
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 Funds New Vulvar Pain Clinic



Since 2006, NVA has funded the creation of vulvar pain clinics in New Jersey, Tennessee, and Michigan. In early 2010, we awarded a grant to Danielle Tonelli, DO, to start a vulvar pain clinic in Milwaukee, Wisconsin. Dr. Tonelli is a fellowship-trained women's health specialist with board certification in family medicine and currently serves as co-clinical director of the Center for Optimal Health and Wellness at the Aurora Women's Pavilion (AWP) in Milwaukee. AWP showed its support of her work by matching the NVA's grant. Dr. Tonelli will develop and implement educational programs for local women with vulvodynia as well as medical professionals. "With the establishment of the AWP Vulvar Pain Clinic, women in our community and their providers will now have a local center with a full range of

services, from outreach and education to compassionate patient care," says Dr. Tonelli. For more information, visit the [clinic's web site](#).

Please Donate to NVA's Research Fundraiser



NVA remains committed to accelerating vulvodynia research because it is the only way to determine its cause(s) and develop effective treatments. We have launched a major initiative, described below, to promote research on treatment efficacy. To make a secure tax-exempt donation, visit [NVA's web site](#), or mail your donation to: NVA, PO Box 4491, Silver Spring, MD, 20914. Thank you!

Although over 20 treatments have been used to manage the painful symptoms of vulvodynia, only two have been rigorously tested. Women with vulvodynia typically try many untested treatments before they find one that alleviates pain. To remedy this situation, we need controlled clinical trials. To this end, NVA funded the first [Vulvodynia Treatment Registry](#), to collect data on treatment effectiveness (for individual patients) and maintains a database of the results. Last month, NVA took this initiative one step further, asking researchers to submit proposals for a multi-center Vulvodynia Clinical Trial Network (VCTN). Based on data collected in the Registry, VCTN researchers would plan and execute large controlled trials on treatments that have shown promising results. The long-term goal of this ambitious project is to establish treatment guidelines based on scientific research rather than trial and error, ensuring timely and appropriate treatment for all women with vulvodynia.

To read summaries of all studies the NVA has funded through our [Medical Research Fund](#) and [Dr. Stanley C. Marinoff Career Development Award](#), please visit our web site.

NVA Mid-Year Report

We are pleased to provide you with a mid-year update, summarizing our recent progress.

New Educational Resources

In addition to updating our patient self-help guide, *I Have Vulvodynia – What Do I Need to Know?*, NVA has developed three new booklets on topics of interest to women with vulvodynia. **Vulvodynia, Pregnancy and Childbirth** will be the *first* resource of its kind for women with vulvodynia who are pregnant or want to become pregnant. It covers conception through the postpartum period, dealing with subjects such as alleviating vulvar pain during pregnancy, ways to make intercourse more comfortable and minimizing trauma to the vulva during childbirth. The second booklet, **My Partner Has Vulvodynia – What Do I Need to Know?**, gives partners a better understanding of the challenges a woman with vulvodynia faces. In addition to suggesting how partners can show their support, it discusses the impact of vulvodynia on relationships and suggests ways to keep sexual intimacy alive. The third booklet, **How to Apply for Disability Benefits**, guides women with vulvodynia who cannot continue to work, through the process of applying for disability benefits from the Social Security Administration. All the new booklets will be available in August at [NVA's Online Resource Center](#) or, if necessary, we can mail printed copies.

NVA to Expand Treatment Registry Sites

In fall 2009, thanks to the generosity of a longtime donor, NVA funded the first [Vulvodynia Treatment Registry](#), a database of treatment outcome data collected from three clinical sites. To accelerate and expand collection of this important data, NVA will add three more sites before the end of 2010. The long-term goal of this project is to develop treatment guidelines based on scientific research rather than trial and error.

NVA Awards Medical Research Grants & Career Development Award

Accelerating vulvodynia research and helping to establish vulvar pain clinics are two of NVA's major priorities. In addition to launching the Treatment Registry, NVA awarded grants for two new research projects and a Milwaukee vulvar pain clinic. [Drs. Steven Witkin](#) and [William Ledger](#) of Cornell University received an NVA grant to analyze the types of bacterial organisms found in the vagina and vulva of women with Provoked Vestibulodynia (PVD, aka vulvar vestibulitis). They will investigate the relationship between specific bacterial organisms, genetic makeup and degree of vestibular inflammation, helping to clarify how the interaction of these three factors affects susceptibility to developing PVD. Our second research grant recipient is [Dr. Ruby Nguyen](#), an epidemiologist at the University of Minnesota, who received NVA's 2010 [Dr. Stanley C. Marinoff Career Development Award](#) to conduct the *first* prospective study of pregnant women with vulvodynia. For many years, women with vulvodynia have been asking health care providers and the NVA about the effect of pregnancy and childbirth on vulvodynia and the answers have been based on anecdotal evidence. Finally, we will have one study investigating whether there is a change in the severity of vulvar pain during pregnancy and the postpartum period.

NVA is currently supporting [12 research projects](#) and recently issued a request for new research proposals on the diagnosis, treatment and/or etiology of Generalized Vulvodynia or Provoked Vestibulodynia. Our Board of Directors will decide which proposals to fund by early fall. In August 2010, we will request applications for the [Dr. Stanley C. Marinoff Career Development Award](#), which provides junior faculty members with seed money for medical research or establishing a vulvar pain clinic.

Thousands View Online Health Care Provider Tutorial

Since its release in January 2010, thousands of health care providers have viewed the updated version of NVA's online course, [Vulvodynia: Integrating Current Knowledge into Clinical Practice](#), which offers Continuing Medical Education credits through 2012. Many knowledgeable members of the vulvodynia medical community have commented that the content in both our health care provider and [patient tutorials](#) is excellent.

NVA Plans Meeting for Vulvodynia Researchers

NVA is collaborating with vulvodynia experts to hold a small conference for vulvodynia researchers in October 2010. At the meeting, researchers will present and review vulvodynia studies conducted between 2004 and 2010; afterwards, the findings will be published in a medical journal. The goals of the conference are to identify critical knowledge gaps and develop both short- and long-term vulvodynia research recommendations.

OCA Launches Campaign to End Chronic Pain in Women



Last month, the NVA and other organizations of the Overlapping Conditions Alliance (OCA) launched the [Campaign to End Chronic Pain in Women](#) at a Capitol Hill briefing, which was held in cooperation with the Congressional Caucus for Women's Issues. The campaign's goal is to raise awareness among US Congressional members, the medical community and public about the lack of federal research into chronic pain conditions that disproportionately or solely impact women, as well as the discrimination faced by women suffering with chronic pain. The conditions include vulvodynia, fibromyalgia, temporomandibular disorders, endometriosis, interstitial cystitis and chronic fatigue syndrome.



Dozens of Congressional staffers and women's health advocates attended the event. (To watch the briefing, visit the [Campaign's web site](#).) Elizabeth Lee (pictured on left), legislative aide for US Rep. [Tammy Baldwin](#) (D-WI), provided opening remarks: "While healthcare reform legislation took an important first step to address chronic pain issues, we have a lot of work ahead of us. I look forward to working closely with the *Campaign to End Chronic Pain in Women* to teach our health care system how to confront chronic pain and ensure that no woman suffers needlessly." NVA's associate executive director Christin Veasley reported that federal research dollars invested in these conditions averaged just \$1.33 per affected woman in 2009: "By appropriately investing in pain research, we have an opportunity to change the lives of millions of American women, their families, and society as a whole," said Veasley.

The briefing featured the release of the Campaign's groundbreaking report, [Chronic Pain in Women: Neglect, Dismissal and Discrimination](#) and the premiere of the short film, *Through the Maze: Women and Pain*, which can be viewed on the [Campaign's home page](#).

After the event, OCA leaders, plus government affairs advisor Peter Reinecke, met with staff members of Senate Majority Leader Harry Reid (D-NV) and Senator Tom Harkin (D-IA), chair of the Health, Education, Labor and Pensions Committee and the Labor, Health and Human Services Appropriations Subcommittee. They also met with Rep. Nancy Pelosi (D-CA), Speaker of the House, and Rep. Frank Pallone (D-NJ), chair of the Energy and Commerce Health Subcommittee. During the meetings, the OCA leaders gained insight into how the campaign goals might be incorporated into programs that will be implemented under the new health care reform bill.

The OCA is working with congressional offices to secure a US House of Representatives hearing specifically focused on these pain conditions. Please take a few minutes of your time to [send an e-mail to your U.S. Representative](#) asking him/her to join Representatives Tammy Baldwin (D-WI), Lois Capps (D-CA) and Betty Sutton (D-OH) in this important request.



Pictured left to right: Peter Reinecke (Government Affairs Advisor), Deanne Clare (TMJ Association), Mary Lou Ballweg & Carol Drury (Endometriosis Association), Christin Veasley (NVA), Terrie Cowley (TMJ Association), K. Kimberly McCleary (CFIDS Association of America)