

## Vulvodynia: A Perplexing Disorder

### Questions and Answers With Stanley Marinoff, M.D.

Dr. Marinoff is an acknowledged international expert on vulvodynia and a member of the NVA Medical Advisory Board. These excerpts are taken from a recent NVA-sponsored presentation. More information on Marinoff can be found in the NVA Medical Advisory Board section on page 7.

**NVA:** How did you become interested in vulvodynia?

**SM:** My interest in vulvodynia was captured ten years ago by a group of patients I saw who had been sent from doctor to doctor and told it was all in their heads.

Upon examination, I could find some visible findings in some of the patients, though in others I couldn't detect anything unusual. However, I didn't believe it was all in their minds, and I decided to do some more in-depth research to see if I could find a cause, or at least a treatment. And that's how I got started.

**NVA:** What causes vulvodynia?

**SM:** Most vulvodynia is idiopathic, which means we don't know the cause. In a few cases, vulvodynia is the result of nerve injury. The nerves pass through muscles, and if these muscles are in a state of spasm, this could cause problems. Sacral nerves and their branches innervate the vulva. An injury to the spine, a tumor, or a cyst also could cause vulvodynia.

**NVA:** Could vulvodynia be caused by a bacteria or virus?

**SM:** We have looked exhaustively for bacteria but have never been

able to culture any. Vulvodynia could conceivably be caused by a virus, but we have not been able to isolate any specific virus. Some cases of vulvar pain are related to herpes viruses. These viruses live on the dorsal root ganglion, and periodically migrate to the skin and form painful vesicles. Some women develop a postherpetic syndrome. These women are treated with acyclovir to prevent or minimize outbreaks.

**NVA:** How is the pain in vulvodynia produced?

**SM:** In this disorder, the nerves send a pain message to the brain. It appears that the nerves "short

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## Psychologist Addresses Sexual, Emotional Aspects of Vulvodynia

**H**aving painful or interrupted sex, not being able to engage in sexual relations at all, and for some women not being able to have children. These were among the emotionally trying issues addressed by a psychologist who specializes in human sexuality and sexual dysfunction during an NVA-sponsored lecture in early November.

Peter Fagan, Ph.D., a clinical psychologist and director of the Sexual Behaviors Consultation Unit at Johns Hopkins Hospital, opened the presentation by conducting a role-playing session with two volunteers

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## LETTER FROM THE EXECUTIVE DIRECTOR

Dear Friends:

Vulvodynia causes a serious crisis in the lives of affected women, both physically and emotionally. For one woman, it means foregoing or delaying having children because of the pain brought on by intercourse. For another woman, it means giving up a job she loves because sitting for eight hours a day is impossible. Still other women fear losing husbands or lovers because intimacy is so painful. And for all of us, vulvodynia causes a serious disruption in our lives. We suffer tremendous pain, which often results in serious depression, not only because of the physical manifestations of the disorder, but also because vulvodynia can rob us of a critical part of our self image — our sexual identity.

The NVA was created in response to an urgent need for a national organization that focuses on vulvodynia. The NVA is committed to offering information and solace to vulvodynia sufferers, and to working with the medical community as it searches for the cause, or causes, of vulvodynia and its effective treatments or cures. These objectives are ambitious and can only be accomplished through public awareness and political recognition of vulvodynia as a debilitating disorder that deserves research funding.

The NVA is governed by an executive board composed of women who believe in a need for a national organization dedicated to improving the lives of those affected by vulvodynia. The executive board members bring experience in the areas of law, nursing, psychology, and business. Because vulvodynia can involve many physiological components, the NVA also has established a medical advisory board that includes health-care practitioners from the fields of gynecology, dermatology, urology, neurology, and psychology. Through their diverse backgrounds, the executive and medical boards are striving to build an organization that examines all viewpoints from a balanced, interdisciplinary perspective.

Until recently, women with vulvodynia have largely been isolated, going from doctor to doctor looking for answers. The NVA plans to change that. We will be a centralized source of information on vulvodynia and its treatments. We will work to gain recognition and awareness of vulvodynia as a serious women's health problem. We will work to secure funding for controlled research studies so that treatments can be tested for their effectiveness.

In the first issue of *NVA News*, Stanley Marinoff, M.D., presents some current theories and practices on vulvodynia, while Peter Fagan, Ph.D., discusses the emotional and sexual issues facing those affected by vulvodynia. *NVA News* also offers two interactive columns. In our "Reader to Reader" column, we provide a forum for subscribers to advise each other about the nonmedical aspects of living with vulvodynia. This issue's topic is whether and how to tell your friends that you have vulvodynia. Send your comments on this topic and in the next issue we will print some additional responses. In future issues, our "Health Forum" column, hosted by the NVA's medical advisory board, will answer medically related questions posed by our readers. We invite you to send in questions for these two columns.

We hope you will get involved in the NVA. Whether you suffer from vulvodynia, care about someone who has it, or work with vulvodynia patients, the NVA needs your input and commitment. We have an important and ambitious agenda ahead of us, and we are confident that we will succeed in our mission — but not without your talent, your support, and your help.

Jacqueline Smith  
Executive Director

## Marinoff (From P. 1)

circuit" and keep reinforcing the pain impulse. Therefore, we believe vulvodynia is a nerve-mediated disorder, and we primarily use tricyclic antidepressants to alter the nerve impulse.

**NVA:** Why do you prescribe the tricyclic antidepressants and how do they work?

**SM:** Ideally, the tricyclic antidepressants will block the nerve conduction of most of the pain impulses. The tricyclics have been widely used in this country since the early 1960s and appear

quite safe. They inhibit the uptake of norepinephrine and serotonin at the neuron juncture, thereby altering the transmission of nerve impulses. If there is no substantial relief, we evaluate the treatment plan and perhaps use another drug or class of drugs. Generally, the drugs in each class have similar effects,

foam rubber donut to take pressure off the perineum, applying topical anesthetics (lidocaine, etc.), using extra lubrication for intercourse, and rinsing the vulva after intercourse and after urinating. Studies have shown that large doses of prescription analgesics do relieve chronic pain, and that

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***"One gynecologist conducted a study on all patients who visited her office over a six-month period and 15 percent had vulvodynia."***

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The National Vulvodynia Association does not engage in the practice of medicine. It is not a medical authority, nor does it claim to have medical knowledge. In all cases, the NVA recommends that you consult your own health care practitioner regarding any course of treatment or medication.

but some people will respond to one and not another. Sometimes we must try several different drugs before we find one that is well tolerated and effective. Another type of antidepressant, Prozac, inhibits the uptake of serotonin by the neurons, but it does not seem to be effective in treating the pain of vulvodynia. In some cases of pain, especially that involving "stabbing pain," one of two anticonvulsants (Tegretol or Klonopin) are used. Some women have found relief from biofeedback, nerve blocks, acupuncture or a low-oxalate diet. When the pain localizes in the vestibule and intercourse is a significant problem, then the patient can be evaluated for surgery.

**NVA:** Anything else?

**SM:** Usually we prescribe comfort measures and wait for the tricyclics to be effective. These measures include placing ice packs on the area, sitting on a

these dosages are appropriate. This type of use does not turn people into addicts. In the extreme, there is a difference between dependence and addiction.

**NVA:** Does a patient ever stop taking the tricyclics?

**SM:** Some people can be weaned off of the tricyclics and do well. Others find they need the drug to be comfortable. At this time, I have patients who have been taking these drugs for up to three and a half years. There does not appear to be any problems with long-term treatment.

**NVA:** Would cutting the nerves help alleviate the pain, and how would that affect sensation in the vulva?

**SM:** Theoretically, cutting the nerves that form the sacral plexus would stop pain impulses. However, the patient would also have no bowel or bladder control either;

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## Marinoff (From P. 3)

therefore, this is not done. Some doctors have tried performing pre-sacral neurectomies (removal of part of a nerve). This type of treatment has not worked, and in some cases patients have become worse.

**NVA:** Can you explain nerve blocks and how they work?

**SM:** Nerve blocks generally consist of injections of local anesthetics and steroids around the nerve. A nerve block can last from one hour to a couple of days. Repeated blocks require that the same nerve be injected each time — something that can be difficult to do. Theoretically, if you were to use the blocks repeatedly, you could build to a point where the relief would last for months. However, nerves can become hypersensitive as a result of repeated blocks.

pain. VVS is one category of vulvodynia. While other subcategories of vulvar pain, such as pudendal neuralgia and essential vulvodynia, do exist, none are as clearly defined nor as consistently identified as VVS.

**NVA:** How do you treat pure VVS?

**SM:** First I use alpha-interferon injections into the vestibular area. This works in about 40 percent of the cases. For patients who still have pain, I perform a surgical vestibulectomy to remove the erythematous [red, inflamed] tissue in the vestibule. The little red spots in the vestibule are trigger points for pain.

**NVA:** What are the results of the vestibulectomy?

**SM:** Most women are improved after surgery. Many women can tolerate sexual intercourse with-

the Bartholin ducts can be blocked and little cysts may form. These can be treated. There also can be little areas that don't heal well and may need some further treatment. As for appearance, the vulva looks as it would after multiple childbirths.

**NVA:** Would you perform surgery on someone who had both pure VVS and fibromyalgia?

**SM:** Yes. Some rheumatologists may think the vulvodynia would return but then again it might not. The patient deserves the chance for a cure to one of her problems.

**NVA:** How many women suffer from vulvodynia?

**SM:** One physician did a study on all patients who visited her office over a six-month period and 15 percent had vulvodynia.

**NVA:** Who gets vulvodynia?

**SM:** It affects women of all age groups, from adolescence through menopause.

**NVA:** Does childbirth have a positive or negative effect on vulvodynia?

**SM:** The effect of childbirth is variable. For some women, it is the instigating factor. Women who have had vulvodynia prior to childbirth have reported effects ranging from feeling worse, to feeling better, to experiencing no change.

**NVA:** Vulvodynia is very difficult to live with emotionally. Do you recommend that patients seek psychiatric help?

**SM:** Yes. Not because vulvodynia is "all in the patient's head." On the contrary, this disorder is

*See MARINOFF, Page 9*

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***"Increased pain may result from changes in the hormone levels; changes in the vaginal pH; increased blood flow to the area, which could cause pressure on the nerves; or from something that alters the immune system."***

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**NVA:** What is vulvar vestibulitis syndrome (VVS) and how is it different from vulvodynia?

**SM:** Pure VVS is localized entirely in the vulvar vestibule, and is painful only to touch, pressure, or insertion (e.g., intercourse, tampon, etc.). Pure VVS is rare. Vulvodynia, on the other hand, literally means chronic vulvar

out any pain, and some women are improved enough to be able to have intercourse with only minimal pain.

**NVA:** What can be the complications of surgery?

**SM:** Hematomas or infections are the main complications, but these are very rare. In the long term,

# Psychologist (From P. I)

who brought up the sexual and emotional issues often associated with the disorder.

Fagan began by discussing "sexual versus sensual estrangement," and noted that the different ways in which men and women communicate may compound the problems brought on by vulvodynia. "There are gender differences in communication," he said, "and it's important to understand and not confuse what your partner is saying to you."

He noted that women whose partners seem to shy away physically and emotionally may be misinterpreting what's being said. "Men have been socially conditioned to respond to situations differently than women," Fagan related. "So just because your partner may not be showing the affection or understanding you expect, doesn't mean he doesn't care. He may be shying away because he's afraid that physical affection will lead to sex, and this makes him uncomfortable because he knows it might cause you pain."

As therapy, he advised that partners practice role-playing with each other to help work out their differences, especially during particularly sensitive or heated times. "There has to be a real changing of the guard on empathy," he noted. "Get out of your anger and your pain, and get into the skin of the other person. In a time when gender issues are being challenged, being polarized, it's important to know that there are differences."

To a certain degree, pain itself creates a barrier between partners. "There's pain and it's just a question as to what degree," said Fagan. "It's physically painful for her and emotionally painful for him. This creates a lot of guilt between the sexes, and a lessening of sexual desire on both of their parts. So unless the masochism scale is way off the chart, both sides are going to naturally recoil."

Fagan's advice: "Put less emphasis on sex and more focus on a slow, gradual building up of the sensual quality in your relationship. With my male patients who have problems with erections, I forbid intercourse. I tell them 'no orgasm.' I do this so they can regain

their sensual appreciation of each other,' he said.

"Playing games, touching, grabbing, doing things that say 'your body's good' also are essential," Fagan noted. "And it's particularly important for women with vulvodynia," he added. "Hearing that she is still desirable, still sexy, despite her condition, is the kind of reassurance a woman with this illness needs."

Fagan also talked about the emotional and psychological aspects of vulvodynia, and how patients and their families might best deal with their feelings.

*See FAGAN, Page 8*

## NIH Needs Volunteers for Study

The dermatology branch of the National Cancer Institute (NCI), National Institutes of Health, is conducting a study to evaluate the efficacy of desipramine for the relief of chronic vulvar pain and burning (vulvodynia). This will be a double-blind, placebo-controlled, cross-over study. Desipramine is a tricyclic antidepressant that has been shown to be useful in the treatment of chronic pain due to other peripheral neuropathies.

For this study, the NCI needs healthy women (age 18-64) with normal cognitive and communicative ability, who have had constant vulvar pain and burning of at least 6 months duration. To be eligible, participants must meet the following criteria:

They must not be pregnant or lactating; they must not have any condition that precludes the use of tricyclics; they must not have another severe chronic pain problem; and they must be off tricyclics, anticonvulsants, and psychotropic agents for at least four weeks prior to starting the study. They also must be willing to undergo tests and invest the time as detailed in the study regimen.

**For more information, contact Inga Tokar at (301) 496-2681.**

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# Meet the NVA Executive Board

## **Rhonda I. Brunell**

Rhonda I. Brunell received her bachelor's degree from the University of Texas at Austin and her juris doctor from Boston University School of Law. Brunell's role as an NVA board member thus far has been to assist in defining and drafting the mission statement and the informational brochure. She also acts as the NVA liaison to the fibromyalgia support-group network. She provides guidance and direction concerning nonprofit organizations, liability, and other legal, organizational and operational topics.

## **Marjorie MacArthur**

Marjorie MacArthur is an Internet computer network specialist for a telecommunications company in the Washington, D.C., area. She graduated cum laude from Michigan State University and has taken MBA courses from The George Washington University. She is developing a communications and public awareness campaign for the NVA. She is a member and volunteer for Fairlington Presbyterian Church, and Women for a Meaningful Summit. MacArthur is married and lives in Northern Virginia.

## **Phyllis Mate**

Phyllis Mate has a master's degree in clinical psychology from Concordia University, Montreal, Canada. She received her bachelor's degree in psychology from the University of Pennsylvania. After working as a school psychologist, Mate was a professor of child psychology for ten years. Recently she has written reports on gifted children and analyzed education issues for the U.S. Department of Education. In her spare time, she researches medical conditions and their treatments.

## **Harriet O'Connor**

Harriet O'Connor received her bachelor's degree in nursing from Georgetown University. She served in the Army Nursing Corps and has been active in forming both the Washington, D.C.-area vulvodynia support group and the NVA. She has gathered medical research on vulvodynia, and is particularly interested in helping patients assess their needs and gain access to medical services.

## **Jacqueline J. Smith**

Jacqueline Smith has been interested in vulvodynia for three years. She started the Washington, D.C.-area vulvodynia support group in November 1993 and the NVA six months later. She has a background in information management and retrieval, and in providing technical assistance. She has a bachelor's degree in sociology/correctional administration from the University of Wisconsin at Madison.

## **The NVA: A Goal and a Mission...**

The National Vulvodynia Association (NVA) is a non-profit organization created in 1994 to improve the lives of women affected by vulvodynia, a spectrum of chronic vulvar pain disorders. In accomplishing this goal, the NVA will:

- educate affected women about vulvodynia to enable them to make informed choices about their treatment;
- encourage patients to develop self-help strategies to deal with the physical and emotional components of this disorder;
- provide a support network for interested members;
- involve and educate loved ones to promote a more supportive family environment;
- coordinate a centralized source of information on suspected causes, current treatments, and ongoing research for health-care practitioners and patients;
- emphasize a coordinated interdisciplinary approach to patients' medical care;
- work cooperatively with other health organizations to improve our understanding of vulvodynia's relationship to other disorders;
- educate the public to bring attention to vulvodynia as a serious women's health concern; and
- encourage further research to find more effective treatments and eventual cures for vulvodynia.



## NATIONAL VULVODYNIA ASSOCIATION MEDICAL ADVISORY BOARD

**Maria Chanco Turner, M.D.** — Dr. Turner is a medical officer in the dermatology section of the National Institute of Health in Bethesda, Md. She received her medical degree from the University of the Philippines Medical School, Manila, Philippines. Dr. Turner also is a clinical professor in the department of Dermatology in The George Washington University School of Medicine, Washington, D.C. Over the past five years, she has published several papers on vulvovaginal disorders. Dr. Turner is currently conducting a National Institutes of Health study on the efficacy of tricyclic antidepressants in the treatment of vulvodynia. She is a member of the International Society for the Study of Vulvar Disease, the American Academy of Dermatology and the Society for Investigative Dermatology, and she serves on the Over-The-Counter Drug Advisory Committee for the U.S. Food & Drug Administration.

**Stanley C. Marinoff, M.D.** — Dr. Marinoff is in private practice in obstetrics and gynecology and serves as medical director of the Center for Vulvovaginal Disorders in Washington, D.C. He also is senior attending physician at Columbia Hospital for Women, and a clinical professor of obstetrics and gynecology in The George Washington University School of Medicine, Washington, D.C. He received his medical degree from The Chicago Medical School and a master's degree in public health from the Harvard University School of Public Health. Dr. Marinoff is a member of the American College of Obstetricians and Gynecologists, where he has served on the International Society for the Study of Vulvar Disease, and numerous other societies and committees. He has published many articles on vulvodynia, pudendal neuralgia, and the use of interferon in treating vulvodynia.

**Helene Emsellem, M.D.** — Dr. Emsellem is a clinical neurologist and director of the Center for Sleep Disorders at the Neurology Center in Chevy Chase, Md. She also is an associate clinical professor of neurology at The George Washington University Medical Center, Washington, D.C. Dr. Emsellem received her medical degree in 1977 from The George Washington University School of Medicine. She is a member of the American Academy of Neurology, the American Epilepsy Society, and the American Sleep Disorders Association. Dr. Emsellem has worked on establishing normative data on pudendal-nerve-evoked potentials, which may be useful in the diagnosis of vulvodynia. She has supervised the use of anticonvulsant drugs in the treatment of vulvodynia.

**David Foster, M.D.** — Dr. Foster is director of the division of general gynecology at Johns Hopkins Hospital in Baltimore, Md. He received his medical degree in 1976 from the Thomas Jefferson School of Medicine in Philadelphia. Dr. Foster has been an assistant professor at Johns Hopkins Medical School since 1989. He is a member of the American Fertility Society and the American College of Obstetrics and Gynecology, as well as an active member of the International Society for the Study of Vulvovaginal Disorders. Dr. Foster has published several recent articles and chapters on vulvar pain, and has worked extensively with vulvodynia patients.

**Betty Jean Reid Czarapata, C.R.N.P., C.U.R.N.** — Ms. Czarapata is the director of the Urology Wellness Center in Rockville, Md. She holds a bachelor's degree in health care sciences and a nurse practitioner certificate from The George Washington University, Washington, D.C. Czarapata is a member of the American Urological Association Allied, the International Continence Society, and the American Geriatric Society. She has experience in treating interstitial cystitis and vulvodynia.

**Peter J. Fagan, Ph.D.** — Dr. Fagan is an associate professor of medical psychology at the Johns Hopkins School of Medicine and a licensed clinical psychologist. He is director of the Sexual Behaviors Consultation Unit at the Johns Hopkins Hospital in Baltimore, Md. Dr. Fagan received his doctorate in clinical psychology from The George Washington University in 1984. He is a member of the American Psychological Association, the Society of Sex Therapy and Research, the International Academy of Sex Research, and the Society for the Scientific Study of Sex. Dr. Fagan has lectured extensively on the effects of medical illness on sexuality.

## Fagan (From P. 5)

"You're probably dealing with a lot of anger," he told the audience. "Anger at doctors you may have gone to who aren't aware of the disorder and who tell you you're frigid, or that the problem will eventually go away. Or anger at your doctor misdirected at your spouse.... And anger at family, friends and employers who don't understand what you're going through, or what it's like to have a chronic invisible illness."

Dr. Fagan also emphasized that it's important to build a support network. "Your group meeting here is an extremely important thing," he said. "Identifying and not pathologizing, talking to others about what you're experiencing is key."

In his closing remarks, Dr. Fagan emphasized the need to educate the medical community, especially with regard to the sexual aspects of the disorder. "Sexual issues are the last ones addressed by medicine," he said. "A lot of doctors haven't had a good sexual education, and sex is different than anatomy."

To further illustrate his point, Dr. Fagan brought up the medical community's past perception of sexual impotence in men. "Previously, 90 percent of all problems with erections were thought to be psychogenic and about 10 percent were thought to be biogenic," he said. "But [doctors are] not telling their male patients that today."

"Doctors need to develop the same sensitivities when treating women who suffer from vulvodynia," he added. "Telling a patient that it's 'all in her head,'

is simply not good diagnostic practice."

Many audience members echoed their agreement. As one participant noted of her experience: "I went to a number of doctors, but

the only medical professional I found who was willing to talk about the physical pain associated with sex was a psychologist. We need to change this."

— Cynthia Price

## READER TO READER

### Q — How do you approach telling people about your illness?

A — I decided to tell only my closest friends. Since most of my close friends are women, that minimizes the embarrassment. Most women have had yeast infections, so they can relate to the symptoms. I found that once I told one person, it was easier the next time. But it's definitely more difficult to reveal that one has chronic vulvar pain than it would be to discuss chronic back pain.

I also have found that people who have not experienced chronic pain do not understand how debilitating it can be. There is this erroneous belief that one can always minimize the pain by not thinking about it. Many people don't realize that the ability to distract oneself varies with the severity of the pain.

I used to have difficulty telling the men I dated about this unusual problem. Some of my boyfriends thought I was sexually uptight because I had pain in the clitoral area, and I never really tried to explain it because I didn't know what it was myself. Twenty years ago when I first started dating, doctors didn't even have a name for it. Now it is 20 years later, and my husband understands that my pain is real and that other women have this disorder.

I would like to be able to tell more people that I have vulvodynia. After all, the public has learned to talk openly about prostate disease, breast cancer, and sexually transmitted diseases. And medication for vaginal yeast infections is advertised constantly on television. So why should it be taboo to talk about vulvar pain? As with other uncomfortable subjects, the more we are willing to talk openly about vulvodynia, the easier it will be to deal with.

*Responses from readers are welcome. Send your reply to NVA, P.O. Box 9309, Silver Spring, Md. 20916-9309.*



## Marinoff (From P. 4)

indeed very real. However, the stress of living with chronic pain is very difficult.

**NVA:** Is heredity a component of vulvodynia?

**SM:** We have identified seven sister pairs and two mother-daughter pairs who have vulvodynia. However, we haven't done enough studies in this area to have a definitive answer.

**NVA:** Many women have cyclic changes in their pain level. For example, their pain may increase right before menstruation. How do you explain this?

**SM:** The ebb and flow of pain could occur for many reasons. Increased pain may result from changes in the hormone levels; changes in the vaginal pH; increased blood flow to the area, which could cause pressure on the nerves; or from something that alters the immune system. Theoretically, if this were true, we should be able to prevent the pain with birth control pills or drugs that stop menstruation. So far this has not worked.

**NVA:** We have recently been hearing that biofeedback may be helpful for vulvodynia. Can you explain?

**SM:** Biofeedback works by teaching people to relax the muscles that are tense or in spasm. It is possible that spasms in the pelvic floor muscles can cause compression of the nerves, resulting in pain.

**NVA:** Can you comment on the oxalate therapy?

**SM:** High levels of oxalate in the urine seems to contribute to vulvar pain in some women. We

don't understand why lowering the oxalate in the urine helps some women and has no effect on others. Perhaps the oxalate acts as a skin irritant. Some women seem to be sensitive to just one or a few foods and should avoid those foods. Rinsing the vulva with plain, cool water after urinating is a comfort measure adopted by many women.

**NVA:** There has been speculation that vulvodynia may be related to some other disorders, especially interstitial cystitis and fibromyalgia. What are your thoughts on this?

**SM:** We know that there is a correlation between those disorders and vulvodynia in the same patient, so that in any single patient it is possible that there is this relationship where she has one and the other. But before we can say the disorders are connected, we need to conduct further epidemiological studies.

**NVA:** Have you tried hormonal creams, such as estrogen or progesterone, and what have been the results?

**SM:** When we first started we used estrogen cream, but we

were not successful when we used it. Estrogen cream has always been known to be valuable in treating the vagina, but it's never been particularly successful in the vulvar area. However, since the vestibule is located at the connection between the vagina and the vulva, it is possible that estrogen cream may have some effect. It may be worthwhile to try it again.

**NVA:** Do you think there have been any significant advances in the field in the last 10 years?

**SM:** I think there have been tremendous advances. The biggest advance is that people now recognize vulvodynia. Doctors are starting to learn what this disorder involves and that it is a real entity, as well as something that needs to be treated. But we are just at the tip of the iceberg; there is still a lot we need to learn, and as we learn more our treatments will change accordingly.

— Harriett O'Connor

### NEXT ISSUE...

**Treating Vulvodynia** — A discussion with David Foster, M.D., director of the general gynecology division at Johns Hopkins Hospital, Baltimore, Md.

**The Politics of Women's Health** — A look at the where the government is spending it's money on women's health care.

**Dealing With Your Insurance Company** — How to get proper medical reimbursement for an illness that often falls through the health-care cracks.

## COPING

### *Sick and Tired of Feeling Sick and Tired — The Book*

Vulvodynia sufferers may gain insights on how to cope with their illness by reading the book, *Sick and Tired of Feeling Sick and Tired: Living with Invisible Chronic Illness*, by Paul J. Donoghue, Ph.D. and Mary E. Siegel, Ph.D.

The authors define invisible chronic illnesses (ICIs), most of which primarily affect women, as being without obvious symptoms. The list includes chronic fatigue syndrome, lupus, endometriosis, fibromyalgia, colitis, Crohn's disease, irritable bowel syndrome, migraine headaches, multiple sclerosis and thyroid disease.

ICIs have the following in common:

- they are difficult to diagnose;
- they do not follow the typical progression of illness;

- there is no cure;
- the patient endures suspicion by others that it may be a psychological condition;
- the patient looks well;
- treatments vary in effectiveness; and
- some symptoms have a social stigma attached to them.

In addition to advising patients on how to deal with the complications of chronic pain, the book doles out practical advice on how to talk to one's employer and how to get the attention of health-care specialists.

The authors discuss how patients, once diagnosed, can put their energy into getting "involved in the associations that disseminate information about their illness and raise funds for research." The authors also advise joining self-help and support groups "to feel less alone." Many such networks

are listed in the back of the book, along with an excellent reading list.

*Sick and Tired of Feeling Sick and Tired* is published by W.W. Norton & Co.

— Marjorie MacArthur

### Some Magic Happens

Some Magic Happens  
In this tight circle  
of Wounded Women  
We feel we have  
been violated  
by some unknown disease  
We know we are different  
But we know we are not odd  
Some Magic Happens  
In this group of women  
Kissed by Fear  
Touched by Anger  
Embraced by Hope  
Sharing Sadness  
from loss so vast  
for parts of our life in our past  
We are temporarily unbalanced  
We long for the days gone by  
for parts of our lives that  
have been taken away  
We know in the end  
We will be special women  
for enduring  
the pain, the anger, and the frustration  
We find substance in each small moment  
With each new treatment  
We face Fear  
We gather strength from the Pain  
Jewels through the Tears  
We know we will never be the same again  
for we have the gift of change  
and to know we received it all  
Through some MAGIC  
In this tight circle  
of Wounded Women

*This poem, contributed by an NVA subscriber, was written by a breast cancer survivor who wishes to remain anonymous.*

## CALENDAR

The NVA sponsors presentations on vulvodynia the first Saturday of every month in Bethesda, Md. Following is a list of upcoming of topics and speakers:

**Jan. 7** — David Foster, M.D., director, general gynecology division, Johns Hopkins Hospital. Topic: Vulvodynia and its treatment.

**Feb. 4** — Lorenz Ng, M.D., National Rehabilitation Hospital, Chevy Chase, Md. Topic: How to deal with chronic pain.

**March 4** — Helene Emsellem, M.D., director, Center for Sleep Disorders, Neurology Center, Chevy Chase, Md. Topic: Neurology and vulvodynia.

Calendar submissions from regional support groups and medical organizations are welcome. To submit an item or for details regarding specific meeting times and locations, call (301) 460-6407.

## Where to Turn for More Information On Vulvodynia and Related Disorders

*For more information on vulvodynia, as well as fibromyalgia and interstitial cystitis — two related disorders that sometimes go with it — you may contact the following organizations:*

### **The International Society for the Study of Vulvovaginal Disease (ISSVD)**

The ISSVD is a group of about 200 gynecologists, dermatologists, pathologists and microbiologists from all over the world. They have devoted time to the study of vulvar skin diseases, vaginal infections and/or vulvar cancer, as well as vulvodynia and vulvar vestibulitis. The ISSVD meets bi-annually to exchange information on vulvar disease.

The ISSVD distributes a pamphlet that describes the organization and lists the names and addresses of members. For a copy of the ISSVD pamphlet, send a self-addressed, stamped envelope to ISSVD, Secretary-General, 930 N. Meacham Road, Schaumburg, Ill. 60173-6016

### **The Interstitial Cystitis Association (ICA)**

The ICA was founded in 1984 by interstitial cystitis (IC) patients. IC is chronic inflammation of the bladder wall. Its cause is unknown and so is its cure. IC can affect people of any race or sex, but it is most commonly found in women. A 1987 epidemiological study estimated that 450,000 people may be affected.

Symptoms of IC include urinary frequency and urgency, and pain in the abdominal, urethral or vaginal areas. Some patients with IC report symptoms such as muscle and joint pain, migraine headaches, allergic reactions, and colon and stomach problems. Many women with vulvodynia report symptoms that may suggest IC, and there is speculation that these disorders are related.

Through the efforts of the ICA, much progress in IC has been made. Congress has earmarked funds specifically for IC, and hundreds of articles have been printed in such publications as *The New York Times*, *The Washington Post*, *Good Housekeeping*, and *US News and World Report* raising the visibility of IC as a serious health condition.

Over 100 ICA support groups operate across North America. For an annual contribution of \$35, contributors receive the quarterly ICA newsletter, *Update*. The ICA also offers a wide range of information on IC.

For details, write to ICA, P.O. Box 1553, New York, N.Y. 10159 or call (212) 979-6057.

### **Fibromyalgia Association of Greater Washington (FMAGW)**

An organization of national and international scope, FMAGW addresses the mission of improving the quality of life of those directly or indirectly affected by

fibromyalgia. The FMAGW focuses on patient and professional education, public awareness and research. It accomplishes this primarily through workshops, seminars, panel discussions, monthly meetings, a quarterly newsletter, the sale of audio and videotapes of past speaker presentations, and a lending and reference library.

According to the FMAGW, fibromyalgia is: a term that means pain in the muscles, ligaments and tendons (the fibrous tissue in the body); widespread musculoskeletal pain; a (sometimes profound) fatigue disorder, the cause of which is unknown; and a diagnosis of exclusion. Routine laboratory testing typically reveals nothing abnormal. Official diagnostic criteria consist of: (1) chronic, widespread musculoskeletal pain in all four body quadrants for a minimum of three months; (2) having at least 11 of 18 tender points that cluster around the neck, shoulder, chest, hip, knee, and elbow regions of the body; and (3) an invisible and very individual condition.

Other symptoms can include, but are not limited to, non-restorative sleep, body stiffness, cognitive difficulties, digestive disturbances, and headaches.

For more information, write to FMAGW at P.O. Box 2373, Centreville, Va. 22020 or call (703) 790-2324.

# 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