



NVA News

May 2021

Vulvodynia Then and Now

By Phyllis Mate, Co-founder of NVA

Phyllis was a psychology professor until representing women with vulvodynia became her life's work. She served as NVA's volunteer executive director for 16 years and is currently President of the executive board.

Recently I was interviewed about the early days of the NVA and started to think about what's changed for women with vulvodynia over the past 30 years. Today, the medical community is more knowledgeable about chronic vulvar pain and more women are diagnosed within months, instead of years. When I had severe vulvar pain in 1991, I searched the National Institutes of Health (NIH) library and found one medical article that described my symptoms. Now it just takes minutes on Google to access hundreds of journal articles about every aspect of vulvodynia. I thought, like many others, that no one else had this kind of pain and today you can join a support group on Facebook. Until recently, the NVA was the only non-profit helping women with vulvodynia in foreign countries and now there are groups providing information and support in at least 12 countries.

Before the first NIH vulvodynia conference in 1997, there was no research on its prevalence, causes or treatments. Over the past two decades, the proliferation of vulvodynia studies has been stunning despite the fact that NIH funding has been disappointing. In particular, many of these studies have significantly increased our knowledge of underlying physiological mechanisms and other factors that may cause or contribute to vulvodynia.

The Road to An Accurate Diagnosis

In the old days, when a woman presented with chronic vulvar pain or pain during sexual intercourse, her doctor, usually a gynecologist, examined the vulva for signs of disease and tested for multiple infections. When there was no visible abnormality or positive test result, some doctors assumed it was a subclinical yeast infection and prescribed antifungal medication (further irritating the vulva). Others prescribed various strengths of topical cortisone, an anti-inflammatory. If those treatments didn't relieve the pain, most gynecologists assumed the pain was psychological in origin. Many women recall their doctor saying, "It's all in your head," or "Have a glass of wine before sex." Some women accepted their doctor's assessment and left the office with a referral to a psychiatrist. Most sought a second opinion.

Since the subject wasn't covered in medical school or ob/gyn residencies, the NVA's medical advisors developed an online tutorial on the diagnosis and treatment of vulvodynia. Over the past decade, about 30,000 health care providers in the U.S. have received continuing medical education credits for taking the tutorial. Additionally, basic science researchers identified several differences in the vulvar tissue of women with vestibulodynia versus controls, forever dispelling the notion that "it's all in your head." Today, most gynecologists recognize that vulvodynia is a chronic pain disorder and many know how to diagnose it.

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The Biopsychosocial Approach

As research evolved and studies identified multiple factors that are associated with the development and maintenance of vulvodynia, vulvar pain experts broadened their perspective. "Vulvodynia is complex and has patient-specific causes and features," stated Caroline Pukall, Ph.D., a psychologist and director of sex therapy at Queen's University, Kingston, Ontario. Based on clinical and research findings, she adopted the view that vulvodynia is a biopsychosocial phenomenon, a complex interaction of biological, psychological and social factors. The biological components include hormonal changes, inflammation, genetic predisposition, musculoskeletal characteristics and neurological symptoms. "Equally important are psychological factors that contribute to vulvodynia," noted Pukall. Depression and anxiety are common in women with vulvodynia, increasing the pain and interfering with sexual functioning. Over time, living with chronic pain often leads to hypervigilance, catastrophizing and fear of pain, all of which exacerbate pain. Pukall described one example of the interplay between psychological and biological factors. "Hypervigilance, a symptom of anxiety, causes tension in the pelvic floor muscles. If these muscles become chronically overactive, vulvar pain increases," she explained. The social component of the biopsychosocial model refers to the impact that people close to you can have on your pain, e.g., how a sexual partner responds to your pain. It also includes societal beliefs and norms, e.g., the belief that sexual intimacy should always culminate in sexual intercourse.

Gynecologist Deborah Coady, M.D., FACOG, was among the first vulvovaginal experts to recognize that vulvar pain patients required more extensive clinical assessments. Most of her patients suffered from vestibulodynia, the most common subtype of vulvodynia, and she found that almost all of her vestibulodynia patients had hypertonic (overactive) pelvic floor muscles. Having diagnosed hundreds of these patients, she also observed considerable variability in their behavior during the vulvar exam. Some women who experienced severe pain with the q-tip test allowed the exam to proceed, while others wouldn't let her touch the area. Coady attributed this variability to a combination of biological factors, e.g., different pain thresholds, and psychological factors,

such as fear of pain. She emphasizes that biopsychosocial assessment, i.e., evaluating a patient holistically, ensures that the treatment regimen will address all aspects of a woman's pain.

The Change to Multidisciplinary Treatment

Thirty years ago, the majority of vulvodynia patients relied solely on a gynecologist for their care and tricyclic antidepressants were the first-line treatment. If the first antidepressant didn't relieve pain, a different one, or sometimes an anticonvulsant, would be prescribed. Over the years, newer antidepressants and anticonvulsants with fewer adverse side effects came into use (both oral and topical), but the trial and error process of trying medication after medication remained the same. While this is still the case for many women, vulvodynia specialists have been advocating for a multidisciplinary treatment approach.

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The National Vulvodynia Association is a nonprofit organization that strives to improve women's quality of life through education, research funding, support and advocacy.

The NVA is not a medical authority and strongly recommends that you consult your own health care provider regarding any course of treatment or medication.

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Remembering Dr. Marilyn Seskin



Dr. Marilyn Seskin dedicated her life to alleviating the suffering of others. She grew up in Stuyvesantown, in New York City's Lower East Side. She loved New York City, and although she lived in Miami over 35 years, she always said, "I'm from New York."

Marilyn received her bachelor's and master's degrees in psychology from

City College of New York (CCNY) and began her career as a teacher in inner city schools. Deciding to pursue a second career as a physician, Marilyn earned her M.D. degree and completed an anesthesiology residency at Albert Einstein College of Medicine in her beloved New York. She began her career in South Florida, where her aging parents resided and thrived under her care. In Florida, she met her husband Bob Sugarman and lived an active and fulfilling life of travel, culture, scuba diving and

hiking. When vulvodynia cut Marilyn's career short, she was determined to learn all she could about the condition, attending conferences and visiting clinicians throughout the country, offering support to fellow patients, lobbying for government funding, and supporting the NVA. Sadly, Marilyn was diagnosed with ovarian cancer in her late 60s and left us in her 70th year. Marilyn's higher power was science, which she believed was worshipped thru research. Her annual donations and bequest to NVA's research efforts was fueled by her desire that her life's work – alleviating human suffering – be carried on by fellow dedicated physicians and researchers. In early 2021, the NVA Board awarded the first Dr. Marilyn Seskin Clinical Research Award to Christine Conageski, M.D., associate professor of obstetrics and gynecology at the University of Colorado School of Medicine. She is currently investigating the efficacy of hemp suppositories in the treatment of provoked vestibulodynia. ■

In Her Own Words

By Laura D.

For six years, I dealt with severe vulvar pain that felt like an iron was burning me. In social situations, I silently prayed that people wouldn't tell me to sit down, because it intensified the pain. To understand what was causing it, I visited my gynecologist many times and had numerous vaginal cultures, which were always negative. Eventually I was diagnosed with vulvodynia by a gynecologist who nervously laughed and led with, "You aren't going to like what I have to say." She was right. From her behavior, I knew that she was not the right doctor for me. For the next five years, I visited gynecologists, nurse practitioners, midwives, naturopathic doctors, physical therapists, and acupuncturists for second opinions, hoping to find someone who could help me. I was depressed, anxious, and in pain. During this period, I encountered many people who helped me and many who made me feel worse emotionally. Now that I am no longer in pain, I want to share my story with the hope of helping others. I also want to give feedback to women's healthcare providers. Often, it seemed like there was no "care" in healthcare. Today, I am grateful for the team of health care providers who cared about me and led me to a life with less pain.

- To the doctor I finally found:

Thank you for talking to me with my clothes on! I was only wearing a paper gown when I first met with the five other medical doctors I saw before I found you. My brain couldn't fully process what they were saying, because I felt awkward and cold.

Thank you for referring me to Pelvic Floor Physical Therapy. Every other doctor wanted me to take medication. Pelvic floor therapy decreased my pain and improved my quality of life immensely!

*Thank you for sharing resources with me and being willing to accept my recommendations and resources. Your recommendation of Amy Stein's *Heal Pelvic Pain* gave me a specific plan to follow, which really helped; I felt comforted having a plan. Every time I shared a name with you, whether it was an acupuncturist, physical therapist, or product that helped me, you genuinely thanked me and said you would share it with other patients. Your kindness, respect, and willingness to collaborate make you an invaluable member of my team.*

- To my acupuncturist and naturopathic doctor:

Thank you for trying so many different approaches. I am grateful you always listen and remind me I will be okay.

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Most doctors I met only had one treatment approach and didn't focus on the cause of my pain. You had many ideas and didn't give up.

- To my support group:

I am thankful the National Vulvodynia Association led me to you. I am so grateful for your support, product recommendations, and willingness to share your different treatment plans. I was both shocked and elated that I was not the only one who felt like this! Before I met you, having vulvodynia was the loneliest condition. Not talking about my symptoms and emotions only made the pain worse. Thank you for talking about your experiences.

- To my pelvic floor physical therapist:

Thank you for listening and for never dismissing my pain. I attribute a large part of my decreased pain to your therapy. You taught me that healing is not linear and gave me so many tools to help myself. My toolbox now includes a Therawand, foam rollers, therapy balls, yoga, stretches, and guided relaxation meditations. Knowing I have these tools makes me less afraid of the pain and empowers me.

Thank you for referring me to resources about my diagnosis. The first few times I heard doctors say "Generalized Vulvodynia" and "Vestibulodynia", my paper gown got soaked with sweat and I was overwhelmed. Fully clothed in the comfort of my own home, I read *Pelvic Pain Explained* and the pelvicpainrehab.com blog. Now I understand what causes my symptoms, and I'm no longer terrified of what's happening with my body. I learned that

hormones, recurrent vaginal infections, tight/weak pelvic floor muscles, an irritated pudendal nerve, and stress play a part in my pain. Knowledge is power! I am grateful you helped me find a knowledgeable doctor and mental health therapist. Your referral for cognitive behavioral therapy and to a doctor who actually listens was so important.

- To my mental health therapist:

Thank you for encouraging me to explore the mind/body connection. I've learned that being anxious increases my pain and that I can control it by changing what I say to myself. The less anxious I am, the less pain I have.

Thank you for teaching me to be kind to myself. Instead of being my toughest critic, I've learned to talk to myself the way I'd talk to a friend. Now when I have pain, I allow myself to rest without feeling guilty about it.

Thank you for teaching me to accept the pain and advocate for myself. I've learned to manage the pain and not let it take over my life. I'm assertive with health care providers, because I know what I need to feel better. Now I'm able to help other women who have vulvodynia.

If you are reading this because you are in pain, please don't give up hope. It may take some time, but you too can find a team of health care providers who will listen and help you learn how to gain control of the pain.

Laura D. can be reached at lem682@gmail.com.

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After reviewing numerous studies, in 2015 the International Society for the Study of Vulvovaginal Disease, International Society for the Study of Women's Sexual Health and International Pelvic Pain Society published international consensus guidelines supporting pelvic floor therapy and psychological interventions as *first-line* treatments for vulvodynia patients. With this change, pelvic floor physical therapists and cognitive behavior therapists became essential members of the multidisciplinary team. Vulvodynia experts have been referring patients to pelvic floor therapy for many years, but an increasing number of gynecologists are learning that a multidisciplinary approach contributes to a more successful outcome.

Gynecologists who read the vulvodynia medical literature also know that the first large controlled studies on the efficacy of a tricyclic antidepressant or an anticonvulsant for vestibulodynia found that they did not provide more pain relief than a placebo. Based on those findings, many experts decided not to recommend these oral medications as first-line treatment for vulvodynia. The American College of Obstetricians and Gynecologists still lists antidepressants and

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anticonvulsants among its treatment recommendations for vulvodynia, but their current guidelines also encourage a multidisciplinary approach.

Choosing Your Treatment Team

The gynecologist or other clinician who accurately diagnosed you may initially be part of your team as long as you have confidence in her/his experience in treating vulvodynia. If your pain is moderate to severe, consider a consultation with a pain management specialist. Gynecologists have had excellent training in pregnancy and childbirth, but minimal training in the treatment of chronic pain. A pain management specialist, on the other hand, has focused on treating chronic pain, knows every pain medication and its side effects, and should be familiar with the benefits of alternative options, such as acupuncture and CBD. Any woman with vulvodynia can benefit from consulting a pain management specialist, but if your symptoms are constant and severe, you definitely need this specialist on your treatment team. If you don't experience adequate pain relief with medication and other conservative treatments, your pain specialist can discuss more invasive options with you, such as spinal cord stimulation.

After a vulvodynia diagnosis, your health care provider should refer you to a pelvic floor physical therapist (PT) or you can choose one on NVA's website or contact the women's section of the American Physical Therapy Association. Symptoms of pelvic floor muscle dysfunction include muscle spasm and decreased muscle strength and coordination. The PT will likely do an overall musculoskeletal assessment, in addition to evaluating your pelvic floor muscles. Therapy involves external and internal manual techniques, including stretching, massage, and myofascial trigger point release to facilitate muscle relaxation, improve circulation and increase mobility. Recent studies indicate that pelvic floor muscle therapy reduces vulvar pain and improves sexual functioning in vestibulodynia patients.

A physical therapist may be the most appropriate person to coordinate your care and monitor your progress (if she's willing), because you see her more often than other health care providers. Many women feel comfortable

talking with their PT and she has the opportunity to observe whether a patient has pain-related anxiety that might benefit from cognitive behavior therapy. After a number of sessions, the PT may also learn about a patient's intimate relationship(s) and consider whether to recommend a sex and couples therapist.

Most chronic pain patients, including women with vulvodynia, suffer from depression and pain-related anxiety. Several studies have shown that cognitive behavioral therapy (CBT) reduces vulvar pain and improves intercourse-related pain, especially when mindfulness training is included. CBT strategies target maladaptive thoughts, feelings and behavior associated with chronic pain. The therapist teaches you to replace negative thought patterns, e.g., "I'll never get better" with positive thoughts, e.g., "This is just a temporary flare." It may sound simplistic, but what we say to ourselves has a powerful effect on pain, mood and behavior. It takes a lot of practice to change thought patterns, but if you suffer from chronic pain, it is well worth the effort. (An online CBT module for vulvodynia will be released in spring 2022.)

Traditional psychotherapy may be beneficial for some women who don't experience sufficient pain relief with medical treatment, pelvic floor muscle therapy and cognitive behavior therapy. Talli Rosenbaum, M.Sc., a sex and couples therapist, described the case of an unassertive woman whose vaginismus and vulvodynia didn't improve with standard physical therapy techniques and graduated dilators. She could tolerate sexual intercourse, but didn't feel mentally present or find it pleasurable. This woman was referred to a psychotherapist to help her confront feelings and behaviors that stemmed from her relationship with an overbearing mother. After one year of psychotherapy, she developed a stronger sense of self, became more assertive and learned to set boundaries. By combining psychotherapy with pelvic floor therapy, her vulvar pain improved and she was able to enjoy sexual intercourse.

Since vulvodynia creates difficulties in intimate relationships, a sex and couples therapist who treats sexual and relationship problems is often an important member of the multidisciplinary team. A sex therapist will ask you

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personal questions that other team members may not consider relevant or may be too uncomfortable to ask. For women (and their partners) with a history of painful sexual intercourse, sensate focus is an essential part of sex therapy. This is an ideal situation for women who fear pain with penetration, because sexual intercourse is prohibited during this period. Sensate focus simply requires that couples set aside time on a regular basis to explore and touch each other in a mutually pleasurable way. For optimal results, sex therapy is combined with pelvic floor exercises and the use of graduated dilators.

For maximum benefit, the members of a multidisciplinary team must update each other on your progress and discuss potential changes to your treatment plan. Even though each specialist has a different expertise, they share the same goal, which is to help restore your quality of life.

Summary

We've finally reached the point where the majority of gynecologists can diagnose vulvodynia and understand that it is a complex pain disorder. Vulvodynia experts, and an increasing number of gynecologists, recognize that a biopsychosocial assessment and multidisciplinary approach are most likely to lead to a successful outcome. Doctors and scientists committed to vulvodynia research have made progress towards understanding its causes, but we lack controlled studies on the efficacy of available treatments and many women still spend years seeking adequate pain relief. What we need to happen now is for vulvodynia experts and other scientists to collaborate in formulating a research strategy that will lead to the development of effective vulvodynia-specific treatments. The NVA is committed to supporting studies that are essential to achieving this goal. ■

IN HER OWN WORDS

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By Crystal



Having vulvodynia has taught me patience, courage and assertiveness, and helped to shape the person I am today. In 2000, I had just graduated from high school and was excited about going to college. I envisioned having a career, traveling, and getting married and starting a family. What I didn't expect

was the struggle that was to come---the struggle to cope and function with chronic vulvar pain. I started having burning pain that, like many women with vulvodynia, I assumed was a yeast infection. Sitting, wearing jeans and riding a bike caused severe pain. For three long years, I saw gynecologists, dermatologists and a urologist, all of whom said, "There is nothing wrong." Finally, with NVA's help and resources, I was diagnosed with vulvodynia. By 2006, I had exhausted my treatment options in Canada and had a vestibulectomy in the U.S. Although surgery didn't completely eliminate my pain, I started to turn the corner. My experience with vulvodynia encouraged me to learn about the benefits of healthy living. Getting enough sleep and exercise, eating healthy foods and managing stress has helped me to such an extent that I no longer experience daily vulvar pain.

Like many women with vulvodynia, I also have chronic pain in other areas of my body and struggle with depression and anxiety. When these feelings overwhelm me, I reach out for help. Through the NVA and my community, I have learned there are mental health resources for women with chronic pain. The relationships I formed through the NVA, many of which are long distance, have become some of the most encouraging and uplifting friendships of my life. Women who have pain in such an intimate area know how to be there for one another. The NVA has also given me the opportunity to be part of a community of strong women who lift each other up and give hope and support to recently diagnosed women.

My husband has been my rock throughout my diagnosis and treatment. I kept putting things on hold, but he believes in making the best of the present. This ordeal taught us what really matters in a marriage and we don't worry about the small stuff. My husband and I dreamed of having children. Although I was nervous that my vulvar pain might return during pregnancy, it did not. Because I had scar tissue from the vestibulectomy, we decided on a C-section instead of a vaginal birth. Now we are the parents of a smart and sensitive 5-year-old boy who makes us smile every day. ■