

The Oxalate Story: A Treatment for Vulvar Vestibulitis

By M. Herzl Melmed, M.D.

Dr. Melmed is a practicing gynecologist in Englewood, Colorado. He is a fellow of the American College of Obstetricians and Gynecologists and the International Society for the Study of Vulvovaginal Disease.

In 1982, one of my patients developed severe vulvar pain after the birth of her second child. I tried various treatments without success and then sent her to see a vulvar pain specialist. Over the next few years, she went to one specialist after another; neither a vestibulectomy nor laser surgery brought relief. By 1985, when she had lost all hope, her psychologist consulted Dr. Clive Solomons, a biomedical researcher. It seemed to him that the burning sensation that she experienced was similar to what a person feels when touching certain "toxic" plants, such as those high in

oxalates. Following his intuition that high oxalate levels in the urine might be causing the vulvar burning, he tested her urine for oxalate content. His analysis showed that, at different times during the day, she had oxalate peaks in her urine that were well above normal levels.

Oxalate crystals, known to cause irritation and burning of the skin, resemble small pieces of broken glass and are a metabolic end product in the body. To minimize the patient's oxalate levels, we placed her on a diet which eliminated high oxalate foods such as spinach, strawberries, peanuts,

and chocolate (see Oxalate Content of Selected Foods, page 4).

Because citrate inhibits the formation of oxalate crystals, we also prescribed calcium citrate (Citracal) supplements to be taken immediately prior to the times of day that she had displayed oxalate peaks in the urine. Calcium citrate is an over-the-counter product that is often used by women who wish to supplement their calcium intake. Within three months of modifying her diet and taking calcium citrate, the patient was feeling better; within a year she was symptom-free and able to return to normal sexual activity. Her story was the subject of a December 1993 *Ladies Home Journal* article titled "The Pain That Would Not Go Away." As a result of our success in treating this patient, Clive Solomons and I

See OXALATE, Page 3

An Overview of Vulvar Vestibulitis

Vulvar vestibulitis syndrome (VVS), one of the largest subsets of vulvodynia, refers to "an exquisitely painful inflammation of the vulvar vestibule," the tissue immediately surrounding the vaginal opening. It is referred to as a syndrome rather than a disease because no consistent cause is known, and the diagnosis is made by excluding all known causes of vestibular pain.

Women who suffer from VVS report chronic burning, stinging, irritation, or rawness upon any direct contact with the vestibule. The pain can vary from mild to severe. In severe cases, sexual intercourse is impossible. In addition to dyspareunia (painful sexual intercourse), many sufferers also experience pain when inserting a tampon, wearing tight pants, riding a bicycle, jogging, or even sitting.

See VULVAR VESTIBULITIS, Page 5

INSIDE

Executive Director Letter.....P. 2
Raising Public Awareness....P. 7
Book Review.....P. 9
Reader-to-Reader.....P. 10
Membership Form.....P.12

LETTER FROM THE EXECUTIVE DIRECTOR

Dear Friend:

As you may already know, Jacqueline Smith resigned as executive director this past October. Jackie was the principal founder of the NVA, and we are grateful to her for recognizing the need for this organization. Our thanks to Jackie for the compassion that she gave to women in pain and for her efforts in establishing vulvodynia as a legitimate women's health disorder. We wish her the best in all future endeavors.

Raising public awareness of vulvodynia depends largely on the efforts of courageous women who are willing to speak out about the disorder's impact on their lives. I would like to recognize one individual whose recent efforts have helped to accomplish this goal. Thanks to NVA participant Ronnie Frankel for having the courage to approach Miami's WPLG-TV with her story, and to Kristi Krueger, WPLG-TV news anchor and medical reporter, for listening and caring.

We are fortunate to have so many talented and committed volunteers on the NVA executive board. At our January meeting, two members from the Washington, D.C., support group were added to the board. We welcome Margery Levine, C.P.A., who was elected treasurer, and LuEllen McCormack, who is responsible for the creation and management of our new database system. This has been an exciting fall for board members Donna Wolf Leyens and Marjorie MacArthur, each of whom gave birth to her first child. Welcome to the world, Seth and Christine! Donna and Marjorie continue to be involved in the organization, even though they have both been granted a "maternity leave."

Last but not least, I want to express my heartfelt appreciation of Harriet O'Connor, director of support services, for working with me throughout the recent transition from Florida to Maryland. She is the hardest-working, most dedicated volunteer anyone could ask for. Harriet has been an invaluable resource for hundreds of women since the NVA's inception.

In the future, if you want to write or call anyone at the NVA, you can reach us at the following new address and telephone number:

P.O. Box 4491
Silver Spring, MD 20914-4491
Telephone: 301-299-0775
Fax: 301-299-3999

Wishing you a healthy and happy 1997,

Phyllis Mate

Oxalate (from P. I)

started to see other patients with vulvar vestibulitis, noting that many of them exhibited marked improvement on the low oxalate/calcium citrate regimen.

In an attempt to bring this information to the attention of our professional colleagues, we published a case report of our first patient in the *Journal of Repro-*

ductive Medicine in 1991. Two years later, at the International Society for the Study of Vulvovaginal Disease (ISSVD) meeting in Quebec City, I presented a paper on the successful treatment of 20 of our first 25 patients. Our medical colleagues raised a number of important questions about the efficacy of the low oxalate/calcium citrate treatment. A question was raised as to whether it is necessary to take

oxalate tests were performed using the enzymatic method, they failed to demonstrate the significant peaks that had been found using the Archer method.

I reported on the discrepancy between the Archer and enzymatic methods of oxalate measurement at the 1995 ISSVD meeting at Iguaza Falls, Argentina. At the same meeting Dr. Michael Baggish reported that, using the

NVA News
National Vulvodynia Association
P.O. Box 4491
Silver Spring, Md. 20914-4491
(301) 299-0775
FAX: (301) 299-3999

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

Editor:
Phyllis Mate

Assistant Editor:
Andrea Hall

Layout:
Cindy Price

Contributors:
Jodi Diedrich
Robin Wiener

The National Vulvodynia Association is an educational, nonprofit organization that disseminates information. It does not engage in the practice of medicine. The NVA strongly recommends that you consult your own health care practitioner regarding any treatment or medication.

At present there is no satisfactory explanation as to why the low-oxalate/calcium citrate regimen works.

calcium citrate precisely before the urinary oxalate peaks, or whether it may simply be taken three times a day before meals. Another issue of concern was the absence of controlled research comparing the results of patients given calcium citrate to those of patients given a placebo.

The original method of oxalate measurement used by Dr. Solomons is known as the Archer method. I was interested in discovering whether the dramatic oxalate peaks that he found using the Archer method could be replicated in another laboratory. I engaged the National Health Laboratory for this purpose, but was told that they only used the enzymatic method for measuring oxalates—a newer, faster, and more cost-effective procedure than the Archer method. When urinary

Archer method, he was unable to find the dramatic oxalate peaks that had been noted by Dr. Solomons. Currently there is no explanation for the fact that two groups using apparently the same method for measuring urinary oxalate, are finding different results. It is clear that more work needs to be done in this area. Based on this discrepancy, however, I decided that testing for oxalate peaks in order to determine the timing of calcium citrate administration did not appear to be justified. As a result, I have my patients' total oxalate levels measured using a pooled 24-hour urine collection, instead of testing individual urine samples over a 24-hour period. (This urinary oxalate analysis is done primarily for research purposes; I instruct my vulvar vestibulitis patients to

See OXALATE, Page 4

Oxalate (from P. 3)

follow a low-oxalate diet and take calcium citrate even if their urine is not tested.)

At the 1995 ISSVD meeting, I reported on 60 vulvar vestibulitis patients who were being treated with the low oxalate/calcium citrate regimen. These patients were initially placed on the diet for two to four weeks. If significant improvement was noted on the low-oxalate diet alone, the diet was continued until no further improvement was evident. Then calcium citrate was added. In the early part of the study, calcium citrate was given in a dose of six to nine tablets daily, timed to be taken before the major oxalate peaks that had been recorded using Archer's method. Halfway through the study, after learning that the enzymatic method had failed to replicate the earlier finding of oxalate peaks, I instructed patients to simply take calcium citrate before meals.

Patients began by taking six tablets per day in equally divided doses and worked up to nine tablets per day, depending upon their response. The change in vulvar symptoms was gradual in most patients; in some cases it took one year to attain significant improvement. Fifty-three (53) percent of patients reported substantial pain relief, while 77 percent reported at least minimal improvement. When this study was published, 28 of the 60 patients had been following the treatment for less than six months, so these results were likely to improve with time.

It should also be pointed out that only 3 percent of these patients were completely relieved of vestibular pain by following the low-oxalate diet alone. However, 50 percent of the same patients reported an increase in vestibular pain in association with certain foods, although not exclusively

those high in oxalate. By avoiding particular foods, they were able to prevent exacerbation of their symptoms. These self-reports suggest that simply following a low-oxalate diet or avoiding certain foods can have some benefit for many patients.

As mentioned before, calcium citrate was originally prescribed for vulvar vestibulitis patients because citrate inhibits formation of oxalate crystals. Today I do not believe that this completely explains why so many patients who have taken calcium citrate have experienced a marked improvement in their symptoms. It is possible that calcium citrate works in two ways. Until now we have only focused on the effect of the citrate, but perhaps the calcium also plays a role by absorbing oxalates in the bowel.

At present there is no conclusive proof of the oxalate theory or any satisfactory explanation as to why the low-oxalate/calcium citrate regimen works. After nearly 12 years of prescribing this treatment, however, I am convinced that following the diet and taking large doses of calcium citrate helps many women who suffer from vulvar vestibulitis. Approximately 75 percent of my patients who have followed this regimen have experienced significant improvement. Because this approach is non-invasive, inexpensive, and relatively easy to carry out, it seems to be a reasonable first-line approach for VVS patients.

As in all chronic pain syndromes, chronic vulvar pain can have significant emotional and physical

See OXALATE, Page 7

Oxalate Content of Selected Foods (Per serving)

Low (<2mg.)	Moderate (2-10mg.)	High (>10mg.)
banana	apple	spinach
grapefruit	orange	peanuts
melon	peaches	celery
avocado	pear	blueberries
cauliflower	pineapple	strawberries
mushrooms	carrot	chocolate
green peas	corn	baked beans
onion	broccoli	okra
eggs	tomato	summer squash
cheddar cheese	asparagus	sweet potato
poultry	sardines	eggplant
lemonade	cranberry juice	wheat bran
milk	coffee	tea

Vulvar Vestibulitis Syndrome (from P. 1)

Although research reports on VVS did not appear until the 1980s, its occurrence was described in medical literature as early as 1889. In his "Treatise on the Diseases of Women," Dr. A.J.C. Skene referred to a disorder characterized by "excessive sensitivity" of the vulva causing women to "cry out in pain" upon contact with the examining finger. In the 1920s, Dr. H. Kelly described a condition causing painful intercourse whose main symptom was "exquisitely sensitive red spots on the mucosa of the hymenal ring." Sixty years later, the first research reports appeared in the medical literature when Dr. Edward Friedrich provided a standardized description of the disorder and introduced the term "vulvar vestibulitis." He defined the diagnostic criteria as "severe pain on vestibular touch or attempted vaginal entry, tenderness to cotton-tipped applicator pressure located within the vulvar vestibule, and physical findings confined to vestibular erythema (redness) of various degrees."

VVS can affect females of all ages, although some doctors report that the majority are in their twenties and thirties. One gynecologist evaluated 210 patients in her OB/GYN practice and found that 15 percent of these patients fit the clinical definition of VVS; another 22 percent displayed some signs of vulvar tenderness. In the questionnaire she administered after the physical examination, 50 percent of the patients who fulfilled the vulvar vestibulitis criteria reported longstanding pain, usually since adolescence.

Suspected Causes

In the majority of cases, the reason for the onset of VVS is

unknown. There are, however, many theories of possible causes. Known or suspected causes include viral infections, vulvar trauma, contact dermatitis, repeated episodes of yeast infections, allergies, chemicals or other irritants, a history of destructive therapies such as carbon dioxide laser surgery or cryosurgery, or psychosexual factors. Mann (1992) reviewed the variables associated with the onset of VVS after comparing 71 patients with the disorder to a control group. According to the study, 80 percent of VVS patients had experienced multiple episodes of candidiasis (yeast infections) compared to 21 percent of control subjects. This study also found a significant increase in allergic reactions in VVS patients. One theory proposes that there may be genetically susceptible women in whom a candidal infection elicits an autoimmune response, resulting in local inflammation, which contributes to the development of vestibulitis.

Complaints of urinary urgency, frequency, and pain all have been associated with vulvar vestibulitis. Some women with VVS also suffer from interstitial cystitis, a painful inflammation of the bladder. Because the vestibule and the bladder are derived from the same embryologic tissue, investigators have started to look for an irritant that might affect both of these structures.

Diagnosing VVS

When a patient complains of vestibular pain upon contact, doctors will typically test for a number of infections and diseases. VVS is a diagnosis by exclusion. In other words, the term is

utilized when other disorders have been ruled out. According to one report, the following conditions should be distinguished from VVS: "psoriasis; allergic or irritant reactions; various fungal infections; certain immunologically caused skin diseases which can cause vulvar ulcers or inflammation; a number of systemic diseases including lupus, pellagra, and Reiter's disease, among others; pain due to genital warts or infection with the virus that causes them (HPV), common vaginal infections caused by candida, trichomonas and bacteria; genital herpes infection; spasm of the vaginal muscles (vaginismus); vulvar irritation due to medications such as corticosteroids; and certain cancers."

In seeking treatment for chronic VVS, it is important to find a doctor who specializes in diagnosing and treating vulvar disorders. Not all gynecologists have this expertise, so obtaining an accurate diagnosis can sometimes be a long and frustrating process. It is common for women to visit a number of doctors before receiving a diagnosis of vulvar vestibulitis. Because of the frequent concurrence of yeast infections and VVS, many women are simply diagnosed as having chronic bacterial or yeast infections.

Diagnosing VVS can be especially difficult because some patients do not present with any visible symptoms. In many cases, however, red spots are observed around the vaginal opening and the patient reports severe pain when a moistened cotton-tipped applicator touches these spots.

See VULVAR VESTIBULITIS, Page 8

Raising Public Awareness

Vulvodynia, like many little-known illnesses or diseases that have no known cause or cure, faces a long, strenuous battle for greater public recognition and funding. The personal nature of the disorder makes building awareness and raising funds an especially difficult challenge. Recently, we have made great strides in both of these arenas.

Our thanks to those individuals who responded so generously to the NVA's November fund-raising campaign. Whether you sent a donation or simply renewed your annual dues, we appreciate your commitment to helping women who have vulvodynia. In addition to furthering our education and support efforts, these funds will be used to raise public awareness of this disorder.

While the NVA as a group is doing its part to raise the profile of vulvodynia, individuals also play an important role. Ronnie Frankel, an NVA participant from Florida, approached the local ABC television affiliate in Miami and succeeded in obtaining television coverage for vulvodynia. Ronnie

and Dr. Betty Bellman, a Florida dermatologist, were featured on the Eye on Health segment of the WPLG-TV news broadcast. The coverage by Kristi Krueger, the station's news anchor and medical reporter, was sensitive and compassionate. In the 48 hours following the broadcast, the NVA received over 100 phone calls from south Florida alone.

Due to the efforts of publicity director Marjorie MacArthur, vulvodynia will be publicized in two upcoming magazine articles. First, be sure to look for Paula Dranov's article on painful sex in the March issue of *Good Housekeeping*. Former NVA executive director Jacqueline Smith was one of the women interviewed by Dranov. In addition, a section on vulvodynia will be included in a women's health article in the April issue of *American Health*.

If you have a newspaper, magazine, or television contact, you can participate in the enormous task of disseminating information and generating interest in

vulvodynia. Please call Marjorie MacArthur at 301-299-0775. Our combined efforts to educate the public can benefit the thousands of women who remain undiagnosed.

Telephone Contact Leaders Wanted

At this time we have established telephone contact leaders in 47 states. They provide emotional support and information to other women in their area.

Harriet O'Connor, director of support services, is seeking leaders in the following regions: San Jose, California; Miami, Florida; Westchester County, New York; Okemos/Flint, Michigan; Oklahoma; Philadelphia, Pennsylvania; London, Ontario; and Montreal, Quebec.

If you live in one of these areas and can give some time to help other women suffering from vulvodynia, please write to Harriet at P.O. Box 4491, Silver Spring, MD 20914 or leave a message at 301-299-0775.

Upcoming Chronic Pelvic Pain Conference

The First Annual Symposium on Chronic Pelvic Pain will be held April 11-13, 1997, in Chicago, Illinois. Speakers will include NVA medical advisory board members Dee Hartmann, P.T., and Stanley Marinoff, M.D.

If you are interested in attending, please call the Continuing Education Network at 804-741-1173.

Computer Needed

Do you own a personal computer (IBM-compatible) that you're looking to give away? Perhaps you've replaced your old 486 or Pentium with a state-of-the-art model. If so, please consider donating your old computer to the NVA for a tax deduction. Call us at 301-299-0775. Thank you!

Oxalate (from P. 4)

effects. Because patients can take many months to realize the full benefit of the low oxalate/calcium citrate treatment, emotional support and sexual counseling are very helpful during this period. In my experience, nurse practitioners can be an invaluable asset in this situation.

For women with vulvar vestibulitis, the major disability is painful sexual intercourse, especially at attempted entry. Discomfort varies from making intercourse impossible to allowing occasional intercourse, but with some pain during or afterward. In a group of 60 patients with vulvar vestibulitis, Terry Rendler, N.P., and I noted that 33 could occasionally tolerate sexual intercourse with some level of pain, 12 patients could tolerate clitoral stimulation but not sexual intercourse, and 13 could not tolerate any form of clitoral stimulation or sexual intercourse. Two patients were not sexually active.

In our work with vulvar vestibulitis patients, we have tried to encourage them to make adjustments in their sexual activity so as not to abandon their sex lives completely. We recommend that some patients adopt sexual techniques that do not involve sexual intercourse, assuming that clitoral stimulation is possible without discomfort. There is a wonderful book by Alan and Donna Brauer, titled *E.S.O.*, which emphasizes the possibilities of making love without pursuing sexual intercourse itself.

Our attempt to find a connection between sexual abuse and vulvar vestibulitis is consistent with other reports that have concluded that there is no relationship between the two. We find that approximately one in eight vulvar vestibulitis patients reports a history of sexual abuse. This is exactly the same incidence of sexual abuse that is found in women in our practice who do not suffer from vulvar vestibulitis.

Finally, as mentioned above, a controlled study to test the efficacy of the low-oxalate/calcium citrate treatment is needed. Since many vulvar vestibulitis patients come to us in severe pain and this treatment takes many months to produce improvement, it does not seem reasonable or ethical to place any of these patients on a placebo. Because of the need for such a study, however, we are considering an approach that will provide the necessary data through a randomized discontinuation trial. (Patients who have been following the treatment and have shown improvement will be divided randomly into two groups—one will continue as before, the other will be switched from calcium citrate to a placebo.) We hope to carry out this research within the coming year.

References

Solomons, C.C., Melmed, M.H., Heitler, S.M. Calcium citrate for vulvar vestibulitis: A case report. *J. Reprod. Med* 1991; 36:879.

Melmed, M.H., and Solomons, C.C. Low-oxalate diet and calcium citrate for vulvar vestibulitis. 12th Intl. Congress of the Intl. Society for the Study of Vulvovaginal Disease (ISSVD), Quebec City, Canada, Sept. 26-29, 1993, Abstracts p. 35.

Melmed, M.H. Treatment of 60 patients with vulvar vestibulitis using low-oxalate diet and calcium citrate. Paper presented at the 15th Intl. Congress of the ISSVD, Iguazu Falls, Argentina, Sept. 25, 1995.

Rendler, T.J., and Melmed, M.H. Vulvar vestibulitis with special reference to sexual functioning. *Nurse Practitioner*, 1995; 20(12): 9-10.

Melmed, M.H. Vulvar vestibulitis: relief with a low-oxalate diet and calcium citrate. *The Cervix and Lower Female Genital Tract*, 1995; 13(4):155-6.

A Special Thank-You To...

Jerry Levine of the Washington, D.C., office of Holland & Knight, for the pro bono legal services he provided to the NVA, and Trudi Wolin of Silver Spring, Maryland, for volunteering her accounting and bookkeeping expertise.

Vulvar Vestibulitis (from P. 5)

Because of the absence of visible symptoms in some cases, doctors have sometimes suggested to patients that the pain is due to stress or other psychological factors. As one exasperated woman recounted, "I saw at least five doctors before I was finally diagnosed with VVS. One of the doctors told me that the likely

also been tried, but with little success. In addition to their lack of effectiveness, some topical agents can actually cause irritation and exacerbate the problem. Application of a topical anesthetic to the vestibule can produce sufficient temporary relief, thus enabling some women to engage in sexual intercourse. For this purpose

drugs inhibit the uptake of norepinephrine and serotonin at the neuron juncture, thereby blocking the conduction of pain impulses from the periphery to the central nervous system.

Alpha-interferon injections are sometimes used as a treatment for VVS. Interferon is an anti-inflammatory substance that interferes with viral replication and was originally used to treat human papilloma virus (HPV) infection. At first, interferon injections were given only to vulvar vestibulitis patients who also were diagnosed with HPV infection. As it became apparent that techniques for determining the presence of HPV were inadequate, doctors began using interferon on vestibulitis patients without proven HPV and noted improvement in some cases. Recent studies on the use of interferon for VVS have shown at least partial improvement in about 50 percent of patients. Unfortunately, studies with a one-year followup revealed that symptoms returned in many cases.

Interferon is injected into the vestibule using a very fine needle, usually twice a week for four weeks. The side effects include influenza-like symptoms such as malaise, muscle aches, headache, and low-grade fever for several weeks following the injections. As one woman stated, "My first round of interferon treatments led to some improvement, so we tried a second round using higher doses. But the second series did not produce any more pain relief, and for six weeks afterwards I was extremely tired."

See VVS, Next Page

Diagnosing vulvar vestibulitis syndrome can be difficult because some patients do not present with any visible symptoms.

cause of my pain was psychological and sent me to a sex therapist."

Potential Treatments

As with dysesthetic vulvodynia (constant vulvar burning), there is no panacea for VVS. Since both the cause and severity of symptoms vary from patient to patient, there is no standard treatment. Women who have "pure" vulvar vestibulitis (pain only upon direct pressure) are likely to receive different treatment than those who have both VVS and dysesthetic vulvodynia.

Since the cause of VVS is unknown, treatment usually begins with one or more methods aimed at alleviating the symptoms. Conservative measures such as sitz baths and mild topical steroids have not been effective in most cases. Antimycotics (antifungals), non-steroidal anti-inflammatory agents, retinoid compounds, sex hormones and antibiotics have

many doctors prescribe 2 to 5 percent Xylocaine gel or solution to be applied to the vestibule 10 to 15 minutes before initiating sexual intercourse. Although Xylocaine is often irritating when first applied, the local anesthetic properties typically take effect within a few minutes. In conjunction with a topical anesthetic, the use of a water-soluble lubricant with few added preservatives (e.g., Astroglide) can also help make intercourse more comfortable by reducing friction on sensitive skin.

Although tricyclic antidepressants have been used successfully to alleviate constant burning, they are not as effective in cases of pure VVS. However, some physicians do prescribe these medications for VVS patients who also experience constant vulvar burning. Over the past 20 years, tricyclic antidepressants have been used successfully in the treatment of nerve-related chronic pain disorders. These

VVS (from p. 8)

One of the treatments with the highest success rate for vulvar vestibulitis is a surgical procedure known as vestibulectomy, or perineoplasty. In this surgery, the doctor removes the vulvar vestibule, including the hypersensitive vestibular glands, and then advances the vaginal mucosa (less sensitive tissue from the vagina) to cover the area. The appearance of the vestibule after surgery is similar to what it would look like after multiple childbirths. Hematomas (localized blood clots) or infections following surgery are rare, but sometimes small areas do not heal properly and may require further treatment.

Surgery is not usually the first line of treatment, but remains an option for patients with severe VVS who do not respond to more conservative measures. Even though the best candidates for surgery are patients with pure VVS, it also has been used in cases that involve constant vestibular pain. Reported success rates for vestibulectomy vary from 60 to 90 percent. One followup study of 93 patients found that, four to eight years following the surgery, 55 percent of the patients were fully asymptomatic, 33 percent were considerably improved, 8 percent were unchanged, and 4 percent were somewhat worse than before surgery. According to another recent study of patients with severe VVS, recurrence of vulvar pain after perineoplasty is rare.

Carbon dioxide laser surgery, which burns off the painful

See VVS, Page 10

BOOK REVIEW

It's Not All in Your Head: Now Women Can Discover the Real Causes of Their Most Commonly Misdiagnosed Health Problems

By S. Swedo, M.D. and H. Leonard, M.D., Harper Publishing: San Francisco, 1996.

This groundbreaking book reveals what most women have known all their lives—that when a woman experiences certain physical symptoms, such as those associated with PMS or chronic fatigue syndrome, the symptoms are “not all in your head.” Drs. Swedo and Leonard, two leading mental health experts involved in research at the National Institutes of Mental Health, relate individual stories to illustrate how the medical profession sometimes dismisses women’s physical complaints as psychological in origin. In a chapter titled “My Doctor Thinks I’m Crazy,” they describe a number of disorders which have biological bases but can be misdiagnosed by physicians. They review the symptoms of metabolic disorders, chronic fatigue syndrome, autoimmune conditions and vitamin deficiency disorders; also included is a summary of medications that can produce psychiatric symptoms. Another chapter, titled “My Hormones are Driving Me Crazy,” examines the hormonal bases of behaviors associated with PMS, postpartum depression and menopause. Contrary to the popular belief that female hormones induce women to act “crazy,” the authors conclude that these hormones cause only minor emotional and behavioral changes in most women.

Swedo and Leonard succeed in making the point that all women’s ailments deserve serious attention, regardless of whether the origin is physical or psychological. An entire section of the book is devoted to the diagnosis and treatment of psychiatric conditions ranging from attention deficit disorder to depression and psychosis. According to the authors, misdiagnoses can also be made when doctors fail to recognize the psychiatric disorders underlying physical symptoms. For example, during a panic attack a person’s chest tightens, the pulse races and breathing is difficult. In sorting through all the possible causes for these symptoms, it might not occur to the emergency room physician that the patient is experiencing a panic attack and needs a psychiatric referral.

It's Not All in Your Head is a book that is intended to help women understand the complexity of diagnosing different physical and psychiatric disorders. Hopefully, it will also succeed in equipping women with the knowledge to assist their doctors in making a proper diagnosis.

Vulvar Vestibulitis (from P. 9)

vestibular tissue, was once used to treat VVS, but the results have ranged from disappointing to disastrous. In some patients, the treatment has actually worsened the pain; third-degree burns and associated scarring have also occurred in some cases. Recently, however, a 43 percent cure rate

has been reported using a different type of laser known as the flashlamp-excited dye laser.

vation that longtime sufferers of VVS often unconsciously develop muscle tension in the pelvis (to protect themselves from the onset of pain), causing instability of the muscles. Through exercise therapy and biofeedback, patients can learn to strengthen and relax these muscles, thereby reducing

For most women who have VVS, coping with the emotional consequences is just as difficult as dealing with the physical pain.

has been reported using a different type of laser known as the flashlamp-excited dye laser.

It has been suggested that VVS may be associated with elevated levels of oxalate in the urine. As a result, some doctors recommend a low-oxalate diet, combined with large daily doses of calcium citrate, a mineral which may inhibit oxalate crystal formation in the urine. Women are cautioned, however, that it is difficult to completely eliminate oxalates from the diet and still obtain all necessary nutrients. Thus it is advisable to consult a nutritionist or doctor before starting this treatment. (See Oxalate Story in this issue.)

Some vulvar vestibulitis patients have undergone rehabilitation of the pelvic floor muscles to reduce pain. This involves pelvic floor muscle exercises and the use of electromyographic (EMG) biofeedback equipment to learn how to reduce pelvic muscle tension. This treatment is based on the obser-

the muscle spasms that can increase vulvar pain.

Psychological Consequences

Because it can destroy the ability to enjoy or engage in sexual relationships, VVS can have a devastating impact on a woman's life. It can inhibit a woman from entering into a relationship or cause the breakup of a marriage. Most sufferers find it difficult to talk about their condition with family, friends, or doctors. Consequently, they feel very alone. The intimate nature of the condition and the resulting isolation can lead to depression and a loss of self-esteem. As one patient described it, "the worst part of vulvar vestibulitis is thinking that something is wrong with me instead of thinking of it as a physical problem that can be fixed." For most women who have VVS, coping with the emotional consequences is just as difficult as dealing with the physical pain, and a partner's support can make a world of difference. In addition to the support of family and friends,

many vestibulitis sufferers find great comfort and reassurance by speaking with other women who have the disorder.

References:

- Baggish, M. and Miklos, J. Vulvar pain syndrome: A review. *Obstet. Gynecol. Survey* 1995;50(8):618-27.
- Bornstein, J. et al. Perineoplasty compared with vestibuloplasty for severe vulvar vestibulitis. *Brit. J. Obstet. Gynecol.*, Aug. 1995; 102:652-55.
- Friedrich Jr., E. Vulvar vestibulitis syndrome. *J. Reprod. Med.* 1987; 32:110-14.
- Glazer, H. Treatment of vulvar vestibulitis syndrome with electromyographic biofeedback of pelvic floor musculature. *J. Reprod. Med.* 1994;40(4):283-90.
- Goetsch, M. Vulvar vestibulitis: prevalence and historic features in a general gynecologic practice population. *Am. J. Obstet. Gynecol.* 1991;164:1609-16.
- Kaufman, R. et al. *Benign Diseases of the Vulva and Vagina* (Mosby Co:1994, 4th edition).
- Koblenzer, C. and Edwards, L. Vulvodynia: A common problem. *Fitzpatrick's J. Clin. Dermat.* 1995; 3(5):9-12.
- McKay, M. Vulvitis and vulvovaginitis: cutaneous considerations. *Am. J. Obstet. Gynecol.* 1991;165(4pt.2):1176-82.

See VVS, Next Page

VVS (from P. 10)

Mann, M. Vulvar vestibulitis: significant clinical variables and treatment outcomes. *Am. J. Obstet. Gynecol.* 1992;79:122-25.

Marinoff, S. and Turner, M. Vulvar vestibulitis syndrome: An overview. *Am. J. Obstet. Gynecol.* 1991;165(4pt.2):1228-1232.

Paavonen, J. Vulvodynia: A complex syndrome of vulvar pain. *Acta Obstet. Gynecol. Scand.* 1995;74:243-247.

Reid, R. Flashlamp-excited dye laser therapy of idiopathic vulvodynia is safe and efficacious. *Am. J. Obstet. Gynecol.* 1995;172:1684-1701.

Solomons, C. et.al. Calcium citrate for vulvar vestibulitis: A case report. *J. Reprod. Med.* 1991;36:879-882.

Back Issues Available To Subscribers

Six back issues of the NVA newsletter are available to anyone who is an NVA contributor. They contain interviews with leading experts in vulvodynia and vulvar vestibulitis. If you wish to purchase all six back issues, please send your name and address, along with a check for \$24, to:

Newsletters
P.O. Box 4491
Silver Spring, MD 20914

READER-TO-READER

Coping With Vulvodynia: One Woman's Story

I began a personal journal in early 1992, shortly before my husband and I became engaged. At that time, I was having frequent yeast infections and intermittent mild pain, yet my condition had not been diagnosed. My early writing reflected events in my life, as well as my feelings about finishing graduate school and embarking on a new career. It was a stressful period for me, and my physician suggested that my pain and yeast infections were due to stress. When my condition worsened and the pain became a continual burning, I was referred to another physician who, fortunately, diagnosed me immediately. He also confirmed that I wasn't the only woman suffering from this condition. My writings reflected anger and frustration about how long my symptoms would continue. Then things became even worse. I couldn't engage in many activities I used to enjoy, my work was disrupted by the pain, and there were increased tensions between my husband and myself. During this period, I was constantly in and out of the doctor's office, and given all kinds of medications to try.

Since vulvodynia is not easy to talk about, I found myself turning to my journal with increasing frequency. It was a way to unburden myself without worrying about someone passing judgment. Sometimes I was so low I didn't know how I'd get through the day. In one entry I described my physical appearance (weight loss, dark circles under my eyes, graying hair) and how I felt old, tired, and completely undesirable. I wrote, "Why me?" and, "Will I ever be normal again?" An especially low point occurred when my husband and I started seeing a therapist, and both of them pressured me to take antidepressant medication. As a health care professional myself, I was embarrassed that I needed that kind of help. I resisted initially, but eventually began taking Zoloft. Looking back on my writings during that time, it is clear that I was very angry and felt as though my husband and therapist were ganging up on me. But several months later, journal entries reveal I was feeling somewhat better and beginning to regain some energy. This renewed energy helped me to continue my struggle with vulvodynia.

Keeping a journal may not work for everyone, but it was beneficial for me. Today when I read my old entries, they remind me of a dark and scary period in my life. But they also help me to see how far I've come. If I have a setback now, I pull out my writings to remind me that my life isn't nearly as dreadful now as it was then. My journal also gives me hope that someday I will be able to make some sense of this physically and emotionally painful condition.

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

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