

The Management of Neuropathic Pain

By Justin Wasserman, M.D.

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Have you ever felt persistent burning, shooting, or electric bolt-like pains somewhere in your body? You may have even noticed a hypersensitivity to touch, when even a bed sheet simply touching the painful region induces yet more pain. If this describes your symptoms, you may be suffering from what is called neuropathic pain. This type of pain is caused by damage to, or dysfunction of, the nervous system. The dysfunction can occur either in the central nervous system, that is, the brain or the spinal cord, or to the

peripheral nervous system, consisting of all the nerves that run both to and from our organs.

When such nervous system dysfunction occurs, one may experience a very unpleasant sensation or pain often described as burning, hot, or shooting. This type of pain can be extremely disabling and has even led to suicide in inadequately treated patients. What is more troubling about neuropathic pain is the fact that it can occasionally be resistant to narcotic medications,

typically the strongest painkillers available. Fortunately for sufferers of neuropathic pain, today we have a better understanding than ever before about what causes it. This has led to the development of better treatments, giving sufferers the best hope yet for relief of this troubling condition.

Neuropathic pain is caused by a hyper-excitability of any sensory nerve or group of sensory nerves.

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Vulvovaginal Pain Disorders and Sexual Functioning

By Howard Glazer, Ph.D.

Dr. Glazer is a clinical associate professor of psychology in the Obstetrics and Gynecology Department at Cornell University Medical College, and an associate attending psychologist at New York Presbyterian Hospital. He specializes in the use of pelvic floor muscle surface electromyography and sexual counseling in the treatment of vulvovaginal pain disorders. Dr. Glazer has recently teamed with Gae Rodke, M.D., to open New York City's first multi-disciplinary center for the treatment of vulvar pain.

I have always been amazed at the lack of an interdisciplinary approach in the treatment of vulvovaginal pain disorders. These conditions overlap a number of specialties including pain management, gynecology, dermatology, urology, gastroenterology, rheumatology, pathology, neurophysiology and not least of all, sex therapy. Each of these fields has its own perspective in treating these disorders. Gynecologists look for infections, dermatologists look for dermatoses, pain physicians look for neuropathic pain; urologists,

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LETTERS TO THE EDITOR

Dear NVA,

I have had vulvodynia for eight years, but the symptoms were largely under control with anti-convulsant medication. Recently, I entered menopause, and because of sleep disturbances, started hormone replacement therapy (HRT). My doctor prescribed estradiol 1 mg. and prometrium 200 mg. One month later, my vulvodynia flared up to its worst level in eight years. I stopped the HRT and six weeks later I felt better. To test out my hypothesis that HRT had caused the vulvodynia flare-up (and still desperate to get decent sleep), I decided to try the medication again. This time I tried taking a half-dose of the same medications. Within a week, my vulvodynia symptoms returned. Once again I stopped taking the hormones and my vulvodynia improved. Is there a physiological explanation for this connection?

Sincerely,
D.M.

Dear D.M.,

You describe a very interesting observation. You started sex hormone replacement therapy and your vulvodynia worsened. Your symptoms improved when you discontinued the hormone replacement. When you restarted hormone replacement at a reduced dosage, your vulvodynia symptoms became worse again. Thus, it appears that in your case, sex hormone replacement worsens the symptoms of vulvodynia.

One caveat in drawing a conclusion from your observations is that

this hormone trial was obviously not placebo-controlled, and you might have influenced your observations by "testing your hypothesis that HRT had caused the vulvodynia flare-up" (Wall, PD: *Pain* 51:1-3, 1992). Therefore, I want to point out that by no means can we conclude from your observation that sex hormones have a negative influence on vulvodynia. However, it is an important observation, and I would like to briefly discuss some of the literature on sex hormones and pain.

There is growing evidence from studies in animals and humans that the response to painful stimuli, as well as the response to pain medications, may be influenced by sex hormones (Berkley, KJ: *Behavioral and Brain Sciences* 20: 470-471, 1997; Wesselmann, U: *Behavioral and Brain Sciences* 20:470-471, 1997). Interestingly, and in support of the hypothesis that sex hormones influence pain perception, some pain syndromes are more common in women, and they seem to occur more frequently during the reproductive years of a woman, rather than before puberty or during menopause. Examples are migraine headache, interstitial cystitis and irritable bowel syndrome.

The influence of sex hormones not only seems to play a role in certain chronic pain syndromes, but in diseases such as multiple sclerosis (MS) and epilepsy. Women are more susceptible to MS than men (mean ratio 2:1). The hormonal milieu during pregnancy has a favorable effect on MS and imaging studies of the brain in women with MS have confirmed a relationship of disease activity and

sex hormone fluctuations (Pozzilli, C. et al.: *Neurology* 53: 622-624, 1999). Further, many women with epilepsy report changes in seizure frequency in relationship to sex hormone fluctuations (Zahn, C: *Neurology*, 53, S34-S37, 1999).

In summary, animal studies and observations in humans have shown that gender and sex hormone fluctuations may influence the response to a given stimulus as well as the severity of diseases. The pathophysiological mechanisms of these interactions still need to be elucidated and will have to take into account the multiple effects of sex hormones both peripherally and centrally, plus the fact that the sex hormones work in concert with other hormones and neuroactive agents.

Sincerely,
Ursula Wesselmann, M.D.
Assistant Professor of Neurology
Johns Hopkins University
School of Medicine

Editor's Note: This patient's letter reflects one woman's experience with hormone replacement therapy. Each individual is different. If you have started hormone replacement therapy or are considering it, discuss your medical situation with your physician. If you are postmenopausal and also have noticed a relationship between hormone replacement therapy and vulvar pain, please send a letter describing your experience to Newsletter Editor, P.O. Box 4491, Silver Spring, MD 20914.

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Vulvovaginal

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gastroenterologists and rheumatologists look for related conditions such as interstitial cystitis, irritable bowel and fibromyalgia, pathologists look for vulvar tissue pathology, and neurophysiologists look for pelvic floor

muscle dysfunction. With all these specialists focusing on the parts they specialize in, the patient may well ask, "Does anybody care if I am having sex?" While pain relief is a major goal for vulvovaginal sufferers, the major functional consequences of these conditions is to limit and often preclude sexual intercourse. This is particularly so with vulvar vestibulitis syndrome in which there is only pain on

poked with a Q-Tip it does not hurt. No, my patients want to be able to have good, loving, intimate, physically and emotionally fulfilling sex with their partner!

The medical specialists are rightfully concerned with identifying and treating the pathology within their field of specialty. Like most people, they are not that particularly knowledgeable or comfort-

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The National Vulvodynia Association is an educational, nonprofit organization founded to disseminate information on treatment options for vulvodynia. The NVA recommends that you consult your own health care practitioner to determine which course of treatment or medication is appropriate for you.

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To have a truly successful therapeutic outcome, our goal must be to restore to our patients full sexual functioning, full gender identity, and full capacity to express love.

pressure, such as that associated with attempted penile-vaginal intercourse. Otherwise, these sufferers have no pain. For many essential vulvodynia sufferers, sexual intercourse raises the level of their chronic pain substantially and also leads to sexual abstinence, as with vestibulitis sufferers. It is my experience that patients do not want to simply reduce or eliminate their pain; they want to do so in order to get back to having sexual intercourse with their partners.

I don't think too many patients would ingest medicines, put creams on their vulvas and in their vaginas, do hours and months of muscle exercises, or undergo surgery so that when their vulvas are

able discussing issues of sexuality. Although this may sound strange for doctors who specialize in treating vulvovaginal pain, many of my patients tell me that when they ask their gynecologist about details of sexual activity, the doctor becomes visibly uncomfortable. Now on the other side of the coin, we have the sex therapists. Before starting my work in pelvic floor muscle rehabilitation in the treatment of vulvovaginal pain, I had many years of training and experience as a sex therapist. Sex therapists are from the ranks of mental health professionals. No matter how much they try or know better, they are trained to look for unresolved or

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unconscious sexual conflicts or repressed memories of child or adult sexual abuse. Many of my patients tell me how frustrating it is to go to couples or sex therapy. Even though the therapists acknowledge that these are medical conditions, they can't help but delve into your psyche looking for psychological reasons why you have unexplained pain in your vulva and vagina. So once again the sufferer is left in the middle, with doctors inspecting the anatomy and therapists inspecting the psyche, but nobody helping you to get back to having sex.

I confess that when I first started working with vulvovaginal pain patients using pelvic floor muscle rehabilitation techniques, I specifically stayed away from dealing with the sexual aspects of these problems, because I too had been clinically trained to assume there must be some psychological underpinnings to these vulvovaginal pain conditions. Since then I have changed my practice dramatically for two reasons. First, a considerable database has now been published demonstrating that vulvovaginal pain patients do not show any psychopathology or abuse history that differentiates them from non-pain control groups. Second, I saw more and more patients who were cured or substantially relieved of their pain and were considered successful outcomes because their vulvar tissue, flora or nerve endings were normalized. But when I asked many of these patients about sex, I discovered that

many, perhaps even the majority, had not resumed sexual activity.

So a number of years ago I started to integrate my knowledge of sex therapy techniques into my work with vulvovaginal pain patients. I began to see all my patients with their sexual partners when possible. I spent considerable time reviewing sexual history information, discussing with my patients issues such as clitoral stimulation, masturbation, orgasms, oral sex, intercourse and nonintercourse sexual positions, thrusting duration, physiology of female arousal, anticipatory anxiety related to sexual pain, libido, vulvovaginal self-examination, and a host of related topics. I had all my patients start re-experiencing orgasms (or for some, learning how to have them for the first time), conducting nonpenetrative sexual activities with their partners; I encouraged them to become friendly with their genitals, their appearance, sensations, anatomy, etc. I continue to be amazed at how otherwise very well-educated people have such little knowledge about matters of sexuality. Many of my patients at first resisted this approach saying just fix my tissue and I will get back to having sex, saying, "I used to have great sex." As it turns out this is simply not the way it works for most vulvovaginal pain sufferers; they do not get back to sex spontaneously after their pain is gone because they have developed powerful habits of sexual avoidance and

fear, and often have little remaining libido. I have found that resexualizing my patients immediately upon initiating treatment makes a marked difference in the final outcome of treatment. Getting my patients to be comfortable with their genitals, to understand how they work, and to maximize pleasurable sensations, is now an integral part of my work. I explain to my patients that it is normal to cut off awareness from areas of pain in your body. When this area is your genitals, you not only lose sensory awareness of pain, but also of pleasure. Reconnecting to your genitals, exploring them as a source of pleasure, and the extended psychological benefit of self-acceptance should be critical aspects in the rehabilitation of all vulvovaginal pain patients. I believe strongly that pain relief alone does not constitute adequate outcome in the treatment of vulvovaginal pain syndromes. We must restore these patients to their full potential as partners, as lovers, as intimates, in short, as complete women and as complete people.

It is my hope that vulvar pain patients, and the health care professionals who treat them, will read this and be convinced that our goal must include more than restoring tissue health to the vulva or eliminating pain. To have a truly successful therapeutic outcome, our goal must be to restore to our patients full sexual functioning, full gender identity, and full capacity to express love.

Internet Resources on Vulvodynia

By Julie Shearer

If the Internet did not exist, I would never have met or spoken to hundreds of women whom I now consider my friends. Without the Internet, it would have taken me years, rather than weeks or days, to find out about the NVA and the various treatments for vulvodynia that I have tried.

The Internet is all about instant communication, and it has revolutionized patient advocacy in ways we are still trying to understand. The greatest bonus and sometimes the biggest pitfall is that anybody with a little money or another way to get space on a server can set up a Web site. The Internet is a new frontier, with no limits on content. While this means that information that usually gets marginalized can have as much exposure as more mainstream ideas, it also means that false, misleading, or outdated information can appear. So how can you tell what's what?

Responding to some of the inherent problems of the Internet as an unregulated medium, an organization called the Health on the Net (HON) Foundation was established in 1996. Sites that adhere to the HON rule do so voluntarily, following the principles enumerated at <http://www.hon.ch/Conduct.html>. These principles require of Web sites that: everything is labeled; page updates are clearly noted; funding and other support is prominently disclosed; no unsupported opinions are displayed as fact; the authorship is identified, etc. These rules constitute ethical and common sense guidelines for medical and health sites on the Net. Look for the HON code symbols and statement on the pages that you visit.

One common problem is that sites that may appear to be informational are, in fact, advertising sites. For instance, drug companies that produce antifungals maintain sites discussing yeast infections. The problem is that these sites do not emphasize the importance of positive tests before treatment, nor do they indicate that there are any other treatment options other than the ones the site is promoting.

Occasionally the connections and misinformation are more subtle. For instance, a site on herpes put out by what seems to be a patient group or nonprofit organization is actually produced by Glaxo-Wellcome, a company that produces antiviral drugs used to treat that disease. A more balanced site for information is the University of Chicago page at <http://uhs.bsd.uchicago.edu/uhs/materials/sexhealth.html#Art10>. A site that handles the potential conflicts of interest in a more responsible manner is hosted by 3M Pharmaceuticals National Vaginitis Association (<http://www.vaginalinfections.org/00f01.html>). This site emphasizes the importance of avoiding self-treatment or treatment without testing for yeast, bacterial infections, or other vaginal problems, and does not recommend specific antibacterial drugs.

Some sites are just too abbreviated to be useful. If you click on the link to lichen sclerosus in the Global Medics encyclopedia (<http://www.globalmedic.com/eng/encyclopedia/encyclopedia.htm>), what comes up is a three-sentence explanation, stating, "Rare skin illness, of unknown cause, characterized by atrophic white spots. The lesions are found mainly on the trunk and on the genital organs. There is no real treatment for this illness but when it affects the vulva, a mild hydrating or corticosteroid cream can be used to relieve the itching." This is an example of outdated and incorrect information. There is an effective treatment for lichen sclerosus, just no cure. Dermatological experts recommend super-potency corticosteroids, not mild corticosteroids.

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Internet

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If you haven't yet checked out the NVA site, you should do so now at <http://www.nva.org>. This is an example of a well-composed site and a good place to send people when they ask you about vulvodynia.

In general, universities have sites with useful information. The University of Michigan has a helpful set of Web pages dealing with vulvar disorders (<http://www.med.umich.edu/obgyn/vulva/vulvedu.html>). Although the beginning of their site looks like an ad for an office visit, explore the other links. This is an example of a site that is run by a for-profit group, but allows the general reader to obtain free information without being steered to a specific treatment. There is an extensive write-up of research by the Ob/Gyn department that was financed by an NIH grant listed at <http://www.med.umich.edu/fp/grants/reed/vulvodynia/vulvodynia.html>.

Another informative university site is hosted by the University of Pennsylvania Cancer Center. This provides information on gynecological cancers, and can be reached at <http://cancer.med.upenn.edu/disease/gynecologic1/>.

The Iowa Women's Health Center (IWHC) has an extremely informative page on how women with vulvar problems can minimize irritation (<http://obgyn.uihc.uiowa.edu/patinfo/Vulvar/skincare.htm>). The IWHC site also has other interesting, though brief, pages linked to it. Another university site, hosted by Harvard's Department of Neurosurgery, has an extensive list of pain references (<http://neurosurgery.mgh.harvard.edu:80/LnkFNCTN.htm>).

The federal government, the creator of the Internet, also maintains many informational clearinghouses. One of my favorites is the one created by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (<http://nhic-nt.health.org/Scripts/Entry.cfm?HRCode=HR0036>). This site has links to a variety of dermatological and other resources. An advantage of Internet sites is the ease with which graphics can be displayed. You can check out the nerve supply in the perineum at <http://www.manbit.com/oa/f21-1.htm> or learn how to do a more detailed vulvar self exam at <http://www.ivf.com/vse.html>.

One of the most important benefits of the Internet is how it allows us to network with other vulvodynia sufferers. There are several listserves (e-mail discussion groups) centering around vulvodynia, including the Vulvar Disorders Onelist, and the Vulvodynia Onelist. Here, people share symptoms, treatments, and just generally provide support to each other. Being able to talk to others via e-mail about this private disorder is invaluable. For information on how to join the lists, see <http://www.vul-pain.dircon.co.uk/>. In addition to the listserves, there are message boards on America Online, and an Early Onset Vulvar Pain Support Group that communicates via e-mail. For information on the Early Onset group, established for women who have had vulvar pain since an early age, send an inquiry to cgd@teleport.com.

It's almost impossible to convey just how much information and support is available through the Internet. I have developed my own Web site, where I have concentrated on presenting relevant information from medical journals. To visit this site, start at <http://www.vulvarpain.icomm.ca/index.html> and check out the extensive bibliography plus some full-text journal articles. Be sure to visit the links page, which is frequently updated.

Neuropathic Pain

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Sensory nerves are the nerves that allow us to feel pain, temperature, pressure, touch, and vibration. Under normal conditions, a sensory nerve is utilized only when the nerve provides a necessary function. For example, if I mistakenly place my hand on a hot stove, sensory nerves in my hand will quickly fire off, sending a message to my brain that I interpret as pain, telling me to quickly move my hand away from the hot stove. When my hand is not being stimulated by an unpleasant stimulus, these sensory nerves normally remain relatively quiet. To the contrary, in a diseased state causing neuropathic pain, such a nerve abnormally continues to be activated even when it should lie dormant. This hyper-excitability of a normally dormant nerve leads to the sensation of neuropathic pain.

Neuropathic pain can develop in any condition that leads to nerve damage. Some of the common examples are: diabetic neuropathy, seen in chronic diabetics; chronic sciatica, seen in low back injuries; post-herpetic neuralgia, caused by the previously dormant virus that causes chicken pox; phantom pain after a limb amputation; and post-traumatic nerve damage, such as after a gunshot wound, a stroke or other brain injury. What all of these examples have in common is an injured or diseased nerve or nerves causing hyper-excitability of the nerve(s), and subsequent pain.

Recent medical research has finally shed some light on what

causes this hyper-excitability of nerves. Using laboratory rat models and human subjects, we have now determined that nerve damage can lead to changes, at the molecular level, in both a nerve's structure and function. For instance, there are small openings in the wall of the nerve called channels, which allow various substances to course in and out of the nerve. Disruption of such channels after a nerve injury changes the way that substances such as calcium and sodium, essential particles for nerve transmission, interact with the nerve, thereby leading to hyper-excitability of the nerve.

Treatment

By having a better understanding of the physiological basis of neuropathic pain, we are now able to use various medications that may affect the abnormal processes that cause it. Indeed, such medications have given many patients

dramatic relief from their pain. One medication that has truly been a breakthrough for many people is Neurontin, a drug originally intended to treat seizures. Two large multi-center randomized controlled studies have proven Neurontin's effectiveness in the treatment of diabetic polyneuropathy and post-herpetic neuralgia, two common neuropathic pain syndromes. In addition, smaller studies and anecdotal reports have documented Neurontin's possible effectiveness in other neuropathic pain conditions.

Besides Neurontin, there are many other medications that are effective for neuropathic pain, either used alone or in combination therapy. Indeed, combination drug therapy is frequently the most effective treatment regimen for sufferers of neuropathic pain. It is not uncommon when treating neuropathic pain to achieve a partial reduction in one's pain with,

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For more information, please contact NVA Executive Director Phyllis Mate at 301-299-0775 or via e-mail at mate@nva.org.

Neuropathic Pain

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say, Neurontin. Then, by adding another medication that has a different mechanism of action, a more complete reduction in pain can often be achieved.

One patient that comes to mind is a man who was suffering for many years with a severe burning pain between his eyebrows. The pain, which started completely spontaneously, was thought to be a variant of a common neuropathic pain syndrome known as trigeminal neuralgia. His pain became so severe and intractable at times that he became extremely depressed and suicidal. Before presenting to our clinic, he had seen multiple doctors and tried many different types of both noninvasive and invasive treatments, all of which either failed outright or provided only a partial positive response. Indeed, although he was already taking morphine, a strong opioid (narcotic) medication, the pain levels were still unacceptable. Finally, the drug Lamictal, a newer anti-convulsant agent like Neurontin, was added to his drug regimen. When the Lamictal was titrated up to the correct dose, his pain was almost completely relieved for the first time in many years. In this case, it was the combination of the morphine and the Lamictal that gave him the relief that he was long seeking.

SSRIs

Because of their widespread use in medicine today, I would like

to comment on the use of selective serotonin reuptake inhibitor (SSRI) medications such as Prozac, Zoloft, and Paxil. Although these medications certainly have a place in the treatment of the depression and anxiety that are often co-morbid with all types of chronic pain, their use as a primary analgesic is limited at best. Although there are undoubtedly select individuals whose pain positively responds to SSRIs, double-blinded placebo controlled studies of SSRIs' utility in treating various pain syndromes have been overall disappointing.

It should, however, be mentioned that a newer antidepressant medication, Effexor, which combines both selective serotonin re-uptake inhibiting effects with selective norepinephrine re-uptake inhibiting ability, has anecdotally been observed to be effective for some patients with various chronic pain syndromes.

The advantage of Effexor is that it may provide all of the scientifically proven neuropathic pain fighting effects of the older tricyclic antidepressants, such as amitriptyline, without the annoying and sometimes dangerous side-effects of this older class of antidepressants. Of course, more definitive research needs to be done with Effexor to prove its possible benefits.

Opioids

This essay would not be complete

without including a brief discussion on the use of opioid medications for the treatment of neuropathic pain. Opioid medications are probably the most misunderstood, as well as unfairly maligned, class of medications in the world. Yet, despite the misinformation traditionally spread regarding opioids, they still remain the most consistently effective painkillers known to man. As mentioned earlier in this article, neuropathic pain can sometimes be stubbornly unresponsive to opioid medications, but this is typically not the case. Indeed, many patients with neuropathic pain, including vulvodinia, can get tremendous relief of their pain with the use of opioids.

One of the reasons why neuropathic pain was previously thought to be unresponsive to opioid medications is that many patients were not placed on a high enough dose of an opioid. In fact, as long as the side effects remain manageable, an opioid dose can be titrated upward as high as necessary in order to relieve one's pain; in other words, there is no dose ceiling for most pure opioids.

Opioid medications have long been withheld from patients who might otherwise benefit from them because many health providers fear that their patients will become addicted to the drugs. In reality, nothing could be further from the truth. The incidence of creating

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narcotic addiction by treating chronic pain with opioids is exceedingly low. One study looked at 11,882 patients with no prior history of drug abuse who were being treated with opioid medications for various pain syndromes. The study found that only four patients, less than 0.1 percent, developed any signs of true addiction. Yet, despite the clear evidence that opioid medications can be extremely effective for treating almost all types of pain and are not particularly addictive when used in the context of pain management, they are still unnecessarily withheld from many patients, causing needless pain and suffering.

Multi-Disciplinary Approach

It is imperative to mention that other approaches, usually used in combination with medications, can be helpful in the treatment of neuropathic pain. Physical desensitization techniques can sometimes be useful in decreasing the sensitivity to light touch that often develops in patients with neuropathic pain. In addition, a general physical reconditioning program is often times essential because of the high degree of physical deconditioning, as well as muscle strength and imbalance problems, that can develop in patients with almost any kind of chronic pain. Psychological therapy, consisting of cognitive-behavioral treatment as well as supportive psychotherapy, can also be quite beneficial in the context

of a multi-disciplinary approach to the treatment of neuropathic pain. For the most intractable pain that does not respond to more conservative medical approaches, invasive procedures such as nerve blocks and denervation procedures, electronic implantable nerve stimulators and medication pumps, and even surgical nerve ablations can be helpful.

In summary, by employing a multi-disciplinary approach to the treatment of neuropathic pain, one that emphasizes decreasing the amount of pain, maximizing physical and social function, and treating all of the disorders commonly associated with chronic pain, such as depression and insomnia, excellent results can be obtained for most patients.

NIH TO FUND VULVODYNIA RESEARCH

The word is out that 2000 will be the year in which the National Institute of Child Health and Human Development (NICHD) earmarks funds for vulvodynia research. Congress' fiscal year 2000 NIH Appropriations conference report directed NIH to move forward with its plan to fund a Request for Proposals as soon as possible. The report's language was as follows:

"Hundreds of thousands of women suffer from vulvodynia, a painful and often debilitating disorder of the female reproductive system. Despite its prevalence, very little attention has been given to this serious women's disorder. In April of 1997, NIH convened an international symposium to exchange information and develop a research agenda. Since fiscal year 1998, the Committee has called on the NICHD to support research on the prevalence, causes and treatment of vulvodynia. To date, a program announcement has been published, but no request for proposals has been made. The Committee is very concerned with the lack of progress made in this important area. The Committee strongly urges expanded research on vulvodynia and again recommends NICHD to issue a request for proposals within the first quarter of the fiscal year and to take additional steps to encourage researcher interest in this area."

"We have waited a long time for federal funding of vulvodynia research," said Phyllis Mate, NVA's executive director. We would especially like to thank Senators Harkin and Specter, and their respective staff, for their efforts on behalf of women with vulvodynia."

Pelvic Varicosities and Pelvic Pain

By Eleanor Brosius, M.S.

Varicose veins deep in the abdomen can be the cause of some women's pelvic pain. Ovarian vein venography and embolization, a relatively new technique performed by interventional radiologists, can find and repair bulging veins in the abdomen. There is no way to know before the procedure if one is a candidate for treatment, but if needed, the embolization is performed at the same time.

Pelvic Congestion Syndrome

Chronic pelvic pain due to varicose veins in the pelvis is called Pelvic Congestion Syndrome (PCS). Patients with PCS report that their pain worsens towards the end of the day, after standing for long periods, and during or after sexual intercourse. Some women describe a feeling that their uterus is falling out. It is more common in those who have varicose veins in other parts of the body. The pain varies in intensity and is often described as throbbing, aching, pressure or heaviness. After lying flat all night, some patients with PCS report that they feel better in the morning. The pain is often worse before or during menses, and, in some cases, there is a sense of urinary urgency or frequency.

The traditional therapies for PCS include medications and surger-

ies. Ovarian vein venography and embolization tends to be better tolerated, minimally invasive, and treats the source of the pain.

The first thing to do if you suspect that you have PCS is to set up a consult with a physician who performs venography and embolization. The doctor may want you to have an ultrasound or laparoscopy to rule out other possibilities. After the two of you agree to proceed and make the necessary decisions (e.g., intravenous sedation or not), you should submit documentation for insurance pre-approval.

Live Action X-Ray Diagnosis

The procedure starts with the patient lying in a horizontal position. Doctors thread a small catheter through a vein (neck or groin) until it reaches the ovarian veins, and a special dye is injected. Continuous x-rays on a video monitor show the dye being released, enabling the doctors to see the shapes of the vessels and the direction of the blood flow.

Veins have valves in them which keep the blood moving forward between beats. If the valves are functioning properly, the x-ray monitor shows normally-shaped vessels and the blood quickly flowing back to the heart. If the valves are not doing their job, however,

the dye enables the doctor to see that the blood is not efficiently returning to the heart. If the blood pools and flows backward, then the vein can bulge under the pressure, becoming varicosed.

To be absolutely sure this is the case, the x-ray equipment and the table the patient is lying on are tilted to a half-standing position. Then more dye is released to see if it flows up or down. The patient is also asked to bear down to see if it makes the situation worse. The doctors assess other veins in the area, checking the left and right sides separately.

Treatment

If the venography shows that the large bulging veins might be responsible for pelvic pain symptoms, metal coils are inserted to clot off the veins that are varicosed. These dacron coated metal coils are injected through the catheter to interrupt blood flow, produce a clot, and block the vein off permanently. This is called embolization. Fortunately, these left and/or right ovarian veins can be sacrificed. One doesn't need them to function well.

As the body adjusts and the blood finds new ways to flow, there can be some painful recovery time.

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Related Disorders

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Others notice immediate relief. Doctors warn that it can take a few menstrual cycles to really assess the amount of improvement. The coils remain in the patients and the treatment does not affect fertility.

Roughly 80 percent of women who undergo embolization experience partial to complete relief. Some women also experience a partial return of symptoms months later. While it isn't going to help everyone, it is an effective treatment for many women who have varicose veins in the pelvis.

Not for Women Only

Interventional radiologists have performed similar procedures on men for the past 25 years. Men's varicose veins are visible on the scrotum and may be responsible for pain and infertility.

For More Information:

Keith Sterling, M.D.
Alexandria, VA
703-504-7950

Society for Cardiovascular Venography and Interventional Radiology
Website: www.scvir.org
Physician referral by specialty and zip code.

Cordts, P.R. et al "Pelvic Congestion Syndrome: Early clinical results after transcatheter ovarian vein embolization." *J Vascular Surg* 1998; 28:862-68. Available at the journal's Website.

Letters

(from page 2)

Dear NVA,

Enclosed is my membership renewal fee and a little extra. After suffering for over three years with vulvodynia I have finally found a treatment that has given me substantial relief. I am currently taking a drug called Lamictal, which is an anticonvulsant. I have found dramatic improvement with this medication and would encourage other sufferers to talk with their physicians about it. It was prescribed for me by Theresa Dews, M. D., an anesthesiologist at the Cleveland Clinic Pain Management Center. I have experienced some side effects such as dry mouth and constipation. I also still cannot sit for long periods of time. But these conditions are mere annoyances compared to the pain I was experiencing. I appreciate so much

the support you have given me. I found Dr. Dews through my NVA support leader and am grateful everyday for their help.

Yours truly,
B.P

Dear B.P.,

We are happy that you have found a treatment that works well for you. It is so encouraging to hear from individuals who have found a way to relieve their pain. Lamictal is one of the newer anticonvulsants and, as far as we know, there are not yet any large randomized control studies on its effectiveness for neuropathic pain relief. It has however, shown promise in smaller, double-blind studies for various neuropathic pain syndromes.

THANK YOU!

We'd like to express our deep appreciation to the Cora and John H. Davis Foundation for its ongoing financial support.

Our heartfelt thanks to the hundreds of individuals who responded to our recent fund-raising drive. Every donation, regardless of size, makes a difference! We were overwhelmed by the number of respondents and touched by all your personal notes.

On behalf of the volunteers at the NVA, I wish you health and happiness in the new millennium.

Sincerely,

Phyllis Mate
Executive Director

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.



NATIONAL VULVODYNIA ASSOCIATION

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