



## **NVA Year in Review: 2010**

As proud as we are of our accomplishments, we recognize that none of them would be possible without the support of our committed donors. The following is a summary of the NVA's most significant achievements of the past year. We have an ambitious agenda in place for 2011 and look forward to updating you on our progress throughout the year. Thank you for your continued generosity!

### **Expansion of the First National Vulvodynia Treatment Registry**

In fall 2009, thanks to the generosity of a longtime donor, NVA funded the first national multi-center [Vulvodynia Treatment Registry](#). With the continued support from this donor and a generous complementary grant from [The Patty Brisben Foundation](#), we have expanded the Registry project to seven data collection sites in Florida, Arkansas, Colorado, Ohio, Maryland and Washington DC, and continue to work on adding a site in California by spring 2011. We funded this extensive groundbreaking study because it is unacceptable for women not to have scientific information on which to base their treatment choices. In addition to gathering preliminary data on which treatments are most effective for vulvodynia, the Registry aims to identify factors that predict treatment success and will guide the development of large controlled trials of promising therapies. Additional information on the Registry project and its investigators can be viewed on NVA's web site: [www.nva.org/treatmentregistry.html](http://www.nva.org/treatmentregistry.html).

### **NVA's Medical Research Fund Accelerates Vulvodynia Research**

Since the creation of our [Medical Research Fund](#) in 1997, we have awarded almost \$700,000 to over 40 vulvodynia research projects. Many investigators have used data collected with NVA grants to secure multi-million dollar funding from institutions such as the National Institutes of Health. As a result of our donors' generous support, NVA was able to allocate 50 percent of our 2010 budget to funding medical research. In addition to supporting the Vulvodynia Treatment Registry, NVA is currently supporting [16 studies](#). In 2010, our Executive Board approved grants for the two projects described below. Additionally, because of our commitment to accelerating vulvodynia research, NVA will now solicit research applications twice a year. The next group of grant recipients will be announced in April 2011.

#### *University of North Carolina - Chapel Hill*



Drs. [Mark Tommerdahl](#) and [Denniz Zolnoun](#) of the University of North Carolina - Chapel Hill, will use their NVA grant to conduct the first large-scale study investigating the underlying mechanisms of Generalized Vulvodynia. They will compare peripheral and central nervous system pain processing in three groups: (i) women with Generalized Vulvodynia, (ii) women with Provoked Vestibulodynia (PVD, aka vulvar vestibulitis), and (iii) women with both vulvodynia subtypes. Understanding the mechanisms

that initiate and maintain abnormal pain processing at all levels of the nervous system - the brain, spinal cord and peripheral nerves - will help to determine which therapeutic agents are likely to be effective in the treatment



of women with Generalized Vulvodynia.

*Cornell University*



Drs. [Steven Witkin](#) (at left) and [William Ledger](#) (at right) of Cornell University received an NVA grant to analyze the types of bacterial organisms found in the vagina and vulva of women with PVD. They are investigating 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.



To read summaries of other NVA-funded projects, please visit [www.nva.org/research\\_fund.html](http://www.nva.org/research_fund.html)

### **NVA Encourages Medical Professionals to Pursue Careers in Vulvodynia**

In 2006, the NVA established the [Dr. Stanley C. Marinoff Vulvodynia Career Development Award](#) to encourage medical professionals to pursue a clinical and/or academic interest in vulvodynia. The purpose of the award is to provide seed money for medical research, the establishment or enhancement of a vulvar pain clinic, or a written publication on vulvodynia. The NVA's intent is to encourage a medical professional's interest in this field and enable him/her to pursue further clinical or academic opportunities.



The 2010 recipient of the Career Award was [Dr. Ruby Nguyen](#), an epidemiologist at the University of Minnesota, who is conducting the *first* prospective study of pregnant women with vulvodynia. For many years, women with vulvodynia have asked 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, Dr. Nguyen is now investigating whether there is a change in the severity of vulvar pain during pregnancy and the postpartum period.

NVA's Executive Board recently selected the 2011 Career Award recipients. [Ahinoam Lev-Sagie, MD](#), an obstetrician-gynecologist at Hadassah University Hospital in Israel, spent several years in the United States training as a specialist in vulvovaginal disorders under Drs. [Paul Nyirjesy](#), [Steven Witkin](#) and [Lynette Margesson](#). Currently, she directs a Vulvar Pain Clinic at Hadassah. She will use her NVA award to conduct a randomized placebo-controlled trial to investigate the efficacy of low-level laser therapy in the treatment of PVD.



The second recipient, [Stephanie Thibault-Gagnon, PT](#), is a physical therapist and clinical researcher at Queen's University in Canada. In preparation for the development of a large controlled trial to investigate the efficacy of physical therapy treatment in women with PVD, she will test the validity and reliability of 3D transperineal ultrasound (a new imaging device) to measure pelvic floor muscle function in women with the disorder.

To read summaries of all NVA-funded Career Development Awards, visit: [www.nva.org/career\\_development\\_award.html](http://www.nva.org/career_development_award.html).



### **NVA Funds New Vulvodynia Clinic**

Over the past four years, 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 demonstrated its support of her work by matching the NVA's grant. Dr. Tonelli will develop and implement educational programs for women with vulvodynia and 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.

### **NVA Updates Tutorial to Educate Medical Professionals**

Thanks again to the generous support of [The Patty Brisben Foundation](#), thousands of health care providers have now viewed the updated version of NVA's online course, [Vulvodynia: Integrating Current Knowledge into Clinical Practice](#), which offers them Continuing Medical Education credits. We also attended several national health care conferences in 2010, distributing thousands of educational packets to health care providers specializing in vulvovaginal disorders, gynecology and women's health.



### **New Educational Resources for Women with Vulvodynia**

Since July, NVA has disseminated thousands of our [new patient booklets](#) to women with vulvodynia and to health care professionals who specialize in its treatment. Written from both the gynecological and chronic pain perspectives, our updated patient self-help guide, [I Have Vulvodynia - What Do I Need to Know?](#), features important self-help strategies for alleviating vulvar pain and maintaining sexual intimacy, while helping women with vulvodynia to make educated decisions about their health care. The first of three new publications, [Vulvodynia, Pregnancy and Childbirth](#), is the only resource of its kind for women with vulvodynia who are pregnant or want to conceive. This booklet covers conception through the postpartum period, dealing with issues such as alleviating vulvar pain during pregnancy, ways to make intercourse more comfortable and minimizing vulvar trauma during childbirth. Another booklet, [My Partner Has Vulvodynia - What Do I Need to Know?](#), gives partners a better understanding of the challenges a woman with vulvodynia faces and discusses how they can show their support. Lastly, [How to Apply for Disability Benefits](#), guides women with vulvodynia who are unable to work through the process of applying to the Social Security Administration for disability benefits.

In November, NVA received a grant from [Purdue Pharma, L.P.](#), to support the translation into Spanish of our introductory brochure and several sections of our web site. Both projects will be completed by summer 2011. Thousands of women continue to view our online patient tutorial, *Everything You Need to Know About Vulvodynia*, launched in 2009 with the generous support of [The Patty Brisben Foundation](#). Additionally, this is the 48th issue of our highly-regarded [newsletter](#), which features vulvodynia experts' articles on the diagnosis and treatment of vulvodynia and the latest research findings.

### **NVA Conducts the First Economic Impact Study on Vulvodynia**

In cooperation with [Wendy Max, PhD](#), adjunct professor of medical economics at the University of California, San Francisco, and [Lizheng Shi, PhD](#), assistant professor in the department of health system management at Tulane University School of Public Health and Tropical Medicine, NVA conducted the first economic impact study on vulvodynia. From an economic impact survey, analysts can calculate the extent to which a particular health condition impacts the nation's economy. The information gathering portion of this study ended in December, and Dr. Shi's research team is currently analyzing the data, which will be published in a medical journal in 2011. NVA will be able to use this information in our continued effort to persuade Congress and federal health agencies to increase vulvodynia research.

### **Progress in NIH Research Funding**

The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) is responsible for funding the majority of vulvodynia research at the NIH. In early August, NVA met with NICHD's new director, [Dr. Alan Guttmacher](#), to discuss a strategic plan for increasing NICHD-funded vulvodynia research next year. Because few investigators familiar with vulvodynia have previously been included in NIH review committees, Dr. Guttmacher committed to organizing a special study section to review vulvodynia research applications during the next three years, and asked NVA to submit for consideration the names of basic and clinical scientists, as well as members of the public. Since the NIHCD has not held a vulvodynia conference in six years, Dr. Guttmacher also committed to organizing a vulvodynia conference to be held in spring/summer 2011. NVA will serve as a member of the planning committee. In preparation for the NIH workshop, the NVA collaborated with Drs. [David Foster](#), [Gloria Bachmann](#) and [Candace Brown](#), and held a meeting of vulvodynia researchers funded by the NVA, NIH or the Canadian Institutes of Health Research. At the meeting, 13 scientists presented data from their research projects and the group identified critical knowledge gaps. At the NICHD's request, we will submit the proceedings for their consideration in planning the 2011 conference and also publish them in a medical journal.



### **Campaign to End Chronic Pain in Women**

In May, 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](#) attended by more than 30 congressional staffers. The campaign's aim is to increase federal funds allocated to both disorder-specific and collaborative scientific research on six chronic pain conditions that often co-exist and either solely or disproportionately impact women: vulvodynia, fibromyalgia, temporomandibular disorders, endometriosis, interstitial cystitis and chronic fatigue syndrome.



At the briefing, held in cooperation with the Congressional Caucus for Women's Issues, the OCA released a groundbreaking policy report, [Chronic Pain in Women: Neglect, Dismissal and Discrimination](#), which details the staggering human and financial toll of these pain disorders and offers policy solutions to improve the quality of medical care for affected women. The report's key findings are: (i) up to 50 million American women suffer from one or more of these chronic pain disorders; (ii) our country's failure to support an adequate

research effort and train medical professionals in the appropriate diagnosis and treatment of these six conditions adds as much as \$80 billion a year in direct and indirect costs to America's annual health care bill, and (iii) despite this enormous burden, **the NIH's research investment in the six conditions averaged only \$1.33 per affected woman in 2009!**



The report's remarkable findings made a lasting impression on representatives from Congress and certain federal health agencies, enabling us to make significant progress in this area in the past six months. This past August, U.S. Representatives [Lois Capps](#) (D-CA) and [Tammy Baldwin](#) (D-WI) requested a congressional hearing to address these overlapping pain conditions. We were successful in including [strong language in the FY2011 Appropriations Bill](#) encouraging long-overdue attention to these conditions, and the NIH responded that it will assemble the first Trans-Institute Working Group on this topic.

Next year, the group will bring together a diverse cross-section of clinical and basic science researchers and convene a scientific meeting on the disorders, with the aim of developing a strategic research plan to identify both unique and shared underlying mechanisms, as well as effective evidence-based treatment strategies. Additionally, the Institute of Medicine (IOM), charged by the Secretary of Health and Human Services to conduct a [consensus study of our country's current state of pain research, medical management and education](#), has added a special section focused on these co-existing pain disorders. As a direct result of our efforts, during the first Institute of Medicine meeting on this effort in November, NIH representatives and IOM study chairs spent a substantial amount of time discussing the importance of addressing these disorders in future research, medical training and awareness efforts.