

Interstitial Cystitis and Vulvodynia

By Ursula Wesselmann, M.D.

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Many women who suffer from vulvodynia also suffer from interstitial cystitis. Some of these patients have had vulvodynia for many years and subsequently develop interstitial cystitis (IC). For another subset, IC is the initial diagnosis and vulvodynia develops afterwards. Alternately, both pain syndromes may evolve simultaneously.

The purpose of this article is (a) to give an overview of interstitial cystitis; (b) to discuss some of the similarities between vulvodynia and interstitial cystitis and (c) to consider a common pathophysiological mechanism that might be responsible for the development of both conditions.

Diagnosis of Interstitial Cystitis (IC)

IC is a chronic, inflammatory condition of the

bladder of unknown origin. The disorder is characterized by pressure and pain above the pubic area, as well as urinary urgency and frequency (up to 50 micturitions/day) and nocturia (frequent nighttime urination). Patients may also report urethral, vaginal or rectal pain, abdominal, lower back and thigh pain. There is no agreed upon etiology or pathophysiology for IC. In addition, there are no universally accepted diagnostic criteria. Those put forward by the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK) have become the criteria for the research-related definition, but have been regarded as too restrictive for use by clinicians. By the NIDDK criteria, IC is primarily a diagnosis of exclusion. The only defining pathology is the presence of mucosal ulcers (Hunner's patch) or

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The Growth of a Patient Advocacy Movement

By Phyllis Mate, NVA co-founder

Phyllis Mate has an M.A. in clinical psychology and has served as the NVA's volunteer executive director and President of the Board of Directors since 1996.

In 1994, five vulvodynia patients in the Washington, DC, area decided that they could not possibly be the only ones in the world with vulvodynia. This realization was a significant leap forward for the women who, like many vulvodynia patients, had suffered for years without receiving a diagnosis, and in some cases, had seen physicians who suggested their condition was psychological. Later that year, those five patients made a long-term commitment to become patient advocates by creating the National Vulvodynia Association (NVA). Little did we realize that what began as a small support group would become an international organization that today serves thousands of women worldwide. We were right—we weren't the only ones.

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glomerulations (small mucosal hemorrhages) viewed cystoscopically after sustained distension of the bladder. The presence or absence of mucosal ulcers separates patients with IC into those with ulcerative and non-ulcerative types. Glomerulations are not unique to IC, but occur in other forms of cystitis such as radiation cystitis (induced by radiation therapy for tumor treatment).

The symptoms of urinary urgency, frequency and suprapubic pressure and pain can be caused by many different diseases. The differential diagnosis of IC includes cystitis (infectious, radiation-induced, or chemotherapy-induced), bladder cancer, endometriosis, pelvic inflammatory disease, and chronic prostatitis (in men). Currently, there is no IC-specific marker. For now, IC remains a diagnosis of exclusion, confirmed only by a thorough clinical evaluation and selected tests to exclude other etiologies that produce similar symptoms.

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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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Etiology

The exact cause of IC is unknown, and is the focus of intense research efforts. Etiologies that have been considered include infection, lymphatic or vascular obstruction, immunologic deficiencies, presence of toxic urogenous substances, bladder wall lining deficiency, neural factors and primary mast cell disorders. It has also been hypothesized that what causes the onset of IC may have resolved, leaving in its wake a chronic visceral pain syndrome. Many researchers believe that a combination of etiologies is likely.

Prevalence

There are an estimated 700,000 cases of IC in the US, with projections running as high as several million. Since IC is under-diagnosed, it is difficult to determine the true prevalence of the disease in the general population. The most recent investigation on the epidemiology of IC used the Nurses' Health Study (NHS) I and II cohort as a study population and reported the prevalence of IC in NHS II as 67/100,000 (67 cases out of every 100,000) and in NHS I as 52/100,000. The majority of patients with IC reported in the epidemiological literature are Caucasian. More than 25 percent of IC patients are under the age of 30. A distinguishing feature of IC is the overwhelming incidence reported by women. Based on the National Household Interview Survey it was estimated that among IC patients the female to male ratio is 9:1. However, IC is not a disease limited to women; it can occur in any sex or age group, striking men, children and teenagers. Preliminary studies of men with nonbacterial prostatitis (inflammation of the prostate) reveal that they may actually have IC.

Treatment

Because the etiology of IC remains unclear, it is difficult to direct treatment against any specific cause or causes. Although there is no cure yet, once diagnosed, many treatment options are available. It is important to understand, however, that there are no uniformly effective treatments that are successful for all IC patients. The most effective

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treatment plans are tailored to the needs of the individual IC patient and include pain management strategies.

Patients with mild cases of IC may be helped by a change in diet, stress reduction, and behavioral interventions such as keeping a voiding diary and pelvic floor muscle training. Acupuncture and a transcutaneous electrical nerve stimulator (TENS) have been advocated for the treatment of IC, as well as several oral medications. In 1966, the oral medication pentosan polysulfate sodium (Elmiron) was approved specifically for the treatment of IC in the US. It is hypothesized that Elmiron may restore the protective lining of the bladder wall known as the glycosaminoglycan layer. Other medications that may help include medications used for chronic pain management, such as tricyclic antidepressants, anticonvulsants, membrane-stabilizing agents, NSAIDs, muscle relaxants and opioids. Medications such as hydroxyzine and other antihistamines that combat possible allergic mechanisms have been advocated. Bladder instillations of dimethyl sulfoxide (DMSO) or other agents (cortisone, silver nitrate, clorpectin, hyaluronic acid) are common treatments for IC. For a minority of patients with severe IC symptoms, implantable sacral nerve root stimulation devices or long-acting opioids have been employed. Non-surgical approaches are generally recommended for the treatment of IC, since irreversible surgical procedures too often have not resulted in the desired therapeutic outcome.

To date, most reports on treatment have suffered from lack of consensus in the medical community about what constitutes a case of IC and valid outcome data. In recent years, the National Institutes of Health, primarily NIDDK, have focused several major research initiatives on IC. Several multicenter controlled trials are currently underway comparing different treatment strategies for the management of IC, and it is hoped that this clinical research will result in improved—logical and systematic—treatment approaches in the near future.

Is there an IC/Vulvodynia connection?

It is a common clinical observation that IC and

vulvodynia often occur together in the same patient. One condition may precede the other, or they may develop simultaneously. In many cases, one disorder dominates, causing women to seek treatment for that disorder only. In the clinical setting, vulvar vestibulitis is the subtype of vulvodynia that seems to occur most frequently with IC. Women with vulvar vestibulitis describe pain at the introitus (entrance to the vagina) with sexual intercourse and upon inserting a tampon. On gynecological examination there is vestibular erythema (redness) and touch of the vestibule is very painful. The clinical observation of vestibular erythema associated with pain during sexual intercourse in vestibulitis patients was described by Kelly (1928). He noted exquisitely sensitive deep-red spots in the mucosa of the hymenal ring as a source of dyspareunia—tender enough at times to make a vaginal examination impossible.

The role of infection

In both vulvar vestibulitis and IC, initial research efforts concentrated on finding an infectious cause for the erythema at the vaginal introitus observed in vulvar vestibulitis and for the ulcerations observed in the bladder wall in IC. In fact, many patients report local infections at the onset of the disorder, i.e., women with vulvar vestibulitis report vaginal infections and women with IC report urinary tract infections. However, despite numerous research efforts, no causes for the inflammatory changes have been identified to date.

Neurogenic inflammation?

Another hypothesis is that neurogenic inflammation plays a role in the pathophysiological mechanisms of IC and vulvar vestibulitis, and that the inflammatory changes observed might be due to neurogenic inflammation, rather than an infection. What is neurogenic inflammation? It is generally accepted that noxious (painful) stimuli can increase the level of “pain-producing” substances by damage to local tissue. It is important to realize that substances contributing to painful sensations are actually present in the nerve endings of the

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nerve fibers that mediate pain and that these substances (e.g., Substance P, calcitonin gene related peptide, neurokinin A, neurokinin B) can be released by the nerve endings. When these substances are released, neurogenic inflammation, characterized by reddening, swelling and pain, is produced. Neurogenic inflammation has been described in numerous tissues, including skin, the joints, the eye, the middle ear, and the respiratory system, but it is not necessarily a pathophysiological mechanism that leads to a disease. In some situations, due to reasons that are unclear and are the subject of intense research, neurogenic inflammation can become maladaptive. There has been increasing evidence supporting the role of neurogenic inflammation in the pathophysiology of several diseases such as asthma, arthritis, and migraine.

A generalized disorder?

Interestingly, in addition to the strong covariation of IC and vulvodynia in women, a covariation of IC and prostatodynia (pain located anywhere in or around the groin, genitalia, or perineum) in men has also been reported. Since these body areas were all derived embryologically from the same tissue, the urogenital sinus, it has been proposed that these syndromes represent a generalized disorder of urogenital sinus derived epithelium. Further research is necessary to prove or disprove this hypothesis.

Conclusion

IC and vulvodynia, specifically vulvar vestibulitis, sometimes occur simultaneously in the same patient. This is an important clinical observation, suggesting that in a subset of patients, there may be a common etiology for the development of both disorders. This has important implications for researchers investigating the pathophysiological causes of these disorders, and ultimately for the development of treatments targeted against the pathophysiological mechanisms. This clinical observation also has practical implications for patients and their health care providers. Women who suffer from IC should know about vulvodynia, and vice-versa, so they can recognize the symptoms and seek proper treatment, if they belong to the

subgroup of patients who have both vulvodynia and IC. Similarly, health care providers need to learn about the concomitant occurrence of both disorders. Thus it is important that urologists, when consulted by patients with IC, ask them if they have vulvar pain in addition to their IC symptoms; similarly, gynecologists, who typically see patients with vulvodynia, should ask patients if they have urinary frequency, urgency and bladder pain in addition to their vulvar pain symptoms. Patients who suffer from both disorders would benefit greatly from this type of integrated approach.

References:

- Curhan G.C., Speizer F.E., Hunter D.J., Curhan S.G., Stampfer M.J. (1999) Epidemiology of interstitial cystitis: a population based study. *Journal of Urology* 161:549-552.
- Gillenwater J.Y. and Wein A.J. (1988) Summary of the National Institute of Arthritis, Diabetes, Digestive and Kidney Diseases Workshop on Interstitial Cystitis, National Institutes of Health, Bethesda, Maryland, August 28-29, 1987. *Journal of Urology* 140: 203-206.
- Hanno P.M., Landis R.J., Matthews-Cook Y., Kusek J., Nyberg L. The Interstitial Cystitis Database Study Group (1999). The diagnosis of interstitial cystitis revisited: lessons learned from the National Institutes of health interstitial cystitis database. *Journal of Urology* 161:553-557.
- Hanno P.M., Ratner V., Sant, G.R., Wein A.J. (2001) Interstitial Cystitis 2001: an evolving clinical syndrome. *Urology* 57 (Suppl 6A): 1-132.
- Sant G.R. (ed): Interstitial cystitis. Lippincott-Raven, New York, 1997.
- Wesselmann U. (2001) Neurogenic inflammation and chronic pelvic pain. *World Journal of Urology*, 19: 180-185.
- Wesselmann U. Vulvar Dysesthesia. In M.M. BLACK, et al., Eds., *Obstetric and Gynecologic Dermatology*. 2nd edition, pp. 161-166; Mosby, London, United Kingdom, 2002. ■

NIH Funds First Controlled Clinical Trial on Vulvodynia

The National Institute of Child Health and Human Development has just committed to funding a long-awaited clinical trial on the use of tricyclic antidepressants for chronic vulvar pain. The investigator, David Foster, M.D., of the department of Obstetrics and Gynecology at the University of Rochester Medical Center, has spent many years gathering retrospective data on the success rate of antidepressants in treating vulvar vestibulitis and performing research on its etiology. Last year, Dr. Foster received an NVA grant to continue his research on the causes of vulvar vestibulitis.

The first aim of the NIH-funded study is to conduct a randomized, placebo-controlled, double-blinded clinical trial to study the clinical efficacy of four medical regimens: topical lidocaine, oral desipramine, topical lidocaine combined with oral desipramine and placebo. Controlled clinical trials measuring the success rate of medication for vulvodynia have never been done. The tricyclic class of antidepressants, represented by desipramine, have gained empiric acceptance for the treatment of vulvar vestibulitis, although favorable therapeutic results have been reported by only a few retrospective studies or uncontrolled clinical trials.

Although the precise mechanism of action remains undefined for tricyclic antidepressants, a "central" action through the dorsal horn and brain stem has been suggested. In contrast to oral desipramine, Dr. Foster proposes that long-term, topical application of lidocaine may act through a "local" mechanism. This randomized, placebo-controlled, double-blinded clinical trial is designed to determine whether "local" or "centrally-acting" treatments alone, or in combination, are effective in treating vulvar vestibulitis. Outcome measures of success will include reduced overall pain, reduced pain to touch, reduced pain to standardized mechanical stimuli, increased pain-free intercourse, improved sexual function, and improved quality-of-life as measured by psychometric tests.

The second part of Dr. Foster's research will examine vestibular tissue samples in order to determine the relationship between certain genetic factors, pro-inflammatory cytokines (inflammatory substances) and response to treatment in vestibulitis patients. The aim of this analysis is to determine whether genetic characteristics and cytokine levels influence treatment outcome. ■

SUPPORT CORNER

Pam Fischer, the NVA support leader in the Chicago area, conducted a survey of her group members that included questions on medical history, current symptoms, and treatment outcomes. To date, Pam has analyzed the survey results of 36 women, and continues to administer the questionnaire to incoming group members. Keeping in mind that the following results are based on a small sample of patients, here are some of the highlights.

The age range of the sample was 21 to 88 years. The most startling medical history finding was that 64 percent of respondents had experienced low back pain (including tailbone injuries) prior to the onset of symptoms. Fifty-eight percent reported a sudden onset of vulvar pain. The most frequently reported symptoms were increased burning on prolonged sitting (84 percent), redness around the

vaginal opening (81 percent), and itching (78 percent). The majority of respondents also suffered from burning with urination and exacerbation of symptoms when walking. An overwhelming 86 percent reported having pain during sexual intercourse and 42 percent said they could no longer engage in intercourse.

The success of different treatment options was difficult to assess, given the small number of respondents who tried a particular treatment. Many experienced temporary relief from sitz baths, cool packs, Crisco shortening, and relaxation techniques. Those who tried physical therapy reported it was most beneficial when accompanied by pelvic floor muscle biofeedback. If you would like further information on the survey or its results, please e-mail Pam Fischer at pampatfish@aol.com. ■

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Educating patients and medical professionals about vulvodynia has been the NVA's top priority, but a lot of other work goes on behind-the-scenes: publicizing the condition and obtaining federal research funding are two of the areas in which we've made great strides. We're aware of all that remains to be done, but it's gratifying to see that some of our hard work has already made a difference.

Publicizing the condition

In 1994, print and TV health reporters expressed little interest in covering vulvodynia. It's amazing how much can change in eight years! A few years later, CBS television aired a primetime special, *The Body Human*, in which an NVA support group leader, her husband and her doctor were interviewed about her vestibulectomy. In February 2001, Drs. Laura and Jennifer Berman discussed vulvodynia and the NVA on Oprah. There have also been dozens of articles on the condition's diagnosis and treatment in popular magazines such as *Redbook* and *Self*.

In July 2001, millions of television viewers learned about vulvodynia on the season premiere of HBO's top-rated show *Sex and the City*. In that episode, Charlotte, one of the show's main characters, is examined by her gynecologist and told that she may have vulvodynia. She is perplexed when her gynecologist recommends an antidepressant and tells her to keep a daily pain journal. Consistent with the series' light-hearted tone, Charlotte's friends joke about her gynecologist's recommendations at lunch the next day. The NVA received hundreds of phone calls from vulvodynia sufferers who were indignant about the show's unsympathetic portrayal of such a painful condition. The NVA immediately issued a press release praising HBO for tackling the subject, but criticizing its insensitive portrayal. Eight major newspapers responded to the release within the next two weeks and published articles on the reality of living with vulvodynia.

While the NVA has been working diligently to generate public awareness, we were taken completely by surprise in October 2001 by the release of best-selling author Susanna Kaysen's second memoir, "The Camera My Mother Gave Me." In

this autobiographical account of her desperate search to find treatment for chronic vulvar pain, she writes, "It isn't cancer. It isn't diabetes. It isn't life threatening. It's just horrible." The memoir details both Kaysen's interactions with numerous medical professionals and the wide array of treatments that she tried. I am sure that many vulvodynia sufferers will identify with her seemingly endless frustrating experiences. (Unfortunately, Ms. Kaysen inadvertently made inaccurate statements about the NVA in her book and subsequently sent us a letter of apology.)

Internet Outreach

Shortly after the NVA's formation, co-founder Marjorie MacArthur Veiga promoted the creation of our Website, www.nva.org. Some board members were skeptical that women with such a personal condition would contact us via the internet, but we trusted Marjorie's judgment. Her foresight has enabled us to reach thousands of women worldwide. Most of our medical referrals and support services are concentrated in the US, but we also serve hundreds of women in Canada, the UK, Australia, Israel and a dozen other countries. In addition to receiving e-mails from women in all 50 states, we have been contacted by women in Malta, India and Yugoslavia! Regardless of the country of origin, the content of these e-mails is universal. Most women write, "I learned so much from your Website and it's so reassuring to know I'm not alone." Another unanticipated result has been the overwhelming number of medical professionals who use our Website as a resource. Christin Veasley, my co-worker of the past two years, quickly recognized the need to provide information tailored to the needs of medical professionals and is currently working on modifying our Website to fulfill this function. In the interim, she has obtained corporate sponsorship of a quarterly electronic newsletter summarizing recent medical journal articles on vulvodynia, which is disseminated to interested medical professionals.

Medical Conferences

For many years, the NVA's medical advisory board

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members have been making clinical and research presentations at meetings of the American College of Obstetricians and Gynecologists (ACOG) and the International Society for the Study of Vulvovaginal Disease. As the NVA has become more established, we have started coordinating vulvodynia presentations at national medical conferences such as the American Women's Medical Association and the American Pain Society meetings.

In April 2001, the NVA exhibited at the ACOG annual meeting for the first time and we were encouraged by the overwhelming interest in vulvodynia expressed by the attendees. When these gynecologists visited our booth we asked them, "Do you treat vulvodynia?" The most frequent reply was, "I try. It's a difficult condition to treat." We were very impressed by their candor as well as their desire to learn more about it. Exhibiting at conferences is expensive, but the NVA plans to attend as many conferences as possible. Other than the Internet, it is one of the best ways for us to reach a large number of medical professionals. By the end of the ACOG conference, we added the names of 500 doctors to our mailing list.

Under the skillful direction of chairperson Maria Turner, M.D., of the National Cancer Institute, the NVA helped organize the first National Institutes of Health (NIH) vulvodynia workshop in April 1997. More than 200 medical specialists from all over the world met to discuss the current state of knowledge on vulvodynia and determine future research strategies. This workshop was a turning point because it "put vulvodynia on the map" and led to the first federal funding of vulvodynia research. The next NIH vulvodynia symposium for medical professionals is scheduled for spring 2003. NVA medical advisory board member Dr. Ursula Wesselmann and I have participated in planning the program with chairpersons Dr. Turner and Dr. Phyllis Leppert, chief of reproductive health sciences in the National Institute of Child Health and Human Development (NICHD).

Lobbying for Research Funding

After the first NIH conference, the NVA approached Peter Reinecke, Legislative Director for US Senator Tom Harkin (D-Iowa), because the Senator

was a well-known women's health advocate. All of us are indebted to Senator Harkin and Mr. Reinecke for championing our cause and ensuring that vulvodynia has been included in Congress' NIH Appropriations reports. Ironically, some members of the US Congress learned about vulvodynia before some medical professionals did!

A recent Senate NIH appropriations report contained the following language: "Preliminary new research indicates that millions of American women suffer from vulvodynia, a painful and often debilitating disorder of the female reproductive system. Since fiscal year 1998, the Committee has called on the National Institute of Child Health and Human Development (NICHD) to support research on the prevalence, causes and treatment of vulvodynia. The Committee urges NICHD to significantly expand research on vulvodynia." Largely as a result of Congressional pressure, the NICHD allocated \$1 million per year for five years for vulvodynia research and funded the first four studies in early 2001. By the end of that year, another vulvodynia research proposal was approved for funding. NICHD's interest in researching the condition is growing and should be significantly advanced by the upcoming 2003 symposium.

One of the first proposals funded by NICHD was a prevalence study by epidemiologist Bernard Harlow, Ph.D, and gynecologist Elizabeth Stewart, M.D., both of Harvard University. (Dr. Stewart recently became a member of the NVA medical advisory board.) This five-year project will determine the prevalence of chronic vulvar pain among American women and differentiate its various subsets. According to Dr. Harlow, the study's preliminary data suggests that 18 percent of American women have suffered from chronic vulvar discomfort in their lifetime. Contrary to previous estimates that were in the hundreds of thousands, it appears likely that *millions* of American women suffer from some type of chronic vulvar pain.

NVA Research Fund

From the NVA's inception, one of our major goals has been to obtain federal funding of vulvodynia

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research. That process has begun and continues to move forward. The NIH typically funds researchers who submit scientifically sound proposals with promising pilot data. The aim of the NVA Research Fund is to pay for these pilot studies, enabling researchers to collect the data necessary to receive substantial NIH funding. Our first research award recipient, neurologist Ursula Wesselmann, M.D., of Johns Hopkins University School of Medicine, subsequently received NIH funding of her vulvodynia proposal in fall 2001.

Dr. Wesselmann has been studying the neurophysiological mechanisms of pain associated with vaginal inflammation and is also interested in examining hormonal effects in post-menopausal women with dysesthetic vulvodynia. Another NVA research award recipient, David Foster, M.D., of the University of Rochester Medical Center, submitted a research proposal to NIH that will be funded this fall. Dr. Foster will 1) investigate the efficacy of a tricyclic antidepressant and lidocaine in the treatment of vulvar vestibulitis patients, and 2) assess whether certain research findings on the causes of vulvar vestibulitis influence treatment outcome. The pilot studies selected for funding by the NVA are those that will advance

knowledge of the causes of vulvodynia and have potential to lead to more effective treatment.

The Power of Volunteers

The NVA's greatest strength lies in the commitment of its volunteers. Dozens of women across the United States, Canada, England, Israel and other countries have served as regional contact leaders. I have had the pleasure of meeting only a few personally, but I know most by name. To Jane, Nancy, Pauline, Pam, Karen and all our support leaders, I'd like to express our deep appreciation for your dedication to helping others. And on behalf of the thousands of women who have come to the NVA for support, I'd like to especially thank Harriet O'Connor, our volunteer Director of Support Services, for continuing to honor a promise we made to each other six years ago. ■

Editor's note: This article was excerpted from the author's chapter in Drs. Glazer and Rodke's Vulvodynia Survival Guide (see book review on p. 10). If you purchase the book by visiting the NVA website, www.nva.org, and click on the book cover, Amazon.com will donate a portion of the proceeds to the NVA.

READER TO READER

Sexual Intimacy and Vulvodynia

By Laura Wittke, a nutrition therapist recently diagnosed with vulvar vestibulitis.

For many of us with vulvar vestibulitis, painful intercourse is the most distressing symptom, and yet little is written about how to have a quality sex life when one suffers from the condition. Some of us are in constant pain that interferes with our desire for sex. Others have sporadic pain or pain mainly during penetration, and are frustrated in our desire for intimacy and sexual satisfaction. It is probably safe to say that most women with vulvodynia, as well as their significant others, experience emotional consequences that affects their relationships.

I interviewed Dr. Marta Meana, an assistant professor of psychology at University of Nevada Las Vegas, to find out what couples dealing with vulvodynia can do to improve their situation. Dr. Meana specializes in sex therapy, and with her mentor Dr. Irving Binik of McGill University, has investigated causes of painful sexual intercourse, focusing primarily on women who have vulvar vestibulitis syndrome (VVS).

Dr. Meana and her colleagues have found that women

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with VVS are no more likely to have predisposing psychological factors that might cause or exacerbate painful intercourse than women without chronic vulvar pain. For instance, the prevalence of past sexual abuse is no greater in women with vulvar vestibulitis. This is an important point for vestibulitis sufferers and their partners to grasp, i.e., the pain we experience during sex is not caused by relationship problems, lack of attraction to our partners, or unresolved sexual issues (although these issues may be important factors for any couple). Painful sex often leads to psychological and physical consequences, including a condition called psychogenic vaginismus. In this case, the woman's body tries to protect her from experiencing pain by constricting the vaginal muscles. Sex therapy can be effective in treating this type of condition and it is often helpful for sex therapists to work in collaboration with medical professionals to provide comprehensive evaluation and treatment.

While in most cases we don't know what *does* cause the pain, Dr. Meana and others have some ideas on how we can have a rich and fulfilling sex life in spite of it. Dr. Michael Plaut, an associate professor of Psychiatry at University of Maryland School of Medicine agrees with Dr. Meana that the first step is to stop thinking of vaginal sex as the only or best way to enjoy lovemaking. Tragically, many couples stop having any physical contact with each other when penetration becomes painful. Most couples tell Dr. Meana that they miss physical closeness and cuddling the most, not sexual intercourse.

The experts offered the following suggestions for what couples can do to enjoy sex despite vulvar pain.

- Above all, never have sex if you really don't want to. One more negative experience is not what you need.
- Concentrate on scheduling time together for closeness. Couples need to make time for each other in general.
- Make honest, loving communication your number one relationship priority. Tell each other the truth about your feelings and anxieties.
- It's OK to be angry! Anger about vulvar pain is a perfectly normal reaction for both of you to have. Let

your anger give you the energy to make positive changes about the things you *can* control.

- When you are feeling close and want to be sexual, spend lots of time getting aroused. "Foreplay" is a misleading term that implies that petting and caressing are only a prelude to "real" sex. Not true! Show and tell each other what feels good to you, and focus on the lovely sensations, not on specific goals.
- Learn to bring each other to orgasm without penetration. Betty Dodson's book "Sex for One" describes and illustrates this in a sensitive and loving way. Even among pain-free women, only 35 percent report being able to achieve orgasm from vaginal intercourse alone.
- Do not attempt penetration unless the woman is very aroused. If penetration is possible, use lots of water-based lubricant (such as *Astroglide*, *Allercreme*, *KY Silky* or *Liquid Silk*.)
- Try different sexual positions to discover which ones are more comfortable for you. (You can find suggestions for different positions in Dodson's book.)
- Remember that even among couples reporting sexual satisfaction as "very high", both partners rated only 40 percent of sexual episodes as "wonderful." Lower your expectations and take some of the pressure off!

Change Your Thinking

You can learn a lot from couples that experience other disabilities. Many people with problems ranging from erectile dysfunction to spinal cord injury have learned to develop satisfying sex lives after they abandoned preconceived ideas about what sex is or should be. Consider getting help from a sex therapist who understands vulvodynia. Adopt the attitude that whatever you can do to relax and enjoy one another will have a therapeutic effect.

References:

Sex for One by Betty Dodson, Crown Publishing, 1996.

Let Me Count the Ways by Marty Klein, PhD, and Riki Robbins, PhD, Penguin Putnam, 1998.

Society for Sex Therapy and Research:
www.SSTARNET.org.

Sex Information Education Council of the US:
www.siecus.org. ■

New Books on Vulvovaginal Health Published

The V Book: A Doctor's Guide to Complete Vulvovaginal Health

By Elizabeth Stewart, M.D. with Paula Spencer, Bantam Books: New York, 2002.

Dr. Stewart is assistant professor of ob/gyn at Harvard Medical School and the director of the Stewart-Forbes Vulvovaginal Specialty Service at Harvard Vanguard Medical Associates.

Dr. Stewart, a renowned gynecologist and vulvovaginal specialist, has written an excellent, reader-friendly guide on all aspects of "V" health, from basic anatomy and birth control, to the treatment of specific vulvovaginal disorders. This invaluable, comprehensive book provides answers to all the questions that women would like to ask their gynecologist, but rarely do. Among numerous other topics, Dr. Stewart offers advice on how to prevent vulvovaginal problems, practicing safe sex and types of birth control; gives a detailed description of a thorough gynecological examination; and even suggests how to evaluate the competence of your clinician.

Of particular interest to vulvodynia sufferers is the book's last section, the "Problem and Answer Guide," which contains detailed descriptions of the symptoms and treatment of vulvovaginal disorders, from the most common vaginal infections to vulvar cancer. This section contains chapters on living with vulvodynia and coping with painful sexual intercourse. Dr. Stewart recently said, "The number of pain patients has absolutely glutted my practice. Yet medical school curriculums are jammed and some gynecologists don't get the training or residency experience necessary to treat vulvar conditions correctly." Although *The V Book* was written primarily for patients, it also contains information that many gynecologists and other health care providers will find useful.

Dr. Stewart has successfully tackled what she refers to as "the last frontier" of women's health, an area that has long been neglected by the medical profession. *The V Book* deserves a place on every woman's bookshelf and it would be wise to give copies to your daughters as well.

Editor's note: If you would like to purchase either book, please log on to www.nva.org and click on the book cover. This will take you to the book's page on Amazon.com, and if you click on "add to cart" before exiting the page, 15 percent of the proceeds (plus 5 percent of all other Amazon purchases) will be donated to the NVA. (Currently, Amazon is offering free shipping on book orders of \$25 or more.)

The Vulvodynia Survival Guide

By Howard Glazer, Ph.D. and Gae Rodke, M.D., New Harbinger Press: Oakland, California, 2002.

Dr. Glazer is an associate professor of psychology in psychiatry and obstetrics and gynecology at Cornell University's Weill Medical College and a member of the NVA medical advisory board. He specializes in the use of pelvic floor muscle electromyography in the treatment of patients with vulvovaginal pain syndromes. Dr. Rodke is a clinical assistant professor of obstetrics and gynecology at Columbia University College of Physicians and Surgeons. In her clinical practice, she treats many patients with vulvodynia and other vulvovaginal disorders.

The Vulvodynia Survival Guide, a book completely devoted to chronic vulvar pain disorders, is the first book of its kind. Drs. Glazer and Rodke faced an enormous challenge here, interweaving findings from the medical literature with 20 years of clinical experience as vulvovaginal experts. This detailed review of the diagnosis and treatment of vulvodynia and vulvar vestibulitis will dispel myths about these misunderstood conditions and will be an invaluable tool for vulvar pain patients, their gynecologists and other health care professionals. References are included for those who want to read further on the subject, and for those in need of help, patient resources are provided.

The authors review all the theories on possible causes of both conditions, explain how to find appropriate medical treatment, and describe a variety of available treatments. *The Vulvodynia Survival Guide* also contains a chapter on support and self-help measures, written by the NVA's executive director. One of the great strengths of the book is Glazer and Rodke's thorough understanding of the consequences of living with vulvodynia, made evident by their inclusion of an extensive chapter on the management of chronic pain, as well as a final chapter on sexuality and pregnancy/childbirth issues. For those who once thought that no one else suffered from these debilitating conditions, rest assured — the publication of this book is further proof that you are not alone. ■

Research Participants Needed

Colorado Vestibulitis Study

Research study at the University of Colorado Health Sciences Center is investigating a new treatment (injections of botulinum toxin A) for vestibulodynia/vulvar vestibulitis. Candidates must not have any other pelvic pain syndrome. The study involves 6 visits over 16 weeks and involves no cost for patients. For more information, please contact Erin Reagan at 720-848-1742 or erin.reagan@uchsc.edu.

Vulvodynia Research in New Jersey

NIH-sponsored study needs women (ages 18-80) who suffer from vulvodynia and are not currently taking amitriptyline (Elavil). Subjects should not have any major medical illnesses. The study is being conducted at Robert Wood Johnson University Hospital in New Brunswick, NJ. For information, contact Andrea at 732-235-7799.

UCLA To Study Vestibulitis

Women with a diagnosis of vulvar vestibulitis syndrome may be interested in a 10 week UCLA treatment study utilizing vulvar and lower back (caudal) nerve blocks, i.e. injection of local anesthetic medicine. Physical therapy evaluation and psychological questionnaires are included. The principal investi-

gators are Andrea Rapkin, M.D. and John McDonald, M.D. For an appointment or further information, please call 310-825-7955 and ask for Joanne.

Self-Image and Social Lives is Focus of Canadian Study

Researchers at the University of Alberta in Canada are looking for women to participate in a study concerning how vulvodynia affects women's self-image and social lives. In particular, this study will focus on women who have had vulvodynia or vestibulitis (whether they knew it or not) before they first became sexually active or attempted intercourse (i.e., women who've been dealing with this condition since they were children or adolescents).

You do not have to live near the university to participate in the study. Participation will include taking part in a one to two hour interview that will be kept confidential. If you are interested in participating or want more information about this study, please contact Amy Kaler at akaler@ualberta.ca or 780-492-7579 (Mountain Time). ■

Moving?

Please send your change of address to:
National Vulvodynia Association
P.O. Box 4491
Silver Spring, MD 20914.
Newsletters are sent by bulk mail
and are not forwarded by the USPS. For
every piece of returned mail, the NVA
pays a first class postage fee.

FOR HEALTH CARE PROFESSIONALS

On October 11, 2002, Harvard Medical School's Department of Continuing Education will hold a one-day course on vulvar disease, vaginitis and vulvodynia. Speakers will include Drs. Elizabeth Stewart, David Foster, Bernard Harlow and Lynette Margesson. For information on attending, visit www.cme.hms.harvard.edu.

THE NVA NEEDS YOUR CONTRIBUTION

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

Name _____

Address _____

Phone (H) _____ (O) _____

E-Mail Address _____

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

\$40 \$60 \$100 Other \$ _____

\$60 Health Care Professional

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

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

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



NATIONAL VULVODYNIA ASSOCIATION

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