National Vulvodynia Association

NVA News

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Aspects of Vulvodynia from a Swedish Perspective

By Nina Bohm-Starke, M.D., Ph.D.

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In 2000, Eva Rylander, M.D., and I established a vulvar clinic at Danderyd Hospital in Stockholm, because we thought that a different approach for treating women with vulvodynia was needed. Professor Rylander was a colposcopist specializing in vulvovaginal disease, so it was natural for her to also examine the vulva. Since the late 1980s she had observed an increasing number of young Swedish women suffering from superficial dyspareunia (painful intercourse) who were given a diagnosis of vulvar vestibulitis syndrome (VVS), pain surrounding the vaginal opening provoked by touch. The precise etiology of the disorder is still undetermined. (VVS is currently known as provoked vestibulodynia (PVD) or localized provoked vulvodynia.) Dr. Rylander was very concerned about these young VVS patients, because they suffered a great deal and were difficult to treat. In the 1990s, surgery was the only viable treatment for the disorder. Even though many patients improved with surgery, others didn't and the outcome was unpredictable. At that time, medical articles began reporting that psychological distress and sexual dysfunction were common among vulvodynia patients. It became obvious to us during treatment that the condition was multifaceted and most patients would benefit from psychological and sexual counseling.

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NVA's History of Patient Advocacy

By Phyllis Mate, M.A., NVA Cofounder and President

Dedicated patient advocates are essential to educating the medical community about little-known chronic pain conditions. It was the persistence of two women at NVA, with the guidance of Stanley Marinoff, M.D., who were instrumental in convincing the National Institutes of Health (NIH) and the U.S. Congress that vulvodynia was a legitimate women's health disorder. Over 25 years, NVA has facilitated progress in the field by promoting and funding research on vulvodynia, changing health care providers' attitudes toward women with vulvodynia and empowering women to discuss their condition with family members, friends and health care providers.

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SWEDISH PERSPECTIVE

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Danderyd Hospital Vulvar Clinic

I was an ob/gyn resident when I was recruited to study the vestibular mucosa in women with VVS. When I began my research, I had not yet seen any patients with vulvodynia, but over time I became very involved in clinical work. The personal histories of VVS patients varied and as I met more of these women, the complexity of the condition became apparent. A large number of patients had comorbidities of anxiety and depression, as well as other chronic pain conditions. By the late 1990s, several studies had found associations between vulvodynia and other chronic pain conditions, such as fibromyalgia and interstitial cystitis. In 2000 we started our vulvar clinic, which included two counselors and two midwives. We adopted a multidisciplinary treatment model, which combined medical treatment, physical therapy and psychosexual counseling. All patients with superficial dyspareunia were first diagnosed by Dr. Rylander or myself and then met with a midwife trained in pelvic floor muscle therapy. Patients were given exercises for desensitizing the vestibular mucosa and rehabilitating pelvic floor muscles. Concurrently, the patients started seeing counselors skilled in cognitive behavior therapy, who assigned cognitive tasks to do between sessions (1). Sometimes medical pain treatments, such as amitriptyline or topical lidocaine, were used to diminish mucosal pain sensitivity.

Our team had frequent meetings to discuss treatment issues and outcomes. These meetings turned out to be one of the most important parts of my education in treating vulvodynia. As gynecologists, we had limited time with patients and only knew part of their stories, whereas midwives and counselors met with patients frequently and followed their progress for 9-12 months. These meetings served as an opportunity to learn more and assess and develop our treatment model. The counselor addressed stress factors in a patient's life, sexuality, relationships and other important issues, such as conception, pregnancy and childbirth. This multidisciplinary treatment model was effective in helping patients' symptoms improve, which was reflected in the reduced number of surgeries. Nowadays, surgery is still an option for cases in which other treatments have failed.

As the number of referrals increased, the vulvar clinic expanded. Most patients were from the Stockholm area, but we also became a national referral center. We recruited several younger gynecologists who became Ph.D. students and researched vulvodynia or the vaginal immune system, specifically recurrent vulvovaginal Candida infections (RVVC). There is a strong association between PVD and RVVC, which is sometimes a trigger for the condition. It is important to treat RVVC appropriately to reduce the risk of developing dyspareunia. Eventually we employed a physiotherapist in the clinic to work alongside the midwives. We had learned that vulvodynia patients were tense in the hip muscles, as well as the pelvic floor muscles.

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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.

SWEDISH PERSPECTIVE

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Several patients used a mouthguard to avoid clenching their teeth, evidence of overall muscle tension that needed to be addressed.

Dr. Rylander and I collaborated with the dermatological department at Danderyd Hospital, because many patients who visited the clinic had severe vulvar skin diseases, such as lichen sclerosus. Pain specialists were also consulted, because some patients with unprovoked vulvodynia required additional treatment. Other patients had vulvar dysplasia, a pre-cancerous condition often located in sensitive areas of the vulvar skin or mucosa. Ideally, the lesions are removed successfully with one surgical procedure, because additional surgeries are likely to lead to pain with intercourse. Recently, patients experiencing dyspareunia after vaginal childbirth have been referred to our clinic. In some cases, pain that occurs after perineal tears requires surgical correction.

The head of our ob/gyn department and the hospital director have always been very supportive of our clinic. It is considered one of the hospital's most important services and serves as a model for other institutions. Our multidisciplinary approach makes it possible for the patient to be completely taken care of in one location by a group of professionals who communicate with each other. Advantages of this approach are that it is easy to access information about a patient's progress and we constantly learn from each other. Clearly, not all clinicians have this opportunity, but still do very important work with vestibulodynia patients. Much can be done in smaller clinical settings in which clinicians have an interest in treating vulvar pain and are willing to learn about it.

Research

The aim of our first research study was to investigate peripheral pain mechanisms of the vestibular mucosa. Frequently, doctors told patients that the pain was "all in your head." Professor Rylander was convinced that part of the problem was in the vestibular mucosa, sensitive tissue with poor resistance to infection and friction. Our first study showed that there was an increased number of sensory nerve fibers in the vestibular mucosa of women with VVS compared to healthy women (2). We also found that these nerve fibers were sensitized, i.e., the lightest stimulation of the vestibule resulted in a pain sensation (3). These findings explained why patients experienced severe pain with touch, tampon insertion and sexual intercourse. The cause of the sensitization is not completely understood, but several triggers are possible. Most likely, the etiology is multifactorial and varies among patients. Following results of these early studies, the International Society for the Study of Vulvovaginal Disease (ISSVD) changed the terminology, because VVS was now considered a pain syndrome rather than a classic inflammatory condition. The term 'Provoked Vestibulodynia' is a more accurate description of the condition and consistent with the terminology used for other pain disorders (4). However, recent research has provided some support for the theory that impairment in the local inflammatory response is involved, resulting in neurogenic (nerve-related) inflammation of the mucosa. In other studies, we investigated hormonal impact on the vestibular mucosa, showing that oral contraceptives induced changes in the tissue that might be harmful to some women (5). Nevertheless, we usually prescribe hormonal contraceptives when needed, and carefully observe side-effects, such as dryness and discomfort.

While pursuing this line of research, we discovered that patients with PVD had lower pain thresholds on other parts of the body as well. This finding was reported by other research groups and we wondered whether PVD was just one component of a genetically-based generalized pain syndrome. With financial support from NVA, we planned a genetic study with PVD patients. Our aim was to investigate whether there was a genetic predisposition for developing PVD by analyzing polymorphisms in genes involved in pain modulation. Our main findings were that specific genetic polymorphisms in the opioid and serotonin

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systems affect endogenous (internally caused) pain modulation and contribute to the risk of developing PVD.

As described above, many women with PVD have dysfunction in the pelvic floor muscles (PFMs) that needs to be rehabilitated. Different physical therapy methods can be used to increase a woman's ability to contract and relax these muscles. However, a positive treatment outcome is not always achieved with physical therapy. In the past, we had performed one randomized clinical trial using EMG biofeedback as a tool for PFM rehabilitation. The results showed a significant reduction in vestibular pain, as well as impaired sexual functioning and psychosocial adjustment (6). Currently, we are conducting a double-blind randomized controlled trial (RCT) of botulinum toxin A (BTX) for women with PVD and PFM dysfunction. Again, we applied for and received financial support from the NVA. The off-label use of BTX for PVD patients is common, but there is only one previously published RCT showing that 20 units of BTX injected into the bulbocavernosus muscles was no more effective in relieving pain than a placebo. In our study, we are injecting 50 units into the same muscles and using the level of dyspareunia as the primary outcome. For secondary outcomes, we are evaluating pelvic floor tension using a new vaginal manometer, and assessing psychological and sexual functioning, as well as quality of life. All patients have been recruited and the results will be announced by fall 2019. Earlier this year, we received major funding to determine whether early pain exposure is a contributing factor to chronic pain, including vulvodynia, and psychological impairment later in life.

Education and Collaboration

In addition to clinical work, the vulvar clinic has gradually taken on more responsibility for educating our colleagues about vulvovaginal diseases and vulvodynia. Unfortunately, there is still a lack of basic knowledge about vulvodynia in Sweden and other countries, but my impression is that interest is growing. More than 10 years ago, my colleagues and I organized a national course for gynecology and dermato-venereology specialists. In 2016, the National Swedish Vulvar Society accepted the responsibility of educating all ob/gyn residents in basic vulvovaginal diseases. In addition to these courses, we teach midwives and medical students on a regular basis, and for the first time this semester, vulvodynia and pelvic pain will be taught in a postgraduate course for physical therapists.

International collaboration is also very important. The congresses organized by the ISSVD and the European College for the Study of Vulvar Disease provide opportunities to present studies and engage in discussion with colleagues. Hopefully, this international collaboration will expand in the future, especially to facilitate clinical trials that require a large number of patients.

Future Challenges

The availability of vulvovaginal experts and sexual health specialists differs between countries and various regions within countries. In Sweden, most vulvodynia patients are taken care of in the Stockholm-Uppsala region, but there are other areas that do not have doctors with this expertise. The National Vulvar Society often discusses this problem and the Swedish National Board of Health recently acknowledged the disparity. They gathered and analyzed relevant data, confirming the uneven distribution of vulvar clinics in Sweden. The investigation found that the number of women with PVD had doubled from 2006 to 2016. It was also shown that, in certain areas of Sweden, very few cases were diagnosed and the number of women seeking consultation was low. Clearly, PVD is under-reported and doctors are confused about the ICD-10 diagnoses that apply, which is one reason why the incidence is lower than expected. We have no reason to think that our situation is any different from that of other European or North American countries, so we have to continue to support and encourage colleagues in all regions and countries to establish vulvar clinics.

In my regular clinical work, I see vulvar patients three days per week. The rest of the time I teach medical

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In Her Own Words

By Leah S.

I was living a typical 24-year-old life in New York City when out of nowhere my vulva started burning. I was so scared and confused by what was happening to my body. I started going to countless doctors, some of whom were gynecologists. Many said it was all in my head, nothing was wrong, or that they just didn't have a solution. I was given medication for yeast infections, steroid creams and antihistamines, but nothing provided relief. Finally, I went to a vulvar pain support group. Although it was disheartening to hear some women's stories, it was ultimately a great decision, because I got the names of two vulvar pain specialists in New York City. It really helped me to hear that there were medical practitioners who understood vulvar pain and offered treatments.

I went to one of the specialists and was diagnosed with vulvodynia and hypertonic (tight) pelvic floor muscles. My doctor explained that when the pelvic floor muscles get very tight, they can trigger a burning sensation. She prescribed an antidepressant and anticonvulsant for pain and gave me valium suppositories to help relax the pelvic floor muscles.

I also started seeing a women's health physical therapist specializing in pelvic pain. She gave me exercises to stretch my pelvic floor muscles and told me to order dilators to stretch the muscles and help them relax. I still had a moderate amount of burning pain, but I did not give up. My doctor injected some pelvic floor muscles with Botox to help relax them and that was a godsend! Botox essentially 'paralyzed' my tight muscles, which were then able to relax. My pain went from being a 5 (out of 10) to a 1. I could have sex without pain again and didn't have the constant itching and burning. I finally felt normal! The best part about Botox is that it lasts three to six months. Additionally, I use the dilators to further stretch the muscles, which helps the Botox last even longer. I do realize, however, that Botox injections are not the answer for everyone. The key takeaway from my experience is that there are treatments for vulvodynia that are now more available, because many gynecologists, physical therapists and other providers finally recognize that it is a common condition. I encourage everyone with vulvar or pelvic pain to do research and be persistent until they find a treatment that works. You can reach out to NVA to connect with a support contact in your area, who may have valuable information on local resources. Whether you are in a relationship, dating someone or single, do not be embarrassed that you have vulvodynia. It can help a lot to discuss your pain with other women and to be optimistic that you will find relief. Vulvodynia is more common than many people realize and you'll be surprised to learn that women you know have had a similar experience.

By Pame Clynes

If you see me smiling, it's because I've made peace with my pain. I feel it, I recognize it and I let it go.

The first time I heard the word vulvodynia was in an episode of Sex and the City. If you watched the show, you may remember when Charlotte mentions it at brunch, saying that "her vagina is depressed." I honestly laughed with her friends, not knowing that years later, I was going to be diagnosed with vulvodynia. Unfortunately, the show handled it unrealistically, suggesting that it's nothing to be worried about. I hated when Charlotte said it doesn't hurt! After my symptoms started and I watched the episode again, I

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Raising Awareness

In the early years, NVA contacted dozens of health writers and magazine editors, trying to convince them to write articles about vulvodynia and its impact on a woman's quality of life. After having success with 'women's magazines,' we faced the challenge of cultivating the interest of newspaper editors and television producers. Fortunately, there have been major breakthroughs in the past 18 years. Among our most memorable successes was the publication of health columnist Jane Brody's in-depth New York Times article on vulvodynia. Many health editors followed suit and articles about vulvodynia appeared in newspapers across the U.S. and on dozens of health websites. Creating even more excitement, NVA was contacted by a producer for Oprah and asked to select four vulvodynia patients to appear on her show. After the segment aired, the producer posted a link to NVA on the show's website and introduced our executive director to Dr. Mehmet Oz, who invited her to appear on the popular Dr. Oz show. Following each of these appearances, NVA's phone did not stop ringing for weeks.

Three years ago, even though our website already received about 4,000 hits monthly, NVA hired a public relations consultant to develop a comprehensive vulvodynia publicity campaign. First, she modified our website to make it more attractive and user-friendly, and most importantly, enhanced search engine optimization to reach a broader audience. Next, she designed a vulvodynia awareness campaign titled *Indivisible*, the focus of which was empowering women with vulvodynia to break their silence. In October 2016, NVA issued the Indivisible press release, launched a Facebook page and posted a powerful video on its YouTube page. The video featured Callista Wilson, a 27-year-old woman who found the courage to appear on camera and describe the vulvar pain she experienced and how it affected her life. Her pelvic floor physical therapist, NVA Board Member Pamela Morrison Wiles, DPT, also participated, presenting essential information about vulvodynia. Over the past two years, thousands of women have viewed the video, illustrating how one courageous woman can make a difference. Many women told us that Callista's video encouraged them to tell family and friends that they suffered from vulvodynia. In Dr. Harlow's landmark prevalence study, 40 percent of women with vulvodynia did not seek professional help for their pain (1). Given NVA's efforts to raise awareness and the increasing number of female gynecologists, we are hopeful that more women with vulvodynia will feel comfortable discussing their symptoms with their doctor.

NIH Vulvodynia Conferences

From the beginning, NVA realized the importance of developing relationships with key officials at the National Institute of Child Health and Human Development (NICHD), which is responsible for vulvodynia research. Our persistence resulted in NICHD holding three vulvodynia conferences in 10 years, attended by clinicians and researchers dedicated to treating and/or researching the cause of vulvodynia. At these two-day conferences, vulvodynia experts gave presentations on different aspects of the disorder. After the last presentation, the entire group discussed the types of studies needed to advance knowledge in the field and submitted their recommendations to NICHD.

In 2011, instead of having a similar conference, NICHD hosted a meeting of 75 researchers from various fields of study to develop a vulvodynia research agenda. By this point in time, vulvodynia was conceptualized as a chronic pain disorder rather than a gynecological disorder. Bringing together these researchers to discuss the pathophysiology of chronic pain created the foundation for interdisciplinary collaborations and innovative approaches to the study of vulvodynia. Two weeks after the meeting, the NICHD and Office of Research on Women's Health co-sponsored three new funding opportunities to promote vulvodynia research.

NVA-Funded Research and Clinics

To date, NVA has awarded over $1.4 million in research grants for 52 vulvodynia studies and funded the

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establishment of seven vulvar pain clinics in the U.S. and two other countries. (To view summaries of these studies, see https://www.nva.org/research.) The purpose of our research grants is to enable researchers to collect and analyze pilot data to improve their chances of securing major research funding. Most of our grant recipients have published their studies in peer-reviewed journals and many have subsequently obtained multimillion dollar grants from NIH or the Canadian Institutes of Health Research. Currently, NVA's priority is funding research on potential causes of vulvodynia, because existing medical treatments for chronic pain are often ineffective in vulvodynia patients. Randomized controlled trials of two widely used oral medications for vulvodynia patients found them to be no more effective than placebo (2, 3). It is our hope that studies investigating genetic abnormalities and pathophysiological mechanisms will lead to the development of more effective vulvodynia treatments. We are also very interested in awarding grants to study Generalized Vulvodynia, because few studies include women with this subtype.

In 2009, NVA funded an ambitious undertaking, a five-year multi-site National Vulvodynia Registry coordinated by Georgine Lamvu, M.D., at Orlando Hospital in Florida. This project collected extensive data on 344 vulvodynia patients from eight clinical sites across the U.S. The purpose of the Registry was to identify vulvodynia subgroups, describe treatment patterns and determine whether there was an association between type of treatment and patient-reported outcomes. The study identified two distinct patient subgroups: women with high sensitivity to pain and high emotional distress versus women with low sensitivity to pain and low emotional distress. High-level emotional distress was the only variable identified that correlated with pain severity, suggesting that this may be a phenotype that modulates response to treatment.

The study's initial assessment measured pain in the vulvar vestibule and vaginal muscles, and administered questionnaires on pain, psychological distress, quality of life. After six months of treatment, the assessment was repeated. Of 344 women diagnosed with vulvodynia, 282 received treatment. An astounding 78 different treatments were identified and categorized by type (e.g., oral, topical) and number. According to the analysis, the most commonly used treatments for vulvodynia are topicals, oral medications and pelvic floor physical therapy. Another finding was that 73 percent of patients used a combination of treatments. There was no association between type of treatment and patient characteristics. After six months of treatment, women reported less pain during the vulvar examination and sexual intercourse, less catastrophizing and anxiety, and improved quality of life. However, all domains of the Female Sexual Function Index indicated worsening of sexual function. Unfortunately, clinicians prescribed so many different treatments and combinations of treatments, investigators could not evaluate the efficacy of individual treatments.

NVA Successes on Capitol Hill

In the late 1990s, NVA was very fortunate to find an ally in Senator Tom Harkin (D-Iowa), women's health advocate and former chairman of the Senate's Health, Education and Labor Appropriations subcommittee. His chief of staff, Peter Reinecke, helped us convince other Senate health staffers that vulvodynia deserved federal research funding. He arranged for NVA's executive director to speak at the same Senate briefing as actor Christopher Reeves, knowing that a celebrity speaker would guarantee excellent attendance. Our goal was to have strong language on vulvodynia added to the Senate's 1998 NIH Appropriations report, directing NICHD to fund research on its causes and treatments. NVA's executive director collaborated with Peter on writing the language and then he convinced Senate staffers to include it in the report. The wording was revised in subsequent years to acknowledge NIH's progress in promoting vulvodynia research. What follows is a sample of vulvodynia

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language included in the U.S. Senate's 2008 NIH Appropriations report:

> In the past decade, the NIH has supported three important research conferences on vulvodynia, as well as the first prevalence study and clinical trial on the disorder. These efforts have both clearly demonstrated the need for substantial additional research and served to heighten the research community's level of interest in studying vulvodynia. The Committee calls upon the Director (of NIH) to build upon these initial successes by coordinating through the Office of Research on Women's Health (ORWH) an expanded, collaborative research effort into the causes of, and treatments for, vulvodynia. The Committee also commends ORWH for working with the NVA and women's health offices in other governmental agencies to plan an educational outreach campaign on vulvodynia, as previously requested by the Committee. Finally, the Committee encourages the Director to work with the Center for Scientific Review to ensure that experts in vulvodynia, and related chronic pain and female reproductive system conditions, are adequately represented on peer-review panels.

Following this success on the Senate side, NVA returned to Capitol Hill to meet with Rep. Tammy Baldwin (D-Wisconsin), a committed women's health advocate. With her encouragement, NVA organized an annual grassroots campaign, asking members to visit Representatives' offices on the same day in April. We gave volunteers a fact sheet and talking points, and over 60 women flew to Washington, DC, the first year. Others met with their Representatives locally during Congressional recess. This nationwide lobbying effort convinced members of the House of Representatives' Health, Education and Labor Subcommittee to add language on vulvodynia to their NIH Appropriations report, ensuring that the mandate to fund vulvodynia research would be included in the final NIH budget and report signed into law by the President.

NVA Promotes Vulvodynia Research Funding

Ten years ago, NVA joined forces with patient advocacy organizations representing women with other chronic pain disorders occurring exclusively or mainly in women: endometriosis, irritable bowel syndrome, interstitial cystitis, fibromyalgia and temporomandibular joint disorders (TMJD). Prior to collaborating, NVA had surveyed vulvodynia patients and found that many reported having one or more of the above pain conditions. The NIH was allocating a small amount of money for research on vulvodynia and these other pain disorders, so our goal was to persuade them to increase funding and promote studies on characteristics or mechanisms the conditions have in common. NIH had recently established a Pain Consortium to promote a comprehensive and forward-thinking pain research agenda and NVA met with this group several times. One of the NIH Pain Consortium's recommendations in the 2010 Affordable Care Act directed the Department of Health and Human Services (DHHS) to evaluate chronic pain as a public health concern. DHHS engaged the Institutes of Medicine (IOM), a non-profit organization that provides evidence-based research and recommendations on public health, to conduct the evaluation.

In 2011, the IOM conducted a comprehensive study to assess the status of pain research, patient care and pain education in the U.S., and their 364-page report, *Relieving Pain in America,* was presented at the first-ever U.S. Senate hearing on chronic pain. NVA's executive director was invited to speak on behalf of chronic pain patients and gave compelling testimony, describing both the physical and emotional consequences of living with pain. The IOM report confirmed that chronic pain disproportionately affects women. Furthermore, the report revealed a gender disparity in pain care, with women more likely to experience delay in diagnosis, ineffective treatment, stigma and/or not having their symptoms taken seriously by doctors. To address this disturbing situation, the report recommended an increase in research funding for women's

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pain conditions and the development of programs that teach health care providers how to treat chronic pain patients. Over the next two years, NIH increased spending on vulvodynia, endometriosis, interstitial cystitis, fibromyalgia, irritable bowel syndrome and TMJD.

NVA's CME/CE-Accredited Vulvodynia Tutorial

When NVA was founded, there were perhaps 25 doctors in the U.S. with the expertise to diagnose and treat vulvodynia. We tackled this problem by asking vulvodynia experts to create a teaching CD for health care professionals, which we distributed to chairpersons and residency directors of ob/gyn departments, as well as to the American College of Obstetricians and Gynecologists and Planned Parenthood clinics. The self-guided tutorial covered prevalence, differential diagnosis and common treatments. In 2008, we launched the first and only online vulvodynia tutorial and raised funds to host it on Medscape, the most widely used online medical resource in the world. Within six months, it became the third most popular CME/CE-accredited program on Medscape! Over the past decade, more than 50,000 health care providers have viewed the tutorial, 22,000 of whom took the post-test and received a CME/CE certificate. Most of the viewers have been gynecologists, dermatologists, pain specialists, nurse practitioners, family doctors and nurses.

International Outreach

As a result of NVA's efforts, today the majority of gynecologists and women's health nurse practitioners in the U.S. can diagnose and treat vulvodynia. Unfortunately, there are still many countries with comprehensive gynecologic services in which health care providers are not knowledgeable about vulvodynia. Women seeking treatment in foreign countries contact us, and in some cases, we have been able to refer them to a doctor in their country or within a reasonable distance. This past month, we were able to help two women from Croatia and one from South Africa find a local doctor. Recently, we were contacted by a woman with vulvodynia living in Mexico who was able to travel to the United States for treatment, but is committed to having vulvodynia recognized by gynecologists in her country. She asked us for advice and would like to affiliate with NVA to add legitimacy to her mission. Working with her has been a positive experience and we plan to do more international outreach by contacting the International Federation of Gynecologists and Obstetricians, which is composed of gynecology associations in 130 countries.

NVA's Dedicated Personnel

Although we have a very small staff, NVA has managed to accomplish a great deal. As a result of declining membership, both our executive director and administrative assistant now work half-time. I started volunteering as editor of NVA's newsletter 25 years ago and also serve as President of the Board. I'd like to express my heartfelt appreciation to Lisa Goldstein, Tamara Matos and Michelle Living for their dedication to helping women with vulvodynia and also thank the hundreds of support leaders (past and present) who have been an invaluable resource for women needing someone to show them compassion.

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IN HER OWN WORDS

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thought, "How dare you say you're not in pain, because you have no idea."

I was living in New York, studying for an MFA at Parsons School of Design, when my symptoms started. It was the best time of my life. I was living in one of the most wonderful cities in the world and going to fashion school, meeting people from different cultures, eating amazing food and enjoying incredible art. I was very happy until, out of nowhere, my vulvar pain sent my happiness down the drain. At first I thought I had a normal yeast infection, which was confirmed by the school's physician. That was the beginning of non-stop antibiotics and a long struggle to regain my life.

I had to go back to Mexico, because the pain was constant and the medications didn't work. People had recommended other gynecologists, but my health insurance had expired. Being a foreigner in the U.S., with no health insurance, was like being invisible. I was alone and feeling miserable, not knowing what was happening to my body and missing my family. Suddenly, I realized that my New York days were over.

I arrived home and went directly to the hospital. At this point, my gynecologist knew something was wrong, but could not diagnose it. All my test results, e.g., bacterial and other infections, came back negative. I felt like I was going crazy, and that maybe it was all in my head.

Next, I met with other gynecologists, urologists, and infectious disease specialists. I even went to see a famous 'chaman' in Mexico, known for his herbal teas that help infertile women get pregnant. I tried other alternative medicines, but I was completely overwhelmed. Still, no diagnosis. During this period, my boyfriend broke up with me and my work was suffering. So, like most people, I googled. After hours surfing the internet, I found the term Vulvodynia, and then I found nva.org. It was a life-saver for me, because I was not alone anymore.

I packed my bags and went to Miami, where my dad was living at the time. I made an appointment with Jay Trabin, M.D., who has a private practice in West Palm Beach, Florida. He is very knowledgeable about vulvodynia and a super-nice person, so I immediately felt comfortable. Dr. Trabin examined me, and within minutes, I got my diagnosis of Generalized Vulvodynia and Pelvic Floor Dysfunction. I felt so relieved. I began a combination of treatments with a pain management specialist. My treatments included pudendal nerve blocks, Botox, antidepressants, topical creams, and most importantly, I started seeing a therapist.

I know many of us are still struggling to find new ways to cope with vulvar pain, praying for new treatments or a cure. Even though I'm getting help, I still have bad days and find sex painful sometimes. I've managed to make peace with the pain, even though it hasn't completely gone away. I'm not ashamed anymore and want to help other women in my country who are still suffering in silence. I have already started the first platform in Mexico dedicated to helping women with vulvodynia, @peacewithpain. With some help from NVA, I am optimistic we will finally break the silence.■

Employer-Matched Donations

Many employers offer a matching gift program that will double—or even triple—charitable contributions made by their employees, retirees, and spouses/partners. Top matching gift companies include ExxonMobil, General Electric, Microsoft, Apple, Home Depot, Starbucks, State Farm, and Verizon. For a list of additional top companies, go to www.nva.org/donate. If your employer isn't on the list, please contact your company's human resources department to see if you are eligible to have your gift matched. Thank you for taking this simple step to multiply your gift to the NVA!

Use of Platelet-Rich Plasma for Lichen Sclerosus?

Adapted from: Behnia-Willison F, Reza Pour N, et al. Use of platelet-rich plasma for vulvovaginal autoimmune conditions like lichen sclerosus. Plast Reconstr Surg Glob Open 2016;11:e1124.

Background

Lichen sclerosus (LS) is an inflammatory dermatosis with autoimmune pathogenesis. Although relatively common, its true incidence is unknown and likely underestimated. LS is usually anogenital, but in 10 percent of patients, it can present as extragenital lesions. Continuous administration of topical corticosteroids is the mainstay of medical treatment. Other treatments are available, but are only occasionally prescribed in addition to or instead of topical steroids. There is evidence that injection of platelet-rich plasma (PRP) into affected areas regenerates normal skin. In this study, we evaluated the safety, symptom resolution, and objective improvement in patients with genital LS after treatment with PRP.

Methods

Over a two-year period at FBW Gynaecology Plus, we had a total of 28 patients with confirmed LS who were unresponsive to topical steroid treatment. After obtaining informed consent, patients' own blood was centrifuged on site and injected under local anesthesia to the external genitalia.

Results

Almost all patients showed clinical improvement in the size of their lesions, and in eight cases, lesions disappeared after treatment with PRP. All symptoms disappeared in 15 of the 28 patients after treatment, with no need for further steroid therapy in 23 patients. Thirteen women experienced partial symptom relief.

Conclusions

Based on our limited findings, we hypothesize that PRP presents a potential alternative to topical steroids for treatment of vulvovaginal autoimmune conditions such as LS. A larger pilot and/or randomized controlled trial study is required to further evaluate this finding.■

Dear NVA member,

As you may know, some small non-profits have ceased operations or scaled back their services. The NVA Board chose to continue serving members by changing our two full-time staff positions to half-time positions. As the only full-time volunteer, my workload has increased considerably. To complete my work and supervise staff, I was only able to produce two newsletters in 2018 and that change will continue in the future. If there are any important clinical or research advances between newsletters, I will certainly send you an article or letter via email. Please email any updates to your email address to admin@nva.org.

We remain committed to sharing the latest information about vulvodynia, and to maintaining our support services and health care provider referral list. Thankfully, a generous donor has enabled us to update our CME-accredited vulvodynia tutorial, which continues to educate thousands of health care providers each year.

I wish you a healthful and happy 2019.

Phyllis Mate

Participants Needed for a Study Designed to Evaluate the Efficacy and Safety of Dysport (Botox A) in Vulvodynia Patients

If you are a woman 18 to 45 years of age who has had vulvodynia for at least six months, but for no more than 15 years, and never had a vaginal delivery (including attempted vaginal delivery), you may be eligible to participate in this study. Participants must have provoked pain at the vestibule with a Q-tip test, but those with deep pain during intercourse are not eligible. Participants cannot have genitourinary conditions or previous surgery that, according to the investigator's judgement, may impact the study outcome. This includes, but is not limited to, hysterectomy, vestibulectomy, urologic surgery, perianal surgery or genital trauma.

This study will be conducted in the following locations: San Diego, California; Washington, DC; Kansas City, Missouri; Omaha, Nebraska; New Brunswick, New Jersey; Bryn Mawr, Pennsylvania; Nashville, Tennessee; and Seattle, Washington. If you are interested in participating, please email clinical.trials@ipsen.com. For more information on the study, please go to https://clinicaltrials.gov/ct2/show/NCT03598777.

SWEDISH PERSPECTIVE

(from page 4)

students and conduct vulvovaginal research. The students are often with me during the clinical work and I think it is also important to discuss preventive measures with them. After many years of experience, I am convinced that the best treatment outcome occurs when we are able to help young women as promptly as possible after they experience symptoms of dyspareunia. The issue is how to reach them. In Sweden, we have adolescent centers where young people can seek help with contraception, infections and/or sexual problems. Many of these centers have midwives and counselors working with dyspareunia patients and there is a constant need to educate them. One Swedish study showed that 65 percent of young women had pain during their first intercourse and that half of them continued to have pain to varying degrees in the following months (7). Not all of them will develop PVD, but the findings indicate it is very important to educate adolescents about sexual health and tell them that sex should not hurt. We also have to organize our health care system to be able to meet the demand for this type of consultation. One avenue is to figure out how we can better use social media to disseminate information on PVD. In addition to discussing preventive measures, PVD symptoms, and sexual implications, it is important to provide information on how to find an experienced clinician.

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