

The *NVA Update*, a bimonthly publication of the National Vulvodynia Association, provides information on recent progress in medical research funding, raising awareness of vulvodynia and Capitol Hill efforts. Previous issues can be viewed on [NVA's web site](#). In addition to news articles, the NVA's printed newsletter, *NVA News*, contains articles by vulvovaginal experts on the diagnosis and treatment of vulvodynia. To subscribe, visit [NVA's web site](#).

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### **NVA Joins Forces with Five Non-Profits to Help Millions Suffering from Coexisting Medical Conditions**

The NVA recently surveyed 1500 women with vulvodynia and found that two-thirds reported also suffering from at least one of the following chronic medical conditions: interstitial cystitis (painful bladder syndrome), fibromyalgia, irritable bowel syndrome (IBS), endometriosis, chronic fatigue syndrome, headaches, and temporomandibular joint/muscle disorders. In an effort to help women with multiple conditions, the NVA has joined forces with five other independent nonprofit organizations to form the Overlapping Conditions Alliance. As part of this effort, the Alliance has launched an informational web site at [www.OverlappingConditions.org](http://www.OverlappingConditions.org).

The goal is to promote research on possible underlying connections between these coexisting conditions. "All of these conditions are characterized by chronic pain, which causes enormous physical and emotional distress for sufferers and their families," says NVA President Phyllis Mate.

Health care providers receive limited training in these conditions, leading to frequent misdiagnosis and inappropriate treatment for millions of patients. In addition, they cost the US billions of dollars each year in medical costs and lost productivity. The mission of the Overlapping Conditions Alliance is to change this situation by advancing the medical, scientific and policy needs of people afflicted with multiple chronic conditions. The Alliance is composed of six independent nonprofit patient advocacy organizations: the Chronic Fatigue and Immune Dysfunction Syndrome Association of America, Endometriosis Association, Interstitial Cystitis Association, International Foundation for Functional Gastrointestinal Disorders, National Vulvodynia Association and The TMJ Association.

### **Support the National Pain Care Policy Act of 2009**

This month, the US House of Representatives passed the [National Pain Care Policy Act of 2009](#), which was recently introduced in the US Senate by Orrin Hatch (R-UT) and Christopher Dodd (D-CT). This important bill would authorize the NIH Pain Consortium to expand research on causes and treatment of pain, and provide comprehensive pain

care education/training for healthcare professionals. It would also create a national public awareness campaign on pain management and authorize a pain conference at the National Academy of Science's Institute of Medicine. Over one hundred organizations, including the National Vulvodynia Association, have joined forces with the [American Pain Foundation](#) (APF), in supporting this bill. Please take a few minutes to visit the [APF's web site](#) and send a brief e-mail to your Senators, urging that they support this critical piece of legislation.

## **Pain Societies Publish First Opioid Guideline for Chronic Pain**

This past February, the [American Pain Society](#) and the [American Academy of Pain Medicine](#) published the first comprehensive clinical practice guideline on prescribing potent opioid pain medications to patients with chronic non-cancer pain. To develop this guideline, they convened a panel of pain management experts, who reviewed more than 8,000 published and non-published studies before issuing 25 specific recommendations.

"The expert panel concluded that opioid pain medications are safe and effective for carefully selected, well-monitored patients with chronic non-cancer pain," said Gilbert J. Fanciullo, MD, a panel co-chair and director, Section of Pain Medicine, Dartmouth Hitchcock Medical Center.

Traditionally, opioids, such as oxycodone, have been used to relieve pain after surgery, from cancer or at the end of life. Today, they are also used to relieve severe chronic pain from other conditions such as low-back injury, arthritis and fibromyalgia. For women with vulvodynia, opioids are appropriate for short-term use during severe pain flares. They can also be useful early in treatment to alleviate pain while patient and doctor seek a long term solution, e.g., while women gradually increase the dose of an antidepressant or anticonvulsant pain medication. In severe cases, if more conservative therapies fail to provide relief, opioids can be used on an ongoing basis to treat vulvodynia. The most common side effects are constipation and nausea.

There appears to be a growing willingness to prescribe opioids among medical professionals. The guideline acknowledges, however, the widespread concern about their possible abuse and addiction. The panel advised that, prior to initiating long-term opioid treatment, doctors assess whether or not the pain can be controlled with other medications. If opioids appear to be the most effective treatment option, providers should conduct a thorough medical history and examination, and evaluate potential risk for substance abuse or addiction. Because of this risk, routine monitoring of chronic pain patients prescribed opioids is required. Additional information on the opioid guideline can be viewed on the [American Pain Society's web site](#).

## **FDA Changes Safety Information for Several Pain Medications**

The FDA Center for Drug Evaluation and Research recently approved safety labeling changes for 28 medications, including several that are routinely prescribed to women with vulvodynia. FDA's web site lists the brand and generic name for each drug and provides a brief summary of the new safety information, including boxed warnings and contraindications. To check if the medication you're taking is on the list, please consult [FDA's web site](#).

## **FDA Approves New Cream for Vaginal Dryness and Pain**

The US Food and Drug Administration recently approved the use of Duramed Pharmaceuticals' new product, Synthetic Conjugated Estrogens-A Vaginal Cream. This cream is a plant-derived local estrogen product indicated for the treatment of vulvovaginal atrophic symptoms associated with menopause, i.e., vaginal dryness and pain with sexual intercourse.

According to the company, the most common side effects in the clinical trials were vulvovaginal infections, upper respiratory tract infection, headaches and hot flashes. The company also warned that individuals with the following conditions should not use this cream: undiagnosed abnormal genital bleeding; known, suspected, or history of certain cancers; stroke or heart attack in the past year; current or previous blood clots or thromboembolic disease including stroke or myocardial infarction; liver problems; and allergy to SCE-A Vaginal Cream or any of its ingredients; or known or suspected pregnancy.

## **National Women's Organization Launches Sex and Intimacy Campaign**

This month, the [National Women's Health Resource Center](#) (NWHRC) and the [American Academy of Nurse Practitioners](#) launched a sex and intimacy awareness campaign. NWHRC created a free 12-page booklet titled, *Let's Talk about Sex! Keeping Intimacy Alive at Midlife and Beyond*. Topics include male and female differences in sexual desire, common sources of painful sex (including vulvodynia) and suggestions for enjoying intimacy at midlife. For additional information, or to order the booklet, please visit [NWHRC's web site](#).

## **Continued Vulvodynia Coverage**

Several articles on chronic pain and vulvodynia have been published since our last *NVA Update*. After you read the article summaries below, please take a few minutes to post comments online or send a brief thank you e-mail (or letter) to the journalist or editor.

In March, Dr. Jennifer Gunter, Pelvic Pain Director at Kaiser Permanente in San Francisco, started an on-line sexual health column at [examiner.com](#). She posts articles five times a week and covers many topics of interest to women with vulvodynia. One of her recent articles, [The Causes of Painful Sex](#), discusses the most common causes of dyspareunia, or painful intercourse. Through this column, Dr. Gunter hopes to raise public awareness about sexual health problems and intimacy issues. You can [sign up to receive e-mails](#) when new articles are posted online.

Also in March, Dr. Mehmet Oz, aka America's Doctor, had an hour-long discussion about vulvodynia with Dr. Howard Glazer, NVA medical advisory board member, on his XM radio show. The doctors discussed "everything vulvodynia," including possible initiating factors and treatment options. You can listen to a four-minute clip of the show on [oprah.com](#). NVA will send an announcement when the program broadcasts again.

In late February, a young woman with vulvodynia gave sound advice to other chronic pain sufferers facing sexual limitations in an [msnbc.com](#) article by Brian Alexander entitled, [Best of Sexploration: Where are they now?](#) Mr Alexander had asked his readers to submit their advice after receiving an email from a woman whose vulvar pain made sex difficult and caused her marriage to dissolve.

The spring 2009 issue of the American Pain Foundation's newsletter, [Pain Community News](#), featured the article, *The Pain Down There*, which included an interview with NVA's Christin Veasley and a vulvodynia sufferer. The article discussed vulvodynia's impact on women's sexual relationships and offered suggestions for keeping intimacy alive.

Finally, a new 'crowdsourced' book, [Vulvodynia Heroes](#), was recently released by Alexandra Carmichael, co-founder of [CureTogether.com](#). (In *crowdsourcing*, a person broadcasts a task or problem to a group of people, typically online, in the form of an open call for solutions.) The book presents several vulvodynia sufferers' stories and summarizes the survey results of 190 women reporting on their symptoms and treatments at [CureTogether.com](#).

### **Please Participate in an Important Survey!**

The NVA needs 100 more women to participate in a cost-of-illness study. Upon enrollment, you will receive a complimentary copy of NVA's self-help guide. After completing the survey, NVA will give you a complimentary 1-year subscription to our newsletter.

If you live in the US and have been diagnosed with either generalized vulvodynia or vulvar vestibulitis syndrome (aka vestibulodynia), you are eligible to participate. The survey asks questions about lost work hours and out-of-pocket expenses related to having vulvodynia. NVA intends to use the survey results to convince Congress and the NIH that we need much more federally funded research on vulvodynia.

Participation requires only 3 hours of your time over the next six months. With the use of an NVA-supplied calendar, you keep track of your vulvodynia-related expenses, such as prescription medications, doctor visits and over-the-counter remedies. For additional information, or to participate, please visit: <http://www.nva.org/costsurvey>

### **Participate in Research**

The following institutions are currently recruiting women for vulvodynia studies. Additional study advertisements can be viewed on [NVA's web site](#).

#### **Cleveland Clinic (Cleveland, Ohio)**

Subject: Pregablin (Lyrica) for the Treatment of Vulvodynia: A Randomized, Double-Blind, Placebo-Controlled, Cross-Over Study.

Contact: Linda McElrath, RN  
Research Nurse Coordinator  
Cleveland Clinic/Department of Ob/Gyn  
216 445-2494  
Beri Ridgeway, MD (Principal Investigator)

Requirements: To be eligible, you must be age 18 years or older and diagnosed with vulvodynia (generalized vulvodynia or vulvar vestibulitis syndrome/provoked vestibulodynia); practice a reliable form of birth control, defined as sterilization, hormonal contraception, abstinence

or IUD; and not have any contraindication for taking pregablin or history of prior use of pregablin. You must also be able to attend five (5) follow up visits over the course of the study, which will last about 11 weeks. The study drug and related tests/procedures/visits will be provided at no cost to you.

### **Beaumont Hospital-Royal Oak (Royal Oak, MI)**

- Subject: A Clinical Trial of CC-10004 for the Treatment of Vulvodynia.
- Contact: Karen Shere, RN, Research Nurse Coordinator  
248-551-3565  
Kenneth Peters, MD (Principal Investigator)  
Donna Carrico, NP, MS (Co-investigator)
- Requirements: This is a 16-week drug trial. All study medication, exams, blood work, ECGs and questionnaires will be provided at no cost. Subjects must be between the ages of 18 to 69, and have a reported history of vulvar pain for at least three months.

### **Online Research Study**

- Subject: Self-report survey data on vulvodynia symptoms and treatments.
- Contact: Alexandra Carmichael  
[Alexandra@curetogether.com](mailto:Alexandra@curetogether.com)  
[www.CureTogether.com](http://www.CureTogether.com)
- Requirements: NVA supporter Alexandra Carmichael, a scientist and former vulvodynia sufferer, is conducting a vulvodynia study through the website she co-founded, CureTogether. Specifically, she is gathering self-report data on vulvodynia symptoms and treatments to try to identify which treatments work best for specific groups of patients. With enough participants, a genome-wide association (GWA) study, that locates genes or genetic regions associated with vulvodynia, can be conducted. Currently, 190 women have participated and a total of 1,500 are required to initiate a GWA study. Participation is entirely voluntary, anonymous and confidential. It involves registering on the web site and then rating symptoms and treatments. The survey takes 15-20 minutes to complete and you can see your results immediately. Registrants will be notified when the genetic study is set to begin and offered an opportunity to participate.