

## Differentiating Vulvodynia from Candidiasis *By Benson Horowitz, M.D.*

*Dr. Horowitz is Clinical Professor of Obstetrics and Gynecology at the University of Connecticut Medical School, and chairman of the vaginitis committee of the International Society for the Study of Vulvovaginal Disease. He has a private practice in Hartford, specializing in the treatment of vulvovaginitis and vulvodynia.*

Patients with vulvar pain, irritation, and erythema (redness), as well as abnormal vaginal discharge, can present diagnostic dilemmas for the majority of health care providers. Difficulties are occasioned by the similarity in signs and symptoms of the disorders of dysesthetic vulvodynia (constant vulvar burning)

and recurrent candidiasis, a common fungal (yeast) infection. Dysesthetic vulvodynia (hereafter referred to as vulvodynia) does not have characteristic signs and symptoms uniquely distinguished from recurrent candidiasis. The problem is compounded further by patient and clinician assumptions that everything that itches, burns, or is irritated in the vaginal or vulvar area is a yeast infection unless proven otherwise. Patients are labeled casually on the telephone and diagnoses are made without laboratory confirmation. In addition, a correct diagnosis is further impeded by patients who present for treatment after they have just

used an over-the-counter vaginal antifungal medication. This self-treatment completely eliminates the accuracy of candidal diagnostic tests.

Furthermore, accurate diagnosis is hindered by the relative rarity of vulvodynia compared with candidiasis, a far more frequent diagnosis than vulvodynia. Most clinicians have rarely seen a case of vulvodynia, but chances are the patient has been previously diagnosed and treated for candidiasis. The patient labeled with a diagnosis of candidiasis, whose symptoms of irritation, discharge, erythema, dyspareunia

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## Congress Directs NIH to Fund Vulvodynia Research

**E**ncouraged by the success of the April 1997 vulvodynia conference at the National Institutes of Health (NIH), the NVA has been instrumental in increasing awareness of the disorder on Capitol Hill. The NVA's goal is to convince members of Congress that vulvodynia is an emerging women's health issue deserving of research funding. In June 1997, the NVA's executive director contacted the offices of Senator Arlen Specter, chairman, and Senator Tom Harkin, ranking minority member of the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education. The Senators' request for additional information was followed up with a letter describing vulvodynia's impact on quality of life, a press kit containing print media clippings, and the NVA brochure and newsletters.

After reviewing the information, Peter Reinecke, Senator Harkin's Legislative Director, called the NVA's executive director and reported that Senator Harkin would support research funding of vulvodynia and discuss the issue with Senator Specter. As a result of the combined commitment of Senators Specter and Harkin, the

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## LETTER FROM THE EXECUTIVE DIRECTOR

Dear Friend of the NVA:

One of the first questions that callers to the NVA line ask is, "Do other women have this condition?" Because of the lack of research we don't have a definitive answer, but the estimates range from 300,000 to 1,000,000 women just in the U.S. As the person who answers hundreds of telephone calls every week, I would not be surprised if this figure even exceeds 1,000,000. It has become increasingly clear to me that this is not a rare disorder—**if you have vulvodynia, you are not alone.**

The NVA was created primarily to disseminate information, but it also functions to encourage the medical community to find better treatments for vulvodynia, and to determine which treatments work best for different types of patients. For example, in recent years it has been shown that while surgery has a high success rate in patients with pure vulvar vestibulitis, it is not very successful in patients with constant vulvar pain. On the other hand, tricyclic antidepressants are likely to be effective in treating women with chronic burning pain, but may not be helpful for those with vulvar vestibulitis.

Because there are so few vulvodynia experts in the United States, it is important that **you** learn as much as possible about available treatments. Many women have only received an accurate diagnosis and appropriate treatment after taking our brochure and newsletter to their doctors. I am gratified that our newsletters are helping people, but at the same time I am concerned about their potential influence. When someone is in pain, there is a tendency to seize upon the first "cure" that one reads about, but this can be a costly mistake. Just because you hear that one person was cured by eating artichokes, does not necessarily mean that it will work for you.

Each issue of the *NVA News* contains articles by different health care professionals with their particular point of view. We strive to provide a sense of balance. To date, we have featured gynecologists, neurologists, psychologists, a rheumatologist, dermatologist, nurse practitioner, and physical therapist. The treatments discussed have ranged from medication and surgery to physical therapy and diet modification.

This current issue features articles by a vulvar disease specialist and a urologist specializing in pelvic disorders. Their approaches to the treatment of vulvodynia are completely different. I have printed these articles in the same newsletter to encourage readers to compare their points of view. **I urge you to educate yourself about all treatment alternatives**, by reading our newsletters and medical journal articles. Then, together with your physician, you will be in a better position to choose a course of action appropriate for **you**.

Very truly yours,



Phyllis Mate

**NVA News**  
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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 provider to determine which course of treatment or medication is appropriate for you.

## Moving?

Please send your change of  
address to the NVA:  
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mail and are not forwarded by  
the USPS. For every piece of  
returned mail, the NVA pays a  
first class postage fee.

## Candidiasis

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(painful sexual intercourse), and vulvar pain stubbornly persist despite appropriate and exhaustive therapy, represents a frustrating experience for the therapist. It is with this historical background that the patient, hopelessly confused and frustrated, presents to the vulvar specialist.

The popular notion that vulvodynia is an ill-defined, vague, and indistinct clinical entity is fallacious. This disorder is as uniquely defined as most clinical syndromes. In fact, the diagnosis of vulvodynia is often made historically and confirmed by negative results on a few vaginal and vulvar cultures. Of course there are always a few cases that are difficult to diagnose, and a few cases that just don't fit the established norms, as is true of any medical diagnosis. I maintain, however, that vulvodynia is no more difficult to diagnose than any other clinical syndrome.

At the April 1997 vulvodynia conference at the National Institutes of Health in Bethesda, Maryland, it was suggested that vulvodynia is due to a specific genetic defect in the production of norepinephrine, resulting in a disturbance of the adrenergic autonomic nervous system. Daniel Clauw, M.D., assistant professor of rheumatology at Georgetown University, explained that this norepinephrine deficit produces specific abnormalities and can result in any of the following eight conditions: frequent, severe or migraine headaches; sleep disturbances (usually characterized by early awakening); anxiety, panic attacks, or

agoraphobia; fatigue, or the chronic fatigue syndrome; irritable bowel syndrome; fibromyalgia; bladder spasm; and vulvodynia.

This genetic defect is believed to be completely inherited and almost always expressed. Therefore, patients with this defect should have parents and siblings with some or many of these eight conditions. Patients with vulvodynia need not have all of these conditions all of the time, but historically most vulvodynia patients have enough of these disorders most of the time, to alert the clinician to a presumptive diagnosis. This suggestion of a specific genetic defect appears to be borne out by the family histories of patients with vulvodynia. Armed with this information, the health care provider can suspect the diagnosis before entering the examining room.

A simplistic diagnosis is complicated, however, by the realization that patients with vulvodynia, due to specific endocrine and immune abnormalities, are more prone to fungal and viral infections, and more resistant to bacterial infections. Patients with vulvodynia have more candidal infections than patients who present without the associated adrenergic deficit disorders. Since at least 12 percent of women in the overall population are colonized by *Candida* in the vagina, how is the physician to know if the symptoms are due to a fungal infection in a patient who otherwise presents as a typical vulvodynia patient?

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## Candidiasis

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The answer is not difficult—candidal culture. If a suspected vulvodynia patient has negative cultures for fungal growth and is still symptomatic, the symptoms must be due to vulvodynia. If the suspected vulvodynia patient cultures positive for fungi, then these organisms must be eliminated before the symptoms can be attributed to vulvodynia. If vulvar burning and irritation disappear after successful treatment of the fungal infection, then the patient's symptoms must have been due to

vulvovaginitis, not to vulvodynia. I must emphasize that only culture results are reliable enough to make this distinction. Diagnosis with the naked eye or the phase contrast microscope is not reliable enough. Almost all hospital and clinical laboratories have the ability to culture fungi and identify them. Health care providers must seek out the facilities in their local area and avail themselves of this technique.

In conclusion, each patient with vulvar pain can become proactive

and guide the clinician in the proper use of candidal cultures to achieve the correct diagnosis. The treatment for either candidiasis or dysesthetic vulvodynia is almost always successful. Failure to achieve a completely asymptomatic patient is usually the result of an incorrect diagnosis. A correct diagnosis is the single most important step toward a successful outcome. Hopefully, meticulous attention to detail can reward patients with the best that medicine can offer. ■

### *Treating Vulvodynia with Medication*

The most successful therapy for vulvodynia and other associated conditions is the class of drugs known as tricyclic antidepressants. Treatment with amitriptyline and desipramine has been described in the literature. My personal choice of medication for vulvodynia is a combination of the tricyclic amitriptyline and the tranquilizer perphenazine. The reason I prefer this medication is that my patients seem to recover more quickly with the addition of perphenazine to the amitriptyline. However, this addition presents certain risks, namely that of tardive dyskinesia (involuntary movements) and peripheral neuropathy, or nerve pain. Clinicians who criticize the use of perphenazine are concerned about these possible side effects. For

this reason, I never use more than 6 mg. of perphenazine per day.

My treatment regimen for vulvodynia is as follows. For the first week, I prescribe 2 mg. perphenazine and 10 mg. amitriptyline (2-10) at bedtime only. The same dosage (2-10) is taken twice a day during the second week, and then three times a day the third week and thereafter. I see my patients monthly. As long as the patient reports improvement, I maintain the same daily dosage. If the patient reports no further improvement, I increase the bedtime dose—maintaining the 2 mg. perphenazine, but raising the amitriptyline to 25 mg (2-25). If necessary, I increase the 2-25 mg. dose slowly to three times a day. If symptoms are still present after a few weeks on this regimen, I add an additional dose of amitriptyline at bedtime.

When the patient reports that she is completely asymptomatic, I tell her to maintain the daily dosage at that level for an additional six months. After this time has passed, I gradually decrease the amount of medication. First, I instruct the patient to eliminate the mid-day dose. If there are no symptoms of pain or anxiety following the reduction in dosage, the patient maintains this level until three weeks have elapsed. At that time, she also eliminates the dose on arising, but continues the bedtime dose for at least another three weeks. If symptoms become apparent during this period, the dose is not reduced further until they disappear. Not every patient remains asymptomatic indefinitely, but recurrences are unusual.

B.H.

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# A Holistic Approach to Treating Pelvic Pain

**By Jerome Weiss, M.D.**

*Dr. Weiss is the director of the Pacific Center for Pelvic Pain and Dysfunction, and Associate Clinical Professor of Urology at the University of California, San Francisco. He has been in private practice for 30 years and founded the Pacific Center in 1995 to treat pelvic pain and dysfunction from a comprehensive perspective.*

The mysteries of the pelvic region have been pondered for thousands of years by Eastern cultures. Today, Western physicians continue to be puzzled by the disorders of this area, which pose a major treatment challenge. To meet this challenge,

that when it was “in balance,” the patient would experience an energizing and healing effect. Considering this esoteric concept from a Western medical perspective, it can perhaps be best explained by focusing on the pelvic floor musculature, which impacts both the body and the mind and is also influenced by them.

Since the pelvis is the anatomic center of the body, musculoskeletal dysfunction of the connecting upper and lower body can create tension in the pelvic floor muscles, and conversely, pelvic floor dysfunction can impact the upper and lower

lose the muscles that control the tail—those of the pelvic floor. Rather, these muscles took on the new duty of support. If we observe the actions of the tail on a dog, we see that they mirror the emotions. The tail wags loosely from side to side with happiness and excitement, but is pulled tightly toward or under the body with fear. These responses are actually controlled by the pelvic floor muscles, which relax with joy and contract with anxiety. The same muscular activity occurs in the tailless man, though without the visible emotional flag. In fact, man’s pelvic muscles are perhaps the ultimate representation of the mind/body connection, for they are constantly responding to fluctuations in feelings.

The difficulty one has in recognizing this muscle tension stems from its connection to a primitive, poorly localizing part of the brain. Instead of the precisely defined pain one has with a stress response to the superficial muscles of the neck, shoulders, or low back, pelvic muscle tension is noted as a distant, vague pain of the pubis, vagina, or anus. It also can result in organ dysfunction, such as urinary urgency and frequency.

As this abnormal pattern becomes established, it initiates a downward spiral toward chronic disease or dysfunction. The body’s initial attempt to lessen the pain symptoms, by contracting and holding the muscles immobile for prolonged periods of time, weakens the muscles and makes them more susceptible to mechanical

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***Trigger points can be created by a host of events that overload the muscle.***

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perhaps we should change the way we look at both the disorders and the scientific findings, by expanding our view to include the entire person, not just the symptomatic skin and organs. We might go back in time and look through the eyes of one of those wise old Chinese healers, who understood the interconnections of body, mind, emotion, spirit and environment, and used this understanding to treat the patient “holistically.”

Practitioners of traditional Chinese medicine have long held that the pelvis is the body’s energy center. Over the centuries, they observed that when this region was “out of balance,” it could cause many symptoms and diseases of both body and mind, and

body. The mind plays a key role as well, because a major target of psychological stress is commonly the pelvic floor muscles.

Because the body’s systems are interdependent, self-perpetuating cycles can be established. Either pain creates anxiety, which in turn creates more pain, or pelvic muscle dysfunction affects other attaching muscles, which in turn cause the pelvic muscles to retain their tension. The tightening of these pelvic floor muscles, caused by anxiety and fear, may be a primitive instinct that developed to maintain continence under extreme stress.

Through the evolutionary millennia man lost his tail, but he didn’t

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## Pelvic Pain

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stresses and strains. The tender spots, or trigger points, which ultimately develop in these areas of muscle damage, are the basis of myofascial (muscle or connective tissue) pain.

Trigger points can be created by a host of events that overload the muscle. These include chronic tension holding patterns from traumatic toilet training, sexual abuse, or guilt

may refer pain to other distant areas of muscle attachment, such as the pubis, low back or lower abdomen, or cause spasm and tightness of the surrounding muscles and connective tissue, which can result in symptoms such as vulvar pain or tightness of the vulvar muscles, urinary urgency and frequency, anal pain and tightness or constipation, and diarrhea resembling irritable bowel syndrome.

for the failure of traditional medical therapies.

What confuses patients about trigger points is that the initiating factor may not be a single event that they can remember. In fact, traumas can be additive and only produce symptoms when a final event "summates" to exceed a threshold in the muscle, thereby changing a latent, asymptomatic point into an active painful one. Sometimes the final triggering event can be so minor that it is not considered a cause. Vaginal infections, cystitis, pelvic surgery, athletic injuries, or even emotional distress may push the muscles beyond their threshold and cause a latent trigger point to become an active one. When this occurs, a variety of conditions can result, including: spasm and tightness of the lower vaginal muscles, making sexual intercourse painful or impossible (vaginismus); a constant burning of the vulvar skin from nerve compression or fixation (dysesthetic vulvodynia); burning or hypersensitivity of the vestibular skin either with or without visible changes (vulvar vestibulitis); a vicious cycle of skin inflammation and muscle spasm initiated by vestibulitis or vulvitis; and other associated problems, such as urinary urgency and frequency, bowel dysfunction, and interstitial cystitis, which occur when spasms in the underlying muscles affect the structures (e.g., urethra and rectum) that pass through them.

### Treatment Philosophy And Techniques

At our center, we utilize a holistic approach, based on the ancient

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**... our program requires the patient's total commitment to the treatment process ...**

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surrounding sexual feelings; repetitive minor trauma or straining, such as constipation or voiding dysfunction; brief, severe overload or stressful movements that can occur in sports, automobile accidents, childbirth, a fall, or unusual or prolonged sexual activity; and inflammation from cystitis, urethritis, vaginitis, pelvic inflammatory disease or proctitis. Because weak muscles are more easily overloaded than strong ones, the women who are most likely to develop trigger points in the pelvic floor are those with underlying weakness resulting from such problems as articular abnormalities or muscle imbalances of the back, hips or legs, or systemic disease created by hormonal and/or nutritional factors, infections or genetics.

Once a trigger point develops, it can disappear or remain latent (unless touched during a pelvic examination or intercourse), or it can become active and cause symptoms. Active trigger points can create pelvic problems in many ways. They

Since the skin and muscle can either share the same nerve or be in close proximity in the spinal cord, they can affect each other. A tender trigger point can result in sensitive or neurogenically inflamed skin, giving the appearance of infection. Furthermore, muscles that contain active trigger points can shorten and widen, thereby compressing and irritating the adjacent pudendal nerve, which enervates the pelvic floor. This may cause pain, irritation, or burning in the skin of the vulva or adjacent areas.

Of particular significance is the fact that trigger point pain can lead to central sensitization, i.e., changes that occur in the nerve endings that enter the spinal cord or brain when they have been exposed to chronic painful input. In this instance, even if the trigger points that have caused the pain are eradicated, the spinal cord nerves have become so sensitive that one will still experience pain. This very important aspect of chronic pain may be responsible

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## Pelvic Pain

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healing principle of balancing or normalizing the entire body to permanently correct the problem, as opposed to isolating and treating the symptoms alone. The method we employ is a Western alternative to traditional Chinese "pulse diagnosis," which is an unpeeling process whereby each layer of body compensatory and defensive response is examined down to the very core of the problem.

We begin by taking a detailed history of potentially contributing events dating back to childhood, and performing an extensive physical therapy evaluation to uncover any musculoskeletal dysfunction. These findings are then used to formulate a treatment plan designed to correct all causative factors emanating from both the mind and the body.

Unlike many Western medical therapies, our program requires the patient's total commitment to the treatment process in partnership with the health practitioner. We fully inform the patient about all aspects of the disorder, outline all of the treatment options, and encourage participation in deciding which course of action to follow. Not only

does this allow us to tap into the patient's intuition based on past treatment experiences, which can be invaluable, but it also empowers and motivates the patient throughout the healing process and future management.

### Body Directed Therapy

From our perspective, women with vulvodynia have pelvic floor muscle dysfunction, representing either the underlying cause of the skin sensitivity or the reflex result. The focus, therefore, is on internal myofascial release techniques, which include the application of firm pressure (similar to acupressure), the stretching of connective tissue and muscle, and occasionally, the injection of anesthetic agents. These procedures are designed to eradicate trigger points and normalize contracted tissue by stimulating specific nerve endings that can block trigger point impulses in the spinal cord. When performed repetitively, they disrupt the trigger point spinal cord reflex pattern, and its accompanying muscle tension disappears. The nerves that are stimulated by normal muscle movement then continue to block any residual painful input.

External physical therapy techniques also are employed to release tight tissues and trigger points, and correct compensating imbalances. Typical predisposing factors that must be addressed are scoliosis, hip or back injuries, abdominal scars, and abnormalities of movement and posture. Compensating problems arise when the muscles that attach to the pelvis (such as the iliopsoas, hip abductors, abdominal and back muscles) attempt to immobilize it to decrease pain and thereby, over time, become shortened, weakened and/or imbalanced.

To re-educate dysfunctional muscles and connective tissue, stretching and strengthening exercises are introduced, along with instruction in proper ways of sitting, standing, and walking. To halt painful nerve stimulation, local or systemic therapies are prescribed for specific infections, herbal barriers or soothing agents are recommended for non-specific irritation, and low oxalate diets are suggested when appropriate. Nutritional counseling is provided to assess and remedy Vitamin B and iron deficiencies, which can lead to abnormal muscle functioning. Thyroid and estrogen imbalances also are identified and addressed. Standard pharmacologic therapy is used only when symptoms are severe or treatment progress is slow.

### Mind Directed Therapy

There are many effective therapies that can be utilized to reduce stress and its resulting negative effect on muscles. Patients are presented with a wide spectrum of options and

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### Letter to the Editor

I would be very interested in speaking with women who have both interstitial cystitis and vulvodynia. If possible, please print my address and telephone number so that others can contact me. Thank you.

Leah Ann Wilkerson  
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## Pelvic Pain

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advised to choose one or more that "feel right" to them. This elective approach ensures compliance and produces optimal results.

General stress reduction techniques, such as meditation, Tai Chi, Qi Gong, abdominal breathing, yoga, and progressive muscle relaxation, form the cornerstone of mind directed healing. Visualization and imagery can be utilized to modify specific symptoms or change abnormal structure, and psychotherapy may be a valuable adjunct to explore traumas that may have led to the problem or have resulted from it.

Patients with pelvic pain frequently disconnect themselves from that area both mentally and physically. The re-education process of strengthening and stabilizing the pelvic floor muscles is best served with the use of EMG-biofeedback, which enables patients to view on a monitor the underlying tension and weakness in the muscles. Through the use of biofeedback, the patient learns to control muscle contraction and relaxation, and distinguish between the two. Strengthening is then achieved by the repetition of Kegel

exercises. As a result of these exercises, the muscles become more stable and pain reduction is achieved.

### The Healing Process

Regardless of the techniques employed, remissions and exacerbations are the rule. Since these setbacks produce anxiety, which can increase symptoms, patients must be counseled in the nature of healing. When they understand the stages of recovery, they are better able to weather the depression that frequently accompanies and contributes to a relapse.

A pelvic disease or dysfunction develops after a trauma or traumas have altered the body's normal pattern. The treatment process attempts to disrupt the abnormal pattern, in many cases also by trauma, as witnessed by the above methods. Symptoms can flare up as the tight and tender pelvic muscles are "shown" how to relax again. Once the mid point between the normal and abnormal patterns is reached, the muscles will tend toward normalcy, resulting in longer symptom-free periods. However, symptoms will continue to recur intermittently until the normal pattern is stabilized, though they will be

present for increasingly shorter periods, and they will be less severe.

### Conclusion

The theory that myofascial dysfunction of the pelvis is an underlying cause or contributing factor to vulvodynia can explain its many subsets and associated conditions. Treatment of the pelvic floor muscles alone, however, cannot be successful if stresses or external muscular abnormalities continue to bombard that area. In patients with long-standing vulvodynia, the nerve endings in the skin, spinal cord and brain have been sensitized by the constant assault of pain impulses. Since we have no appropriate drug therapy with which to reverse this process, the most effective treatment is to stop all of the painful stimuli coming from the skin, muscles, connective tissue, and mind for a sustained period of time, so that a "normalization" of the pelvic floor muscles and their sensitive spinal cord nerve endings can occur. This can be achieved by a broad-based, holistic approach of evaluating and treating the total person, as practiced for millennia by ancient Eastern cultures. ■

### Subjects Needed

Researchers at Johns Hopkins University are seeking volunteers for a study concerning the effect of the menstrual cycle on pain perception in vulvodynia. They need subjects aged 18 to 45 who are currently menstruating, do not take oral birth control, and have been diagnosed with either vulvar vestibulitis syndrome or essential vulvodynia for at least six months.

You **do not** have to live near Johns Hopkins to participate in this study. If you would like more information, please contact Chris Sanders at 410-955-3218 or via e-mail at [clsander@welchlink.welch.jhu.edu](mailto:clsander@welchlink.welch.jhu.edu).

### Vulvodynia and The Internet

Our new web site, [www.nva.org](http://www.nva.org), has received 1,800 "hits" since 10-22-97.

An updated list of back issues of *NVA News* is available at the site.

## Genetic Link In Vulvodynia?

We are conducting a survey to evaluate whether vulvodynia has a hereditary component, and invite women with vulvodynia and vulvar vestibulitis who have close relatives with the disorder (sister, mother, daughter, aunt or grandmother) to answer a questionnaire. We also request that health care providers ask appropriate patients to consider enrolling in our survey.

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.

If you are willing to participate, or have a patient who fits the above criteria, please contact one of us.

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## BOOK REVIEW

### **Dr. Susan Love's Hormone Book: Making Informed Choices About Menopause**

By *Susan M. Love, M.D., with Karen Lindsey, Random House, New York, 1997.*

For those who are approaching or have just passed menopause, it is a time for making important decisions about your well-being and future health. Knowing the options beforehand will enable you to engage in intelligent discussions with your doctor, and arrive at a decision with which you are comfortable. As vulvodynia patients we have learned to educate ourselves about treatment options. We now have the opportunity to apply this proactive approach to another area that affects us both physically and emotionally.

*Dr. Love's Hormone Book* provides a comprehensive, in-depth review of research on perimenopause (the years immediately preceding the cessation of menses) and menopause (the years following the cessation of menses). This excellent book can help you assess your postmenopausal health risks and decide how to deal with unpleasant symptoms such as hot flashes, insomnia, and vaginal changes, while taking risk factors into consideration.

The author begins by describing the stages of menopause, identifying the most common symptoms, and examining cultural differences. She views menopause as a natural stage of life, analogous to the hormonal changes of puberty, and criticizes the "medicalization" of menopause, i.e., treating it as a disease that needs to be corrected with medication. In this regard, she is skeptical of the role drug companies play in the promotion of hormone replacement therapy.

*The Hormone Book* devotes chapters to osteoporosis, heart disease, and breast cancer, explaining the impact of hormone replacement therapy on each of these medical conditions. Dr. Love provides detailed information on the various types and methods of estrogen replacement, as well as alternative measures such as acupuncture, herbs, and diet. She emphasizes that hormone replacement therapy is not the solution for everyone who experiences menopausal symptoms, and includes a chapter that describes lifestyle changes (e.g., increased exercise and calcium intake) that can help prevent some of the health problems associated with menopause.

Every woman over the age of 40 should go to the library or bookstore to find a copy of this extremely readable, informative, and occasionally humorous book. Reading *Dr. Love's Hormone Book* feels like you're sitting down to discuss menopause with an old friend, who just happens to be one of the foremost experts in the field.

*(Editor's note: You may also be interested in reading Dr. Susan Love's Breast Book, an up-to-date review of breast care, screening, diagnosis, and treatment.)* ■

## READER TO READER

### WHY ME ... WHY NOT?

Slightly more than six years ago, I was struck by a car while riding my bicycle. There was no way I should have made it through the next 24 hours, much less to this day. The physicians told my family that if I had been any older than I was (15 years), or not in as good athletic condition, I would have been dead instantaneously. Contrary to what the doctors thought at that time, I now know there is another reason why I am alive and well today. After extensive rehabilitation and a few more minor surgeries throughout the next year, my physical abilities were restored. However, one very important thing in my life changed—my attitude. I no longer take simple, yet miraculous, things for granted as I did before my accident, and I realize that life is an incredible gift. To do things as simple as breathe, walk, and talk are marvelous gifts we don't think about twice unless forced to do so by illness. Above all, I was thankful that I could now live a life free from physical pain. I had suffered night after night in the hospital with pain that I thought would never go away. But it did. It went away, and I prayed that I might be granted one wish—not to live in any sort of physical pain ever again.

Well, three years after my accident I was diagnosed with vulvodynia. I prayed the pain would go away, but it hasn't to this day. My story from this point on is probably very similar to yours. Living with vulvodynia has not been an easy task and continues to be a challenge. There have been many long days and even longer nights. But through it all I do my best to move forward.

I have asked myself the question, "Why me?" many times during the past three years. Just recently, we celebrated the life of Dr. Martin Luther King Jr., and I found an answer to this question by reflecting on the meaning of his life. I realized that some of us have been given unpleasant things to deal with for the sake of a larger good. I am sure there were times when Dr. King woke up and said to himself, "I wish that for just one day, I did not have to deal with the racism and bigotry I face in my life." But he continued to confront it day after day. Because he had a greater purpose in mind, he turned a negative situation into a positive initiative, and stood up against that which was painful to him. I challenge you to do the same.

Dr. King mobilized individuals to struggle for a better life for African Americans; those of us with vulvodynia have to work for a better life for ourselves and for others who are yet to be diagnosed. Instead of asking, "Why me?," ask yourself, "Why not me? What can I do to better my circumstances and ensure that others will not have to travel down the same painful road?" I know that vulvodynia is difficult to deal with on many levels. But instead of letting this illness control you, take charge and try to improve the situation. Be encouraged to educate yourself about the disorder and demand research on better treatments.

It is not easy to stand up and disclose that you have vulvodynia, but if we are unwilling to do so, there will be little progress made in favor of our condition. Of course it is easier to let a few individuals fight for all of us. But we can be a much greater force if we all stand together and do everything within our power to change the misconceptions and mistreatment associated with vulvodynia. I encourage you to talk with family, friends, co-workers, and health care providers in an effort to spread awareness of the disorder. I challenge you to start right now.

You may be wondering, "What can I do?" You can start by making a list of all the people you or your family and friends know. Do you know anyone who works at a newspaper, magazine, or t.v. station? These connections are a powerful source for spreading information on little-known medical disorders. Are you a writer or do you know anyone who writes? Can you write an article about how vulvodynia affects your life? Do you have contacts in government? Do you work in a health care facility where you could post flyers

*See READER TO READER, page 11*

## Reader To Reader

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or hold educational symposiums on women's health issues? Do you know anyone in a position to help you with this?

Fundraising is also an essential component of the battle against this disorder. Do you have funds that can be donated towards vulvodynia research? Do you know any family, friends, or business owners who may be willing to give a donation to this cause? Even if you cannot make a donation at this time, there are still ways you can raise funds. Do you belong to a strong social or religious community where you could hold a fund-raising event, such as a craft or bake sale? Could you clean out your basement and closets, and hold a garage sale to raise funds? Could you spare one outing a month or the purchase of a new blouse to make a donation? The possibilities are endless; I'm sure you can think of many more.

If you answered yes to any of the above questions, there *is* something you can do. Talk to your local NVA support leader or group about working together on a project. We **can** beat this, but we need everyone's best effort to do so. I'm asking you to make a commitment to helping yourself and the thousands of other women who suffer from vulvodynia. We all dream of a pain-free life, but we will have to work for it. I have challenged you—now challenge yourself.

Correspondence may be sent to:  
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## Congress

(from page 1)

Senate Appropriations Committee reported out the Labor, Health and Human Services, and Education bill with the following language on NIH: "Hundreds of thousands of women suffer from vulvodynia, a painful and often debilitating disorder of the female reproductive system. Despite its prevalence, very little attention has been paid to the disorder by health care professionals or researchers. However, in April, NIH convened an international symposium to exchange information and develop a research agenda. The Committee is concerned about the lack of attention to this important women's health problem and has included sufficient funds to carry out research on the prevalence, causes, and treatment of vulvodynia."

The inclusion of this language in the Senate Appropriations Committee Report, although a victory, was not a guarantee that the reference would remain in the final conference report to be voted on by both houses of Congress. The NVA executive board waited anxiously to hear the results of the negotiations between Appropriations members of the House and Senate. Six weeks later, Mr. Reinecke relayed the wonderful news that a portion of the report language on vulvodynia had survived.

This past November, Congress passed the 1998 Labor, Health and

Human Services, and Education conference report, stating that, "**The conferees encourage the Institute to carry out research on the prevalence, causes, and treatments of vulvodynia.**" (The Institute referred to is the National Institute of Child Health and Human Development, which oversees research on gynecological disorders). The fact that these 17 words remained in the 1998 conference report was a major victory for the NVA and vulvodynia sufferers. It may not be recognized by your local gynecologist, but vulvodynia has now been officially recognized by the U.S. Congress!

Last month, Dr. Florence Haseltine, of the National Institute of Child Health and Human Development (NICHD), Dr. Maria Turner, chairperson of the NIH vulvodynia conference, and Phyllis Mate, the NVA's executive director, met with Mr. Reinecke to discuss strategies for funding this research. Dr. Haseltine proposes to include vulvodynia in a pelvic floor pain and dysfunction program to be created at NICHD, and invited the NVA's executive director to attend the program's planning meeting in March. Within the next six months, NICHD also intends to inform the medical and scientific communities that it is interested in funding vulvodynia research. ■

### Our Heartfelt Thanks To ...

The Himmelfarb Foundation and the John and Cora Davis Foundation for their generous grants to the NVA.

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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.

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NATIONAL VULVODYNIA ASSOCIATION

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