National Vulvodynia Association

NVA News

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Multidimensional Treatment of Chronic Pelvic Pain

By Robert Echenberg, MD, FACOG

Dr. Echenberg, a board-certified OB/GYN for 51 years, is a member of the International Association for the Study of Pain and served on the Board of the International Pelvic Pain Society. He has specialized in treating chronic pelvic, genital, and sexual pain disorders for more than two decades.

In 2001, after practicing OB/GYN for 30 years, I attended a departmental meeting in which the following question was raised: Why do so many women with pelvic pain symptoms undergo multiple tests and various surgeries and still suffer from pelvic pain? That question prompted me to focus on persistent pelvic pain as a chronic ***pain*** condition, something we were not taught in medical school or OB/GYN residency.

During the next year, I learned that there had been an explosion of scientific research on pain processing and read extensively about the neurochemistry of chronic pain. With this newfound knowledge, I began developing a comprehensive individualized protocol for pain in the pelvic region. Over the next two decades, our clinical practice treated more than 2,300 patients, most of whom experienced significant pain relief and enhanced quality of life. Recently, I wrote an e-book describing the essential components of a chronic pelvic pain (CPP) protocol. In this article, I will describe the program and recent pain research findings relevant to women with CPP.

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The Search for Novel Treatments

In recent years, NVA's main priority has been funding researchers investigating novel mechanisms that lead to chronic vulvar pain. This line of research has identified inflammatory processes in vestibular tissue that resolve in healthy controls, but do not resolve in women with localized provoked vestibulodynia (LPV).

With initial funding from NVA and grants from NIH, a University of Rochester Medical Center (URMC) team spent two decades identifying precise inflammatory mechanisms that lead to LPV. Concurrently, they kept up-to-date on new treatments for inflammation in other chronic pain conditions. In 2017, with a grant from NVA, Megan Falsetta, M.D., of URMC began studying whether lipid mediators used to reduce inflammation in other pain conditions could resolve the pro-inflammatory process in LPV. Over the next few years, she tested lipid mediators known as SPMs (Specialized Pro-resolving Mediators), which are derivatives of Omega-3 and Omega-6. Using a mouse model, she showed that an SPM known as maresin-1

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Some Basics of Chronic Pelvic Pain

Among the first things I tell CPP patients is that approximately 20 percent of the world's population has a genetic predisposition for developing a chronic pain disorder during their lifetime. Furthermore, it is well-established that women are more likely than men to develop chronic pain and inflammatory syndromes, a difference pain researchers study that is not attributable to hormones.

Anatomically, the pelvic region consists of every structure between the umbilicus (belly button) and the mid-thigh. So, the lower back, lower abdomen, hips, sacrum, upper thighs, and "saddle area" are all incorporated into this area. In addition to pelvic structures supporting the upper body, the bladder, lower bowel and reproductive organs turn this region into the busiest part of the body. Over a lifetime, there can be a myriad of cumulative dysfunctions and traumas to any of the pelvic region's functional and structural parts, including the skin, fascia, nerves, muscles, joints, and cartilage.

Over the years, cumulative physical and psychological trauma can cause changes in the central nervous system (CNS). These traumas can be surgical, obstetric, athletic, accidental, physical or sexual abuse, or even the loss of a loved one, among others. Modern science has demonstrated that cumulative trauma and dysfunction can ultimately change neurochemistry in both the CNS and peripheral nerves, resulting in hypersensitivity. This phenomenon, known as central or peripheral sensitization, then commonly translates into chronic regional pain syndromes, such as migraine, TMJ, low back pain, IBS, painful bladder syndrome, pelvic pain or genital pain. Thus, prior to the first office visit, it is important that patients answer a questionnaire about their lifetime biopsychosocial history. (Many patients told us that they had never been asked such detailed questions before.)

After years of speaking with patients suffering from chronic pelvic pain, one realizes that many have a history of participating in sports, dance, or fitness activities, such as gymnastics, track and field, contact sports, cycling, tennis, ballet, and weightlifting.

- Running, especially long distance, can cause cumulative stress on the core musculature and hips, exerting excessive pressure on the pelvic floor and 'dialing up' of nerves and other structural parts of the pelvic region.

- Gymnastics or ice skating, with its many falls on the hips and tailbone, can cause cumulative physical trauma that leads to higher levels of sensitization.

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relieved vestibular inflammation and pain in mice. Drs. Megan Falsetta and David Foster have patented the use of maresin-1 for LPV and are now advisors to SPM Therapeutics, a Canadian pharmaceutical company that will begin a Phase 1 clinical trial of this promising treatment in June. Phase 1 tests whether the preparation is safe to use on the vulva of human subjects. The company expects this trial will be successful and aims to start a Phase 2 trial in the fall.

NVA Awards Two Research Grants

Researchers at several universities are investigating other potential treatments for LPV patients. In January 2025, NVA's Board awarded a grant to Emanuelle Chrysilla, M.D., also from URMC, to study whether soluble epoxide hydrolase inhibitors can relieve the inflammation and pain of LPV. (Soluble epoxide hydrolase (sEH) is an enzyme involved in fatty acid metabolism.) It has already been shown that sEH inhibitors relieve inflammation and pain in osteoarthritis and other health conditions.

Another research group, Drs. Andrea Rapkin and Jennifer Labus of UCLA and Andrea Nackley, Ph.D., of Duke University, is focused on identifying biomarkers that differentiate subsets of provoked vestibulodynia (PVD). Many vulvovaginal specialists have noted that PVD patients present with a wide variety of symptoms, suggesting that there may be more than one cause. With their NVA grant, this team will compare vulvovaginal tissue and blood samples from patients with primary (PVD1) versus secondary (PVD2) vestibulodynia. Their hypothesis is that PVD1 patients will have increased levels of inflammatory bio-markers in the blood, whereas patients with PVD2 will have increased bio-markers in vulvovaginal tissue. If their hypothesis is confirmed, future research will focus on developing specific treatments for each subtype.

Update on Research Summit

Last year, NVA and four other patient advocacy and professional groups co-funded a research meeting at which 15 scientists presented the latest findings on novel treatments with potential to relieve the suffering of women with vulvodynia. Following each presentation, there was discussion of the feasibility of using the proposed treatment in clinical practice. After the meeting, attendees were asked to choose which treatments appeared the most promising and organizers started writing a white paper to cultivate the interest of other pain scientists and accelerate the search for novel vulvodynia treatments. This paper, to be published in summer 2025, will be distributed to scientists, NIH representatives and women's health researchers at pharmaceutical companies.■

Do I Need a Pain Specialist?

Although vestibulodynia is a more common diagnosis, many women suffer from Generalized Vulvodynia (GV). If you have constant pain that has not subsided after trying a few treatments prescribed by your health care provider, ask for a referral to an interventional pain management specialist. Why? Because they have extensive experience with pain-relieving medication and other procedures for treating chronic pain.

In addition to being knowledgeable about pain medication, an interventional pain specialist is experienced in administering various injections and nerve blocks to relieve pain. Some are trained acupuncturists as well. Whereas most OB/GYNs and other practitioners rarely prescribe an opioid, most pain specialists will prescribe a limited amount if you have a pain flare. Lastly, if you suffer from severe pain and have not found relief with more conservative treatments, an interventional pain specialist will discuss whether spinal cord stimulation or an intrathecal pump is an appropriate treatment for you.■

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- Cheerleading, cycling, and horseback riding can traumatize the 'saddle area,' sometimes causing numbness, tingling, burning, and other painful genital and neuromuscular symptoms.

Although most serious athletes and dancers do not eventually develop chronic pelvic pain, I am concerned about the 20 percent that has a genetic predisposition for developing chronic pain. For them, overuse of the neuromuscular core and cumulative physical trauma can have long-term consequences.

In chronic pelvic pain patients, any combination of bladder, lower bowel and reproductive organ dysfunction can trigger ongoing irritative neuropathic pain signals that travel to the lumbar and sacral regions of the spinal cord. Hypersensitive nerves can then lead to myofascial spasms and neuromuscular pain, which further exacerbates symptoms in the pelvic and genital region.

Essentials of a CPP Practice

Doctors who plan to specialize in chronic pelvic pain must understand the neurochemistry of chronic pain and the impact of central sensitization. They must also have a working knowledge of both acute and chronic pain medications (NSAIDs, short- and long-acting opioids, tricyclic antidepressants, anti-anxiety agents, and anticonvulsants).

The other key elements of a successful pain management practice of the pelvic and genital region are:

- Well-trained and empathetic nurse practitioners (NPs) or physician assistants (PAs) who are knowledgeable about CPP and licensed to perform office-based procedures. Utilizing skilled NPs or PAs gives patients the extended time they need and shortens the wait time for an appointment. The office staff, practitioners, and doctors work as a team in caring for patients, most of whom are very distressed after many months or years of living with pain.

- Developing, if possible, a referral database of caring health care providers in the community that includes myofascial massage therapists, pelvic floor physical therapists, orthopedists, urogynecologists, gastroenterologists, physiatrists, rheumatologists, acupuncturists, yoga instructors, psychologists, psychiatrists, and sex therapists.

- Becoming familiar with local practitioners of mind/body relaxation techniques, mindfulness and Reiki, as well as grief/trauma counselors and other specialists that have earned your trust. It is not just the modality that matters, but whether a practitioner has the intuitive skills that fit your patients' needs.

It is only a matter of time before third-party payers realize that chronic pain, including pain in the pelvic region, is costing our system far more than it should and that patients would benefit most from the use of less expensive modalities and more quality time with their health care providers.

Office-based Treatment of CPP

Generally, the sooner a CPP patient is diagnosed, the sooner they respond to treatment, stay improved, and can be safely discharged from the program. However, it is important to note that patients with severe and persistent symptoms may require a CPP provider's care for a prolonged period. Every women's health practice should include a comprehensive evaluation, which screens for early signs of what may become more serious in the future. This would include checking each GYN patient in the sitting, prone, supine, and lithotomy positions, as

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well as detailed vulvar examinations not commonly done at routine yearly checkups.

At the first office visit, the NP/PA reviews the patient's questionnaires, takes a thorough medical history, and listens carefully to the patient's description of their symptoms. Regardless of age, patients are asked about their history of involvement in sports, dance, or fitness activities. The NP/PA shares this information with the doctor, and one of them performs a complete pelvic physical examination.

Additional time is often necessary when patients have multiple pelvic symptoms, the pain complaint is out of proportion to physical findings, and/or pain has persisted after prior repeated medical or surgical therapies. During this visit, we describe pelvic anatomy and function and explain the difference between acute and chronic pain. We also introduce the concept of central sensitization and encourage patients to review books and websites that explain the science of chronic pain and nervous system physiology.

After the assessment is complete, we develop an individualized treatment plan. In our practice, we recommend minimally invasive pain management procedures and modalities. Among these treatments, when considered appropriate, are superficial peripheral nerve blocks, various types of medication, trigger point therapies, Botox injections into pelvic floor muscles, and bladder instillations. Since estrogen may enhance neurogenic inflammation and lower the patient's pain threshold, we are cautious about prescribing topical hormone therapy, especially in pre-menopausal women. We are committed to a multidisciplinary approach to relieving chronic pelvic pain because it produces the best results. Once we have assessed all the patient's needs, we make referrals to one or more local health practitioners who provide specific services.

I am often asked if we studied the outcomes of our program. My reply is that to do a proper study, it is necessary to assess the effectiveness of one treatment out of many. When patients see doctors at large, prestigious institutions, they typically receive one specific treatment rather than an individualized multidimensional treatment plan. At our clinic, we have seen a complex population of referred and otherwise treatment-failed CPP patients. Even though the average pain score at intake was high (8/10), pain scores averaged 3/10 after treatment. A university research group has submitted a collection of our program's data and outcomes to an online medical journal for publication.

Understanding the Patient Experience

Chronic pain is an illness that afflicts more than 20 percent of the world's population while also affecting the lives of their family members. Yet, complex pain disorders get such short shrift in medical training and clinical care that I hear a continuing chorus of hopeless, exhausting, and harrowing tales of trauma and grief from our "new" patients. In this instance, I am talking about the added trauma of not being heard or feeling dismissed by otherwise excellent practitioners. More than a few have told us: *"I wish I had a life-threatening disease because then I would be believed, and there would be a plan of action."*

These patients have researched extensively and spend sizable amounts of money searching for a diagnosis and treatment plan. Many carry notebooks filled with documentation of multiple trips to many different specialists, well-known national and international clinics, as well as self-kept files of failed or near-failed treatments, surgeries, and invasive testing. Our practice became the end of the line for many of these folks, most of whom had consulted or been treated by multiple health care practitioners.

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As mentioned above, there is a huge spectrum of manifestations of chronic pain anywhere in the body, partially dependent on cumulative lifetime trauma. I have noted that another variable -- where an individual falls on the neurodivergent spectrum -- appears to contribute to an individual's manifestation of chronic pain. All of us perceive via our senses (sight, sound, taste, smell, and touch) in a person-specific way. Hundreds of patients told us that before their chronic pain started, they were averse to loud sounds, bright light, certain tastes or smells, or some fabrics touching their skin – even in childhood.

Conclusion

Observing and listening to 2,300 individuals with CPP has led me to some conclusions that chronic pain sufferers need to know:

Everything in the body is connected.
A flare is a flare and does not mean you're going backward.
Dialing down hypersensitivity takes time and persistent work.

From my professional experience, I learned something important that other health care providers, including pediatricians, need to know:

Asking the right questions and proper screening at younger ages can prevent the likelihood of developing chronic pain syndromes. So, the prevention of these disorders needs to be studied and applied in the clinic.

I hope that my e-book helps to bring pelvic, genital, and sexual pain disorders out of the shadows. Identifying and treating these chronic pain conditions can be taught, learned, practiced, and successfully managed by many health care practitioners. I believe it will happen, and that these long-suffering patients will finally receive the attention and pain relief they deserve.■

Editor's Note: If you would like to read more about Dr. Echenberg's protocol for treating chronic pelvic and genital pain or purchase his e-book, visit the following website: www.TheEchenbergInstitute.com.

Can Diet Affect Chronic Pain?

It is well-established that a diet full of simple carbohydrates (white flour, sugar), red or processed meat, and omega-6 fatty acids can cause inflammation and contribute to serious illness, such as heart disease. On the other hand, a Mediterranean diet (e.g., whole grains, vegetables, fish, nuts) can reduce your risk of diabetes and heart disease.

Recently, a study at the University of South Australia investigated whether a Mediterranean diet is associated with lower pain levels. They found that, regardless of body weight, people who consumed a diet full of vegetables, whole grains, fruit, fish, nuts and lean meat reported lower pain levels and better physical functioning than people who rarely consumed these foods. Of particular interest is the fact that this finding was more significant in women than in men.

In order to prove that the diet itself **causes** a decrease in pain, researchers would have to conduct a longitudinal controlled study in which one group adheres to a Mediterranean diet and another group consumes a largely processed food diet. It would take years to complete this type of study, but in the meantime, the Mediterranean diet will certainly improve your overall health.■

Doctors Advocate for Treatment Coverage

Over the past decade, too many vulvodynia patients have contacted the NVA because their insurance company, Medicare or Medicaid refuses to cover a treatment recommended by their doctor. In all cases, we tell patients they need to submit an appeal, including a letter from their doctor explaining why the treatment is necessary, along with medical articles showing the treatment's effectiveness.

OHSU Doctors Tackle Medicaid

Today, even though dozens of medical journal articles show that vestibulectomy and pelvic floor muscle therapy relieve pain in women with provoked vestibulodynia (PVD), some insurance plans and Medicaid (in some states) refuse to pay for these treatments.

Five dedicated doctors in Oregon decided to challenge their Medicaid's lack of coverage for these widely used treatments. In 2023, vulvodynia specialist Catherine Leclair, M.D., and four colleagues in the vulvar health program at Oregon Health & Science University (OHSU) collaborated in writing a letter to Medicaid explaining why vestibulectomy and pelvic floor therapy are necessary to relieve pain in many PVD patients. Their letter stated the following regarding PVD and its treatment:

- Most women with PVD have to consult three or more doctors to be accurately diagnosed and receive treatment. Their quality of life is significantly impaired by the pain, which limits their ability to sit, exercise, work, and/or engage in sexual intercourse.
- NIH-funded studies have shown that oral medications commonly used to treat chronic pain (tricyclic antidepressants, anticonvulsants) do not provide more pain relief than a placebo in PVD patients.
- Topical medication and other nonsurgical treatments are often prescribed, but do not relieve pain in most PVD patients.
- The vast majority of vulvodynia specialists prescribe conservative treatments, such as medication and pelvic floor therapy, before recommending a vestibulectomy.
- Vestibulectomy, a 45-minute outpatient procedure, is performed using deep sedation. (Painful tissue at the vaginal opening is removed and vaginal tissue is advanced to cover the area.) At discharge, patients receive a prescription for pain medication and post-op instructions.
- Thirty-three published studies show the success rate of vestibulectomy is relatively high. On average, 64 percent of patients report complete pain relief and 80 percent report some pain relief.
- After healing occurs, pelvic floor muscle therapy and dilators are recommended to deal with remaining pelvic floor tension and reduce pain with sexual intercourse.

After submitting the two-page letter and speaking at Medicaid regulatory meetings, Dr. Leclair and her colleagues were notified that Oregon Medicaid would change its policy and provide coverage of vestibulectomy and pelvic floor muscle therapy for PVD patients.

The NVA is hopeful that their success will inspire more health care providers to join forces to challenge unfair insurance practices in their state.■

Please Donate to Research

You can partner with the NVA to fund critical research on treatments for vulvodynia. Donations can be made online or by mailing a check, made payable to NVA, to: NVA, PO Box 4491, Silver Spring, MD 20914-4491. Another option is to make a gift of an appreciated asset (stocks, bonds or even works of art). For additional information, please email Phyllis Mate at pmate@nva.org. Thank you!