

## Interferon and Surgery in Treating Vestibulitis *Questions and Answers with Jacob Bornstein, M.D.*

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*What are the possible causes of vulvar vestibulitis?*

I often feel that the more I deal with patients with vulvar vestibulitis, the less I know about the cause of this disease. Several theories have been suggested in the past as possible causes for this condition. Unfortunately, no theory has been substantiated so far. The truth is that we do not know--nor do we even have a clue about--the precise cause of vestibulitis.

Nevertheless, I use the following "working hypothesis" to help patients

understand their condition. I explain that the disorder may be the result of an inflammatory process that causes the nerve endings in the vestibular mucosa to become hypersensitive. I also emphasize to my patients that vestibulitis: a) is not an infectious disease; b) is not a psychological disease; c) is not contagious; and d) in most cases, is not going to disappear spontaneously.

It is amusing to note how new theories arise periodically, accompanied by passionate proofs to validate them. After time passes, all these long

forgotten "definite causes" of the disease are collected as, "The multiple etiologies of vulvar vestibulitis."

*How do you diagnose this disorder?*

I believe that confirmation, and especially dismissal of a diagnosis of vestibulitis, should be made only by a gynecologist with experience in diagnosis and treatment of vulvar disease. This is not because complicated procedures or techniques are involved; on the contrary, it is a "clinical" diagnosis that involves a physical examination only. But to correctly diagnose the condition, the clinician must be familiar with a very small, specific region hidden in the vulvar vestibule, the "sulcus" or fissure, located between the

*See VESTIBULITIS, page 3*

## NIH Invites Research Proposals

**O**n September 29, 1998, the Center for Population Research of the National Institute of Child Health and Human Development (NICHD) issued a Program Announcement entitled, "Vulvodynia-Systematic Epidemiologic, Etiologic or Therapeutic Studies." This comprehensive announcement invites institutions to submit research proposals on the prevalence, causes, or treatment of vulvodynia. The NVA has been working for the past two years to obtain funding for vulvodynia research from the National Institutes of Health (NIH) and this is an important step in that direction. The entire Program Announcement (PA-98-112) can be accessed through the NIH home page at <http://www.nih.gov/grants/guide/pa-files/PA-98-112.html>. The following excerpt summarizes the subtypes of vulvodynia and suggests possible areas of research.

*See RESEARCH, page 6*

### INSIDE

<i>NVA Support Areas.....</i>	<i>p. 2</i>
<i>NVA Awards Grant.....</i>	<i>p. 7</i>
<i>NIH Hosts Workshop on</i>	
<i>Pelvic Floor Disorders.....</i>	<i>p. 8</i>
<i>Letter to the Editor.....</i>	<i>p. 9</i>

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## Vestibulitis

(from page 1)

base of the labia minora and the vagina, surrounding the hymenal remnants. In order to expose this tissue, the labia should be stretched aside; pinpoint pressure with a Q-tip applicator should then be applied, to document the sensitivity. I

have seen many cases in which women with dyspareunia (painful intercourse) or apareunia (inability to have sexual relations because of pain) were told that their vulva was normal because the Q-tip applicator was applied a few millimeters away from that specific "sulcus."

mentation and biofeedback pelvic muscle training. (Penetration should be assisted by lubrication with K-Y Jelly or baby oil.)

2. Intravestibular interferon injections.
3. Perineoplasty (surgery).

If one of the above treatments does not provide relief, the application of another may prove more successful. The order of treatment carries no significance. I strongly dis-

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The National Vulvodynia Association is an educational, nonprofit organization founded to disseminate information on treatment options for vulvodynia. The NVA recommends that you consult your own health care practitioner to determine which course of treatment or medication is appropriate for you.

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*After the diagnosis is confirmed, what is the next step?*

Once the diagnosis of vestibulitis has been confirmed, patients usu-

***I am convinced that there is no one preferred method of treatment, but rather that the response of each patient ... is distinct.***

ally want an immediate solution to their pain. This is especially true if the diagnosis follows many years of misery, with the patient having tried all kinds of creams, suppositories, and promises, to no avail. In a previous edition of the NVA newsletter, the significance of reassuring the patient and referring her to a support group was discussed. My approach is to inform the patient about all currently available treatments and their approximate success rates, based on the experience I have obtained in treating more than 1,000 women with vestibulitis. Then I outline a program of treatment according to the patient's choice.

*What are the treatment options?*

Patients can start with one of three approaches:

1. A combination of low-oxalate diet with calcium citrate supple-

agree with the notion that it is best "to leave surgery to the last resort" or that "no treatment works after surgery." These ideas only cause patients premature despair. In my practice, I try to have available all the possible treatments for vestibulitis and to be aware of new developments. I am convinced that there is no one preferred method of treatment, but rather that the response of each patient to the various methods is distinct. Sometimes a patient hears about another for whom a specific treatment such as biofeedback or surgery was not beneficial, and prematurely concludes that she should avoid that treatment because it only leads to failure. These patients would be better served to keep an open mind until they un-

*See VESTIBULITIS, page 4*

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## Vestibulitis

(from page 3)

derstand the whole picture.

*Based on your experience, what is the success rate of the low oxalate diet and calcium citrate supplementation?*

Despite the enthusiasm for nonsurgical vestibulitis treatments, so far, long-term success rates have not been published by centers other than those of the original authors advocating these therapies. Recently, we compared the use of this regimen in two groups of vestibulitis patients. The first group of 20 patients was treated with the low-oxalate diet and calcium citrate supplementation; the second group of 20 followed the same regimen, but also took continuous oral doses of fluconazole (an antifungal medication). Initial results indicated a success rate of about 15 percent in both groups. This modest outcome still justifies, in my opinion, the use of the low oxalate diet and calcium citrate as a first line of treatment for women with vestibulitis.

*Why is interferon used in the treatment of vulvar vestibulitis?*

As in many other cases in medicine, the reason that interferon was introduced to the treatment is incidental. In 1988, the human papillomavirus (HPV) was considered the causative agent of vulvar vestibulitis. Indeed, in some women with vestibulitis, molecular biology techniques clearly demonstrated the presence of HPV genes in the vestibule. Consequently, interferon, an antiviral agent, was used in these cases with some success. Although the HPV theory of vestibulitis has not been substantiated,

interferon is still currently used, as it leads to a cure in about 30 percent of sufferers.

*How is interferon typically administered?*

The administration of interferon may be done either locally (injecting it into the vestibule) or systemically (injecting it subcutaneously in the arm). In both cases interferon should be given 9-12 times. Each injection causes flu-like symptoms such as high temperature, shivering, headache, malaise, and extreme weakness. We have shown that the systemic administration of interferon can lead to the same success rate as the local injections. However, after three years, more women who received the interferon systemically had a recurrence of the pain than those who received it locally. Therefore, we now prefer to administer the interferon locally.

*Is there a difference in the success rate of alpha and beta interferon?*

The type of interferon administered has only a slight significance. We have experience using all commercially available preparations of interferon, such as the various alpha and beta interferons. Beta interferon was discovered and initially synthesized in Israel. It is associated with fewer side effects than alpha interferon. Today, beta interferon is well-known for its favorable effects in the treatment of multiple sclerosis, as well as several infectious and neoplastic diseases.

*What are your short and long-term success rates with interferon?*

Our short-term success rate using

interferon is 25 percent. We have found, however, that about 50 percent of patients initially cured experience recurrence of the vestibular pain. They are given the choice of repeating the interferon injections or undergoing a different treatment.

*Do you ever use interferon after surgery?*

I use interferon in a few ways: as a primary treatment; after another treatment, including surgery, has failed; or in combination with surgery, whereby I remove the back part of the vestibule and inject interferon into the front tissue around the urethra. The rationale for the combined approach is to benefit from the high success rate of surgery, and at the same time avoid any accidental damage to the urethra and clitoris during surgery.

*How did you become a specialist in the surgical treatment of vulvar vestibulitis?*

My surgical training for performing perineoplasty in the treatment of vulvar vestibulitis took place in 1985-1987, at Baylor College of Medicine, Houston, Texas, under the guidance of Dr. Raymond Kaufman.

*Can you briefly describe the surgical procedure that you use?*

During the time I worked with Dr. Kaufman we introduced several modifications to the operation. Recently, I have described several additional "variations on the theme." Basically, during the operation all

*See VESTIBULITIS, page 5*

## Vestibulitis

(from page 4)

sensitive vestibular tissue should be excised. It is inadequate to remove only a small piece of tissue from the back part of the vulva. I have had women come to me with "surgical failures" where, in fact, the scope of the surgery was too limited. It is important to realize that in about 75 percent of women with vestibulitis, the sensitivity encompasses the anterior (front) vestibule as well as the posterior (back) vestibule, and that both parts should be examined and treated. Suturing the edges of the tissues back in the introitus (entrance to the vagina) introduces a second cause of "surgical failure." A sensitive scar may result which, when subjected to friction during intercourse, could become a new cause of pain to the patient, even after the operation. To avoid that condition, the vagina should be advanced quite a bit, to the halfway mark between the introitus and the anus. The cosmetic result is usually very satisfactory. Recently, several distinguished surgeons have advocated removing deeper structures of the vulva, the Bartholin glands, during the same procedure. These glands also may be involved in vestibulitis. Indeed, I have concluded that removing the Bartholin glands increases the success rate somewhat.

*What advice do you have for women who are afraid to have this surgery?*

I frequently hear and read of women warning others against surgery for vestibulitis. I find these cautions misguided, as there are

definitely women who have not found relief through nonsurgical procedures, for whom surgery might provide a cure. If the patient is an appropriate candidate, she should be encouraged to undergo surgery, rather than be discouraged. Obviously, surgery of the vulva should be carried out by an experienced surgeon. I usually supply new patients with the telephone numbers of my previous surgery patients who are willing to share their experience with other women still suffering from this unfortunate condition.

*What factors are associated with unfavorable surgery outcomes?*

In a recent study, we compared 19 cases of women for whom surgery failed (24 percent of patients operated on during a three-year period) with 60 patients (76 percent) who had experienced a successful outcome. We define "success" as a complete disappearance of pain due to sexual intercourse. We found that women who continued to have vulvar pain after the operation were those who had experienced constant pain of introital origin, and not only dyspareunia (painful sexual intercourse). We termed this type of combined pain "vestibulodynia." In addition, the operation was five times more likely to fail in women who had a prolonged period of pain, ever since their first attempt at intercourse, than in women with a "secondary" onset of pain. Also, the more severe the pain, the less chance the patient had for cure. For example, surgery was less likely to

bring relief to women who experienced pain on urination, caused by the touch of urine on the hypersensitive vestibule. These women should not be operated upon unless all other measures fail.

*When surgery does not lead to symptom relief, what do you recommend to these patients?*

I tell them that surgery is not the end of the road. These patients can be offered any other treatment that is used for vestibulitis patients prior to surgery, such as interferon, low oxalate diet and calcium citrate, or biofeedback. In many cases these treatments are very successful, even postoperatively!

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## Research

(from page 1)

### RESEARCH OBJECTIVES

#### Background

Although a number of focal pain syndromes of the urogenital area have been well described, they remain underrecognized and poorly understood. Vulvodynia, one of the types of focal pain syndromes in the female, is a complex, multifactorial, underdiagnosed clinical syndrome of unexplained vulvar pain, sexual dysfunction and psychological disability. An earlier controversy surrounding this group of disorders ranged from opinions questioning their existence to suggestions that they were of a purely psychosomatic origin. More recently, this has been largely counterbalanced by an extensive recent literature attesting to the organic nature of these disorders. At present, neither the prevalence nor the etiology of this enigmatic condition is accurately known. A specific secondary cause can usually be diagnosed in only a small minority of the patients experiencing the symptoms of vulvodynia. Only empirical treatment options are available at present. While cures are uncommon, some measure of pain relief can be achieved in nearly all patients using a multidisciplinary approach involving pain medications, local treatment regimens, physical therapy and psychological support. Medical management usually employs medication protocols designed to treat neuropathic pain and has been under-investigated to date. Pain management techniques such as biofeedback and behavior therapy have been reported in some instances to provide positive outcomes. Surgery involving invasive and often irreversible therapeutic procedures has been stated, arguably, to be the treatment option with the highest

success rate for certain subtypes of vulvodynia.

Vulvar pain syndrome (vulvodynia, burning vulvar syndrome) was first described as a syndrome at the end of the last century. Although more than a hundred years have passed in the interim, the cause(s) of the disorder remain(s) undiscovered. Several subtypes of vulvodynia have, however, now been recognized and identification of the distinct subset of patients presenting with vulvodynia has been stated to be a prerequisite for its successful management. The most common subtypes recognized are vulvar vestibulitis syndrome, cyclic vulvovaginitis, and dysesthetic vulvodynia.

Vulvar vestibulitis, thought to be the major subtype of vulvodynia, has been found in some studies to be present in as many as 15 percent of patients in a general clinical practice. Vulvar vestibulitis syndrome (VVS) characterized by severe, chronic pain on vestibular touch or attempted vaginal entry is thought to be the most frequent cause of dyspareunia in premenopausal women. Other frequently misdiagnosed vulvar or vaginal conditions which can also cause vulvodynia are vulvar papillomatosis, cytolytic vaginosis, lactobacillosis, and desquamative inflammatory vaginitis. In addition, many vulvar dermatoses can cause acute or chronic vulvar itching or pain, and are a frequent confounding problem in the differential diagnosis of vulvodynia. While studies have been reported that describe the histological abnormalities observed in patients with vulvar vestibulitis as the result of a chronic inflammatory reaction of the mucosa

of the vulvar vestibule, the cause of the latter remains unclear. Reports proposing a clinical role of urinary oxalates as nonspecific irritants, contact allergy, candidiasis or human papilloma virus (HPV) infection in women presenting with vulvodynia remain without consensus and are controversial.

#### Scope

Systematic epidemiologic, etiologic, and therapeutic studies of vulvodynia should be undertaken to better define its prevalence, establish diagnostic criteria for discriminating between its major and minor subtypes, elucidate its underlying pathophysiology, clarify its mechanism of pain and develop improved clinical therapy options designed to either cure it or alleviate its symptoms. Examples of hypothesis-driven research approaches that are encouraged include, but are not limited to:

- Conducting experimental pre-clinical or clinical studies in animals and/or humans, respectively, designed to evaluate the presence and extent of abnormal neurophysiological mechanisms that underlie inappropriate sensory and motor pathway activities associated with vulvar pain.
- Determining the role of neurogenic inflammation in vulvodynia, including vulvar vestibulitis.
- Evaluating whether there is widespread or regional autonomic dysfunction in patients presenting with vulvar pain.

*See RESEARCH, page 7*

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## Research

(from page 6)

■ Developing chronicity and inclusion/exclusion features/factors as criteria for refining the definition for and diagnosis of vulvodynia and its subtypes. A rigorous definition will permit uniform study design leading to comparability at the national and/or international levels of study.

■ Carrying out population-based epidemiology studies to define the prevalence of vulvar vestibulitis and other subtypes of vulvodynia. Conducting case controlled epidemiological studies to determine if a group at high risk of vulvodynia can be identified for prospective or interventional studies. Accomplishing population-based epidemiology studies that include psychological measures useful in defining the psycho-social component of vulvodynia.

■ Conducting well-controlled clinical studies of therapeutic protocols for treating vulvodynia in a well-defined population with rigorous inclusion/exclusion enrollment criteria. Studies might include multidisciplinary therapeutic trial designs involving medication, aerobic exercise, and cognitive behavioral therapy. For vulvar vestibulitis only, the use of surgical procedures for treating this disorder might be explored, especially with regard to both the roles of pre- and post-surgical interventions and surgical therapy outcomes.

■ Defining the vaginal microflora in patients with vulvodynia, including the role of past or present candidiasis, bacterial vaginosis, trichomoniasis, gonorrhea, chlamydia, herpes simplex virus (HSV) and/or human papilloma virus (HPV) colonization or infection. ■

## NVA Awards Grant and Establishes Research Fund

In August 1998, the National Vulvodynia Association (NVA) awarded a \$6,000 research grant to Dr. David Foster, associate professor of Obstetrics and Gynecology, University of Rochester School of Medicine, Rochester, New York. For several years, Dr. Foster has been treating vulvodynia patients and researching potential causes of vulvar vestibulitis. This NVA research grant was awarded to further his study of the neuro-inflammatory mechanisms of vulvar pain.

Dr. Foster's research will compare the vestibular tissue of vulvar vestibulitis patients with that of asymptomatic women who underwent vaginal surgery for other reasons. He is systematically studying two major physiologic responses within the body: the cytokine system that mediates inflammation and the neurokine system that mediates pain. To date, Dr. Foster has found that women with vulvar vestibulitis demonstrate elevated cytokines in their vulvar tissue. The ultimate

goal of this research is the development of specific therapies which would interfere with the cytokine-neurokine pathway, thereby reducing the level of vulvar pain.

The funds for this grant were donated by a longstanding NVA supporter who specifically requested that her gift be earmarked for research. To encourage similar donations, the NVA executive board has decided to establish a research fund for contributions greater than \$500 that have been designated for this purpose. Ninety percent of these donations will be used to award grants to vulvodynia researchers; the remaining 10 percent will be used to defray the NVA's operating costs. As with any other gift to a 501(c)(3) organization, these donations are tax-deductible. If you want to make a contribution to the research fund, please contact NVA Executive Director Phyllis Mate at 301-299-0775 (or via e-mail at [matenva@graphcom.com](mailto:matenva@graphcom.com)). ■

### SUPPORT 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 ([matenva@graphcom.com](mailto:matenva@graphcom.com)).

## NIH Hosts Workshop on Pelvic Floor Disorders

On September 28<sup>th</sup> and 29<sup>th</sup> 1998, the National Institute for Child Health and Human Development (NICHD), in conjunction with four other National Institutes of Health (NIH), sponsored a multidisciplinary meeting of 50 medical experts to lay the groundwork for development of a research agenda on pelvic floor syndromes. Urologists, obstetricians, gynecologists and neurologists specializing in disorders such as urinary incontinence, pelvic organ prolapse and pelvic pain shared their knowledge and discussed some of the problems facing clinicians and researchers in the field.

In recent months, several NIH officials have expressed their commitment to expanding knowledge in this area, as was evidenced by the opening remarks made at the workshop. "During the past three years the NIH has acknowledged the importance of creating a comprehensive program on pelvic floor dysfunction," began Dr. Florence Haseltine, director of the Center for Population Research in the NICHD. She further explained that the aging of the current U.S. population necessitates a greater focus on pelvic floor disorders, the majority of which are associated with aging in women. Following Dr. Haseltine's comments, Dr. Duane Alexander, director of the NICHD, told workshop participants that their ultimate goal would be to assist NIH in prioritizing areas for future research funding.

### **Starting from Scratch**

A recurring theme throughout the meeting was the inadequacy of current medical knowledge in this field.

Participants expressed the need for basic research on the neurophysiology and musculoskeletal structure of the pelvic floor; they also recommended further investigation into the specific effects of hormonal changes on pelvic floor functioning.

Dr. Charles Paidas, a pediatric surgeon from Johns Hopkins University, illustrated the need for basic research during his presentation on the pelvic development of the fetus. His recent research suggests that the medical textbooks currently in widespread use are largely incorrect in their description of fetal pelvic development. Dr. Paidas made the compelling point that physicians cannot fully understand pelvic floor dysfunction without first knowing the normal evolution of pelvic development.

Several other physicians agreed with Dr. Paidas' concern, pointing to the lack of research on pelvic floor changes in the average woman as she ages. Others remarked that medical science provides little information regarding the changes in the pelvic floor during pregnancy and childbirth. The consensus was that it is difficult to identify and treat abnormal pelvic functioning, without sufficient knowledge of what is "normal."

### **Urinary Incontinence**

One of the most common pelvic disorders, and certainly the most widely publicized, is urinary incontinence. This disorder occurs about twice as frequently in women as it does in men. Prevalence statistics for this condition vary, depending upon which study is cited. Dr. Veronica Mallet, director

of the Continence Center at Wayne State Hospital, Detroit, Michigan, stated that in various studies, the prevalence of the disorder in women ranged from 10 percent to 58 percent of the sample population. There is increasing prevalence with age, the largest number of cases occurring among women in their fifties and eighties. Stress incontinence, the most common type of urinary incontinence in women, refers to leakage of urine caused by an increase in abdominal pressure during activities such as coughing, laughing, or lifting a heavy object. The second most common type, urge incontinence, refers to the inability to postpone urination once the need to urinate is sensed.

Based on her review of the literature, Dr. Mallet enumerated the following risk factors for urinary incontinence: vaginal childbirth, pregnancy, hysterectomy, obesity, frequent cystitis, childhood enuresis, and smoking. Menopause also was mentioned, but Dr. Mallet commented that the research on the relationship between menopause and urinary incontinence was inconclusive. Dr. Mallet was followed by Dr. Jeannette Brown, Department of Obstetrics and Gynecology at the University of California-San Francisco, who focused on those risk factors which can be modified or prevented. Since multiple vaginal childbirths are the greatest risk factor for stress incontinence, Dr. Brown recommended that medical researchers study routine procedures during vaginal deliveries, such as the use of forceps and episiotomies. She also

*See PELVIC FLOOR, page 9*

## Pelvic Floor

(from page 8)

asserted that the length of the second stage of labor is an important variable to be studied. Many workshop participants emphatically agreed with Dr. Brown that research on childbirth practices be designated a major priority, adding that vaginal childbirths appear to be the greatest risk factor for fecal incontinence and pelvic organ prolapse as well.

Additionally, Dr. Brown recommended that researchers investigate whether the use of hormone replacement therapy in post-menopausal women can prevent urinary incontinence. If the depletion of estrogen contributes to a weakened urethra (thus reducing the resistance to urine flow), estrogen replacement could prove a useful preventive therapy in post-menopausal women.

### **Pelvic Organ Prolapse**

Based on data collected from the Women's Health Initiative, an ongoing NIH-sponsored longitudinal study of women aged 50-79, Dr. Susan Hendrix of Wayne State University Hospital assessed the prevalence of pelvic organ prolapse in 100,000 healthy, ambulatory women. Prolapse (a condition in which an organ slips out of place) typically involves either the bladder, rectum or uterus. Cases range from mild to severe, and may or may not be accompanied by symptoms such as difficulty with urination or defecation, or sexual dysfunction. Increased risk for pelvic organ prolapse is associated with multiple childbirths, as well as increasing age.

*See PELVIC FLOOR, page 10*

## LETTER TO THE EDITOR

Dear NVA:

I am personally interested in other women's experiences with the use of acidophilus. My doctor never recommended this approach and it is not a remedy I have seen mentioned in the many articles I have read on vulvodynia. About a year ago, my friend suggested that I try it. Acidophilus has been the single most consistently effective treatment for my symptoms. I cannot go a day without it or I experience severe flareups. I change the dosage daily depending on the severity of symptoms, and most of the time it provides relief.

I would be especially grateful if one of your medical board consultants would comment on why acidophilus might be effective in alleviating vulvar pain. My doctor shrugs his shoulders and says, "if it works, use it." But I'd like to know why it works. Thank you for your response.

Sincerely,  
Carolyn Piper

Dear Carolyn:

You asked why acidophilus helps your vulvodynia. There are many people, including myself, who believe that yeast can be a major component in vulvodynia. From this perspective, anything that helps to control yeast may also alleviate chronic vulvar pain. There are numerous over-the-counter antiyeast vaginal creams, but these medications often make symptoms worse and have on occasion even precipitated vulvodynia. In my practice, I have found that oral antiyeast medications frequently result in significant improvement. I usually prescribe the oral Nystatin tablets or powder. As an alternative, sometimes Diflucan is prescribed, but it may not be appropriate for long-term use because of its potential effect on the liver.

Acidophilus is a safe choice because it is a "good" bacteria that helps to control yeast. There are usually no unpleasant side effects. It is often available in capsule form and is sold in health food stores, as well as in some supermarkets and drug stores. Because it is considered a food supplement rather than a drug, it is not regulated as rigidly as medications. Consequently, the strength varies. I recommend that you follow the dosage instructions on the bottle. You may also find it helpful to decrease the sugar and refined carbohydrates (breads, pasta) in your diet.

Sincerely yours,  
B.J. Czarapata, CRNP

*(B.J. Czarapata is a nurse practitioner specializing in urinary dysfunction and vulvodynia. She practices in Rockville, Maryland, and is a member of the NVA medical advisory board.)*

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## Pelvic Floor

(from page 9)

Of the 100,000 participants in the Women's Health Initiative, cystoceles (bladder protrudes into vagina) occurred in 25 percent, rectoceles (rectum protrudes through anus) in 14 percent, and uterine prolapse (uterus protrudes into vagina) in 12 percent. Dr. Hendrix concluded

cause, i.e., essential vulvodynia or vulvar vestibulitis.

Dr. Turner then summarized the research priorities which emerged from the vulvodynia workshop. Because most vulvodynia treatments are based solely on anecdotal evidence, the con-

professor of neurology at the Johns Hopkins School of Medicine, described the different types of pelvic pain and noted three common characteristics of all pelvic pain disorders. First, the prevalence of these conditions is unknown; second, there are few significant findings upon physical examination of these patients; and third, the medical profession lacks effective treatments for these chronic pain syndromes.

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### ***[T]he aging of the current U.S. population necessitates a greater focus on pelvic floor disorders ...***

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from this data that pelvic organ prolapse, especially cystoceles, is quite common in aging women.

#### **Vulvodynia**

Dr. Maria Turner, NIH dermatologist and a pioneer in the treatment of chronic vulvar pain, presented the recommendations and research priorities proposed at the 1997 NIH workshop on vulvodynia. The first workshop recommendation discussed by Dr. Turner was the request that the International Society for the Study of Vulvovaginal Disease clarify the definition of vulvodynia. She pointed out that the lack of uniform terminology among physicians makes it impossible to compare research results. Dr. Turner explained that some physicians equate the term vulvodynia with "vulvar pain," thereby including bacterial infections, fungal infections, and vulvar dermatoses. On the other hand, many experts in the field use the term only in reference to chronic vulvar pain without identifiable

sensus was that controlled research on therapeutic outcomes is very important. One of the conclusions was that multicenter studies comparing the success rates of different pharmacological agents should be started. Additionally, a group of surgery experts recommended a prospective multicenter study to ascertain the results of surgery among patients with vulvar vestibulitis. Research on possible causal factors in vulvodynia was considered a high priority, especially investigations into the role of herpes simplex virus, human papilloma virus and chronic yeast infections. The workshop also highlighted the importance of basic science studies, particularly the development of animal models to delineate the neuropathic (nerve-related) pathways in vulvar pain. Finally, experts on pelvic floor dysfunction recommended the development of validated, standardized methods for evaluation of pelvic floor function in vulvodynia patients.

#### **Pelvic Pain Syndromes**

Dr. Ursula Wesselmann, associate

professor of neurology at the Johns Hopkins School of Medicine, dispelled the notion that chronic pain of the reproductive organs is unique to women. She summarized the treatment outcomes of male patients with chronic testicular pain, a neuropathic pelvic pain syndrome. Among 25 male patients treated for this condition at Johns Hopkins Hospital, opioids (e.g., MS Contin and methadone) and tricyclic antidepressants provided the most effective pain relief. Dr. Wesselmann compared the results of the male patients to those of 39 women treated for chronic pelvic pain. About 60 percent of the female patients experienced pain relief with opioid medication, but the majority did not respond to tricyclic antidepressants or anticonvulsants.

As with other pelvic floor disorders, there has been little research in this area. Dr. Wesselmann suggested that this lack of research is due to the absence of animal models and the difficulty in ascertaining the physiological processes that cause pelvic pain. In her concluding remarks, Dr. Wesselmann emphasized the urgent need for more research and the development of effective treatment strategies for chronic pelvic pain syndromes. ■

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## GENETIC LINK IN VULVODYNIA?

The goal of this survey is to evaluate whether vulvodynia has a hereditary component, by inviting women with vulvodynia and vulvar vestibulitis who have close relatives with the disorder (sister, mother, daughter, aunt or grandmother) to answer a questionnaire. By comparing the characteristics of a group of women with familial vulvodynia to a matched control group of vulvodynia patients without affected relatives, we hope to characterize the syndrome of familial vulvodynia and obtain ideas for future research. Knowledge derived from this survey may enable us to anticipate the probability of a sibling (or other close relative) developing vulvodynia or vulvar vestibulitis—and may ultimately lead to the development of preventive methods.

We also request that health care providers ask appropriate patients to consider enrolling in our survey. If you are willing to participate, please contact either of the following:

Dr. Jacob Bornstein,  
Dept. of Obstetrics and Gynecology,  
Carmel Medical Center,  
7, Michal Street, 34362, Haifa, Israel  
Tel: 972-4-8250597  
Fax: 972-4-8340548

Dr. Howard Glazer  
340 E. 63<sup>rd</sup> St., Suite 1A  
New York, NY 10021  
Tel: 212-832-0477  
howardg@idt.net

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## SUBJECTS NEEDED

Researchers at Johns Hopkins University are looking for volunteers to participate in a study concerning changes in pain perception over a 3-4 month period. You do not have to live near the university (Baltimore, MD) to be a subject in this study, i.e., correspondence can be done via mail or phone.

If you are between the ages of 18 and 45, are currently menstruating, are not pregnant, and have been diagnosed with either vulvar vestibulitis syndrome or essential vulvodynia for at least six months, you are an appropriate candidate for this research. **If you are currently taking birth control medication, you are especially needed at this time.** (Volunteers also are required for a control group consisting of women who **do not** suffer from chronic vulvar pain.)

If you are interested in participating, or want more information about this study, please contact Chris Sanders at Blaustein Pain Center, Johns Hopkins Hospital, at 410-614-5775 or via e-mail (clsander@welchlink.welch.jhu.edu).

Principal Investigator:  
Ursula Wesselmann, M.D.  
Asst. Professor, Department of Neurology, Johns Hopkins University

## HEALTH CARE PROFESSIONALS

The National Institutes of Health (NIH) has a limited number of manuscripts of the 1997 NIH Vulvodynia Workshop proceedings. The workshop's purpose was to develop a vulvodynia research agenda.

If you would like to obtain a copy of this manuscript, call 301-496-8176, state your name and address, and specify that you want the Vulvodynia Workshop publication.

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# 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.



NATIONAL VULVODYNIA ASSOCIATION

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