

## Vulvodynia and Coexisting Pain Disorders

### Questions and Answers with Barbara Reed, MD, MSPH

*Dr. Reed is a professor of family medicine at the University of Michigan in Ann Arbor. In addition to caring for women with vulvodynia in her clinic, for more than a decade, she's dedicated her research efforts to understanding vulvodynia's prevalence, biological mechanisms and subtypes.*



**NVA:** Please tell our readers a little bit about your Michigan Woman-to-Woman Health Study.

**Dr. Reed:** This five-year study, funded by the National Institutes of Health (NIH) in 2008, is one of the first longitudinal ethnically diverse studies to include women from the general population. In a prior study, Harlow and colleagues found that more than half of women with symptoms of vulvodynia do not seek medical care, and of those who do, an accurate diagnosis is infrequently made. We con-

firmed these findings and also recently published data showing that less than two percent of women with symptoms suggestive of vulvodynia who sought medical care were given an accurate diagnosis. Since such a small percentage of women with vulvodynia are currently being cared for in medical practices, if we are to get an accurate picture of how vulvodynia develops and progresses, it's very important to study a broad group of women from the general population. Doing so may help us to identify risk factors associated with the development of vulvodynia and understand how the disorder typically begins and progresses. We also

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## Striving for Happiness in the Face of Pain: A Patient's Perspective on the Emotional Burden

**By Cristina Shea**

*Ms. Shea began with the NVA in early 2012 while completing her bachelor's degree in chemistry at Stanford University and has continued with the organization since graduating. She'll start medical school in the fall and plans to dedicate her medical career to researching and caring for those with chronic pain.*

The prevalence of depression among chronic pain sufferers is significant, with studies suggesting rates as high as 50 percent (Bair 2003). It's no surprise then that many women with vulvodynia also report depression. We struggle with the

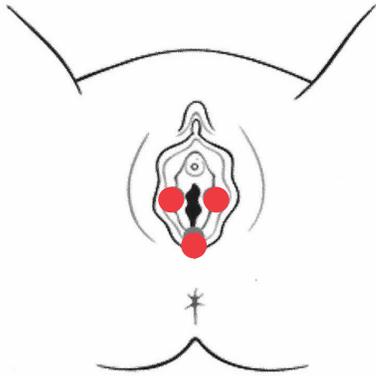


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## Definitions and Types of Vulvodynia

Many different terms have been used to describe vulvodynia. As a result, confusion among patients and medical professionals is common. To encourage consensus and clarify terms used in this newsletter, we have provided a brief summary of the most current definitions and classification. For more detailed information, please visit [http://learnprovider.nva.org/historical\\_overview.htm](http://learnprovider.nva.org/historical_overview.htm) and [http://learnprovider.nva.org/terminology\\_classification.html](http://learnprovider.nva.org/terminology_classification.html).

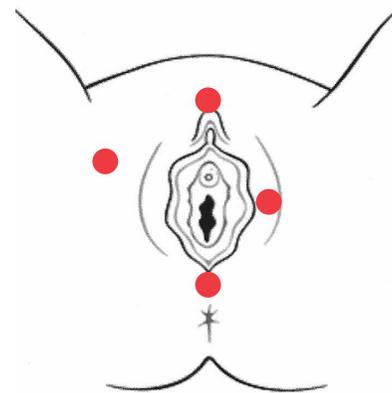
Vulvodynia is *chronic (more than three to six months) vulvar pain without an identifiable cause*. The location, constancy and severity of the pain vary among women. The two main subtypes of vulvodynia, which may co-exist, are:



### **Provoked Vestibulodynia (PVD)**

*(Previously: Vulvar Vestibulitis Syndrome)*

Women with PVD only have pain in the vestibule (around the vaginal opening), that occurs during/after touch or pressure, e.g., with intercourse, tampon insertion, prolonged sitting. PVD is further classified as *primary (pain since the first attempt at penetration)* or *secondary (pain that starts after a period of pain-free penetration)*.



### **Generalized Vulvodynia (GVD)**

*(Previously: Dysesthetic or Essential Vulvodynia)*

Women with GVD have spontaneous pain in multiple areas of the vulva. It is relatively constant, but there can be some periods of symptom relief. Activities that apply touch or pressure to the vulva, such as prolonged sitting or simply wearing pants, typically exacerbate symptoms.

#### **NVA News**

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

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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# 2012: A Year of Significant Achievement

Thank you for your continued commitment and generosity this year. Just some of our most notable achievements are highlighted in this article. For a fully detailed report, please e-mail [chris@nva.org](mailto:chris@nva.org).

**First Vulvodynia CME Course on Medscape.** The gift of a generous donor helped the NVA to revise our online course, which offers an hour of continuing medical education (CME) credit to physicians and other medical professionals. It will be the first comprehensive vulvodynia CME course on Medscape, the leading provider of continuing education programs, and will be marketed to 250,000 clinicians in gynecology, primary care and women's health. To receive a notification when the program releases, please send an e-mail to [cshea@nva.org](mailto:cshea@nva.org).

**NVA's Advocacy Efforts Result in 1200% Increase in Federal Research Investment.** For a decade, the federal investment in vulvodynia research was stagnant at \$1 million annually, but has steadily climbed to \$12 million since 2009. This is particularly impressive now because the percentage of grants submitted to the National Institutes of Health (NIH) that receive funding is at an all time low of 10 percent. Additionally, the number of NIH Institutes/Centers that contribute funding has increased from two to five. To read summaries of new and previously funded NIH studies, visit [www.nva.org/nih\\_funding.html](http://www.nva.org/nih_funding.html).

**Forging New Relationships with the Departments of Defense (DoD) and Veterans Affairs (VA).** Women now make up a sizable percentage of the military, and as a result, are frequent users of the military healthcare system, which is the largest in the world. This year, for the first time, the significant prevalence of vulvodynia in women veterans returning from the current conflicts was studied and reported on in two journal publications. Through a series of meetings, we've identified multiple avenues of collaboration with the DoD and VA to ensure that vulvodynia is in-

cluded in ongoing military initiatives to advance pain care and research.

**NVA Director Testifies at First US Senate Pain Hearing.** In February, Christin Veasley was invited by Senator Tom Harkin (D-IA) to testify at the historic Senate hearing, *Pain in America: Exploring Challenges to Relief*. As the only witness asked to share the patient perspective, she was in a key position to raise awareness of and educate members of Congress about the urgent need for research and educational initiatives focused on this long-neglected and life-altering disorder.

**Secretary of Health Directs IPRCC to Develop National Pain Strategy.** NVA's Director was asked by the Secretary of Health and Human Services (HHS) to serve on the first federal oversight committee on pain research – the Interagency Pain Research Coordinating Committee (IPRCC). After discussing with HHS the stagnant state of the landmark 2011 Institute of Medicine report, *Relieving Pain in America*, the HHS Secretary assigned to the IPRCC the enormous and monumentally important task of developing a comprehensive nationwide population-level strategy for all of pain prevention, treatment, management and research, the main recommendation of the IOM Report. Once again, by serving in this key committee position, Christin is able to voice the needs and concerns of women with vulvodynia and to ensure that the disorder is included in the nationwide strategy developed by the Committee.

**NVA Secures Grant to Further Expand National Vulvodynia Treatment Registry (NVR).** The NVR, established through a generous gift from an

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hope that it will help us to better identify ways to intervene early and stop vulvodynia's progression, as well as discover methods of preventing it from developing altogether.

### **NVA: What interested you in researching vulvodynia's relationship to other pain disorders in this study?**

**Dr. Reed:** Initially, when vulvodynia was studied in a vacuum, it was thought to possibly result from infections or skin disorders. Over time it's become clear that nerve hypersensitivity is central to the condition. Peripheral nervous system alterations are present (e.g., nerve branching), and in a sizable percentage of women, dysfunction of the central nervous system is found (e.g., fMRI changes in the brain, pain hypersensitivity in other areas of the body). Similar research findings have emerged for other pain disorders such as fibromyalgia (FM), interstitial cystitis/painful bladder syndrome (IC/PBS) and temporomandibular disorders (TMD). Early studies of these conditions suggested an increased probability of one or more pain conditions co-occurring, associated with increasing medical (and other) costs. At the same time, medical literature documented their underdiagnoses, suggesting that unless clinicians ask about associated symptoms, most will fail to recognize these disorders in their patients. Our research group was interested in understanding how pain conditions that frequently co-occur relate to one another, and whether common mechanisms underlie these conditions and can explain their shared features, so we included validated screening questions for several of them in our Woman-to-Woman Study. Then, in June 2011, the Institute of Medicine (IOM) released its report, *Relieving Pain in America*, documenting the widespread prevalence and cost of chronic pain in our country, with one-third of adults re-

porting some form of chronic pain that results in an annual cost of more than \$500 billion dollars. The IOM report stressed the need for expanded and improved data on the prevalence of pain diagnoses in order to reduce their impact and resultant suffering. These findings further stressed the importance of understanding the relationship among comorbid pain conditions, including vulvodynia. Our Woman-to-Woman Study is now starting to generate and publish data that can help to answer some key questions about the disorders' inter-relationship.

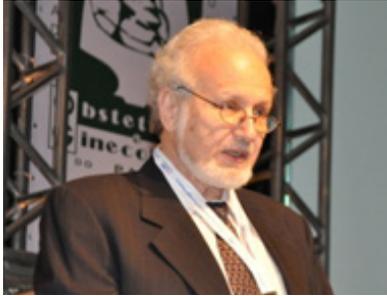
### **NVA: What did participation involve?**

**Dr. Reed:** Women 18 years or older were recruited using random digit dialing. After randomly identifying one eligible woman within a household, our trained interviewers obtained informed consent and conducted a brief telephone interview. We then sent each woman a more extensive online or written survey, which assessed demographic characteristics, potential environmental exposures, urogenital symptoms and medical history. Thereafter, we mailed follow-up surveys every six months to assess changes in symptoms, diagnoses and potential risk factors. In addition to including screening questions for vulvodynia, the survey included validated screening questions for several pain conditions from the FM Impact Questionnaire, Rice High Specificity Definition for IC/PBS and Rome II Criteria for irritable bowel syndrome (IBS). Briefly, the screen for vulvodynia required women to report more than three months of vulvar discomfort at the vaginal opening that was either provoked or unprovoked. Women screening positive for IC/PBS had to report urinary frequency and painful urination, and those screening positive for FM had to

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## NVA Medical Board Member Receives Distinguished Professorship



Longtime NVA Medical-Scientific Advisory Board Member Steven Witkin, PhD (pictured left), was recently named the first re-

recipient of The William J. Ledger Distinguished Professorship for Infection and Immunology in Obstetrics and Gynecology. The professorship, established in April 2012, is named in honor of William Ledger, MD (pictured below), The Given Foundation Professor Emeritus of Obstetrics and Gynecology at the Weill Cornell Medical College in New York.

With accolades too numerous to summarize, for five decades, Dr. Ledger has been an internationally recognized pioneer in the treatment and research of vulvovaginal infection and disease. He chaired the department of obstetrics and gynecology and directed the department's residency program for twenty years, founded the International Infectious Disease Society for Obstetrics and Gynecology and has authored hundreds of medical journal articles and several books. After caring for women with vulvodynia in his clinical practice for two decades, in 2000, Dr. Ledger began conducting scientific research on the underlying mechanisms of provoked vestibulodynia (PVD) in collaboration with Dr. Witkin.

Since their first publication demonstrating PVD patients' propensity towards an altered proinflammatory immune response, Drs. Witkin and Ledger have been among the forefront in advancing scientific understanding of vulvodynia.

They've been awarded five NVA research grants and published novel study findings in a dozen medical journal articles. These studies have aided in the legitimization of this once mysterious disorder and have significantly contributed to our understanding of the complex interplay of genetic, immuno-inflammatory and neurologic mechanisms responsible for the development and maintenance of PVD. Their long-term research goal is to use scientific evidence to delineate distinct mechanism-based PVD subgroups. This will provide a rationale for utilizing specific therapeutic interventions, as well as aid in the subsequent development of more specific and individualized prevention and treatment strategies.

In addition to his impressive contribution to this field, for decades, Dr. Witkin has been recognized for his research on immune mechanisms of infertility, biomarkers of gynecologic malignancies, genetic variations and susceptibility to obstetrical and gynecological disorders, immune consequences of gynecologic infections, and pregnancy-specific immune regulatory mechanisms. He has trained and collaborated with numerous fellows from Europe, Asia and South America, who have subsequently become leaders of obstetrics and gynecology research in their respective countries. Dr. Witkin has served as the director of the Division of Immunology and Infectious Diseases at Weill Medical College for 27 years.



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experience chronic pain or discomfort in four quadrants of the body. Women positive for IBS had to report a combination of abdominal pain associated with altered bowel frequency, function, or both. Although no validated screening questions were included for TMD, we did ask women if they were diagnosed with the disorder and included this in our data analysis when possible.

### **NVA: What were the demographics of your study population?**

**Dr. Reed:** Our recent publication in *Obstetrics & Gynecology* and my presentation at the August 2012 NIH Workshop on Chronic Overlapping Pain Conditions (see page 9) summarized data obtained from the six-month follow-up survey of 1,890 women. Participants' mean age was 50 years. Three-quarters were white, 16 percent black, 2 percent Hispanic, and 5 percent endorsed other ethnicities. Two-thirds were married, 96 percent were high school graduates, and 40 percent reported paying for basics as somewhat to very hard. Two-thirds reported having had intercourse in the six months prior to completing the survey. Among those with vulvodynia, symptoms were present for an average of 12 years, 42 percent reported pain with their first intercourse (aka primary vulvodynia), 65 percent had pain that was provoked only and just 6 percent had been given a vulvodynia diagnosis.

### **NVA: What did your analysis show?**

**Dr. Reed:** Seven-and-a-half percent of women screened positive for IC, 8.7 percent for vulvodynia, 9.4 percent for IBS and 11.8 percent for fibromyalgia. About 5 percent reported a TMD diagnosis. In general, these figures are fairly similar to those from other population-based studies using

similar screening criteria, with the exception of FM, whose prevalence in our study was somewhat higher, perhaps due to the older average age of our participants. Women with vulvodynia, compared to those without, were two to three times more likely to report any one of the other pain disorders, although 73 percent screened negative for all of them, and only half of those with any one pain diagnosis met the criteria for at least one additional condition.

As the number of coexisting conditions women had increased from zero to four, the odds of having vulvodynia increased more than five-fold. Fibromyalgia sufferers appeared to be at highest risk, with our analysis showing that they were much more likely to have all three other coexisting pain diagnoses than were those with one of the other disorders. The risk of IC or IBS was increased among women with vulvodynia, but the prevalence of FM was similar whether or not vulvodynia was present. However, in those with more than one comorbid pain condition, each combination of conditions was more likely to be seen among women with vulvodynia compared to those without.

We also looked at prevalence rates of the disorders across age decades. Vulvodynia tended to be high and fairly stable until over age 70, while FM and IC exhibited an inverted U-shape pattern with maximal prevalence in middle to older age groups. Conversely, IBS demonstrated a U-shaped pattern with a maximum prevalence in both younger and older age groups. The prevalence of a TMD diagnosis was fairly consistent across all age groups, as was the probability of having more than one disorder.

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## Recent Studies Highlight Novel Treatments

In the October 2012 issue of the *Journal of Lower Genital Tract Disease*, Gilbert Donders, MD, PhD, and Gert Bellen, RN, from Femicare Clinical Research for Women in Tienen, Belgium, published the results of their small double-blind, randomized, placebo-controlled, crossover study investigating the effectiveness of the skin cream Neogyn in treating women with provoked vestibulodynia (PVD). The cream, which contains a variety of anti-inflammatory proteins and growth factors (derived from fibroblasts) known to play a role in wound healing, has demonstrated utility in repairing epithelial and muscosal skin. Because prior studies of women with PVD have shown that their vestibular skin can be altered and frail, the group proposed that the Neogyn cream may help to normalize the skin's structure and reduce vestibular pain. Twenty-six women between the ages of 18 and 55 who suffered from PVD for at least six months and had visible vestibular redness completed the study. Half of the women first received and applied a pea-sized amount of the Neogyn cream to the vestibule twice daily for three months, while the other half received the inert control cream to use during this time. Then both groups stopped using their respective creams for one week during the "washout period" and were given the opposite cream to apply twice daily for another three months. In this crossover study design, researchers are able to investigate the effectiveness of both the active and control treatments in each of the participants.

Both creams were well tolerated and initial irritation experienced by some decreased with continued use. During the first 12-week phase, a substantial and statistically significant 20 to 30 percent reduction in intercourse-related pain and vestibular redness was found in women using the Neogyn cream, but not the control cream. Interestingly, women with secondary PVD (i.e., those

who develop the disorder after a period of pain-free penetration) had a 30 to 50 percent reduction in redness and pain with sex. These findings did not hold up throughout the course of the entire study, which may be due to the small number of patients included and/or the profound carryover effect with the crossover design. Nevertheless, since research suggests that there are likely many distinct mechanisms at play in different PVD subgroups, Dr. Donders believes this finding is a clinically important observation for a condition that currently has no accepted effective evidence-based treatment, and that Neogyn may be a promising new treatment, particularly for women with secondary PVD. A large multisite randomized controlled trial is currently enrolling participants in Washington DC, Arizona (Phoenix), California

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### In Memoriam



The NVA remembers a longtime contributor and volunteer, Trudi Wolin, who passed away on Monday, October, 8, 2012. In its earliest days, Trudi helped the organization by graciously volunteering her time and professional accounting services, as well as communicating with women in need of information and support. She will be greatly missed by the NVA, her son (Lance) and daughter-in-law (Lisa), granddaughters (Kali and Camden) and her friends. ■

## Treatment Studies

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(San Diego) and Pennsylvania (Philadelphia). For additional information, visit [www.nva.org/participate.html](http://www.nva.org/participate.html) and click on these states.

In January's issue of the same journal, Filippo Murina, MD, from the department of vulvar disease at V. Buzzi Hospital in Milan, Italy, reported the findings of his small randomized controlled trial of twenty women with PVD that compared the effectiveness of transcutaneous electrical nerve stimulation (TENS) combined with two oral medications versus TENS and a placebo medication. According to Dr. Murina, due to the complex neuropathology of PVD, an effective therapeutic approach should target both peripheral and central nervous system sensitization. TENS, a device that has been helpful for some women with vulvodynia, blocks peripheral pain impulses and abnormal pain-related activity in the central nervous system. Studies have also demonstrated that women with PVD have an increased number of vestibular mast cells, which are implicated in tissue inflammation and proliferation/sprouting of pain-sensing nerve fibers. Based on these findings, Dr. Murina and colleagues wanted to ascertain whether the addition of two oral compounds that counteract these biological processes would enhance the effectiveness of TENS. They gave half of the study participants an oral placebo medication and the other half received 400mg of oral palmitoylethanolamide (PEA), proposed to decrease the activity of mast cells and resultant sensitization of vestibular nerves, and 40mg of oral polydatin, a compound that may decrease levels of the proinflammatory cytokine IL-17, to use twice daily for two months. After familiarizing women with the protocol in the doctor's office, all of the women self-administered TENS therapy through a vaginal probe at home three times weekly for the trial's duration.

The preliminary data analysis showed that both

groups improved, although not to a degree of statistical significance. Further analysis revealed that TENS therapy combined with PEA and polydatin was more effective than TENS plus placebo in women whose PVD onset was recent. This finding suggests that inflammation may play a role in early stages of PVD's development or that TENS and these medications act synergistically to interrupt vestibular nerve sensitivity triggered by inflammation. What's unclear, however, is whether treatment with PEA and polydatin (without TENS) – either alone or in combination – would have resulted in the same findings. A future study that includes a large number of patients with multiple treatment arms (e.g., TENS alone, medication alone, TENS plus medication, placebo medication) would help to determine how effective each are in treating certain subgroups of women with PVD.

In the February issue of *Obstetrics and Gynecology*, Jose Andres, MD, PhD, and colleagues from the departments of anesthesiology and multidisciplinary pain management at the Valencia University General Hospital in Spain, published a case study describing the successful treatment of a 35-year-old woman with a three-year history of generalized vulvodynia. She suffered from severe continuous pain that she described as burning, stabbing, stinging and shooting in multiple areas of the vulva that worsened with pressure and sometimes extended into her perineum, inner thighs and mons pubis. The slightest touch, such as that from her underwear, was painful and caused her to avoid intercourse completely. She had a normal psychiatric assessment prior to the onset of vulvar pain, and suffered from depression and anxiety as a result of her pain, for which she was being treated. She failed a host of conservative therapies, in-

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# NIH Releases First Federal Plan to Advance Research on Overlapping Pain Conditions

Since 2009, the NVA, in cooperation with the Chronic Fatigue and Immune Deficiency Syndrome (CFIDS) Association of America, Endometriosis Association and The TMJ Association, has led the Chronic Pain Research Alliance (CPRA) – the first and only collaborative advocacy effort in our country dedicated to advancing both disorder-specific and collective federal research efforts on eight prevalent, but longtime neglected disorders that frequently co-occur and disproportionately affect women. They include: vulvodynia, temporomandibular disorders (aka TMJ), fibromyalgia, endometriosis, chronic fatigue syndrome, chronic headache, interstitial cystitis/painful bladder syndrome and irritable bowel syndrome.

By joining forces and creating a powerful and cohesive advocacy voice, the CPRA has had many achievements in a short period of time. Most recently, the Alliance worked to encourage the National Institutes of Health (NIH) to convene the first federal scientific meeting focused solely on overlapping pain conditions. A diverse group of clinical and basic science researchers came together with the goal of developing a strategic research plan to identify both unique and shared underlying disease mechanisms, as well as effective evidence-based treatment strategies. In a letter sent to NIH Director Dr. Francis Collins prior to the workshop, U.S. Senators Bernie Sanders (I-VT), Tom Harkin (D-IA) and Sheldon Whitehouse (D-RI) expressed their concern about the number of women affected by these disorders, as well as their impact on rising health care costs and women's health and quality of life. They urged the NIH to lay out clear and concrete recommendations for an aggressive, NIH-wide research agenda to accelerate scientific progress in this understudied area, and for the Trans-NIH Working

Group on Chronic Overlapping Pain Conditions to swiftly implement them.

*A Workshop on Chronic Overlapping Pain Conditions* convened in August 2012 and was sponsored by the National Institute of Neurological Disorders and Stroke and the National Institute of Dental and Craniofacial Research, together with the NIH Pain Consortium. Meeting co-chairs were Daniel Clauw, MD, professor of medicine in the division of rheumatology at the University of Michigan, and Elizabeth Unger, MD, PhD, chief of the Chronic Viral Diseases Branch at the Centers for Disease Control and Prevention. CPRA organizational leaders Terrie Cowley (TMJ Association), Kim McCleary (CFIDS Association) and NVA's Christin Veasley participated as panelists, as did NVA and CPRA medical-scientific advisory board member Ursula Wesselmann, MD, PhD, professor of anesthesiology at the University of Alabama. Several other CPRA scientific advisory council members served as panelists, including Allen Cowley, Jr., PhD, chairman of physiology at the Medical College of Wisconsin; Karen Berkley, PhD, professor of neuroscience at Florida State University; Jon Levine, MD, PhD, director of the NIH Pain Center at the University of California, San Francisco; Richard Lipton, MD, chair of the department of neurology at Albert Einstein College of Medicine; William Maixner, PhD, DDS, director of the Center for Neurosensory Disorders at the University of North Carolina, Chapel Hill; and Suzanne Vernon, PhD, scientific director of the CFIDS Association.

The objective of the two-day meeting was to develop a forward-thinking and coordinated strategy

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to guide future research efforts in: developing diagnostic criteria for overlapping pain conditions; understanding risk factors associated with their development and persistence; discovering common trajectories of their onset, progression and reversal; delineating disease mechanisms; and developing outcome measures for clinical research. It incorporated short presentations by panelists along with extensive discussion periods. Break-out groups met separately to discuss knowledge needed, research opportunities and training needs in several topic areas, and the meeting concluded with attendees reconvening to discuss recommendations from the break-out groups.

The panel identified six critical needs areas upon conclusion of the workshop. First, the group deemed it essential that the NIH quickly develop a case definition for chronic overlapping pain conditions, as well as standardize terminology and classification, to ensure that scientists and clinicians from different institutions share a common language and that study findings across the board are comparable and can be generalized to the wide spectrum of sufferers. Likewise, the panel recommended that basic (preclinical) and clinical research be coordinated right from the start so that what's being studied in the laboratory setting is applicable to the clinical population (and vice versa). The group agreed that longitudinal studies (i.e., studies that follow the same group of people, sometimes for a decade or longer, and collect information and/or biological samples several times over the course of the study) are needed to understand how overlapping pain conditions develop and persist, and to study what is different between those with one condition versus multiple pain disorders. Since sensitivity of the central nervous system (i.e., brain and spinal cord) is a consistent finding across various pain diagnoses, the panel felt that studying this phenomenon could lead to

the discovery of common mechanisms that underlie these disorders. Additionally, simple and easy-to-use measures of central sensitivity could be developed and used as diagnostic markers in the clinic, and by targeting the mechanisms of central sensitization, health care providers may be able to treat multiple conditions simultaneously with the same therapeutic intervention.

Further, there are several large ongoing studies that already include patients with some of these disorders, such as the NIH's *Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network* and the University of North Carolina's program project, *Complex Persistent Pain Conditions: Unique and Shared Pathways of Vulnerability*. The panel felt that it was very important to coordinate efforts between these studies and investigators to maximize the utility of resultant data and information, as well as to develop a central repository for storage and analysis of biological specimens and biomarkers. Since this area of research is relatively new and the number and quality of scientists interested in researching these conditions is beginning to increase, the panel recommended that the NIH develop multidisciplinary training programs for both scientists who conduct their research at the NIH itself and for those from universities and institutions across the country who receive NIH grants to support their research. Finally, since medical research is conducted with the main goal of translating its findings into improved health and quality of life for those afflicted, the panel recommended that the NIH swiftly develop medical professional training programs and materials to facilitate the quick and accurate translation of findings into medical care. (Specific sub-recommendations in each of these areas can be reviewed

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We further assessed characteristics of chronic vulvar pain that might predict the co-occurrence of multiple pain conditions and did not find any association with age at onset of symptoms, duration of vulvodynia or maximum severity of vulvar pain women had ever experienced. We did find that screening positive for more than one pain condition was associated with difficulty paying for basics, such as food, clothing and housing, suggesting that those impacted most by multiple conditions may be those least likely to be able to afford medical care and treatment.

**NVA: We discussed the importance of research including women from the general population, as you did in this study. In comparison, studies of clinic-based populations have found much higher rates of comorbidity. Why do you think this is?**

**Dr. Reed:** Women being seen in medical practices often differ in many ways from those in the general population. In general, the former group is more likely to have severe, persistent or impactful symptoms. They are also more likely to seek care for the symptoms they experience, as evidenced by their presence in your office, and hence may be more likely to be diagnosed with other pain disorders. Being seen for another pain disorder might also result in a referral for an assessment of vulvar pain that had previously not been addressed. Studying vulvodynia as it occurs in the general population can give us a better idea of its actual prevalence, women's symptom severity and how likely it is for sufferers to have multiple pain conditions. Study findings can also be generalized to the wide spectrum of sufferers, rather than only those receiving medical care.

**NVA: What conclusions can be drawn from your study?**

**Dr. Reed:** Our results concur with those of many other studies suggesting that not all women with vulvodynia are alike. Our finding that some women present with multiple conditions while others report only one suggests differing underlying mechanisms of disease, differences in the peak ages of onset of pain diagnoses (i.e., other disorders may be destined to occur later) or a lack of "central nervous system sensitivity," which may be the relevant neurologic condition that underlies this predominant grouping of conditions. Coexistence of these disorders appears not to be universal, but rather a characteristic of a subset of women affected by vulvodynia.

**NVA: How can medical professionals integrate these findings into their clinical practice and improve the medical care they provide to women with vulvodynia?**

**Dr. Reed:** Although this data strongly suggests an association between vulvodynia and other chronic pain disorders, not all women will suffer from more than one disorder. Hence, the lack of a comorbid condition does not rule out vulvodynia, but the evaluation of a woman with symptoms suggestive of any of these disorders should include questions about other pain conditions. Similarities in recommended treatment protocols for coexisting pain conditions have become increasingly evident, with tricyclic antidepressants (e.g., nortriptyline, amitriptyline), atypical antidepressants (e.g., duloxetine, milnacipran) and anticonvulsants (e.g., gabapentin, pregabalin) being used for a number of these disorders. The use of centrally acting agents such as these may have the potential to address symptoms across multiple conditions. For those with vulvodynia only, treat-

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ment may be similar or it may include the use of local regimens (e.g., topical creams, pelvic floor physical therapy), which address the localized vulvar issue without systemic effects.

### **NVA: What might additional research in this area reveal?**

**Dr. Reed:** Future studies on the inter-relationship of these disorders, as well as the differences between women with a solitary condition versus multiple disorders, may help us to clarify whether women with multiple pain diagnoses differ in underlying mechanism of disease, presentation and course of vulvodynia and/or in treatment responses – findings that will substantially impact patient satisfaction, treatment outcomes and quality of life.

[Editor's Note: The results of Dr. Reed's study are reported in full in: Reed BD, Harlow SD, Sen A, Edwards R, Chen D, Haefner HK. Relationship between vulvodynia and chronic comorbid pain conditions. *Obstet Gynecol* 2012;120:145-51.]

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# In Her Own Words

## *Tougher Than a Month-Old Macaroon*

By *Pattie M.*

We embark on many journeys in life – some by choice, others by chance and some that seem forced upon us. How we choose to navigate through these situations speaks loudly of who we are and who we can become.

The pain started in the fall of 2008. After 14 months of doctors' visits with no answers, I was finally diagnosed with interstitial cystitis/painful bladder syndrome, then pelvic floor muscle dysfunction and finally vulvodynia. My life hasn't been the same since.

I had an active lifestyle as a full-time volunteer minister and small farm owner. I was happily married to the most wonderful man. I enjoyed working with and riding my own horses, as well as helping friends with theirs. That active life came to a crashing halt when the pain started. I thought my life was over. I even contemplated ending my life. Instead of choosing to learn from this journey, I simply wanted to end it. Thankfully, with much help from therapy and medication, plus support from my husband, family and friends, my journey continues. I hope that by sharing my experience I can in some small way help others.

I have learned so much about myself these past few years. For one, I've always considered myself a bit of a wimp. Was I ever wrong! I didn't realize it until recently, and still doubt it on some days, but I now know I am a lot tougher than I ever thought. No one could go through what I've been through without strength. I've learned that being tough doesn't mean that you can't ask for help. Before the pain, I was the person others asked for help, not the one seeking it. After, I felt virtually useless and incorrectly assumed that no one

would want to help me. Was I ever wrong! In fact, I found that people wanted to help because they loved me for me, not because of what I could do. I now know that despite my disability, I am still a useful person. It just takes a bit more creativity.

This journey has also taught me that some parts of life are uncontrollable. I cannot control the fact that I have these pain disorders, but I can control how I face these obstacles. I've realized the importance of staying informed, seeking treatment – both conventional and alternative – and never being too timid or embarrassed to ask questions or for help. I've spent a lifetime helping others, but now I am comfortable focusing on my own needs before trying to meet the needs of others.

My journey continues. I see my doctors on a regular basis and am still experimenting with medications and therapies. I'm able to spend a few hours a week in the ministry, and our horses are happily enjoying retirement on our farm.

A friend recently sent me a card that read, "Like a month-old macaroon, you are one tough cookie." For better or worse, this has become my battle cry! ■



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## Depression

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challenges faced by those with other pain disorders, plus the specific difficulties that arise from dealing with pain in such a private place (Ponte 2009, Cantin-Drouin 2008). Chronic pain and depression are oftentimes described as a vicious cycle. Pain's profound impact on all aspects of our lives can lead to negative feelings and depression, which in turn intensifies the pain, making us feel more depressed, and so on in a cyclical fashion. In this article, I share some of my experiences dealing with vulvodynia and its emotional burden as a college student. I hope that this will encourage fellow sufferers to seek treatment and employ coping strategies for their physical pain and its emotional consequences, as well as help clinicians to better understand the complexity of our struggle.

### **The Many Levels of Emotional Suffering**

One of the first (and ongoing) emotions experienced by newly diagnosed women is frustration. Mirroring other women's accounts, I felt this when, as a newly diagnosed patient at the age of 20, no doctor could explain the root cause of my pain. Frustration ensued when information on treatment that could bring me quick and sure pain relief was not available because of the prior lack of research on vulvodynia. More frustration grew when I grasped how profoundly I would need to adapt my daily lifestyle to minimize pain while searching for effective treatment. Biking and even walking to class were suddenly painful. I had to stop jogging and give up wearing my prized skinny jeans. Experiencing these new limitations as a healthy young person was extremely difficult.

Like many women with vulvodynia I also felt very isolated. Although studies indicate that vulvodynia is quite prevalent, affecting as many as one in four women (Reed 2012), few report feeling com-

fortable openly discussing this condition. NVA's survey of 2000 women found that only 25 percent felt at ease disclosing their situation to female friends (Nguyen 2012). With few women speaking openly about their condition and experiences, sufferers are unlikely to know how prevalent vulvodynia really is and are bound to feel alone. This was certainly true for me. In the beginning I only felt comfortable sharing what I was going through with my closest family members and friends. I felt like I was the only one in the world dealing with vulvar pain. I was so envious of my friends and classmates who could ride bikes, wear skin-tight jeans, have painless sex and exercise however they like. Since I didn't come to know anyone else with vulvodynia for a long time, I felt all alone in a sea of happy, healthy, normal college students. It was terrible. This loneliness, plus the feeling that no one else understood my pain and suffering, caused me to isolate myself. Since I found it hard to relate to others and for others to relate to me, I no longer wanted to be social. Of course I now realize that this only worsened my feelings of isolation and let vulvodynia take over and degrade my social life.

After talking to people with all kinds of chronic pain, I realize that feelings of loneliness and isolation are common to them all. On the other hand, while other pain disorders negatively affect sexual function, what is unique to vulvodynia is how directly the condition interferes with a woman's sex life and warps her perception of self. Not surprisingly, in a study examining quality of life among vulvodynia sufferers, most reported "that their condition often or always affects how close they can be with those they love, makes showing affection difficult, and interferes with their sex life" (Ponte 2009). Not being able to engage in painless sexual activity with a partner can make a woman

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## Depression

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with vulvodynia feel guilty, and as one study described, like an inadequate woman and partner (Ayling 2008).

For me, though I had (and still have!) a very supportive boyfriend, vulvodynia put a huge strain on our love life. Knowing that I had to put intimacy on hold for an undetermined amount of time made me feel like an inadequate girlfriend, and I certainly felt less confident about myself in general and like less of a woman. Since I often felt sad and depressed, non-sexual aspects of our relationship also deteriorated, and there were many times when dealing with the challenges that vulvodynia imposed was so difficult that we contemplated going our separate ways. At times like this, the thought of being alone was terrifying. I wondered if I would feel relief if I were single, or just feel more isolated and alone.

This stress, frustration and loneliness can take a heavy toll. Considering all of the ways in which vulvodynia affects a woman's life, it's not surprising that ensuing depression is common. As a chemistry major with an overwhelming workload, some nights scraping by with just a few hours of sleep, the additional stress and sadness that resulted from dealing with vulvodynia caused me to sink into a deep unhappiness. The good news is that after two of the hardest years of my life and trying what seemed like a million treatments – when I was positive that things would *never* get any better – I was amazed when a new combination of physical therapy and medication finally provided some pain relief. This made me feel a bit better emotionally and marked the beginning of a long period of slow recovery. As the pain improved, I was able to identify ways to regain happiness and combat vulvodynia's emotional burden.

***“You may be given wrong diagnoses from amazing doctors and treatments that are expensive and challenging. My message is to not give up your search! Your effective treatment might come from doctor number seven, but it is up to YOU to keep searching!”***

***- Allison***

### Stopping the Cycle

I learned that although difficult, combating depression is essential to feeling better – emotionally and physically. The methods you'll need to employ clearly depend on the severity of both your chronic pain and depression. There is no one-size-fits-all rule. On one end of the spectrum, women whose vulvodynia is severe and uncontrolled and who also suffer from clinical depression will need more aggressive medical care and treatment that addresses both issues. At the other end, women whose vulvodynia is well-controlled with treatment and who experience mild or intermittent depression may be able to utilize more self-help strategies.

It's important to be able to identify the signs of clinical depression and put aside any hesitation or shame in seeking professional help. If you experience any of the following daily for two weeks or more, or are having suicidal thoughts, you should seek professional help immediately: overwhelming feelings of sadness and hopelessness, often with crying spells; feelings of worthlessness and/or guilt; changes in sleep (too much or too little) and/or weight (loss or gain); loss of interest in usual activities; poor concentration or memory; or feelings of restlessness or fatigue. If you occasionally experience some of the above, seeking professional help is still a good idea and will likely be very beneficial. In addition, there are also many

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## Depression

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coping methods you can utilize to help yourself feel better.

### Coping Strategies

How can someone feeling so down take steps to feel better? The first thing you need to know is that millions of women have vulvodynia and you are very far from alone, although it may feel that way at times. Some women choose to combat isolation by seeking out a support group with members that either meet in person or online. It can be hard to open up at first, but many women feel less alone after sharing their story and listening to others share theirs.

***“I read everything I could and found great comfort reading about other women’s experiences. I would never wish vulvodynia on another woman, but it helped to know I wasn’t alone.”***

**- Alicia C.**

Like me, you may also have a handful of loving encouraging friends and family members that you can turn to. A phone conversation with my mom when I felt especially frustrated or hopeless helped me to get through the day. I also sought the help of a counselor from my school’s health clinic to deal with the depression I faced. There are many forms of therapy, and therapists’ personalities are different, so finding what works best for you may require some trial-and-error.

Staying engaged and active – even if you don’t feel like it – is also key. Having been through this, I admit that this can be hard and unpleasant at first, especially if you’ve been isolated and inactive for a long time. Some suggest making a list of activities you enjoy, such as calling a friend or doing a craft project, and incorporating these activities into small daily goals for yourself. As you begin to feel more comfortable, set incrementally

bigger goals for yourself, like planning a lunch date with a friend or taking a day trip. Engaging in activities that you enjoy will help to decrease stress and anxiety, and provide a positive distraction, which can improve your day-to-day pain levels. Sometimes you will have to push yourself, but finding the motivation becomes easier over time.

After I understood how important it was to tend to my emotional health by staying engaged and active and how vital this was to improving my physical pain, I was much more comfortable devoting less time to work and more time to fun. I watched funny TV shows, spent more time outside and made plans to get frozen yogurt with friends, all of which helped me to divert my focus from the pain and all that I *couldn’t* do to all the enjoyable things I still *could* do.

***“I always try to appreciate all that I still CAN do. I can still read, enjoy time with my friends, go to the movies...it’s just that life is now altered in a very profound way. I’ve acknowledged that my life’s trajectory has been changed by this disorder, but that I still have the choice of how I am going to live my life.”***

**- Nora K.**

You may want to start a gratitude journal and on a daily basis, start keeping track of things you are still able to do and enjoy, even if they’re small. As you go back and read through prior entries, you start to become aware of all that you have to be grateful for. I’m sometimes even thankful for this experience, especially as I begin to prepare for medical school. It’s helped me to understand relatively early in my life how important stress reduction, relaxation and tending to my emotional health are, and has pushed me to improve my work-life balance.

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## Depression

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Another obvious way to increase your activity is through exercise. Unfortunately, women with vulvodynia find that many forms of exercise exacerbate their pain. If certain types of exercise are painful, don't push it. Search instead for activities that don't increase your pain. I used to jog for exercise, but vulvodynia has forced me to try other things, which I now really like and often prefer. Aim for gentle physical activity to help you stay fit and improve your mood. "Start low and go slow," is a good motto to follow for general activity, exercise and tackling the tasks on hand for the day.

***"When the tasks at hand seem overwhelming, break them down into smaller pieces. I would tell myself, 'Just make the bed and see how it goes. Just fold the laundry and take a break.' Concentrate on one foot in front of the other, not the finish line."***

**- Lyn F.**

In addition to regular activity, research has demonstrated the positive impact of healthy eating and restorative sleep on regulating pain levels and improving mood. If you're regularly having trouble falling (or staying) asleep and/or need help with your nutrition, talk to your health care provider.

Additionally, it's really important to be aware of and avoid pessimistic and defeatist thoughts. After two years of treatment with no improvement, I often pessimistically told myself, "No treatment will ever work for you. You are going to feel this way for the rest of your life." Unfortunately, since I repeatedly told myself that what I was experiencing was so miserable – like a self-fulfilling prophecy – I felt worse and became more miserable. I focused on every pang during a pain flare, but failed to celebrate days when the pain was less severe and I was able to be more active. I would've been able to stop the

vicious cycle much sooner had I understood the significant impact of negative thinking and been able to substitute some of my defeatist thoughts with more positive ones like, "This pain does not control me – look at how much I accomplished today."

***"Sometimes we have to encourage ourselves. I preempt negative thoughts by imagining what I'd say to a friend who was in my shoes, and then make the choice to speak those compassionate and encouraging words to myself."***

**- Kristin S.**

Finally, maintaining a healthy relationship (sexual and otherwise) with your significant other is vital to coping with chronic pain and maintaining emotional health. Every relationship is different and this issue can be quite complex for some, but there are many ways to have a loving and fulfilling intimate relationship in spite of vulvodynia. Experts cannot overemphasize how important it is for you and your partner to maintain physical and emotional intimacy even when you cannot have sex, and communication plays a key role in this.

***"Talking to counselors has been helpful because it has pushed me out of my comfort zone and made me talk about some painful things. Doing this has made me more relaxed and open towards sexuality, which has made it easier to communicate with my partner, also making it easier to cope."***

**- Jess**

My boyfriend and I talked through our feelings about sex after vulvodynia was in the picture, and this open discussion, although very personal and sometimes difficult, has actually strengthened many aspects of our relationship. Some couples

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## Depression

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may need or want to seek the help of a sex therapist and this should not be looked at as a failure. The NVA's online learning program (available at <http://LearnPatient.nva.org>) patient/partner booklets and 'books of interest' page on the NVA web site are also great resources.

***"I live a normal life now. I love my husband and daughter and I participate in most activities. I've had to adjust various parts of my lifestyle and I've learned to be grateful for very basic functions. Whenever a whisper of pain returns, I listen to it, take it seriously, learn from it and answer it. I found my life again."***

**- Anika F.**

### Conclusion

As I've experienced and shared, it can be difficult to work towards a happier, healthier life when suffering from the physical pain of vulvodynia and its emotional burden. It takes time and effort, but it's a necessary part of the overall healing process and worth it! Although I struggled through a few very painful and stressful years, my vulvar pain has improved, I'm happy again and I excitedly look forward to the future. I'm even back to jogging and wearing my skinny jeans! I feel strong and empowered knowing that I pushed through difficult times and stopped vulvodynia from controlling my life. This only resulted from addressing both the physical *and* emotional suffering that I experienced. I encourage you to do the same as you continue your search for effective treatment. Never give up!

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### Help Others by Sharing Your Story

Many women find it helpful to read about the experiences of others, as well as share what they've gone through. If you are interested in sharing your story, either anonymously or in name, we'd like to hear from you. Please send an e-mail to Cristina Shea ([cshea@nva.org](mailto:cshea@nva.org)).

## Treatment Studies

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cluding topical creams of various kinds and oral “pain-blocking” medications, as well as two trials of interventional pain medicine, specifically sacral spinal cord stimulation and sacral neuromodulation with pulsed radiofrequency.

Due to her complete lack of social and sexual life, she returned to the pain clinic in search of any remaining therapeutic options. Although previously unstudied in vulvodynia patients, based on scientific and clinical evidence from studies reporting its success in treating various pain conditions, such as postherpetic neuralgia, cervicogenic headache, hip pain and occipital neuralgia, the physicians recommended a trial of subcutaneous peripheral nerve stimulation. This treatment involves the placement of electrical leads under the skin of the painful area, which then stimulate the region of the affected nerve(s), whose input converges back to the spinal cord. The patient underwent surgical implantation of two electrodes under her labial skin and a connected pulse generator into a pocket created in her lower back. The treatment significantly reduced the patient’s pain, allowing her to discontinue all narcotics, sleep aids and other pain medications. One year later, she continued to report significant improvement in pain levels, daily functioning and sexual function, and was highly satisfied with the treatment. Based on this long-term positive outcome in treating such a severe case, Dr. Andres believes that further research on the effectiveness of this treatment in a large patient sample is warranted, and in the interim, should be considered as a potential treatment option for women with severe vulvodynia who fail conventional therapy.

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## NIH

(from page 10)

at: [www.ninds.nih.gov/news\\_and\\_events/events/meeting-summary-chronic-pain.htm](http://www.ninds.nih.gov/news_and_events/events/meeting-summary-chronic-pain.htm).

We are hopeful that the meeting’s recommendations will be included in a 2013 federal research funding announcement, providing members of the medical-scientific community with the opportunity to apply for and receive grant support to advance the study of overlapping pain conditions. The NVA, along with the other CPRA organizations and our scientific advisory council, look forward to working with the NIH Pain Consortium and Trans-NIH Working Group on Chronic Overlapping Pain Conditions on this and other initiatives to advance scientific knowledge in this long-neglected area, ultimately to improve the health and well-being of those affected by these life-altering and debilitating conditions. ■

## Year in Review

*(from page 3)*

NVA donor, is the first and only study that prospectively follows women undergoing treatment to collect data on the effectiveness of vulvodynia therapies and identify clinical predictors of treatment success. The Patty Brisben Foundation for Women's Sexual Health has provided three additional grants to expand this project, the most recent of which enables us to collect numerous biological measures related to inflammation, immunity and infection. All of this data will be correlated to treatment outcomes, genetic susceptibility, physical exam components and validated questionnaire findings, yielding first-of-its-kind data that will help us to better understand the disorder's various subtypes and identify the treatments that are effective for each.

**Results of Seven NVA-Funded Studies Published.** Publications summarizing the results of prior NVA-funded studies for the first time reported the high individual and societal cost of vulvodynia, as well as the disorder's profound impact on women's quality of life. The results of two treatment studies described the effectiveness of a series of multi-

level nerve blocks in women with generalized vulvodynia, and enoxaparin injections, which may counteract vestibular skin degradation, in women with provoked vestibulodynia (PVD). Two publications by a Swedish group summarized the results of their studies investigating genetic variations in women with PVD, as well as predictors of treatment outcome, highlighting the difference in improvement between women with primary versus secondary PVD, and those with one versus multiple coexisting pain conditions. Other publications described women's attitudes about openly discussing vulvodynia, as well as their feelings of isolation and invalidation, which appear to worsen as the number of co-occurring pain conditions increases.

### **NVA Funds New Studies and Career Awards.**

We were able to fund three new studies this year at the University of Minnesota, St. Louis University and UCLA, the results of which will help us to: i) understand how vulvar tissue is altered in women with vulvodynia, ii) identify via MRI, biological markers ("biomarkers") in the brain that are associated with different vulvodynia subtypes, and iii) delineate vulvodynia's temporal relationship to other pain disorders. Through our Marinoff Career Development Award, we also funded the establishment of two vulvar pain clinics in South Carolina and Poland. Project summaries are available at [www.nva.org/career\\_development\\_award.html](http://www.nva.org/career_development_award.html) and [www.nva.org/research\\_fund.html](http://www.nva.org/research_fund.html). ■

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## Witkin

*(from page 5)*

He is a member of several editorial boards and has published 300 peer-reviewed journal articles.

The NVA expresses its most sincere appreciation to both doctors for their steadfast commitment to advancing our scientific understanding of vulvodynia and other poorly understood vulvovaginal disorders, which has improved both the treatment and quality of life of women and girls worldwide. Their dedication and achievements are inspiring and we couldn't think of two people more deserving of this recognition. ■

The NVA appreciates the generous grant support of the Patty Brisben Foundation for Women's Sexual Health, Purdue Pharma, L.P. and the Enterprise Holdings Foundation.