National
Vulvodynia
Association

NVA News

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Summer 1995

Chronic Pain: A Neurologist's Perspective

Questions and Answers with Helene Emsellem, M.D.

Dr. Emsellem is a practicing clinical neurologist in Chevy Chase, Md. and a faculty member of the George Washington University Medical School in Washington, D.C. She also serves on the NVA medical advisory board.
(A glossary of terms used in this interview can be found on page 8.)

NVA: When did you first become interested in vulvodynia?

HE: I was on the George Washington University faculty when Dr. Maria Turner, a dermatologist on staff, spoke to me about a patient whom she thought had a sensory loss. We determined that the patient did have a sensory loss in certain sacral dermatomes, commonly referred to as S2, S3 and S4. From my training in neurology, I identified this syndrome as pudendal neuralgia, nerve pain generated along the pudendal nerve. Dr. Turner saw several other patients with similar symptoms and was instrumental in describing this pain syndrome, now referred to as vulvodynia.

NVA: What can cause pain in the pelvic region?

HE: Pain can be produced by either the bony structure, muscles, organs or nerves. Bone abnormalities, for instance, cause deep aching pain which can secondarily lead to muscle spasms. The most common bone pain in the pelvis is caused by arthritic change in the sacrum and midline spinal structures, but the hips and sacroiliac joints themselves can be involved. Very rare structural problems with the distal part of the spinal cord can present as a perineal pain syndrome. Abnormalities along the posterior pelvic wall sometimes produce pain. Sacral cysts can compress the sacral nerve roots and cause pain, but these are also very rare. For these reasons, an MRI is appropriate when patients present with constant pain in the pelvic region.

NVA: What is the relationship between muscle spasm and pain?

HE: There are intrinsic pre-programmed reflexes which take over when certain pain is perceived. Pain causes a layer of

See EMSELLEM, Page 3

Improving the Status of Women's Health

The Society for the Advancement of Women's Health Research

From health care delivery to research priorities, almost everything concerning health and medicine is organized according to the male model. Much of what is known presently about the causes, treatments, and prevention of diseases that affect both men and women is the result of studies conducted solely on men. The consequences of this can be quite serious.

By the year 2010, there will be more than 21 million American women who are 50 years of age or older, compared to 5 million at the turn of the

See HEALTH, Page 5

INSIDE

Letter from the Executive Director

Dear Friend of the NVA:

Time flies quickly between newsletters and so much has happened since our last edition. I returned to Washington D.C. in June for the third annual Congress of the Society for the Advancement of Women's Health Research. The Congress is an important event, bringing together researchers, practitioners, and political activists to examine current issues in women's health. Both Hillary Rodham Clinton and Dr. Bernadette Healy, former director of the National Institutes of Health (NIH), spoke on the status of women's health research. Dr. Maria Turner, a dermatologist at NIH and NVA medical advisory board member, gave a presentation on vulvodynia which included data from the NVA patient self-report survey. This presentation was a significant step towards raising interest in vulvodynia among those at the forefront of women's health policy and research.

Analysis of the patient surveys is ongoing and we will report on some of the findings in our next newsletter. Dr. Maria Turner will present the data again in October at the Interstitial Cystitis Association's national conference. Dr. Stanley Marinoff, a vulvodynia expert and member of our medical advisory board, took a poster presentation of the survey results to last month's conference of the International Society for the Study of Vulvovaginal Disease (ISSVD). The ISSVD is an international group of physicians who meet every two years to present and discuss research on vulvar diseases, including vulvodynia.

We are excited about the expansion of the NVA national support system. Over the last several months new groups have been established in five states. A more detailed support update is contained in this newsletter.

Despite our recent progress, we still have a lot of hard work ahead if we are going to achieve our goals; these include supplying current information to patients and health care providers, obtaining federal funding for vulvodynia research, and expanding support services to our contributors. The NVA relies entirely on donations to fund its activities, and we need your financial help to continue our efforts. Any additional contribution that you can make will be greatly appreciated. Please consider asking friends and family members to make a tax deductible gift as well. Your contribution will help cover the cost of printing, photocopying, postage, and telephone. All these expenses are necessary to create materials on vulvodynia that will educate patients, health care professionals, medical researchers, government agencies and the public. At this time the NVA staff, myself included, consists entirely of hard-working volunteers.

Over the past several months, I have received many letters and phone calls thanking me for the valuable information provided in the NVA News. I truly appreciate your compliments and assure you that we will continue to strive for the highest quality in all our publications. I think that you will find this newsletter as informative as past issues. Any suggestions that you have for future articles are always welcome.

Wishing you a healthful and peaceful autumn.

Sincerely,

Jacqueline J. Smith
Executive Director

Emsellem (From P. I)

muscle around the site to clamp down, immobilizing the area. Often more pain is produced by these continuous muscle contractions than from the original insult. As the muscle spasm continues, it requires an enormous blood supply which is not adequately provided. Lactic acid accumulates and aggravates the muscle, creating more pain and in turn causing another layer of muscle to go into spasm.

NVA: Could muscle spasm account for pudendal nerve pain?
HE: I have not seen extensive muscle spasm in my patients with pudendal neuralgia. Most of the time when we see a pudendal nerve pain syndrome, we can't find any explanation.

> "Most of the time when we see a pudendal nerve pain syndrome, we can't find any explanation."

NVA: How do organs cause pain?
HE: Organs have stretch receptors, but they don't have specific pain receptors. Organ pain is usually felt as deep aching pain. Pelvic organs receive their nerve supply from the pudendal nerve which is made up of nerves exiting from sacral dermatomes S2, S3, and S4. Occasionally a uterine problem or other structural lesion in an organ produces referred pain that may be experienced as pudendal neuralgia.

NVA: Can you describe, as simply as possible, how pain perception occurs?
HE: Peripheral nerves possess specialized receptors (nerve endings) for hot, cold, position, and light touch. Pain is perceived by these raw nerve endings and along the entire course of the nerve. If something hot touches the skin, the nerve ending will transmit this information to the brain and a person perceives pain at the burn site. If you hit your elbow, you may feel radiating, electric-like pain down to your fingers, via the ulnar nerve.

NVA: What causes nerve pain?
HE: Neuralgias may result from direct injury, metabolic dysfunction or altered blood supply anywhere along the course of the nerve. Abnormal glucose metabolism in diabetics, for example, often causes peripheral neuropathy, perceived as burning pain in both feet. The precise cause of pudendal neuralgia has not been determined.

NVA: Does nerve surgery cure pain?
HE: Severing the nerve anywhere up to the dorsal root ganglion, where the nerve enters the spinal cord, or even where the nerve enters the brain, may still leave the patient with pain. The patient may continue to perceive pain in the same nerve distribution, because the brain interprets an impulse from part of the nerve to be an impulse from the entire nerve. This explains why cutting off nerve endings usually doesn't eliminate pain. Individuals with phantom limb syndrome still

See EMSELLEM, Page 4

NVA News
National Vulvodynia Association
P.O. Box 19288
Sarasota, FL 34276-2288
(941) 927-8503
FAX: (941) 927-8602

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Executive Director:
Jacqueline Smith

Editor:
Phyllis Mate

Contributors:
Marjorie MacArthur
Harriet O'Connor
Donna Wolf
Lynne Beauregard

Emsellem (From P. 3)

perceive pain in the amputated limb because the nerve still "thinks" it is supplying the whole limb.

NVA: How is pain in the pelvic region evaluated?
HE: An initial gynecological exam is performed to determine whether the pelvic structures are normal. Often the patient is seen by an urologist to evaluate any urinary aspects of the problem. If it is determined that there is not a treatable gynecological, urological or structural neurological condition, then general treatment strategies for pain are introduced. Since neurologists find pudendal nerve pain in disorders other than vulvodynia, blood work is necessary to rule out certain metabolic, auto-immune and infectious disorders. Specifically, a blood sugar test for diabetes and a syphilis test are indicated. In my practice I have even seen a woman with Lyme disease who presented with pudendal neuralgia.

> "Neuralgias may result from direct injury, metabolic dysfunction or altered blood supply anywhere along the course of the nerve."

NVA: How are neuralgias treated?
HE: Tricyclic antidepressants are generally the first class of drugs that are used. The specific tricyclic selected should fit the needs of the patient, as every medication may produce side effects. Some patients with depression tolerate high dosages of amitriptyline. If someone is sleepy on amitriptyline, a less sedating drug such as imipramine could be tried. Each person's dosage must be adjusted to suit her various needs and tolerances. Antidepressants are usually started at a low dose and gradually increased until an effective response is noted.

NVA: What other drugs are used to treat neuralgias?
HE: The newer serotoninergic antidepressants such as Prozac, Paxil, Zoloft and Effexor appear reasonably effective in managing neuropathic(nerve) pain. Recent studies in diabetic neuropathy confirm the efficacy of Prozac in relieving this type of pain. Luvox, a new antidepressant drug which has just been released in the U.S., may also prove to be useful in controlling nerve pain.

NVA: Are there drugs other than antidepressants which relieve the pain of neuralgia?
HE: Anticonvulsant drugs such as Dilantin, Tegretol and Klonopin are used in the treatment of neuropathic pain. Dilantin has a moderate pain-relieving effect. Tegretol, which has a different structure than traditional anticonvulsants, has been prescribed in the U.S. for more than twenty years. It has been used extensively in the treatment of trigeminal neuralgia and post-herpetic neuralgia, and seems particularly effective in vulvodynia patients who experience a stabbing type of pain. Once again, the dose should be increased slowly to minimize side effects. Although it is required that patients on Tegretol undergo routine blood monitoring, it is considered a very useful and safe drug. Klonopin, a benzodiazepine derivative, was marketed as an anticonvulsant in the 1970s and is a distant relative of the valium family. It has sedating effects, mild muscle relaxant properties, and tranquilizing effects. If someone has not found pain relief with other drugs, Klonopin might be considered. Like many other related drugs, however, it can precipitate a serious depression.

NVA: How do tricyclic antidepressants and anticonvulsants work?
HE: These brain-active compounds alter the availability of neurotransmitters at nerve endings and in central pain-related pathways. The net result is the alleviation of perceived pain.

See EMSELLEM, Page 8

Health (From P. I)

century. Breast cancer afflicts one in every eight women, yet we do not know what causes the disease, and 70% of new cases are diagnosed in women who have no known risk factors. Osteoporosis has struck more than 20 million Americans and is a main reason for nursing home admissions. The disease affects 50% of women 45 years and older and 90% of women 75 years and older. Depression afflicts women twice as often as it does men. One out of every seven women will experience an episode of major depression during her lifetime, and an estimated 15% of these women will commit suicide each year. Despite these figures, 75% of American women who experience clinical symptoms of depression go untreated.

Established in 1990, the Society for the Advancement of Women's Health Research is a national advocacy organization whose sole mission is to improve the health of women through research. The Society was formed because of mounting concern that the health of American women was at risk due to biases in medical research. During the past 5 years, the Society has helped expose gender inequities in biomedical and behavioral research. To secure much needed changes in this area, the Society's aims have been threefold: to ensure the inclusion of women as participants in clinical research; to increase the resources – in both dollars and brainpower – allocated to research on women's health conditions and diseases; and to increase the number of women in leadership positions within medical and scientific communities.

"One of the most important ways to ensure that more attention is given to women's health research is to place these concerns at the top of the nation's research agenda," states Phyllis Greenberger, the Society's executive director. This often means working within the established scientific, medical and academic communities to raise questions, increase the focus on gender-based differences in research and treatment, and pinpoint important areas for research. To further these aims, the Society convenes meetings of health leaders, researchers, and consumers at both the national and regional levels.

Each year the Society hosts a scientific advisory meeting that brings together medical and health specialties representatives. Through interdisciplinary dialogue among researchers and clinicians these meetings unveil new research findings, draw scientific attention to areas of neglect, and stimulate future interdisciplinary discussions. These educational events complement the scientific advisory meeting to promote discourse among researchers, health care providers, leaders of women's organizations, and consumer groups across the country. In addition, the Society conducts regional symposia on a variety of women's health topics.

Several months ago, Jacqueline Smith met with the Society's Phyllis Greenberger to explain the urgent need for research on vulvodynia and vulvar vestibulitis. Since then they have been working together to increase awareness of vulvodynia as a women's health issue deserving of federal research funding.

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Special Thanks

to Forsyth Industries, Inc. for their generous contribution to the NVA. We hope that this will be the first of many corporate donations.

Empower Yourself

Understanding your own medical condition is one of the first steps to empowering yourself and regaining control of your body. Because vulvodynia is a complicated disorder with a range of treatments, you will need to make decisions regarding your treatment options. But what if you do not feel well-equipped to make those decisions, and you are not even sure what questions to ask your doctor? This lack of knowledge can result in a loss of perceived control over your health and even your life. The answer to this problem is to gather as much information as possible about the disorder, as well as specific treatments you are considering. Many women have told us that becoming more knowledgeable about vulvodynia has helped to relieve their frustration and anxiety.

> "This lack of knowledge can result in a loss of perceived control over your health and even your life."

How does one go about researching a medical disorder? You have already made a good start by subscribing to this newsletter. Local support groups, where you can exchange experiences and information with fellow patients, are also a good resource. But if you want or need more specific information than these sources provide, the next step is to find some literature on the subject. Suppose, for instance, that you and your physician are considering surgery, and you would like an independent, detailed description of what the surgery entails, what the success rates are, and whether success is predicted by any predisposing factors. You might be able to find answers to your questions by reading studies published in medical journals. Such studies could also alert you to issues worth discussing with your doctor.

The NVA has prepared a bibliography of selected journal articles on vulvodynia, which you have already received. The articles on this list are a good starting point for your research. Although you can find most consumer publications at your local library, it probably will not carry many medical journals, which contain the most substantive information. If the journals you need are not available, ask your librarian if she can get them for you through an inter-library loan. If not, try a medical school or university library. Most colleges and universities allow the public to use their library facilities for free. Also, many people are not aware that most hospitals have excellent library facilities which are open to the public, so your local hospital could be the best place to begin. In addition, the National Library of Medicine maintains a national network of regional medical libraries open to the public. For a list of all Regional Medical Libraries, call (800)338-7657.

Some of you may be inclined to do some digging beyond the bibliography, especially since new studies are published on a regular basis. Many science and medical libraries subscribe to Medline, and will allow you to use it. Medline is a computerized database, maintained by the U.S. National Library of Medicine, which can be accessed on-line or on CD-ROM. It contains references and abstracts to worldwide journal literature covering medicine, dentistry, nursing, and related topics. The program allows you to conduct a search using key words such as vulvodynia, vulvar vestibulitis, vulvar disease, dyspareunia (painful intercourse), and pudendal neuralgia. If Medline is not available, the Index Medicus is the "Readers Guide" for medical journals. Printed in monthly and annual volumes, the Index Medicus contains references to current articles from 3,030 of the world's biomedical journals. In addition, for those who have personal computers, many of the on-line services such as CompuServe and Prodigy, provide access

See EMPOWER, Page 7

Empower (From P. 6)

to medical literature databases, including Medline. However, it is generally expensive to use the databases through these services, and most only provide references and abstracts, so you will still have to visit the library to obtain the full text of the articles.

Once you retrieve the articles, you will need a good medical dictionary to help you understand them. You should also read these studies with a critical eye. If a paper gives a success rate for a particular procedure or treatment, take note of how it defines the success parameters. For instance, while you might think success means 100% improvement, the researcher's definition might include the slightest symptom decrease. Follow-up of the patients in the study is also important. The longer the follow-up period, the more confidence you can place in the long-term results of the procedure. And be aware of the size of the study. Since success rates change as the number of patients using a particular treatment grows, the results of a study that looks at 100 patients are usually more significant than those of a study using only 15 patients. Controlled studies are also more reliable, although they are rare in vulvodynia research. A controlled study uses two groups of subjects, one which receives the treatment, and a comparison group which does not receive the treatment. In such a study, researchers look to see if there is a statistically significant difference between the two groups, with regard to the percentage of patients whose symptoms improve or resolve during the course of the study.

Retrieving and discovering information about vulvodynia can be empowering, and reading published medical research can be a helpful tool in your decision-making process. If you have questions about something you read, you might want to discuss them with your physician. By gaining knowledge about your medical problem, you can become an active partner in your own healthcare. Good luck!

> "Many people are not aware that most hospitals have excellent library facilities which are open to the public."

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.

Emsellem (From P. 4)

NVA: Are anti-inflammatory drugs such as aspirin and ibuprofen effective in relieving neuralgias?
HE: I have not been too successful in using the anti-inflammatory drugs for the chronic management of neuropathic pain. They may be helpful at times, if there is superimposed musculoskeletal pain and spasm.

NVA: Are narcotic pain relievers useful in the treatment of neuralgias?
HE: Narcotic pain relievers are ineffective if used on a chronic basis and have no place in the daily management of neuropathic pain.

NVA: Under what circumstances would nerve blocks be used in the treatment of vulvodynia?
HE: Nerve blocks might be considered if the patient demonstrates a pronounced intolerance for, or lack of response to, medication.

NVA: What has been your experience with the efficacy of nerve blocks for this condition?
HE: Responses to nerve blocks are variable. Some patients experience only a transient degree of pain-relief and others have partial, long-term relief.

NVA: In your work with neuralgias, does pain appear to increase or decrease over time?
HE: Most neuralgias tend to decrease over time. Pudendal neuralgia seems to be the most persistent neuralgia.

NVA: What other strategies can be used to manage chronic pain?
HE: Stress management techniques such as relaxation and guided imagery can be used to control pain. TENS (transcutaneous electrical nerve stimulation) units send an electrical impulse to the spinal cord which interferes with the reception and conscious perception of pain. Acupuncture seems to work for a percentage of patients. It may be a useful therapy for women who need to be off medication for certain periods of time, such as during pregnancy. Hypnosis may also provide pain-relief for some patients. All of these drug-free, non-invasive techniques can play a role in pain management programs.

> "Tricyclic antidepressants are generally the first class of drugs that are used. The specific tricyclic selected should fit the needs of the patient..."

GLOSSARY OF TERMS

Dermatome - an area of skin supplied with afferent nerve fibers by a single posterior spinal nerve root; a sacral dermatome refers to the skin area supplied by a specific sacral nerve.
Perineal - pertaining to the perineum; in females it refers to the region between the vulva and the anus.
Neuropathy - a functional disturbance or pathological change in the peripheral nervous system.
Peripheral neuropathy - a disturbance of the distal nerves, such as those in the hands and the feet.
Serotoninergic - containing or activated by serotonin, a neurotransmitter.
Trigeminal Neuralgia - excruciating, lancinating, episodic pain in the face, along the trigeminal nerve.
Postherpetic neuralgia - persistent burning pain along the distribution of a cutaneous nerve, following an attack of herpes zoster; it may last for a few weeks or several months.
Benzodiazepine - any of a group of minor tranquilizers which have anti-anxiety, sedative, anticonvulsant and muscle relaxant effects.
Neurotransmitter - a biochemical substance, such as acetylcholine, norepinephrine, serotonin, etc., that transmits or inhibits nerve impulses.

Reader to Reader

Q — When my vulvodynia flares up, I lose perspective and get depressed. How do other women cope with this?

First respondent:
I am a 31 year old long-term sufferer of vulvodynia. But for the past two years I have been virtually pain-free, without burning. That was until two weeks ago, when my vulvodynia flared up while I was sitting at my work desk. I became filled with anxiety, fearful that it had returned permanently. I waited a few days and called the pain-management clinic. My unique, supportive doctor of the past three years calmed me down, assuring me that symptoms fluctuate and suggesting that I would probably improve in a few days. He also let me know that if I didn't feel any better, there were plenty of alternatives to reduce the intense pain.

Iattended my regularly scheduled support group meeting which I look forward to each month. We discussed our fears about flare-ups and reminded each other that flare-ups come and go. By the time the meeting ended, I felt better.

My family called often during this period and was a source of great comfort to me. With all the emotional support from my family and NVA friends, I survived this flare-up and am back to feeling like my usual self. Support is great medicine to aid recovery!

Second Respondent:
I have had vulvodynia for the past four years and I can truthfully say that today I feel 90 percent better than I did when it started. In fact, most of the time I feel no discomfort from it. I have found a combination of treatments that works very well for me. Once in a while, however, the pain flares up for no apparent reason. I always feel frustrated when this happens and I start to get very anxious, wondering if I will be able to stop the pain. These episodes bring back memories of what it was like in the beginning, when I knew nothing about vulvodynia except that it caused terrible pain.

The first thing I do during a flare-up is call one of my friends with vulvodynia. No one can reassure me as much as a fellow sufferer. My friend reminds me that we have both been down this road before and have always bounced back to a comfortable place. Often humor works its way into our conversation and we move on to other topics, reminding me that I am much more than a woman with a chronic pain disorder. At least I am in control of what it does to my mind, if not always my body.

Next issue's question: *When you're having a particularly uncomfortable day from vulvodynia, what home remedies make you feel better?*

Support Update

The NVA support network is growing rapidly. Groups currently meet in Chicago, Buffalo, New York City, Long Island, Washington D.C., Boston, and southwestern Missouri. In an effort to expand the services provided to NVA supporters across the country, we recently sent out a questionnaire regarding participants' interest in local telephone networks and support groups. The form also asked for volunteer coordinators. We have already heard from a number of women interested in getting involved as leaders or participants, and we hope to hear from many more. If you have not yet returned this form, please do so as quickly as possible. The sooner we hear from you, the sooner we can institute telephone contacts and form more groups.

Donna Wolf and Harriet O'Connor, co-directors of affiliate affairs, are in the process of contacting all potential volunteers. Creating and organizing a national support system is a time-consuming process, so we ask for your patience. Donna or Harriet will contact you as soon as there is enough interest in your area to start a telephone network or support group.

Vulvodynia in the Workplace

Although some vulvodynia patients are physically unable to go to work, many of us are able to manage our pain and major work responsibilities. Often we find ourselves making excuses to our bosses for frequent doctor visits, the unpredictable side effects of medication, and other difficulties involved in living with chronic pain. We often wonder what it would be like if our co-workers and managers knew the truth. "If only they knew how much pain I'm in, they wouldn't criticize me, ask me to do one more thing or give me a poor performance appraisal," we say to ourselves. But we resist telling our colleagues and bosses that we have vulvodynia, not simply because of the embarrassment, but because we fear the consequences of revealing our condition.

Each work situation is unique and there is no guarantee that you won't regret sharing your pain. Dr. Mary Siegel, psychologist and co-author of Sick and Tired of Feeling Sick and Tired, writes, "You have to balance your fears of the effect of your disclosure with the stress of keeping your illness secret." Below are some suggestions for managing vulvodynia in the workplace.

RESEARCH COMPANY POLICIES

Do your homework. Research your company's human resources policies regarding disabilities, discrimination, and employment options (e.g., tele-commuting, part-time, job-sharing). As part of this research, try to answer the following questions. Does my company have written policies regarding these options? Are there minimum or maximum leave requirements? For example, a job-sharing arrangement may require a one year commitment from both partners. More specifically, consider the attitudes of your superiors. Sometimes your supervisor can be really understanding, but his/her boss is not quite as sympathetic. Think of chronic illness as a diversity issue. Do your supervisors seem tolerant of diversity? Do they have any other employees with special health circumstances? Do they themselves have parents or children who are ill? Is your superior a woman? If the answer is yes to any of the above, you may find more sympathy for your situation.

> "You have to balance your fears of the effect of your disclosure with the stress of keeping your illness secret."

WHY DO YOU WANT TO TELL ANYONE?

Decide what you expect to gain by being open about your situation. Do you want to be transferred to a less stressful job? Do you want to explain why your performance has been impaired? Do you want to take sick leave? Are you feeling guilty about calling in sick so often? If you want to change your hours or pay, be sure to have a specific plan to propose.

WHAT DO YOU SHARE AND WITH WHOM?

You may choose to tell only your boss. In deciding how much to reveal, consider what you would need to know if someone working for you had a health problem. If you are asking for a change in employment status, remember that your supervisor will have to tell his/her superior. If you work particularly closely with others, you may want them to know that you have a physical condition that occasionally interferes with your attendance. Expect several questions, both out of concern and curiosity. You are entitled not to answer questions that make you uncomfortable. You could say something like, "I don't want to discuss my condition, but I thought it was only fair to let you know why I won't be here at

See WORKPLACE, Page 11

Workplace, (From P. 10)

certain times." You are not usually required to divulge a medical condition unless you are taking extended leave. If that is the case, you may have to provide the human resources personnel with a confidential diagnosis from your physician.

WHEN TO BEGIN DIALOGUE
Timing is critical. If you are applying for a new position within the same company, it is probably best to explain how your schedule and performance will be affected. If you're concerned that you won't get the new job if people know, also consider how your boss will feel if you are eventually forced to reveal your circumstances. If you are job-hunting outside of your company, however, you may have difficulty getting hired and obtaining health insurance with a pre-existing condition.

IS REVEALING YOUR ILLNESS A CAREER-KILLER?
Consider the consequences. What's the worst thing that can happen? It's not likely you'll be fired, as that could lead to a discrimination lawsuit. You may fear that this will ruin your chances of advancement; on the other hand, chronic pain sufferers sometimes have to accept their limitations. If you fear that your job will be cut back, think about what you would do if you had more free time. Mary, a corporate manager who began a job-sharing arrangement because of her illness, felt that it gave her the time to become a better wife, daughter, sister, and aunt. From Mary's perspective, if you can afford it financially, accepting a reduced workload could be the best thing that ever happened to you! **(The next segment of this series will discuss what to say if you decide to share your personal challenge at work.)**

Board News

Donna Wolf elected to NVA executive board

The NVA is pleased to announce the addition of Donna Wolf to its executive board. Donna has an MBA from New York University and a bachelor's degree in English from the University of Rochester. Her experience includes human resources administration, financial analysis and business writing. Donna was active in forming the New York area vulvodynia support group and is its current leader. As the NVA's co-director of affiliate affairs, she is coordinating our national support network and volunteer program.

ISSVD 25th Anniversary Meeting

The International Society for the Study of Vulvovaginal Disorders (ISSVD) held its twenty-fifth anniversary meeting in Iguazu, Argentina from September 17-20, 1995. The purpose of the ISSVD is to promote international exchange on vulvar diseases between gynecologists, pathologists, dermatologists, and other physicians. Numerous presentations were given on vulvodynia, vulvar vestibulitis, lichen sclerosus, lichen planus, and vulvar cancers. Among several posters displayed was one summarizing the results of the NVA patient self-report survey.

The dedication of the ISSVD to treating vulvodynia was best summarized by one of the speakers who said, "At our meeting two years ago, we spent about 80% of our time on vulvar cancers and only 20% on vulvar pain. This meeting has nearly reversed that, with 80% of the presentations related to vulvar pain and only 20% to vulvar cancers." The ISSVD's commitment to clinical investigation, research, and dissemination of knowledge increases the likelihood that more effective treatments for vulvodynia will be discovered.

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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V
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NATIONAL VULVODYNIA ASSOCIATION
P. O. Box 4491 ❖ Silver Spring, MD 20914-4491