonist (IL-1ra), a down-regulator of inflammation, is polymorphic and less than 10 percent of women have the allele (form) of the gene called 2,2 homozygotes. However, about 50 percent of the vulvar vestibulitis patients were IL-1ra 2,2 positive. It was already known that individuals with inflammatory bowel disease or lupus erythematosus who possessed

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the 2,2 allele had more prolonged and more severe inflammatory reactions than did women with these conditions who had other IL-1ra alleles. This suggested that women with the 2,2 form of the IL-1ra gene had a greater susceptibility to develop a prolonged inflammatory response and/or a more severe response. The IL-1ra polymorphism in women with vulvar vestibulitis was shown to be independent of their HPV status. These findings were recently reported in the *American Journal of Obstetrics and Gynecology.*[6]

Identification of this genetic variation in some women with vulvar vestibulitis provided a plausible mechanism for the observation of a chronic inflammation of the vestibule. Regardless of the event that triggered an inflammation in this region, women with the 2,2 IL-1ra allele were perhaps less able to stop the inflammation even after the trigger was no longer present. If confirmed in further investigations on larger numbers of women with vulvar vestibulitis, this genetic analysis will decrease the numbers of patients whose diagnosis remains idiopathic. In addition, it suggests possible new areas of intervention that specifically deal with the deficiency caused by this genetic allele.

Given these findings, what future direction should be taken to improve the quality of care for these women? There are a number of things that can be done. A starting point would be an emphasis upon increasing the accuracy of diagnoses of various vulvovaginal conditions, particularly vulvar vestibulitis, among practicing physicians. A number of trends in the past decade have diminished these office skills. NIH-sponsored studies of bacterial vaginosis, designed to determine its role in preterm labor and delivery, have noted a delayed laboratory diagnosis by Gram stain after the patient has left the office, rather than the immediate diagnosis by the physician in the office. In the United States, governmental regulations against office laboratory testing (known as the Clinical Laboratories Improvement Amendment) have caused many office physicians to give up the use of a microscope and there has been diminishing emphasis upon microscopy competence in medical schools and residency training programs in Obstetrics-Gynecology, General Internal Medicine, and Family Practice. Office microscopy and pH determinations provide valuable diagnostic information for the doctor and add a few minutes of contemplation about the patient's complaints while viewing the slides under the microscope. Since the majority of our patients with vulvar vestibulitis are mistakenly diagnosed with a chronic yeast vaginitis, this in-office emphasis upon immediate diagnosis should encourage physicians to be more focused on patients' vulvovaginal complaints.

Is this a mission for the NVA? I believe so. Pressure by the lay public in recent years has modified the provision of care for women in such areas as mammographic screening and the length of hospital stay for the post-partum patient. Why not for vulvar vestibulitis?

Finally, funding is needed from the National Institutes of Health, industry, and private sources to better understand the etiologies of this disorder and to carry out random controlled intervention trials to determine more appropriate future care. For physicians to properly treat this condition, an understanding of its pathophysiology is essential.

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SELF-HELP TIPS FOR VULVAR SKIN CARE

While you are seeking effective treatment for vulvar pain, here are some coping measures to relieve symptoms and prevent further irritation. Even when your symptoms are under control, these guidelines are recommended as a preventive strategy.

Clothing and Laundry
Wear all-white cotton underwear.
Do not wear pantyhose (wear thigh high or knee high hose instead).
Remove wet bathing suits and exercise clothing promptly.
Wear loose-fitting pants or skirts.
Use dermatologically approved detergent such as Purex or Clear.
Double-rinse underwear and any other clothing that comes into contact with the vulva.
Do not use fabric softener on undergarments.

Hygiene
Use soft, white, unscented toilet paper.
Use lukewarm or cool sitz baths to relieve burning or irritation.
Avoid getting shampoo on the vulvar area.
Do not use bubble bath, feminine hygiene products, powder, or any perfumed creams or soaps.
Wash the vulva with cool to lukewarm water only.
Rinse the vulva with water after urination.
Urinate before the bladder is full.
Prevent constipation by (a) adding fiber to your diet (if necessary, use a psyllium product such as Metamucil) and (b) drinking at least 8 glasses of water daily.
Use 100-percent cotton menstrual pads and tampons.

Sexual Intercourse
Use a lubricant that is water soluble, e.g., Astroglide.
Ask your physician for a prescription for a topical anesthetic, e.g., Lidocaine gel 5%.
(This may sting for the first 3-5 minutes after application.)
Apply ice or a frozen blue gel pack (lunch box size) wrapped in one layer of a hand towel to relieve burning after intercourse.
Urinate (to prevent infection) and rinse the vulva with cool water after sexual intercourse.

Physical Exercise
Avoid exercises that put direct pressure on the vulva such as bicycle riding and horseback riding.
Limit intense exercises that create a lot of friction in the vulvar area (try lower intensity exercises such as walking).
Use a frozen gel pack wrapped in a towel to relieve symptoms after exercise.
Enroll in a yoga class to learn stretching and relaxation exercises.
Don't swim in highly chlorinated pools.
Avoid the use of hot tubs.

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Chronic Pain in America

The majority of individuals with severe chronic pain describe their pain as "out of control," according to the "Chronic Pain in America" survey, conducted by Roper Starch Worldwide. This survey, sponsored by Janssen Pharmaceutica, the American Pain Society and the American Academy of Pain Medicine, interviewed 805 people reporting a chronic pain score of five or higher on a 1-10 point pain scale. In spite of the fact that many physicians specialize in pain management, this study found that 68 percent of people in the most severe chronic pain category had never been referred to a pain clinic or pain management physician.

Many chronic pain sufferers change doctors in their search for relief. Almost half of those interviewed had changed doctors at least once and 25 percent had switched 3 or more times. The primary reasons given by patients for changing physicians included their continued suffering (42 percent), physicians' lack of knowledge about pain (31 percent), and physicians' unwillingness to treat their pain aggressively (27 percent).

The survey results indicate that it takes time to get chronic pain under control. Forty-six percent reported that their pain was reasonably under control, but that it had taken more than a year to achieve relief. The more severe the pain, the longer it took to get it under control.

One of the goals of the survey was to determine the impact of untreated or uncontrolled pain on quality of life. According to the survey results, not being able to exercise or get a good night's sleep were problems for an overwhelming majority. The ability to work, socialize, and engage in sexual relations were also negatively affected (see chart). Furthermore, 25 percent of chronic pain sufferers reported feeling depressed.

The majority of patients reported that their closest family members and friends provided strong emotional support, helping them to cope with their pain. Sixty-three percent also felt that their doctors were supportive, while only 48 percent considered their employers supportive.

Impact of Chronic Pain on Quality of Life

Activity	% reporting
Inability to exercise	81
Difficulty sleeping	79
Lack of enjoyment of leisure activities	67
Inability to perform household chores	65
Interference with socializing	65
Difficulty walking	59
Interference with sexual relations	54
Difficulty concentrating	49
Inability to work	41

Self-Help

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Everyday Living

Use a foam rubber donut for long periods of sitting.

If you must sit at work, try to intersperse periods of standing (e.g, rearrange your office so that you can stand while you speak on the phone).

Learn some relaxation techniques to do during the day *(The Relaxation and Stress Reduction Workbook* by Davis, Eshelman and McKay or *The Chronic Pain Control Workbook* by Catalano and Hardin are recommended.

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 $ _____

❑ 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

P. O. Box 4491 ❖ Silver Spring, MD 20914-4491