



National



Vulvodynia



Association

NVA News

June 2024

The Search for Novel Treatments

After two years of planning, the Vulvodynia Research Summit was held on April 19th thru 21st in the Washington DC area. In addition to the varied group of researchers invited to present their studies, there were representatives from patient advocacy organizations, the International Society for Women's Sexual Health Research and the gynecologic division of the National Institute of Child Health and Human Development. The goal of the Summit was to advance the most promising areas of study for developing novel treatments for neuroinflammatory vestibulodynia. (Hormonally-mediated vestibulodynia is treated with topical estradiol.)

Over the course of two days, renowned researchers in chronic pain and vestibulodynia presented their latest findings and proposed a treatment. Each presentation was followed by a 40-minute discussion of the treatment's potential efficacy and feasibility. Some of the therapeutic possibilities were derived from animal studies of vestibulodynia, while others, e.g., ketamine and cryoneurolysis, are treatments that have been used for other neuropathic conditions.

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Treating Painful Sex After Menopause

In a 2022 study by Martha Goetsch, M.D., emeritus assistant professor of obstetrics and gynecology at Oregon Health Sciences University, postmenopausal women that experienced pain during sexual intercourse were asked to describe their symptoms. "Burning" was the most common response. Among other terms used were raw, sharp, ripping and knife-like.

"What these women describe is dyspareunia (painful sexual intercourse), one of the most overlooked and under-treated symptoms of menopause," said Goetsch, a specialist in vulvovaginal conditions who has treated hundreds of women with these symptoms. Although dyspareunia can occur at any life stage, it is more prevalent after the menopausal transition.

"We don't know precisely how common it is after menopause, because many women and doctors are uncomfortable raising the subject," says Lauren Streicher, clinical professor of ob/gyn at Northwestern University. As a result, many women don't receive the care they need for dyspareunia despite the fact that it's easy to treat. They think "OK, well, I guess my sex life is over," said Dr. Streicher.

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NOVEL TREATMENTS

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Patient Engagement

An important issue presented by clinical practitioner and NVA Board member Susan Kellogg Spadt, PhD, was establishing researcher/patient partnerships. The engagement of patients in the conception, design and execution of treatment studies is a growing trend that has become a funding requirement at some institutions. Among the advantages is that it increases the likelihood that patients will accept a treatment once it becomes available.

Spadt described how researcher/patient collaborations can benefit both parties. For example, a researcher that learns fear of pain prevents patients from participating in research can modify a procedure to minimize discomfort. When patients know their concerns have been addressed, they're more willing to participate in a study, speeding up recruitment and data collection. In turn, patients benefit from having the treatment available sooner.

Many of the research presenters welcomed input on their novel treatment ideas from patients in attendance at the Summit. Patient advocate Noa Fleischacker, executive director of Tight-Lipped, emphasized the need to develop vestibulodynia treatments that are low-risk, low-pain and can be delivered in a doctor's office.

Research Funding

Helena Ahn, Ph.D., of the Gynecologic Health and Disease Branch of the National Institutes of Child Health and Human Development (NICHD), encouraged the group of researchers to submit their treatment proposals to NICHD, because research on therapeutics and devices for gynecologic conditions are currently a high priority at the Institute. She suggested that they flood NICHD with proposals to increase the likelihood that vulvodynia studies will be funded. Dr. Ahn also recommended submitting proposals to the NIH HEAL initiative, which supports clinical research that evaluates innovative

strategies for pain management. (HEAL was established in 2018 to accelerate scientific solutions to stem the opioid and pain public health crises.)

Summit Follow-up

In fall 2024, there will be a virtual meeting at which each Summit researcher will present a research proposal incorporating feedback from April's brainstorming session. This virtual presentation will be open to societies, foundations and stakeholders. Each presentation will be followed by a question and answer session open to the entire audience.

The final event will be the presentation and publication of a consensus paper, titled Research Areas of Promise for Vulvodynia, which will be distributed to funding agencies, such as private and public foundations, and pharmaceutical companies. ■

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National Vulvodynia Association
P.O. Box 4491, Silver Spring, MD 20914-4491
Tel: (301) 299-0775
www.nva.org

Editor: Phyllis Mate
Layout: Lisa Goldstein

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

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TREATING PAINFUL SEX

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Why Does Sex Become Painful?

The drastic drop in estrogen at menopause and afterwards is the main reason sex can become painful. Among its many functions, estrogen keeps the vaginal walls lubricated and elastic. Estrogen maintains the folds in the vaginal wall that provide this elasticity. When estrogen declines, the vaginal walls become thin, the folds disappear and lubrication decreases. As Streicher noted, "When we use the speculum and look inside the vagina, we can see that the little folds are gone and the vaginal lining is dry."

The loss of estrogen also affects the vulvar vestibule, the highly sensitive entryway to the vagina that's packed with nerve endings, which Dr. Goetsch described as, "the two square inches that can wreck your life." From her research and clinical practice, Goetsch learned that most women who experience painful sex suffer from pain in the vestibule, not in the vagina.

After menopause, the vestibule can become extremely sensitive. Research findings suggest that the drop in estrogen causes a proliferation of nerve endings, leading to an increase in pain. "Quite a few animal studies show that when estrogen declines, various nerves sprout new nerve endings; but when the estrogen level goes back up, those nerve endings are pruned back," Goetsch explained. Not all postmenopausal women will experience severe symptoms with the drop in estrogen, but even mild changes in the vulva and vagina can make pain-free sex elusive. Many women report increased irritation, and in some cases, tiny cuts in the brittle vulvovaginal tissue.

There are several other factors that can contribute to vulvovaginal pain among postmenopausal women. Hormonal changes alter the acidity level in the vagina, which can lead to recurrent urinary infections. These infections can cause discomfort in the vulva regardless of whether you are having sex. Also,

some common health conditions among older people, such as diabetes and cardiovascular disease, can have a drying effect in the vagina.

What are the Treatments?

An experienced gynecologist or vulvovaginal specialist will do a thorough examination to determine the appropriate treatment. If vaginal dryness is the only symptom, over-the-counter products, e.g., lubricants and moisturizers, may be sufficient. For more severe symptoms, topical lidocaine and/or estrogen may be prescribed.

Lubricant. For women with vaginal dryness only, adding temporary moisture before sex may be all that is needed. Gynecologists recommend warming lubricant before use, because cold is a vasoconstrictor and will reduce natural lubrication. An easy method is placing the bottle of lubricant in a bowl of hot water a few minutes before applying it.

Vaginal Moisturizer. There are a number of over-the-counter creams and gels that help to increase the water content in mucosal cells lining the vaginal wall. Moisturizer, when used regularly, helps to restore vaginal lubrication and elasticity. It can also make sex more comfortable for women who have pain in the vulvar vestibule.

Unlike lubricant, which is used just before sex, moisturizer is applied two to three times each week. Since many lubricants are marketed as moisturizer, consumers should read the instructions. If they say to apply the cream or gel on an ongoing basis, the product is a moisturizer.

Estrogen. When there's significant atrophy of the vulvovaginal tissue, a doctor may prescribe low-dose topical estrogen. Many studies have found that this prescription option is highly effective for relieving pain during sex. The standard instruction is to insert

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TREATING PAINFUL SEX

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the estrogen cream inside the vagina, but for many postmenopausal women the pain is located in the vulvar vestibule. In a 2023 NVA-funded study, Goetsch found that estrogen cream applied nightly to the vulvar vestibule was very effective in treating dyspareunia.

Lidocaine. A topical anesthetic, lidocaine is applied to the vulvar vestibule 30 minutes before sex. Dr. Goetsch prescribes 5% lidocaine for many patients with dyspareunia, especially those who cannot use hormones, e.g., breast cancer survivors. Lidocaine is highly effective and women who use it rarely report residual pain after the anesthetic effect wears off. Liquid lidocaine is the preferred choice, because it doesn't numb the partner.

Summary

Postmenopausal women who have tried using a vaginal lubricant or moisturizer and still experience painful sex need to see a gynecologist or nurse practitioner. There are safe and effective treatments for this common condition.

(Editor's note: This article was adapted from Alisha Gupta's 2023 New York Times article, What to Do About Painful Sex After Menopause.)■

Research Updates

McLean Awarded Canadian Grant

In 2018, Dr. Linda McLean of Queen's University received an NVA grant to compare low-level laser treatment (LLLT) to a sham intervention in the treatment of provoked vestibulodynia (PVD). (LLLT, or light therapy, is used to treat inflammation and pain.) In her pilot study, LLLT led to a greater reduction in pain sensitivity at the vulvar vestibule than the sham intervention. This past year, McLean submitted the results in her research proposal to the Canadian Institute of Health Research and was awarded a grant to conduct a large randomized controlled trial of LLLT in women with PVD.

Nortriptyline and Topical Lidocaine/Estradiol Study

Three years ago, NICHD funded a randomized controlled trial comparing the effectiveness of the tricyclic antidepressant nortriptyline and topical lidocaine/estradiol in the treatment of two vestibulodynia subtypes. In the peripheral subtype, pain occurs only in the vulvar vestibule; in the centrally-mediated subtype, pain occurs in the vestibule and one or more areas of the body. Last month, Erin Carey, M.D., and Andrea Rapkin, M.D., completed data collection on the study's 400 vestibulodynia patients. Data analysis has begun and we will report on the results as soon as they are released.

Nackley Awarded NVA Grant

The final piece of the Carey and Rapkin study (above) was to measure inflammatory markers, e.g., cytokines, in the peripheral and central vestibulodynia (VBD) subtypes. It was hypothesized that they would find an increase in cytokines in the vulvar tissue of women with peripheral VBD versus an increase in cytokines in the blood of women with central VBD. If true, the treatment implication is that topical medication should be effective for peripheral VBD, but that systemic medication is necessary to treat central VBD.

Because of Covid delays during which their research assistant had to be paid, the investigators lacked funds for completing the last part of the study. In 2023, co-investigator Andrea Nackley, PhD, of Duke University applied to NVA and was awarded a grant to measure inflammatory markers in the two subtypes. ■

Medical Treatment Survey

To learn which medical treatments are most often prescribed for newly diagnosed vulvodynia patients, NVA sent a brief survey to 400 doctors on our referral list. Invasive treatments, such as nerve blocks and vestibulectomy, were not among the options. It should be noted that the questions allowed doctors to choose more than one treatment.

The survey results show that treatment depends on whether a woman is diagnosed with vestibulodynia (VBD) or generalized vulvodynia (GV). Most doctors prescribe topical treatment for newly diagnosed women with vestibulodynia, but rarely for women with GV. Oral medication is, in most cases, the only treatment prescribed for women with GV.

Vestibulodynia Treatment

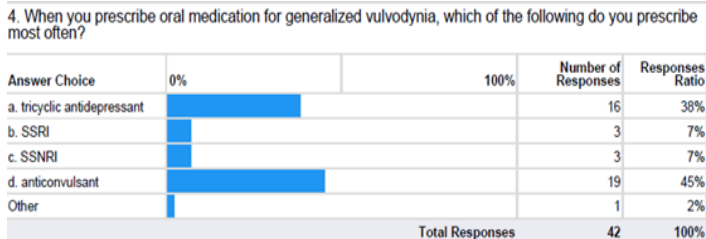
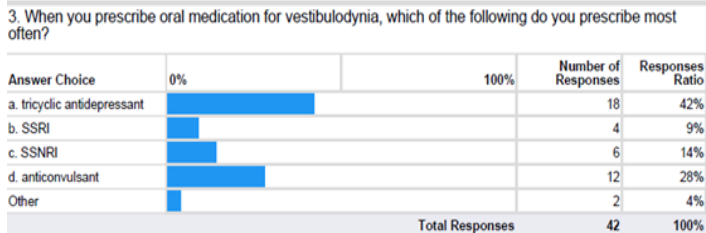
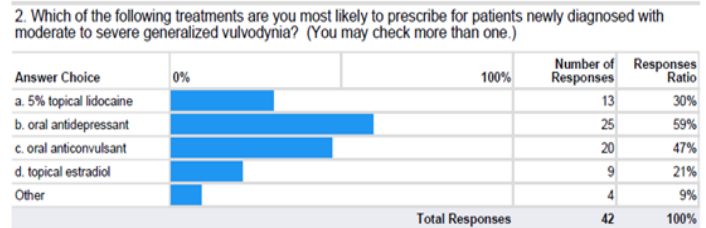
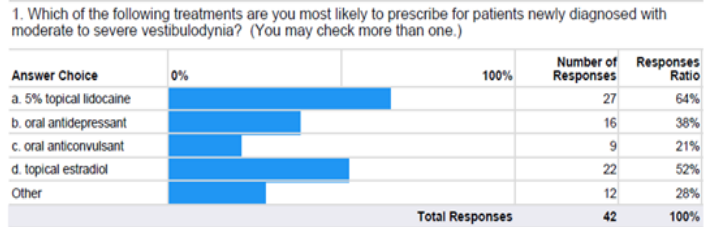
Almost two-thirds of respondents prescribe the topical anesthetic lidocaine for vestibulodynia. Over 50 percent prescribe topical estradiol, an effective treatment for hormonally-mediated VBD. Many VBD patients are treated with oral medication in addition to a topical. Of the 60 percent of respondents that prescribe an oral medication for VBD, most choose a tricyclic antidepressant. Other types of antidepressants, SSRIs and SSNRIs, are rarely prescribed.

Generalized Vulvodynia

All doctors surveyed prescribe an oral medication for generalized vulvodynia. TCAs are prescribed by 59 percent of respondents, anticonvulsants by 47 percent. Doctors who prescribe an anticonvulsant are most likely to choose gabapentin (Neurontin). Only 30 percent of respondents prescribe lidocaine for generalized vulvodynia.

Summary

Survey results show that topical lidocaine and topical estradiol are common treatments for patients recently diagnosed with vestibulodynia. The only treatment prescribed for most women with generalized vulvodynia is a TCA or anticonvulsant. ■



Donate to Research

Please 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 Research, c/o Phyllis Mate, 9016 Rouen Lane, Potomac, MD 20854. Another option is to make a gift of an appreciated asset (stocks, bonds or even works of art), or you can donate an old car. If you need additional information, please email Phyllis Mate at pmate@nva.org. Thank you!

From Vaginismus to Vulvodynia

The Long Road to Recovery

By Allyson Rudolph

The first time I tried to use a tampon, it didn't work. It was the summer of 1998. *Saving Private Ryan* was dominating the box office and I was dealing with my own bloody mess: my first-ever period. I remember trying out the suggested poses. Seated on the toilet? Standing with one foot on the bathroom counter? No matter how I positioned myself, when I tried to insert the tampon it felt like trying to poke through a tambourine. There was no pain, but it wouldn't go in. After I told my mom what had happened, a tube of K-Y Jelly appeared on the bathroom counter. It didn't help, so I gave up and used pads.

When I decided to have sex for the first time with a boyfriend in college, the experience was similar. I felt a dull pushing sensation in the vaginal area, and significant embarrassment for both of us. I expected some pain and bleeding while losing my virginity, but didn't understand my Barbie-doll anatomy. After a few more tries over a couple of weeks, we managed to achieve intercourse, but his penis felt like it was wrapped in sandpaper.

I went to the college ob/gyn who had previously put me on hormonal birth control to relieve the extreme cramping that came with my periods. She performed a pelvic exam, told me that the entrance to my vagina appeared "angry" and suggested calendula cream to soothe the inflamed tissue. It gave me an itchy rash, nothing got better and I didn't follow up. The few times I tried penetrative sex after that were painful, so I quit trying. I felt like my vagina was cursed. (I didn't learn until years later that other women experience pain during penetration.)

After college, I moved to DC and began seeing someone. After a month of dating, I drank a lot of alcohol and tearfully confessed that sexual intercourse was painful for me. We didn't talk about it again. Over

the course of two years together, I found satisfaction in kissing and cuddling and he found satisfaction having sex with other people. When we broke up, I decided it was time to find the person of my dreams — a doctor who could tell me what was wrong with me.

I expected to be single for awhile—yearslong dry spells had been my norm between relationships—and I was determined to use the time to get the better of my pain. I made an appointment with a new doctor, a kindly older man. During the pelvic exam I mentioned I wasn't dating anyone and was considering going off birth control. "Oh, I think you'll have found someone special by the time you're in here next year," he replied, as though he had a crystal ball. Together we decided that I would stop the hormonal birth control, since in some cases it could dampen desire and arousal and lead to vaginal dryness. (I'd later learn that stopping birth control is not recommended for patients who experience pain with penetration.) He also told me to look up *vaginismus* and prescribed a set of vaginal dilators, which I ordered online. The dilators were a set of smooth, bullet-shaped silicone ... well, dildos. They came in varying sizes and were hollow, fitting together like a set of Russian nesting dolls. I was to insert one into my vagina every night, gradually increasing from smallest to largest. I kept the dilator in place for a few minutes in order to stretch and expand my pelvic floor muscles. Because the process is cold and unpleasant, the ob/gyn advised me to "do something relaxing while you're using them," so I watched *Lost* on my laptop.

After several months off birth control, I experienced sexual desire for, frankly, the first time ever. Eventually, I could use the largest dilator with bearable

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amounts of pain and even used a tampon or two. Within a year I had a new boyfriend, as my kind ob/gyn had predicted. Maybe it was the nightly close encounters with my vagina, or maybe I was just becoming more mature, but I was able to tell my new boyfriend about my pain without dying of embarrassment. He, in turn, did something no boyfriend had done before and asked me what did and didn't feel good when we were intimate, a conversation we'd continue throughout our relationship. In addition to the dilators and my newfound courage, I found *really* good lube in magazines for gay men. If we were careful, we could have honest-to-goodness sexual intercourse. Sometimes it was fun. Sometimes, a lot of fun. When we broke up, it wasn't for reasons related to intimacy.

Before long, I had relegated the dilators to a box under the bed. I moved to pursue a career in publishing in Brooklyn, where I found the man whom I'd eventually marry. We were able to have careful, well-lubed, enjoyable sex. It wasn't completely pain-free, but I'd learned how to talk about what hurt ... and what felt good.

Then, on the advice of a new ob/gyn, I decided to try a low-hormone IUD. I screamed when my doctor inserted it. The next morning, I woke up with swollen red patches under my eyes, which the ob/gyn assured me were unrelated. Looking like a sunburned panda wasn't a good omen, though. The sheer pain of IUD insertion must have shocked my body back into its defensive default, re-establishing the association between penetration and pain. The more I tried to push past it, the stronger the connection got, making sex even more unbearable. My partner and I would begin having sex like before—and then suddenly I'd have to call it quits, sobbing onto his shoulder. I felt broken.

The prospect of a new ob/gyn always gave me hope—maybe this one would know how to fix me.

It wasn't long before we moved to Los Angeles and I saw the next ob/gyn. Like those who'd come before, she could not find anything wrong with my vagina, but did not doubt I was experiencing pain. She referred me to a physical therapist who was recently certified to treat vaginismus. Once a week I'd take an extended lunch break from my office job so I could lie on a table while the physical therapist used her fingers to gently massage and stretch my pelvic floor muscles. She told me to dust off my dilators and gave me homework: I'd hole up in the bedroom each night, starting with the smallest dilators, and perform a series of stretches. I'd text my boyfriend when I was almost done, and find him waiting outside the bedroom door, arms open to encircle me in a hug.

Those physical therapy and dilator sessions should have helped, but they didn't. Maybe I stopped too soon. I didn't even want to try having sex anymore. I went through cycles—feeling depressed, doing research, finding a promising book to read or writing to a sexologist's advice column, repeat. We started couples therapy and learned to be creative in the bedroom, which helped make us braver about communicating our feelings and desires. During one of the “doing research” phases of my loop, I found Andrea Rapkin, M.D., a specialist in genito-pelvic pain at UCLA. At that point I knew I had vaginismus, but suspected there might be more to my pain than misfiring muscles—why would muscle spasms make me sting? I hoped a specialist might have the answers and made an appointment.

In late 2019, I sat at Dr. Rapkin's nurses' station to complete a long survey about my history of vulvovaginal pain. I circled words that described the pain I felt with different experiences. Menstrual cramps: *gnawing, throbbing*. Inserting a tampon: *rasping, tugging*. Penetrative sex: *splitting, pinching, sharp*,

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stinging. It was the most detailed information collected about my condition in 15 years. By the time I was undressing for the pelvic exam, I was nervous but hopeful. Shortly after Dr. Rapkin began the visual exam, she said, “I can tell already that this is hormonal, but we’ll do blood tests to be sure.” I started crying. Finally, a doctor didn’t just *believe* I had pain. She *saw* it.

After my bloodwork came back, we met to discuss my results. My testosterone levels were low, similar to that of a woman who’s already gone through menopause. Rapkin had already seen that my vulva was atrophied, i.e., the tissue was thin and fragile, instead of plump. Vulvar atrophy is only apparent if you’re looking for it and she was the first ob/gyn I’d seen who knew what to look for. In addition to vaginismus, which was now improving with physical therapy, I received a diagnosis of *provoked vestibulodynia*, which means I only experience pain when something touches the vaginal entrance. Dr. Rapkin prescribed a hormone cream to apply once a day to the painful vestibular tissue. Within one week I noticed a significant change—healthy discharge, reduced pain, and significantly increased desire to have sex with my partner. And I could even use tampons!

It was an easy decision to take part in Dr. Rapkin’s treatment study at UCLA. For several months I applied a cream and took a pill (not knowing if either one was a placebo), filled out surveys, and was poked and prodded with instruments ranging from cotton swabs and blood-drawing needles to high-tech pressure sensors. My part was over in six months, but the study will take four years to complete, during which the researchers will enroll 400 participants. Then the results will be published and give medical professionals more information about the effectiveness of the treatment.

What I’ve Learned

I know what makes my pain worse: ignoring it and attempting to muscle through it. And I’m still learning about what works. A hormone compound helps to restore the thinning vulvar tissue that causes vestibular pain. Physical therapy seems to help relax my hypervigilant pelvic floor muscles. Couples therapy helps me talk to my partner about our boundaries and our desires. Learning more about these conditions and participating in efforts to further the science help me feel less isolated. Even though I’ve never met someone else with this condition—at least not that I know of—I’ve learned I’m not alone. It’s a relief. ■

Visit Pelvic Pain and Vulvodynia Websites

Mypelvicplan.com, developed by Drs. Georgine Lamvu of Orlando VA Health Care System, and Sara Till, ob/gyn at the University of Michigan, was created to help women with pelvic pain conditions. This comprehensive website contains information about vulvodynia and other pelvic pain conditions, such as irritable bowel syndrome, interstitial cystitis and myofascial pain. One of the site’s main features, titled Managing Symptoms, provides advice and techniques for managing pain and improving quality of life. Among the topics covered are relaxation exercises, pacing yourself, physical therapy, acupuncture and cognitive strategies for reducing pain.

The section on Cognitive and Behavioral Strategies includes techniques from Cognitive Behavior Therapy (CBT), an effective psychological intervention for chronic pain patients. CBT focuses on reducing pain and emotional distress by modifying catastrophic thinking, i.e., it teaches you to recognize negative thoughts and replace them with positive ones.

Dr. Lamvu also developed the NVA-funded website vulvodyniaeducation.com. At this site, you can view videos of health care providers describing the causes and diagnosis of vulvodynia, as well as Lamvu’s video on a multidisciplinary treatment approach. ■