N National
V Vulvodynia
A Association

NVA News

Volume III, Issue II

Spring 1997

NIH Holds First Symposium on Vulvodynia

Physicians and medical researchers from nine countries convened at the National Institutes of Health (NIH) on April 2nd and 3rd, 1997, to exchange current knowledge about vulvodynia and establish future research directions. The NIH-sponsored conference, chaired by NIH dermatologist Dr. Maria Turner, was the result of a two-year collaborative effort of the National Vulvodynia Association, the Society for the Advancement of Women's Health, and several NIH institutes.

The workshop began with presentations by experts in the diagnosis and treatment of vulvodynia, and researchers in chronic pain. On the second day, attendees split up into smaller groups to discuss specific aspects of the disorder, such as vaginal ecology, neurophysiology of the pelvic floor, pain medication, and surgery. Following these group sessions, participants reconvened to hear summaries of the different group discussions, as well as suggested research priorities.

In her introductory remarks, Dr. Vivian Pinn, director of the NIH Office of Women's Health, informed the audience that the workshop recommendations would be incorporated into the institute's research agenda at this November's national meeting. Both Dr. Alan Moshell, Skin Diseases Program director, National Institute of Arthritis, Musculoskeletal and Skin Diseases, and Steve Groft, Pharm. D., director of the Office of Rare Disease Research, stated their expectation that vulvodynia would shortly be removed from the category of rare disease. The definition of a rare disease is one that affects less than 200,000 people in the U.S. Their view is consistent with the speculation of several physicians who have been treating vulvodynia for the past 15 years. "Prevalence studies are necessary to confirm that vulvodynia is not a rare disease; we need to know what the numbers are in order to lobby congress for research funding," said Dr. Maria Turner, chair of the program committee.

The presentations began with Dr. Turner's review of selected results

See NIH SYMPOSIUM, page 4

A Nurse Practitioner's Perspective

B.J. Reid Czarapata, CRNP, CUNP, is the director of the Urology Wellness Center in Rockville, Maryland, a private, independent practice specializing in continence, interstitial cystitis, and urgency/ frequency syndromes of the bladder. She is a member of the NVA medical advisory board.

As a nurse practitioner, B.J. Reid Czarapata treats not only the physical symptoms of vulvodynia, but also helps her patients manage the emotional and lifestyle side effects that often accompany the disorder. She understands that vulvodynia can affect womens' sexual relationships, participation in physical activity, and overall quality of life. Moreover, she is known for her compassion, sense of humor and a maternal quality that has led many patients to comment, "a visit to B.J. is like seeing your mom."

See NURSE PRACTITIONER, page 3

INSIDE

LETTER FROM THE EXECUTIVE DIRECTOR

Dear Friend of the NVA:

For the past 18 months, the NVA medical advisory and executive boards have been involved in preparations for the first NIH vulvodynia symposium. Two years ago, the NVA approached Florence Haseltine, Ph.D., director of the National Institute of Child Health and Development (NICHD) and Phyllis Greenberger, executive director of the Society for the Advancement of Women's Health, to seek their collaboration on a vulvodynia conference. With the support of Dr. Haseltine and the sponsorship of NICHD, the effort was subsequently joined by the National Institute of Arthritis, Musculoskeletal and Skin Diseases, the Office of Research on Women's Health, and the Office of Rare Disease Research, co-sponsors of the symposium.

This workshop would not have taken place without the tireless efforts of Dr. Maria Turner, NIH dermatologist and pioneer in vulvodynia research. After extensive discussions with the NVA executive and advisory boards, she planned and organized the entire conference. We are grateful to both Dr. Turner and to former NVA Executive Director Jacqueline Smith, who served as conference coordinator.

During the workshop, NVA executive board members met and spoke with doctors from all over the country who are treating vulvodynia and vulvar vestibulitis. In addition to learning about different treatment regimens, we were able to obtain a great deal of practical information. When I told a few specialists that some vulvodynia patients had to wait months for appointments, they recommended that patients specify that their problem is vulvar pain when calling for an appointment. It appears that in certain doctors' offices, vulvodynia patients receive preferential treatment.

The significance of the NIH conference is threefold. First, we anticipate that it will stimulate much-needed research on vulvodynia, investigating causes as well as treatments. Second, it will help to increase awareness of the disorder in the medical community. Lastly, it is generating the publicity that is critical for reaching vulvodynia sufferers. As a direct result of the conference press releases sent out by the NVA, New Woman and Shape magazines are planning articles on vulvodynia for upcoming issues.

I'd like to take this opportunity to express my gratitude to all the hard-working NVA volunteers, especially our regional contact leaders, who continue to devote time and effort to helping others. Without their participation, we could not possibly provide the one-on-one support that means so much to women who have been living in isolation with this disorder.

Very truly yours,

Phyllis Mate

Nurse Practitioner

(from page 1)

Soon after she opened the Urology Wellness Center in 1992, patients with other chronic pelvic pain conditions began to appear. Today, at least 15 percent of her practice is composed of women who have vulvodynia; many of her patients suffer from both vulvodynia and interstitial cystitis. In treating the disorder, she focuses on assessing and treating symptoms, rather than diagnosis. Traditional treatments include antibiotics, antifungal, and pain medication; complementary treatments include musculoskeletal therapy, diet management, bladder and bowel training, exercises, biofeedback, and counseling. The goal of treatment is to get patients "back into living real life, even though they don't feel 100 percent," said Czarapata. These goals may include the ability to enjoy sexual intercourse, getting pregnant, and/or being able to participate in physical activities.

She believes that there is a certain advantage to having nurse practitioners treat vulvodynia patients. (Nurse practitioners must complete a two-year nurse practitioner program after receiving their baccalaureate nursing degree. Although they cannot perform surgery, nurse practitioners can diagnose, treat, and prescribe medication.) Vulvodynia can affect many aspects of the body, including stress levels, sex, bowels, bladder, and skin. Unlike many physicians, nurse practitioners focus on the whole patient instead of just one organ system. "For some conditions where quality of life is a significant issue, I think that trying things that are fairly simple and noninvasive may work better initially," she commented.

Czarapata's initial treatment protocol for vulvodynia includes antibiotics plus Nystatin to control yeast. In addition, patients are placed on the preliminary interstitial cystitis (IC) diet, evaluated for musculoskeletal problems, and educated on bladder and bowel functioning. In some instances, patients may be referred to physical therapists, chiropractors, or podiatrists (even the way a person walks can refer pain to the pelvic area).

In Czarapata's experience, many vulvodynia patients have fastidious bacteria in their urine, i.e., bacteria that that does not grow on standard culture plates. These patients often have negative cultures when tested in a doctor's office, but if a broth culture is used for a longer time, specific bacteria sometimes emerge. If a patient tests positive for bacteria, antibiotics are prescribed, typically 100 mg. Macrodantin or 250 mg. Augmentin, three times a day. In order to control yeast growth, this is combined with Nystatin three times

See NURSE PRACTITIONER , page 9

The goal of treatment is to get patients "back into living real life."

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

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

Editor:
Phyllis Mate

Assistant Editor/Layout:
Andrea Hall

Contributors:
Dee Hartmann, P.T.
Nicki Sideris

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

NIH Symposium

(from page 1)

from the NVA's patient survey. The self-report survey, completed by 500 women with vulvodynia or vulvar vestibulitis, includes questions on the development of symptoms, associated chronic pain disorders, and quality of life. The average age of respondents was 43 and the average number of years with vulvodynia was five.

Survey results indicated that vulvodynia impacts on several areas of a woman's life. As a consequence of vulvar pain, 61 percent of respondents experienced difficulty sitting, 50 percent limited their participation in aerobic exercise and 53 percent were restricted in their clothing choices.

With regard to sexual behavior, 81 percent of survey respondents reported that vulvodynia significantly limits their ability to engage in sexual intercourse. Dr. Turner added that, in her own data collection, 44 percent of her vulvodynia patients experienced pain during sexual intercourse, while 27 percent experienced pain after intercourse.

NVA Web Site

The Web Site address has been changed to: http://www.sojourn.com/~nva

If you have an email address, please send it with your name to: P.O. Box 4491 Silver Spring, Maryland 20914

Difficulties in Diagnosis

One of the key issues underscored at the workshop is the need for well-defined, consistent terminology. Many doctors use the terms vulvodynia and vulvar vestibulitis interchangeably because they are both vulvar pain syndromes. In order to compare research results, it is essential that these terms be defined and used correctly. "Part of the problem is that vulvodynia can have multiple causes and is not a diagnosis in itself," said Dr. Raymond Kaufman, chief of obstetrics and gynecology at Baylor College of Medicine. "Some doctors use the diagnosis of vulvodynia loosely to refer to any chronic vulvar pain; others use it exclusively when a cause cannot be found and the pain may be neuropathic," added Dr. Stanley Marinoff, director of the Center for Vulvovaginal Disorders, Washington, D.C.

Several speakers emphasized the importance of differentiating vulvodynia from vulvar pain disorders which have identifiable causes. Dr. Marilynne McKay, professor of dermatology at Emory University School of Medicine, described three such vulvar dermatoses: lichen planus, lichen simplex, and lichen sclerosus. As is also the case with vulvodynia, these disorders typically flare and remit. A biopsy can confirm the diagnosis of these dermatological conditions. The vulvar dermatoses respond to treatment with high-potency steroids, whereas vulvodynia does not. "Topical steroids are the mainstay of therapy for vulvar dermatoses, but high-potency steroids should not be used on normal-looking skin because they can induce redness and burning, as well as tissue thinning," cautioned Dr. McKay.

Dr. McKay also emphasized that doctors must rule out several other disorders before diagnosing someone with vulvodynia. These might include endogenous eczema, reactions to an allergen or irritant, or a "steroid rebound effect." Irritants such as alcohol, soap, vinegar, and anti-yeast medications tend to produce an immediate stinging reaction.

On the other hand, allergic reactions to substances such as poison ivy, neomycin or mycolog take over 48 hours to develop and last from two to three weeks. As previously mentioned, steroid use for undiagnosed conditions can also result in a dermatitis. Unfortunately, doctors who are unfamiliar with the diagnosis of vulvodynia may unknowingly prescribe steroids and thereby exacerbate the problem.

Speaker Dr. Benson Horowitz, clinical professor of obstetrics and gynecology, University of Connecticut Medical School, stressed that vulvodynia must be differentiated from vulvovaginitis, an infectious disease that results from any one of a number of pathogens. The most common form of vulvovaginitis is candidiasis, typically

See NIH SYMPOSIUM, page 6

Medical Therapy for Vulvodynia

by Libby Edwards, M.D.

Dr. Libby Edwards is chief of dermatology at Carolinas Medical Center, Charlotte, North Carolina, and associate professor of dermatology at Bowman-Hill School of Medicine, Winston-Salem, North Carolina. She is a member of the NVA medical advisory board.

The nonsurgical therapy for vulvodynia can be divided into four major elements. First, the clinician should search for and correct any abnormalities, and identify what, if any, subset of vulvodynia the patient exhibits. This evaluation requires a careful history with special care to identify past trauma or illnesses, which factors produce pain, the location of pain, and timing.

The physical examination should include both a careful inspection of the skin to rule out very subtle skin changes of lichen planus, lichen sclerosus or irritant dermatitis. The vagina should be inspected for abnormalities such as erosions or atrophic epithelium. In addition, a microscopic examination of vaginal secretions, a culture of these secretions, and a determination of the vaginal pH are required to identify irritating or infectious secretions such as a nonalbicans Candida infection. Although a definitive cause of vulvodynia is rarely established, the correction of even minor abnormalities can sometimes substantially improve symptoms.

When no objective abnormalities are found that explain the patient's symptoms, the clinician should perform the Q-tip test, and when positive, ensure that pain is always limited to the vestibule before conferring a diagnosis of vulvar vestibulitis. Older women who have spontaneous burning, generally without pain to touch, are diagnosed with dysesthetic vulvodynia. Those premenopausal women with cyclic flares of their symptoms often associated with mild erythema (redness) or scale may exhibit cyclic vulvitis, a condition related to infection with or hypersensitivity to yeast.

Second, the patient must be supported emotionally, and the disease explained as well as possible. Although the causes of vulvodynia are primarily speculative, women benefit from both validation of their pain as real rather than "psychosomatic," and reassurance that vulvodynia is a fairly common symptom (to reduce their sense of isolation). Patients should also be told that the causes of vulvodynia are not medically dangerous, that it is not sexually transmitted, and that they will probably improve substantially with trial and error therapy. Information on local skin care to avoid irritation from overwashing or the application of multiple medications can be useful, and the application of lidocaine jelly 2 percent before sexual intercourse is beneficial in some women.

Third, most patients, especially those with dysesthetic and idiopathic vulvodynia, improve with tricyclic antidepressant medication. Even women with vulvar vestibulitis often experience dramatic improvement with these medications. Amitriptyline and desipramine are most frequently prescribed, starting at very low doses. The dose is gradually increased until improvement occurs, to a maximum of 150 mg. The patient should be advised that these medications are being used for their benefit on nerve pain rather than for their antidepressant effects, and that improvement usually takes several weeks or months.

Fourth, "specific" therapy for any identified pattern of vulvodynia should be instituted. Women with vulvar vestibulitis can be treated with local injections of alpha-interferon. One million units of alpha-interferon is administered three times a week for four weeks, with each injection instilled at the lateral border of the vestibule. The total of twelve injections during the course of therapy encircle the vestibule. About one-third of women who have undergone this treatment experience significant, lasting improvement. Up to 80 percent of women with vestibulitis, dysesthetic vulvodynia and idiopathic vulvodynia derive significant benefit from pelvic floor electromyelography with biofeedback. Some believe that a low-oxalate diet and oral calcium citrate to decrease irritation from abnormally high urinary and tissue oxalate levels is useful for women with vestibulitis, but this therapy has been less well studied and reported. Women with cyclic vulvitis sometimes improve with chronic antifungal therapy, including fluconazole 150 mg. once a day to once a week. Although anticandidal creams can be used also, the alcohols in cream vehicles sometimes produce burning and irritation. ■

NIH Symposium

(from p. 4)

referred to as a yeast (fungal) infection. Many yeast infections, such as those caused by candida albicans, are successfully treated with over-the-counter antifungal products such as Monistat. (***Editor's Note**: Some topical antifungal medications can produce burning and irritation. A patient should inform her doctor immediately if she suspects that she's having a negative reaction to one of these medications.*)

Some fungal infections, however, result from different strains of candida or other pathogens that are more difficult to eradicate. To treat an infection, one must determine the organism that caused it and choose an appropriate antifungal medication. In some cases of persistent and/or repeated fungal infections, some doctors prescribe a six month regimen of oral antifungal medication such as Diflucan. "Because most fungal infections produce symptoms similar to vulvodynia, it is prudent to culture several times during the course of therapy to be sure that no infection has surfaced," advised Dr. Horowitz.

Disorders of the pelvic floor that can account for a small subset of vulvar pain cases were presented by Dr. David Foster, medical director of gynecologic specialties and ambulatory care at the University of Rochester Medical Center. These disorders include nerve injury from surgical entrapment, episiotomy damage, muscular dysfunction, or infection, most commonly from the Herpes virus.

Obstetrical trauma, vaginal resuspension of a prolapsed uterus, or mechanical trauma to the vulva can produce pudendal nerve injury, but studies have shown that only a small percentage of such injuries result in vulvar pain. Damage to the illioinguinal nerve in

See NIH SYMPOSIUM, page 7

NVA Announces Research Grant

At the conclusion of the NIH vulvodynia symposium, the NVA announced the availability of a $15,000 research grant for one or more pilot studies on vulvodynia. This grant was donated to the NVA by a longstanding supporter who requested that it be used specifically for research purposes. Research on disorders such as chronic fatigue syndrome and interstitial cystitis began with small pilot studies funded by patient advocacy organizations. Based on the outcomes of those pilot studies, NIH subsequently allotted funds for more extensive research on those disorders. The NVA is hopeful that this initial research grant will lead to greater funding for the study of vulvodynia.

Moving?

To ensure that you will continue to receive your NVA newsletter and information on other activities, please send your new address to:

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

The newsletters are sent by bulk mail and are not forwarded by the post office.

NIH Symposium

(from page 6)

the lower abdomen during surgery can also result in neuropathic pain. These patients generally present with a loss in touch sensation and a burning, lancinating pain that radiates to the labia majora and inner thigh on the side where the surgery was performed. In these cases, pain is relieved by injecting local anesthetics into the region of the illioinguinal nerve.

Another cause of vulvar pain can be a Herpes Zoster infection, resulting from an activation of the latent virus in those people who have been rendered partially immune following an attack of chicken pox. This infection usually occurs on only one side of the body, producing vesicles (small blisters) over the affected nerve and severe neuropathic pain. This can eventually result in postherpetic neuralgia, nerve pain that persists after the initial infection.

Medical and Surgical Treatments

Libby Edwards, M.D., chief of dermatology at Carolinas Medical Center, presented nonsurgical treatment options for vulvar pain. "Vulvodynia is a symptom, not a disease. There may be more than one thing going on and it is important to pay attention to all facets of pain," she told her colleagues.

Before Dr. Edwards makes a diagnosis of vulvodynia, she also begins by treating any observable skin disorder. If the patient still has vulvar pain after being treated for any obvious dermatosis, a diagnosis of vulvodynia, vulvar vestibulitis, or cyclic vulvitis is made. Treatment may include tricyclic antidepressants, anticonvulsants, biofeedback, and/or a low oxalate diet with calcium citrate. In addition, vulvar vestibulitis patients may receive alpha-interferon injections. Cyclic vulvitis patients, who experience symptom flares related to the menstrual cycle may also be treated with antifungals. (See Medical Therapy for Vulvodynia, page 5.)

Dr. Stanley Marinoff reported on the benefits of vestibulectomy (surgical removal of painful vestibular tissue) in vulvar vestibulitis patients. His criteria for selection of surgery patients is twofold. First, the patient preferably has pain only upon contact with the vestibule, and second, the pain always or almost always prevents the patient from having sexual intercourse.

In Dr. Marinoff's study of his surgery patients, 86 percent reported elimination or reduction of pain following vestibulectomy. His study uncovered two variables that were predictive of post-operative success. In general, the shorter the duration of overall symptoms and the shorter the duration of post-coital pain, the greater the pain relief after surgery. Based on these findings, Dr. Marinoff believes that the key to successful vestibulectomies is careful patient selection.

Mechanisms of pain

Richard Gracely, Ph.D., pain researcher at the National Institute of Dental Research, presented his clinical studies on peripherally-initiated central pain (PICP). These studies raised the possibility that vulvar pain might be reduced or eliminated by blocking persistent peripheral input to the central nervous system. Preliminary findings in six vulvodynia patients supported this hypothesis. By injecting 2 percent lidocaine into the opening of the major, and in some cases, the minor vestibular glands, pain was reduced or abolished in adjacent locations. Gracely's results suggest that future therapies might focus on altering pathological peripheral input from the vulvar area.

Some researchers are pursuing this approach by having vulvodynia patients use capsaicin, a hot pepper extract that destroys certain peripheral nerve endings known as "C" fibers. Capsaicin was originally used for the pain of interstitial cystitis. In an ongoing study by Halina Zyczynski, M.D., director of the division of gynecology, Magee-Women's Hospital, nine patients who applied capsaicin topically to

See NIH SYMPOSIUM, page 8

Doctors must rule out several disorders before diagnosing someone with vulvodynia.

NIH Symposium

(from page 7)

the vulva for six weeks reported significant relief.

In spite of such promising results, some pain specialists hesitate to recommend capsaicin to vulvodynia patients because of the burning sensation it produces upon application to the skin. Researchers are working on the development of capsaicin analogues that do not have this undesirable side effect.

Lankveld et. al. (1996) found women with vulvar vestibulitis to be psychologically healthy, but with slightly higher scores than standardized normals on somaticization and sexual dysfunction.

Because of the stress that vulvodynia places on sexual relationships, many doctors recommend psychological counseling as an adjunct to medical treatment. While integration of psychological and medical treatment is widely promoted in the literature as well, research has not yet been performed on the efficacy of specific psychological interventions with vulvodynia or vulvar vestibulitis patients.

"Vulvodynia is a symptom, not a disease."

Psychological Issues

Psychologist Dr. Peter Fagan, director of the Sexual Behaviors Medical Counseling Unit, Johns Hopkins Hospital, reviewed the research on the psychological, social, and sexual effects of vulvodynia. In one of the earliest and most comprehensive studies by Schover et. al. (1992), 45 women undergoing surgical and psychological treatment for vulvar vestibulitis were assessed using standardized instruments. In general, the women fell in the normal range on an adjustment scale and symptom inventory, but 54 percent reported severe marital conflict, 42 percent somaticization disorder [physical ailment whose origins are psychological] and 36 percent depressive symptoms.

Somewhat in contrast to previous studies, a recent study by Van

Symposium Recommendations

After two days of presentations and discussions, research priorities formulated at the workshop were summarized by Dr. Peter Lynch, professor and chairman of the department of dermatology at University of California-Davis. First, the International Society for the Study of Vulvovaginal Disease will be asked to examine the definition of vulvodynia and establish more specific diagnostic criteria. Once this is accomplished, gathering information on the incidence and prevalence of vulvodynia should be one of the highest research priorities. At the same time, it is important to design an epidemiological survey that seeks to identify risk factors and other characteristics of vulvodynia patients.

Regardless of the fact that the causes of vulvodynia remain unknown, the need for randomized, controlled studies to determine the efficacy of different treatments for vulvodynia and vulvar vestibulitis was recognized. These studies must use rigorous selection criteria in order to ensure well-defined populations, thereby enabling researchers to compare the results of one study to another.

The workshop's surgery group recommended that a randomized, multicenter study be carried out to determine the selection criteria for vulvar vestibulitis patients who are potential candidates for surgery. In addition, the group decided it would be beneficial to create an audiovisual tape of different types of vestibulectomies, specifically for physicians.

In a brief discussion of laser surgery, the participants concurred that carbon dioxide laser surgery should not be used on vulvodynia or vulvar vestibulitis patients because of the potential dangers of the procedure.

After summarizing the workshop outcomes, Dr. Lynch suggested that a working group be established to follow-up on the recommendations.

See NIH SYMPOSIUM, page 11

Nurse Practitioner

(from page 3)

a day, subsequently increased to six capsules per day. After symptoms subside, the antibiotics are reduced to twice a day, then once a day at bedtime. Eventually, most patients can eliminate the antibiotics and Nystatin. In some patients, however, antibiotics are habitually prescribed to suppress bacteria after sexual intercourse.

Vulvodynia patients also are placed on Czarapata's IC elimination diet, a combination of three IC diets and the American Diabetic Assocation exchange list, structured to provide an 1,800 calorie minimum daily intake. The preliminary IC diet eliminates all bladder irritants, such as caffeine, alcohol, and artificial sweeteners; all fruits except pears and blueberries, including all fruit juices, foods flavored with fruit extracts, and herb teas made with fruits; vinegar and tomatoes, and all items that contain them, such as mayonnaise and salad dressing.

The diet excludes almost every food that has irritated any patient Czarapata has treated. It is used instead of a rotation diet, in which the patient never eats the same food more than once in a four-day period, because it is easier to live with on a permanent basis. While it is unclear whether symptoms are caused by the action of a specific food, chemical, or food allergy, Czarapata has found that most patients obtain significant relief from the diet.

See NURSE PRACTITIONER, page 10

Book Review

From Fatigued to Fantastic

By *Jacob Teitelbaum, M.D., Avery Publishing Group New York, 1996*

Many vulvodynia patients suffer from the long-term fatigue, poor sleep, achiness, bowel disorders, and recurrent infections associated with chronic fatigue syndrome (CFS) and fibromyalgia (FM). Dr. Jacob Teitelbaum, who has had personal experience as a CFS sufferer, outlines his approach to these problems in the handy guide, *From Fatigued to Fantastic.* In this book, he clearly appreciates the psychological dimension of chronic illness, particularly since these are illnesses that the medical profession has been slow to recognize. Moreover, *From Fatigued to Fantastic* is written in a friendly tone that reflects the author's compassion for those who are suffering.

When a patient exhibits chronic fatigue, Dr. Teitelbaum explores a number of possible systemic disorders. He checks for hormonal deficiencies (especially underactive adrenal and thyroid glands), yeast overgrowth, and bowel parasites. In addition he explores the possibility of food allergies, chemical sensitivities, rare infections, sinusitis, sleep apnea, and medication side effects. Whereas some medical practitioners investigate one aspect at a time, Dr. Teitelbaum's holistic approach involves treating all symptoms at once. "Most sufferers of chronic exhaustion have a mix of five or six underlying problems, because there's a vicious cycle in which each problem causes several others," he writes.

Although the comprehensiveness of Dr. Teitelbaum's approach may be somewhat daunting, readers should find comfort in his optimism that CFS and FM are treatable. His treatments range from conventional to controversial. Dr. Teitelbaum advises patients to "start with easy things first." Patients should eat a healthy diet and avoid sugar, white flour, caffeine, and alcohol. (Maybe that's not so easy!) He also recommends vitamin and mineral supplements, particularly the B vitamins and magnesium.

Conventional treatments also include advising patients to increase their exposure to fresh air and to participate in an appropriate exercise program. Among his more controversial treatments are the prescription of potent antifungal medications for possible systemic yeast overgrowth and vitamin B-12 injections.

Even if one does not completely agree with Dr. Teitelbaum's approach, *From Fatigued to Fantastic* is a readable and useful book for anyone who experiences extended periods of fatigue. Appendices include guidelines for physicians, a treatment protocol, and questionnaires for evaluating yeast overgrowth and fibromyalgia. Also included are lists of patient support groups, physicians who specialize in CFS, suggested readings, and mail-order resources. ■

Nurse Practitioner

(from p. 9)

If the patient becomes asymptomatic from this combination of treatments, foods may be reintroduced one at a time, in single-serving amounts, each day for three days. Symptoms may appear immediately or up to three days after eating a particular food. If symptoms do not reappear at the end of three days, the food may then be consumed regularly. If symptoms reappear, the patient makes her own choice whether to continue to consume the food, understanding the consequences. When a patient has consumed an "offending" food and experiences considerable pain, ingesting one-half teaspoon of baking soda in eight ounces of water may be helpful.

Czarapata does not believe in placing patients on a low-oxalate diet because she considers it unhealthy. According to the research, diet only controls 10 percent of the oxalates excreted in the urine. "I do not see the logic in having people consume an unhealthy, restrictive diet to impact only 10 percent," she said. In addition, the elimination of green vegetables in the low-oxalate diet can contribute to constipation, and "vulvodynia is really exacerbated by constipation," she added.

Assessment also includes the investigation of muscle spasms, trigger points, and abnormalities of the feet, ankles, knees, and hips that may result in referred pain, burning, and spasm in the pelvis and pelvic organs. Czarapata finds that there is a strong musculoskeletal, trigger point component to nerve problems. Muscles evaluated include the piriformis muscle, rectus abdominus muscle, and pubococcygeus muscle. The piriformis muscle contracts when the patient has her knees apart, such as during intercourse or a gynecological examination. The sacral and pudendal nerves run from the sacrum (lower spine) to the pelvic floor, urethra, and bladder. These nerves run through a notch in the pelvis that is also occupied by the piriformis muscle. When the piriformis is in spasm, it presses on these nerves as well as major blood vessels to the pelvic floor. This can cause severe pain.

To treat piriformis spasms, Czarapata prescribes specific exercises, and uses ice and muscle stretching. The treatment begins by filling a styrofoam coffee cup with water, freezing it, removing the top three inches of styrofoam, and placing the remaining ice and cup in a resealable plastic bag. The patient lies on her side on the exam table with the affected side up, knees and thighs bent at a greater than 90 degree angle. Czarapata runs the ice from the sacrum, over the hip and halfway down the thigh for 10 minutes, numbing the area. Then she applies a stretch to the muscle by moving the top leg across the midline by letting it extend over the side of the examination table. At the end of treatment, hot wet towels are applied for 10 minutes. This technique can also be done at home with assistance.

Trigger points on the abdominus rectus muscle can refer pain to the internal abdominal organs. To treat these muscle spasms, Czarapata again uses ice and muscle stretching, stroking the abdomen from the rib cage to the pelvic bones in overlapping vertical strokes.

Spasms in the pubococcygeus muscle can create pain and burning, and can inhibit voiding and defecation because of its involvement with the urethral and rectal sphincters. To reduce these spasms, biofeedback is used to teach relaxation and urge control. Patients are also taught to perform Kegel exercises, alternately contracting and relaxing the internal sphincter muscles.

Another component of the treatment protocol is bladder and bowel training. Many vulvodynia patients suffer from constipation because of pelvic floor muscle spasm, diet restrictions, and anticholinergic medications such as amitriptyline or

See NURSE PRACTITIONER, page 11

Thanks

Our thanks to Vicki Ratner, President of the Interstitial Cystitis Association, for her continued support of the NVA.

Nurse Practitioner

(from page 10)

desipramine. Czarapata instructs patients to drink four ounces of fluid (mostly water) each hour, from the time they wake up until dinner. This helps patients slowly achieve their ideal 24-hour fluid intake; the number of ounces a patient should consume can be calculated by dividing body weight (in pounds) by two. For bowel training, she may recommend that a patient drink eight ounces of hot water one-half hour before eating breakfast, and put one teaspoon of Miller's bran on cereal or in eggs.

While she has been able to help many vulvodynia patients feel better, Czarapata sees the greatest challenge as teaching patients to maintain their improvement. Many people lead stressful lives, and "stress usually impacts on vulnerable organs, whether it's the neck, heart, or vulva," she said. After many years of treating women, her universal advice to patients is, "Set limits for yourself; don't try to be superwoman." ■

NIH Symposium

(from p. 8)

The symposium concluded with the NVA's announcement of its first research grant for the study of vulvodynia. (See NVA Announces Research Grant, page 9.)

***(Editor's Note:** Drs. Stanley Marinoff, David Foster, Peter Fagan, and Libby Edwards are all NVA medical advisory board members who served on the Program Committee for this conference.)* ■

Chronic Pelvic Pain Conference

During April 11-13, the Continuing Education Network of Richmond, Va., sponsored the First Annual Symposium on Chronic Pelvic Pain in Oak Brook, Ill. Eight health care professionals, including NVA medical board members Stanley Marinoff, M.D., and Dee Hartmann, P.T., participated in the instruction.

The program focused on medical diagnosis and treatment of chronic pelvic pain, including vulvodynia, as well as assessment and treatment utilizing EMG biofeedback and physical therapy techniques. This was a rare opportunity for physical therapists from across the United States to familiarize themselves with the specific techniques used to alleviate pelvic pain.

Vulvodynia sufferers seeking a physical therapist can obtain the list of symposium attendees from Dee Hartmann at (630) 527-9105, via fax at (630) 527-9194, or email: healthyexp@aol.com. ■

Support Leaders Needed

The NVA is still seeking telephone contact leaders for San Jose, California; Westchester, New York; London, Ontario; and Montreal, Quebec. If you can devote some time to helping other women with vulvodynia, please write to:

Harriet O'Connor
P.O. Box 4491
Silver Spring MD 20914-4491

or call Phyllis Mate at 301-299-0775.

If you are an NVA supporter and would like to receive the name of the contact leader in your area, you need to fill out a brief support survey that can be obtained by writing to Harriet O'Connor at the above address.

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