N National
V Vulvodynia
A Association

NVA News

Volume II, Issue I

Spring 1996

Disorders Associated with Vulvodynia

Summary of a Lecture by Daniel Clauw, M.D.

Dr. Clauw is a rheumatologist and Assistant Professor of Medicine at Georgetown University Medical Center in Washington, D.C.

There is a wide spectrum of conditions which share many symptoms: fibromyalgia (FM), chronic fatigue syndrome(CFS), migraine headaches, affective disorders, irritable bowel, female urethral syndrome, interstitial cystitis (IC), and vulvodynia. "I believe that all of these disorders are part of the same spectrum and that the same underlying problems lead to all of these syndromes," states Dr. Clauw. As an example of the overlap between these conditions, he points out that many women with fibromyalgia also have vulvodynia. And according to the Interstitial Cystitis Association, 26% of IC patients also suffer from vulvodynia or vulvar vestibulitis.

Two of the best documented of these conditions are FM and CFS, systemic conditions characterized by chronic pain and fatigue. FM was not defined until 1990. In order to receive this diagnosis, the patient must have chronic, widespread pain in all four quadrants of the body and pain in at least 11 of 18 trigger points. In 1994 a new definition for CFS was accepted. It is not based at all on the physical exam, but rather on a history of chronic fatigue plus four or more of the following: impaired concentration, sore throat, tender nodes, muscle pain, joint pain, recent onset of headaches, poor sleep, and post-exertional malaise. Five of these symptoms are types of pain. It is now clear that 50-75% of patients who meet the criteria for FM will likewise meet the criteria for CFS and vice versa.

Both FM and CFS are unusual rheumatological conditions in that they cause people to feel pain all over their bodies. In general, rheumatoid arthritis, lupus, and other rheumatological disorders cause pain in specific organs or joints. It is likely that FM pain is centrally, as opposed to peripherally, mediated, and results from a neural hypersensitivity of the central nervous system. Even

See CLAUW, Page 3

Acupuncture Today: A Brief Overview

by Bruce Rind, M.D.

Dr. Rind, a board-certified anesthesiologist, practices in Rockville, MD. He uses several acupuncture techniques, as well as other treatment methods, in his chronic pain-management practice.

Introduction

This article is intended as a brief overview of acupuncture as it is practiced today as a pain-management technique. When most people think of acupuncture, they think of an ancient Chinese method of healing using needles, that works for reasons unknown to Western medical science.

This notion of acupuncture is only partly true. For one thing, there are quite a few different acupuncture techniques besides traditional Chinese

See ACUPUNCTURE, Page 5

INSIDE

Letter from the Executive Director

Dear Friend of the NVA:

Recently I received a phone call from someone whose 35-year-old daughter committed suicide; it is only since her death that her family has discovered that the intractable pain she was experiencing was caused by vulvodynia. Although she visited many doctors, they couldn't find anything physically wrong with her, and she was told that her pain was "all in your head."

As some of you already know, Dr. Jack Kevorkian was recently acquitted for assisting in the suicide of Marjorie Wantz, who suffered from vulvodynia for many years. Although it was common knowledge that Marjorie Wantz had vulvodynia, several press reports referred to it as "pelvic pain." In fact, one Associated Press article described her condition as "psychogenic pelvic pain."

It seems that we are still in the dark when it comes to speaking about vulvodynia; this disorder remains taboo. People react with disbelief when they are told that a woman took her life because the pain of vulvodynia was so severe. They say there must have been something else wrong or that she must have been depressed or mentally ill. In one sense they are right – a woman with vulvodynia, or any person in severe pain who commits suicide, is undoubtedly depressed – but the depression is likely caused by the excruciating chronic pain.

I have spoken with countless women who are too embarrassed to speak openly about having this disorder. But there is an urgent need for vulvodynia patients to come out of the closet. If we don't publicize this disorder too many women will remain untreated; for a tragic few, it will mean the difference between life and death. So many times when I have spoken to people about vulvodynia, the listener has said, "I can't believe it-- my sister (mother, friend) has the same symptoms but couldn't figure out what was wrong with her." Recently I received a letter that expressed so eloquently the desperation of living alone with vulvodynia. It said in part, "For four years I believed that I was the only one living with vulvodynia...to discover you, your organization and a possible support group is overwhelming... Now because I know that you are there, I have been able to let go of some of that raging anxiety and push some of the fear and pain to the sidelines of my life."

To make the world aware of the severity of this condition, we, the patients, have to start talking to our friends, our families, our doctors, and the community at large. In addition to reaching women who are suffering and don't know where to turn, every time someone speaks up we inch forward toward the day when vulvodynia will be a universally recognized medical disorder. We need only to look at those who came before us, e.g., people with chronic fatigue syndrome, interstitial cystitis, or fibromyalgia, to understand the impact that patients can have when they find the courage to speak out. Through education and advocacy efforts, these patients have convinced the public and the medical profession that they have serious medical conditions deserving of greater medical attention and research. Now we must do the same.

Jacqueline J. Smith
Executive Director

Clauw (From P. 1)

though a diagnosis of FM is based upon pain in trigger points, the FM patient's entire body is more tender than that of the average person. But the brain only has the capacity to process a certain amount of pain at one time. In most FM cases, the patient has one or two areas where pain is most intense. If the initial focus of pain is relieved and the underlying problem is not addressed, the second most intense area of pain becomes the primary complaint. In order to achieve a complete reduction of pain, the underlying disorder, e.g., fibromyalgia, must be treated.

In addition to the major symptoms of fibromyalgia and related disorders, individuals who are diagnosed with these conditions often display a wide variety of allergic-type symptoms such as adverse reactions to drugs and environmental stimuli. Many also meet the criteria for multiple chemical hypersensitivity syndrome, a heightened reaction to chemicals and other types of sensory stimuli such as bright light, loud noise, touch, or foods. These symptoms may result from the activation of the central nervous system which is clearly demonstrated in FM. Dr. Clauw's contention is that people with FM, CFS, and vulvodynia are globally hypersensitive to sensory stimuli and also have "target areas" of acute sensitivity. For women with vulvodynia the target area is the vulvar region, but these patients may also be more sensitive to pain throughout their entire bodies.

Dr. Clauw believes that a genetic predisposition may account for the development of these related conditions. When he takes a comprehensive history from FM patients, he finds that their problems first surfaced in the teen years. Many patients experienced "growing pains," severe PMS, dysmenorrhea, or migraine headaches. A higher than average number also displayed attention deficit disorder. As young adults they often developed regional pain syndromes, usually resulting from physical, emotional, or immune stressors.

> "....people with FM, CFS, and vulvodynia are globally hypersensitive to sensory stimuli and also have "target areas" of acute sensitivity."

Tension or migraine headaches, anxiety, and depression also occur with higher frequency in individuals who have FM, CFS, vulvodynia, and IC. "My personal opinion is that people in constant pain are more likely to become depressed," says Dr. Clauw. It appears that there are neurotransmitter abnormalities at the level of the spinal cord or in the brain that can cause affective disorders. Similar types of neurotransmitter abnormalities may be responsible for FM and CFS. The drugs used to treat these conditions may be effective because they raise the level of serotonin, or even more likely, because they have effects

See CLAUW, Page 4

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

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

Executive Director:
Jacqueline Smith

Editor:
Phyllis Mate

Contributors:
Marjorie MacArthur
Harriet O'Connor
Carlotta Nelson

Clauw (From P. 3)

on other neurotransmitters. Some doctors believe that FM and CFS are primarily psychiatric conditions whose symptoms result from somatization. The preponderance of data does not support this, but it is difficult for some clinicians to change their attitude.

Dr. Clauw's experience is that many individuals who have FM and concurrent vulvodynia respond reasonably well to a regimen of education, medication, and exercise. Vulvodynia may require some additional local treatment. Patients need to learn how to manage these conditions. Elavil and Flexeril are the two most effective drugs for FM; Elavil also works for vulvodynia. They produce side effects which can be minimized by starting at an extremely low dose and increasing it very gradually. Many doctors who treat these regional pain syndromes commonly start Elavil at too high a dose and increase it too quickly. If taken two or three hours before bedtime, morning lethargy can be minimized. Dr. Clauw starts the patient on 5-10 mg. and increases the dosage 5-10 mg. every two weeks. Other tricyclic antidepressants may have fewer side effects, but they don't appear to be nearly as effective in treating FM and vulvodynia when they appear concomitantly.

Some of the newer antidepressant drugs (selective serotonin reuptake inhibitors) such as Zoloft, Prozac, or Paxil can also be effective, especially when used in conjunction with a low dose of Elavil or Flexeril. Wellbrutin, Effexor and Serzome may be more useful for CFS because they raise central nervous system levels of norepinephrine, which may be more helpful for people who are experiencing severe fatigue. The non-steroidal anti-inflammatory drugs do not appear to be very useful in treating these pain syndromes and can also cause gastrointestinal irritation with extended use. At this time, approximately 25% of Dr. Clauw's patients use Ultram, a new non-narcotic pain reliever. He also recommends hypnotics such as Ambian or Trazadone for patients experiencing sleep difficulties, who cannot tolerate Elavil or Flexeril at night.

Researchers are trying to raise the tissue levels of magnesium as a treatment for FM, but this is still experimental. Increasing levels of magnesium does help some people with FM and CFS, but it has yet to be determined which types of patients will benefit.

Aerobic exercise seems to produce more improvement in FM and CFS than any medication; drugs alone work at best 50-75% of the time. Getting patients into an exercise program that they can tolerate is the greatest problem. Women with vulvodynia have additional limitations, for example, bike-riding is impossible in most cases. Water exercise and swimming are often the best tolerated exercises for FM patients and may work for women with vulvodynia as well.

Five years ago very little was known about FM and CFS, but current research is rapidly expanding our understanding of, and ability to treat, patients with these conditions. Dr. Clauw believes that within the next decade, improved treatment strategies and pharmacological interventions for FM, CFS, and vulvodynia will be available.

"....many individuals who have FM and concurrent vulvodynia respond reasonably well to a regimen of education, medication, and exercise."

Correction

Our sincere apology to Dr. Gae Rodke for an error in her interview in the last issue (Winter 1996) of NVA News. Page 8, column 3, line 14 should read as: "....a diaphragm that has not previously been used for contraception, much as spermicidal jelly would be. She can then ..."

Acupuncture (From P. 1)

acupuncture, just as there are different styles of cooking, e.g., French, Italian, German. Each acupuncture style seems to work, although some styles work better for certain problems. Within each type, there is also great variation from practitioner to practitioner. Although two acupuncturists may have studied the same techniques and may be using the same guidelines for treatment, no two will treat the same problem in exactly the same way.

Types of Acupuncture

Let us start our overview of acupuncture with the approach called Traditional Chinese Acupuncture. Traditional Chinese healers believe that life energy, called "chi," flows through the body via a series of energy channels or pathways called "meridians." Treatment involves stimulating the body's own natural healing energies by influencing the "chi," using needles at specific points along these meridians.

These points can be influenced in a number of ways—for example, through insertion of extremely thin needles, through heat, and through pressure-massage. The theory is that this stimulation allows the body to release energy blockages which exist when a person has chronic pain or any other type of physical or emotional problem.

The traditional Chinese acupuncture approach also stresses the unity of body and mind. Its practitioners believe that anyone with chronic pain also has emotional symptoms, while anyone with mental illness has significant emotions that can block energy circulation, which, in turn, usually leads to physical pain.

A second type of acupuncture, Ryodoraku, was developed 40 years ago by a Japanese physician, Yoshio Nakatani, M.D. A Western-trained physician who was also skilled in traditional Chinese acupuncture, Dr. Nakatani developed a system of measuring skin resistance at various representative acupuncture points and used this information to aid in diagnosis and treatment. Unlike traditional Chinese acupuncture which attempts to influence the flow of chi, Ryodoraku attempts to

See ACUPUNCTURE, Page 6

NVA Support Network Expanded

At this time, NVA telephone contact groups have been created in twenty-two states — New York, Pennsylvania, New Jersey, New Hampshire, Connecticut, Delaware, Maryland, North Carolina, Georgia, Illinois, Wisconsin, Michigan, Iowa, Kansas, Ohio, Mississippi/Louisiana, Florida, Colorado, Arizona, New Mexico, and California. A group has also been established in England.

In order to create local groups, we need individuals who are willing and able to act as telephone contact leaders in their areas. Once we find a leader, we supply her with a list of the NVA participants in her region. Then she contacts these individuals by phone or in writing, and gives them her name, address and telephone number. It is recommended that the contactees communicate with the area leader every one to three months.

The purpose of these groups is to provide information and support to participants. We plan to keep the groups small enough to facilitate communication and exchange of information. We hope that this will alleviate the isolation that most vulvodynia sufferers experience. Often it is comforting just to know someone with the same condition, with whom you can share feelings once in awhile.

This effort has been very exciting for the NVA. Speaking with those of you who have volunteered to be leaders has given us additional information and insight into the treatment of vulvodynia. Your NVA is moving as quickly as possible to create telephone contact groups. If you feel that you can devote some time to serving as a leader in your area, please write to Harriet O'Connor, NVA, P.O. Box 4491, Silver Spring, MD 20914-4491.

Acupuncture (From P. 5)

establish a balance or equilibrium between the meridians by stimulating or sedating them as the situation requires. This is based on the notion that good health requires a proper balance between the meridians.

A third type of acupuncture, Koryo Sooji Chim, or Korean hand acupuncture, was discovered and developed in Korea in 1971 by Dr. Tae-Woo Yoo, an accomplished acupuncturist who originally trained in the traditional Chinese method. This type of acupuncture uses only points on the surface of the hand. Its practitioners believe that every acupuncture point on the body has a corresponding acupuncture point on the surface of the hand. Thus, if one wants to treat a painful shoulder, one might insert a needle on the point of the hand that corresponds anatomically to the shoulder, e.g. the "shoulder" acupuncture point on the hand.

Another type of acupuncture is Modern Western Acupuncture. Although this resembles traditional Chinese acupuncture in its appearance, it is really quite different. The difference lies in the reason for inserting the needles.

In placing a needle at the acupuncture point located in the web between the thumb and index finger, the traditional Chinese practitioner would be placing a needle at the "Ho-Ku" point in order to influence a meridian and the flow of chi. Practitioners of modern Western acupuncture would place the same needle in the same location, but would say that they were doing it to stimulate peripheral branches of the radial nerve in order to stimulate production of endorphins, which are natural morphine-like substances produced in the brain that cause us to feel less pain. Similarly, stimulation of a peripheral nerve may be used in order to produce a reflex vasodilation—that is, greater blood flow to a designated area by producing relaxation of the walls of the blood vessels in that area.

> "Although two acupuncturists may have studied the same techniques....., no two will treat the same problem in exactly the same way."

Another type of acupuncture is called Auricular Acupuncture. This involves placing needles into acupuncture points on the ear. In this system, different functions and anatomical locations are represented on the surface of the ear. Thus, if one were to have a painful elbow, one might treat it by placing a slender needle at the point corresponding to the painful elbow.

These acupuncture points can also be treated without needles by applying a gentle stimulation such as a weak electrical current or laser beam onto the surface of the ear where the needle would have been inserted. The amount of current used is extremely small and barely felt by the patient. Nonetheless, it can afford great relief.

When the ear is stimulated without the use of needles, this is called Auriculotherapy. This form of reflex therapy was discovered and developed approximately 40 years ago by Dr. Paul Nogier, a French physician. Dr. Nogier found that certain points on the outer ear, when stimulated, can influence the way pain is felt in parts of the body distant from the ear and which have no apparent anatomical relationship with the ear. Prior to Dr. Nogier's discovery, the Chinese had found only a small number of points on the ear which corresponded to parts of the body or body functions.

Reflexology is another technique for influencing an area of the body by stimulating points or areas at a distance from the painful area. In this case, areas on the foot that correspond to the painful area of the body are massaged.

See ACUPUNCTURE, Page 7

Acupuncture (From P. 6)

How Does Acupuncture Work and What Conditions Can it Help?

Before you decide whether or not you might like to try acupuncture, it is important to understand what acupuncture can and cannot do. I will be using the Western model for this purpose, since it should be easiest for readers to understand.

Acupuncture is a type of treatment that involves reflexes. A reflex is an automatic response to a stimulus that cannot be consciously controlled. Acupuncture influences function rather than structure. Structural problems—a broken bone, severed nerve, or irreversibly damaged internal organ, for example— cannot be helped by acupuncture. On the other hand, functional problems such as muscle spasms, joint pain or swelling, allergic reactions, and digestive disturbances can be influenced by acupuncture.

By now you might be tempted to say, "Hey, wait a minute! Surely our bodies were not fashioned in such a way that eventually we would discover acupuncture and begin sticking needles in ourselves as a cure for various problems! This just doesn't make sense!"

But it does make sense when you look at it from a different perspective. Both animals and humans were designed so that their central nervous systems only receive signals of deep tissue trauma in the event of serious injury. Our bodies were not designed with antibiotics and emergency rooms in mind! Rather they are supposed to be capable of healing themselves, on their own, after a severe trauma such as an animal bite or broken bone.

If any of our deep tissues are severely traumatized, a series of reflex responses intended to help us heal and protect ourselves come into play. Stimulation of the peripheral nerves makes the brain begin to produce endorphins, the morphine-like substances that decrease the amount of pain we perceive. This is perfectly reasonable to expect since, if we were to be in intense pain for days after an injury and thus be unable to eat or rest properly, our chances of surviving the injury would be greatly decreased.

See ACUPUNCTURE, Page 8

Additions to the NVA Medical Board

The NVA is pleased to announce the addition of Libby Edwards, M.D., and Dee Hartmann, P.T., to its medical advisory board.

Dr. Edwards is Chief of Dermatology at Carolinas Medical Center, Charlotte, N.C. She is also Clinical Associate Professor of Dermatology at Bowman Gray School of Medicine, Winston-Salem. Dr. Edwards received her medical degree from Bowman Gray School of Medicine in 1976. Her professional memberships include the American Academy of Dermatology and the Women's Dermatologic Society. Dr. Edwards is also a member of the International Society for the Study of Vulvovaginal Disease (ISSVD) and was the program chairperson for the Fourth ISSVD World Congress. She currently serves on their executive committee.

Dee Hartmann is a physical therapist who specializes in women's health and has been involved in the treatment of vulvodynia for several years. She is a graduate of the Northwestern University Medical School of Physical Therapy in Chicago, Illinois. Ms. Hartmann is a leader in the education of other physical therapists interested in the treatment of vulvodynia. She serves as Program Chairman of the American Physical Therapy Association's (APTA) section on Women's Health. Her professional memberships include the APTA, the Society of Urologic Nurses and Associates, the National Association for Continence, and the Interstitial Cystitis Association.

Acupuncture (From P. 7)

An injury might also be expected to stimulate our immune system and increase blood flow to the injured area, in anticipation of infection which often develops within 24 hours of an acute injury.

So you see, in looking at acupuncture in a Western sense, the stimulation of acupuncture produces a controlled, sterile, and harmless trauma which fools the body's defenses into responding with a desirable response such as increased endorphin production, improved circulation, improved immune response, and decreased inflammation. The practitioners of traditional Chinese acupuncture use their concepts of meridians and chi to explain what they observe when this type of controlled trauma is deliberately produced.

Unfortunately, this does not explain why we would have points corresponding to any part of the body on the surfaces of the hand, ear, or foot. It is my personal belief, along with that of many other acupuncture practitioners, that the body responds to acupuncture techniques as if a complete, replica image of the entire body can be found on the surface of all "end organs," such as the ears, hands, and feet.

Perhaps there is some type of yet-to-be identified neurological connection between given points on the brain and corresponding points on the ear, hand, or foot. Perhaps not. At this time, we do not know enough to answer these questions in a way that is acceptable to Western science.

In fact, there are many physicians who argue that a positive response to acupuncture is merely due to a placebo effect, such as hypnotic suggestion, where faith in the practitioner leads to a belief that the treatment will help. Although suggestion accompanies any type of treatment, I am convinced that a placebo response is not solely responsible for the positive results of acupuncture, since it has been shown to be effective in animals as well as people.

Questions About Acupuncture

Is Acupuncture Safe?
Acupuncture is very safe if practiced by a trained, qualified acupuncturist using sterile, disposable needles and proper skin cleansing methods. A few acupuncturists may use silver or gold needles which must be sterilized after each use. Be sure to ask the acupuncturist whether he or she uses sterile, disposable needles, and if not, what sterilization methods and precautions are being used.

What does acupuncture feel like?
The sterile, disposable needles used are quite slender and normally cause only slight discomfort upon insertion.

How long does it take for acupuncture to help?
Some people experience pain relief after only one or two sessions, while others may require as many as a dozen sessions before improvement is achieved. Not everyone is helped by acupuncture.

Are there people for whom acupuncture may not be safe?
Yes. Extreme caution is necessary in the treatment of individuals who are pregnant, have bleeding disorders, or take prescribed blood-thinning medication. Caution should also be used in cases of extreme susceptibility to infection or if the area to be treated is infected.

How can I find a qualified acupuncturist?
Talking to others with chronic pain who have had success with acupuncture is often a good way to find an accomplished practitioner. Both physicians and non-physicians practice acupuncture. Substantially more training is required of non-physician acupuncturists because they need to learn what conditions are appropriate for treatment, which locations on the body can be safely treated, and the importance of using safe, sterile technique. Most states require physicians, as well as their non-physician counterparts, to be licensed to practice acupuncture. It is essential that non-physician acupuncturists be licensed or certified in their state.

This article has been excerpted, with permission, from the September 1990 issue of Lifeline, the quarterly newsletter of the National Chronic Pain Outreach Association, Bethesda, MD.

Book Review

Screaming to be Heard: Hormonal Connections Women Suspect... and Doctors Ignore

by Elizabeth Lee Vliet, M.D., New York: M. Evans and Co., 1995.

"Won't someone listen to me? I know something is wrong. It's not all in my head!" These are typical utterances of the exasperated patients who arrive in Dr. Elizabeth Vliet's office. Dr. Vliet is a physician advocate for women, an endocrinologist specializing in Preventive Medicine and Women's Health. *Screaming to be Heard* contains a wealth of material on the interrelationship of women's hormones, health, and behavior. Dr. Vliet decided to write this book because she could no longer ignore the "screams" of women across the country. The author discusses dozens of problems affecting women, including fibromyalgia, interstitial cystitis, menopause, migraines, PMS, chronic allergies, and yeast infections.

During twenty years of medical practice, Dr. Vliet has found that many women have questions about their health that have not been adequately answered. These women also find that doctors do not listen to their concerns and that when they try to transmit information about their bodies, they are often dismissed as hypochondriacal, hysterical or neurotic. Among other personal stories, the author relates her own experience of having been treated this way, and empathizes with patients' feelings of helplessness in this situation.

Screaming to be Heard explores new insights about important, overlooked hormonal conditions that contribute to a wide variety of women's health problems. Each chapter identifies one unrecognized physical/emotional/hormonal connection. For example, one chapter discusses the relationship between hormones and chronic yeast infections. Dr. Vliet has found that repeated vaginal yeast infections decrease in frequency once a patient reaches a more normal hormone balance, thereby eliminating the need for antifungals.

In addition to its main focus, the book emphasizes the importance of the patient-physician relationship, including some advice on finding the right doctor. The author also stresses that it is essential to your health to gather information on the medical background of family members.

Screaming to be Heard is highly recommended reading for both patients and physicians who want to understand the complexity of women's health problems; this book is a good starting point for listening to what women have to say about their own physical health.

The NVA:

on the World Wide Web...

Thanks to the efforts of Michigan NVA participant Sandra Kosek, the National Vulvodynia Association now has a home page on the World Wide Web on the Internet. Individuals searching for information about vulvodynia can find the NVA brochure, press release, medical advisory board biographies, and excerpts from previous newsletters at http://www.sojourn.com/~nva/web/

The NVA has been on the web for nearly a year with fragments of our information located in multiple sites. We would like to thank these site providers for their generous donations of time and computer space.

on America On-Line...

The Vaginal Pain message center available on America Online has been moved to the Personal Empowerment Network (keyword: PEN). If you are an NVA contributor and an AOL subscriber, please identify yourself to MGMNVA by e-mail.

Vulvodynia in the Workplace

Employment Options
In this series' first article, the issue of whether or not to tell your employer and co-workers that you have vulvodynia was discussed. In the second part, practical tips for an open dialogue with your employer were presented. In this segment, we'll consider your employment options in depth.

You've decided to tell your employer, and perhaps a few co-workers, that you have a chronic condition and need to make changes in your work life. Before you take the next step, you need to prepare a proposal that optimizes your contributions as an employee without sacrificing your health. There are several alternatives which may be acceptable to both you and management: working part-time, job-sharing, taking advantage of the Family and Medical Leave Act(FMLA), employment on a consulting or temporary basis, taking a sabbatical, or going on disability. Let's consider each option.

Part-Time Employment
Benefits of part-time employment include days off to visit the doctor, time to try new treatments without fear of side effects, and reduced stress. The obvious disadvantage, if you are currently employed full-time, is a reduction in salary. If you're working full-time and have decided to cut back, it is sometimes possible to find a job in your firm that doesn't require a 40-60 hour week. On the other hand, this can be a great opportunity to create your own position. One woman observed her company's need to train its technicians and was able to set herself up as the project manager, working 20-25 hours a week on her own schedule. Be careful here though, because you can easily end up working full-time for a part-time paycheck! If you're not currently working, part-time employment can be a good way to get you out of the house and provide a healthy distraction to your pain, while helping to pay medical bills.

"....prepare a proposal that optimizes your contributions as an employee without sacrificing your health."

Job-Sharing
This is a relatively new concept for most employers, but many companies and job-sharing employees have found it an effective way to retain two employees who might have otherwise resigned. Job-sharing can take two forms: the employees share the same work responsibilities, or the employees divide the work according to their strengths. For example, if you were sharing a sales position with a partner, you could either divide the accounts or you could both maintain all the accounts, with one of you being pre-sale oriented and the other focusing on post-sale activities. The benefits of job-sharing are the same as those of a part-time position. The only difference is having a partner who does the work on your days off. Although this can be an advantage, some may find extensive communication with a partner burdensome.

Family and Medical Leave Act (FMLA)
In February 1993, Congress passed the Family and Medical Leave Act. This Act requires companies with more than 50 employees to provide employees with up to 12 weeks of unpaid leave during any calendar year, for any of the following reasons:

1) birth of a child or to care for that child;
2) placement of a child by adoption or foster care;
3) care for spouse, child, or parent if the spouse, child, or parent has a serious health condition (see FMLA for this definition); or
4) a serious health condition which makes you unable to perform any of the essential functions of your position.

See WORKPLACE, Page 11

Workplace, (From P. 10)

Before taking advantage of the FMLA, make sure you understand your company's policies regarding reinstatement to your position, years-of-service accrual, and maintenance of benefits while you're away. If the company is reasonable, taking a leave may be an excellent way to evaluate if the job is affecting your health. If you are married and your husband's company offers FMLA, you might also consider having your spouse take leave to care for you and your family.

Consulting or Temporary Employment

For flexibility and an income, consulting or temporary employment may offer you the option to work when you are well. As a consultant, you can work for a firm that has employed you in the past, as long as there are no rules against hiring former employees or "double-dipping," i.e., being paid a fee and collecting a pension. Consulting may not reduce stress as you must generate your own income and find reasonably priced health insurance. Temporary work, if you have the necessary skills, provides a consistent flow of opportunities from which you can choose. Be sure to research several employment agencies before signing up with one.

Sabbatical

If you feel well enough to pursue a higher level of education, a sabbatical is a form of sanctioned absence. Some companies allow a one or two year sabbatical and may even pay your college tuition, provided that you return to the firm for a pre-determined period. Again, you'll need to confirm how your salary, benefits, and tenure are treated while you're away, and what to expect when you return.

Disability

Going on disability is the most extreme option, but may be appropriate if you are in desperate circumstances. Disability policies vary with the employment situation, but in most cases you are eligible if you and your doctor declare that you are unable to "perform the essential functions of the job" due to a "physical or mental impairment which substantially limits one or more life activities." Life activities include walking, reading, and talking.

Resigning/Layoff

If you find your firm inflexible or unwilling to help in your search for an employment compromise, you can offer to resign. If your employer values you, this may result in the negotiation of a reasonable alternative. Before resigning, find out if there is a "force management program (FMP)," aka layoff plan. If you wait for the FMP you can volunteer to leave before retirement, with the benefit of receiving some or all of your pension and possibly a severance package. Why resign if the company will pay you to leave?

Most vulvodynia sufferers have good and bad days. If you are currently employed, you do not necessarily have to resign to pursue treatment. You should try to work at a level that allows you to manage your pain and maintain some financial security and health insurance.

Suggested Resources:
Breaking Out of 9 to 5, by Maria Laqueur and Donna Dickinson
Working from Home, by Paul and Sarah Edwards
Your human resources department or benefits administrator
Your yellow pages under Employment Agencies

Fundraising Committee

The NVA is forming a committee to explore innovative ways to raise money. If you are willing to work on this important committee, please contact Jacqueline Smith at 941-927-8503 (Fax# 941-927-8602) or write to her at the NVA office.

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.

N
V
A

NATIONAL VULVODYNIA ASSOCIATION

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