
The *NVA Update*, a publication of the National Vulvodynia Association, provides information on recent progress in medical research funding, raising vulvodynia awareness and Capitol Hill efforts. Previous issues can be viewed on [NVA's web site](#). 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](#).

NVA Awards Research Grants



Epidemiologist Receives NVA Career Award

The NVA is pleased to announce that [Ruby Nguyen, PhD](#), assistant professor in the division of epidemiology and community health at the University of Minnesota's School of Public Health, is the recipient of the 2010 [Dr. Stanley C. Marinoff Vulvodynia Career Development Award](#). To date, researchers have not investigated how pregnancy and childbirth affect the severity of vulvodynia, leaving obstetricians without guidelines for vulvodynia patients who are, or want to become, pregnant. Dr. Nyugen will conduct a prospective study of 160 pregnant women, half of whom suffer from vulvodynia. At each trimester and two months postpartum, these women will complete questionnaires on vulvar pain intensity and factors that can modify pain levels, including vulvovaginal infection, dermatological conditions, vulvar varicosities, mode of delivery and episiotomy/tear with vaginal childbirth. Dr. Nguyen will assess whether pregnant women with vulvodynia experience a change in vulvar pain severity or remission of symptoms over the course of pregnancy or the postpartum period and/or have an increased risk of developing postpartum vulvovaginal pain.



Cornell Researchers Awarded Grant

[Steven Witkin, PhD](#), professor of immunology, and [William Ledger, MD](#), chairman emeritus and professor, both of the department of obstetrics and gynecology, Weill Medical College of Cornell University, have been studying the etiology of Provoked Vestibulodynia (PVD, aka vulvar vestibulitis syndrome) for the past decade. Women with PVD report a variety of events that initially trigger their symptoms, including vulvovaginal infection, childbirth and hormonal alteration; researchers have not yet identified a single etiology of the condition and most investigators propose that it is likely multifactorial.

One cause of PVD may be a local, chronic inflammatory immune response that eventually induces localized peripheral nerve damage and increased pain sensitivity. Witkin and Ledger have demonstrated that subgroups of women with PVD have polymorphisms (alterations) in genes associated with prolonged inflammation in response to vulvovaginal infection; women with PVD show a reduced capacity to 'turn-off' inflammation, an increased capacity to initiate inflammation and a reduced ability to combat *Candida albicans* infection.



According to Witkin (above photo) and Ledger (photo on the right), what remains undetermined is (i) a detailed analysis of the types of bacterial organisms, or endogenous flora, found in the vagina and vulva of women with PVD, and (ii) the relationship between specific organisms and the carriage of these gene alterations or appearance of vestibular inflammation. They hypothesize that it is the interaction between specific types of bacteria and a woman's genetic makeup that determines the extent of vaginal and sub-surface vestibular inflammation and the degree of susceptibility to developing PVD.

With their current NVA grant, Witkin and Ledger will analyze the vulvovaginal flora in 40 PVD patients when they are symptomatic, and then eight weeks after treatment, comparing the findings to those of an

equal number of controls. They will also use a new instrument to visualize the extent of patients' vaginal and vestibular inflammation. The researchers will obtain DNA samples to determine whether polymorphisms associated with inflammation, vulvovaginal infection and peripheral nerve damage are more prevalent in women with PVD than controls. Furthermore, they will quantify levels of immune mediators, pro-inflammatory cytokines and anti-inflammatory cytokines in vaginal secretions.

Harlow Receives Second NIH Vulvodynia Grant



In 2000, [Bernard Harlow, PhD](#), professor and head of the division of epidemiology and community health at the University of Minnesota School of Public Health, and co-investigator [Elizabeth Stewart, MD](#), assistant professor of obstetrics and gynecology at Harvard Medical School, were awarded a [5-year grant](#) from the National Institutes of Health (NIH) to study the prevalence of vulvodynia. Harlow and Stewart surveyed a diverse group of women from the general population, showing that vulvodynia is a highly prevalent condition affecting millions of women of all ages and ethnicities. Furthermore, they found that 60 percent of women consult at least three doctors to receive a diagnosis and 40 percent remain undiagnosed after three medical consultations.

In 2007, Dr. Harlow received an NVA pilot grant to determine whether the vulvar tissue of women with vulvodynia and controls differed in levels of proinflammatory mediators, cytokines (substances released by the immune system) and bactericidal proteins. Their ongoing analyses suggest that vulvodynia may result from an altered immuno-inflammatory response that may occur before menarche. Earlier this year, Harlow used data obtained with NVA funds, combined with his prior data, to secure his second 5-year NIH vulvodynia grant entitled, [Immunological Factors and Risk of Vulvodynia](#). This project will test the hypothesis that vulvodynia results from an altered immuno-inflammatory response occurring as a consequence of reproductive, gynecologic, environmental or psychological exposures, which can be modified by factors such as abnormal vaginal bacteria and genetic variations. Specifically, he will screen a diverse sample of 24,000 women from community health clinics in Minnesota to identify 325 women with vulvodynia. These women will undergo a gynecological examination to confirm their diagnosis and then each one will be paired with a matched control. Data collection and analyses will determine whether the following factors influence the likelihood of developing vulvodynia: (i) reproductive, gynecological and environmental exposures; (ii) psychological factors; (iii) presence of immuno-inflammatory markers; and (iv) an increase in vestibular nerve fiber density. Harlow will also assess the extent to which a woman's genetic makeup and vaginal flora modify these factors.

NVA Year in Review: 2009

In addition to [NVA's many ongoing programs](#), this year's most significant achievements include:

Vulvodynia Treatment Registry

Our most notable achievement of 2009 would not have been possible without the commitment and generosity of a longstanding donor who gave NVA a \$50,000 grant to fund the creation of the first [Vulvodynia Treatment Registry](#). With very few NIH- or pharmaceutically-funded clinical trials on treatments for vulvodynia, we decided it was a priority for NVA to launch this project to study treatment efficacy. The Registry's investigators will gather clinical data on the long-term effectiveness of different vulvodynia treatments. Their findings will help to identify which subgroups of vulvodynia patients are likely to benefit from a particular treatment and also guide the development of future clinical trials.

New Online Tutorials for Patients and Providers

With support from [The Patty Brisben Foundation](#), NVA created a novel online tutorial for women with vulvodynia and updated its online tutorial for health care professionals. The patient tutorial, [Everything You Need to Know About Vulvodynia](#), was designed to help women make informed decisions about their health care and build stronger partnerships with their medical providers. The tutorial covers gynecologic and pelvic anatomy, diagnosis and treatment of vulvodynia, coping with chronic pain, and practical advice on sexual and relationship issues. Since its launch in June, over 15,000 women have viewed the tutorial and many have sent us emails expressing how much it has helped them.

In recent months, under the guidance of NVA medical advisory board members, Drs. Stanley Marinoff, Paul Nyirjesy and Steven Witkin, NVA revised its health care provider tutorial, [Vulvodynia: Integrating Current Knowledge into Clinical Practice](#) to incorporate the most recent research findings in the field. The updated tutorial provides continuing medical education credit for health care professionals until 2012.

Research Grants & Career Development Award

NVA is currently funding 11 ongoing studies. In addition to launching the Vulvodynia Treatment Registry, we awarded six research grants this past year. In December, 15 medical professionals submitted proposals for the [Dr. Stanley C. Marinoff Vulvodynia Career Development Award](#), which encourages the involvement of junior faculty in the vulvodynia field. Our 2010 award recipient is [Ruby Nguyen, MD](#), assistant professor of epidemiology in the School of Public Health at the University of Minnesota, who will study the effect of pregnancy and childbirth on vulvodynia. Summaries of all NVA-funded projects can be viewed online at: www.nva.org/research_fund.html and www.nva.org/career_development_award.html.

NVA on Capitol Hill

NVA collaborated with Senator Tom Harkin's (D-IA) staff to include strong language on vulvodynia in Congress' FY2010 National Institutes of Health (NIH) Appropriations Bill. NVA also participated in a Capitol Hill meeting attended by the director of the National Institute of Child Health and Human Development, who subsequently designated vulvodynia as a "high-priority" area of research. In 2009, four of the 20 vulvodynia researchers who submitted NIH grant applications were funded.

Media Coverage

In addition to numerous print articles, vulvodynia was featured on three television shows: [20/20](#), [The Doctors](#) and [The Tyra Banks Show](#). NVA also contributed chapters to two new books – [Female Sexual Pain Disorders](#) by Drs. Andrew Goldstein, Caroline Pukall and Irwin Goldstein, and [Secret Suffering](#) by Susan Bilheimer and Dr. Robert J. Echenberg.

Media Coverage in the New Year

In the first month of the New Year, vulvodynia was featured on two television programs. After you watch the segments, please take a few minutes to submit a brief email to the producer. Let him/her know that you appreciate the coverage of this under-recognized women's pain condition and that you'd like to see it covered again in future programs.



On Monday, January 11th, Dr. Mehmet Oz discussed the diagnosis and treatment of vulvodynia with Jennifer Ashton, MD, a New Jersey-based obstetrician-gynecologist and CBS News medical correspondent, on his new medical talk show. The segment also featured interviews with Lisa and Debbie, two vulvodynia sufferers, as well as Christin Veasley, NVA's associate executive director, and her husband Melvin. (Pictured left to right: Christin, Debbie, Lisa, Melvin.) You can [view a 5-minute clip](#) and [read a thorough summary](#) of the segment on the show's web site. (We expect the full episode to re-run later in the year and will send an announcement when it does. To submit a comment, visit: <http://doctoroz.com/contact>.)

The following day, [Dr. Jennifer Gunter](#), director of pelvic pain and vulvovaginal disorders at Kaiser Permanente San Francisco Medical Center, appeared on ABC-7's *The View from the Bay* to discuss vulvovaginal yeast infection. She also briefly reviewed other vulvovaginal conditions that can have similar symptoms, including vulvodynia. Click [here](#) to view the segment and read a summary article.

Also in January, Wired Magazine's article, [The Decision Tree: How Smarter Choices Lead to Better Health](#), detailed NVA member Alexandra Carmichael's struggle to find proper diagnosis and treatment for vulvodynia.

Shop at Amazon and Fund Research

Did you know that you can help the NVA fund medical research by shopping at Amazon? If you are interested in purchasing the book below, [other books of interest on NVA's web site](#), or anything else at Amazon, please visit www.nva.org first, click on the Amazon logo on our home page, and a percentage of your total purchase price will be donated to NVA, at no cost to you!



Isa Herrera, MSPT, a New York City-based physical therapist, recently published a self-help book for women suffering from chronic pelvic and urogenital pain disorders entitled, [Ending Female Pain: A Woman's Manual](#). Ms. Herrera draws on medical research and her experience treating women with these disorders to provide a wealth of information on exercises and stretches that can relieve pelvic pain.

NVA Cost-of-Illness Survey Needs Your Participation

The NVA needs 50 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 one-year subscription to our newsletter.** If you live in the US and have been diagnosed with either generalized vulvodynia or vulvar vestibulitis syndrome (aka provoked vestibulodynia), you are eligible to participate. The survey asks questions about lost work hours and out-of-pocket expenses related to having vulvodynia. NVA will use the survey results to convince Congressional representatives and the NIH that we need much more federally funded research on vulvodynia. Participation requires only three hours of your time over the next six months. With the use of an NVA-supplied calendar, you would 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



There are many opportunities for women with vulvodynia to participate in scientific research studies. For a complete list of studies that are currently recruiting participants, please visit the [NVA's web site](#).

Treatment of Vaginal Pain with Injection of Numbing Medicine (UCLA)

Women aged 18-65 with a diagnosis of vulvodynia, who are not currently pregnant and do not intend to become pregnant in the next three months, may be interested in a UCLA study to see if vaginal and lower back nerve blocks (injection of local anesthetic medicine) are helpful in treating the disorder. Pelvic muscle evaluation and psychological questionnaires are also included. The study will last up to seven months and includes 3-5 treatment sessions, a 2-month follow-up visit, and a phone call to assess progress two months after the follow-up visit. For further information, call 310-825-6963. (Principal Investigators – Drs. Andrea Rapkin and John McDonald)

Pregabalin (Lyrica) for the Treatment of Vulvodynia (Cleveland Clinic, Ohio)

Eligible participants must be age 18 or older and diagnosed with vulvodynia (generalized vulvodynia or vulvar vestibulitis). Participants must practice a reliable form of birth control, defined as sterilization, hormonal contraception, abstinence or IUD. Women must not have contraindication to pregabalin or history of prior use of the medication. The study will last approximately 11 weeks and participants must be able to attend five follow-up visits during that time. The study drug, tests, procedures and visits will be provided at no cost. For additional information, contact Linda McElrath, RN by phone – 216-445-2494. (Principal Investigator – Beri Ridgeway, MD)

A Clinical Trial of CC-10004 for the Treatment of Vulvodynia (Beaumont Hospital, Michigan)

This is a 16-week drug trial. All study medication, exams, blood work, ECGs and questionnaires will be provided at no cost. Women must be between the ages of 18-69 and have a reported history of vulvar pain for at least three months. For additional information, please contact Karen Sherer, RN, by phone (248-551-3565). (Principal Investigator – Kenneth Peters, MD)