

## NVA UPDATE

June 2007

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The following e-newsletter is adapted from the spring 2007 issue of the NVA News, published by the National Vulvodynia Association. It includes just a few of several important articles from the printed newsletter; a complete table of contents can be found on the bottom of this page. If you are not a current NVA donor, you can subscribe to the full printed version of this newsletter online: <http://www.nva.org/join-splash.htm>

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### NVA Campaigns for Increased Research Funding

During the third week of April 2007, thousands of NVA supporters throughout the US and Canada participated in our third annual Grassroots Research Advocacy Campaign. The campaign's goal is to increase vulvodynia awareness and lobby our nation's legislators for increased government funding of vulvodynia research.

On Capitol Hill, NVA Director of Research Chris Veasley met with key members of Congress serving on the health-related committees that oversee NIH appropriations. During the same week, women with vulvodynia and their family members met with or sent e-mails to their Senators and Representatives urging an increase in vulvodynia research funding. NVA supporters met with legislators in 15 states, including more than half of the senators serving on the Health Appropriations Subcommittee, as well as the first female Speaker of the House, Representative Nancy Pelosi (D-CA). In addition, 2,500 letters were sent to more than 400 Congressional members. NVA's Canadian constituents wrote letters to their provinces' Health Ministers, explaining how the condition impacts their lives. Crystal Suitor, a dedicated volunteer and support leader from Calgary, Alberta, led the Canadian arm of the campaign. She wrote the following heartfelt, compelling letter to Alberta's Health Minister.

*Dear Health Minister,*

*After graduating from high school, my dreams of college and travel soon ended when I started experiencing chronic vulvar pain. I had severe pain when walking, sitting or even wearing pants. The symptoms were debilitating. After three years of seeking help, and six doctors later, I was finally diagnosed with vulvodynia. I spent the next three years trying a combination of treatments with minimal results. I got to the point where I had exhausted available treatments and was told that I would be living the rest of my life in chronic pain. At the age of 23, it was a devastating thing to hear. Although I had much to be thankful for in my life, I wondered if I would ever travel, get married and have a family. I wanted to get up in the morning and not have to worry if it was too cold outside to wear a skirt, because wearing pants would be too painful.*

*I knew I had to be persistent and keep searching and researching. I contemplated surgery and eventually went outside Canada to have a vestibulectomy, a surgery with relatively high success rates. Now it is one year later and I can sit and walk without pain! I am in a wonderful strong relationship that has grown throughout this hardship. I continue to do as much as I can to help other women who suffer from vulvodynia and feel that I survived this difficult experience for a purpose. I am urging you to promote funding of vulvodynia research through the Canadian Institutes of Health Research, so that all women with vulvodynia can receive the quality of treatment that everyone in chronic pain deserves.*

NVA's Chris Veasley spent several days on Capitol Hill meeting with legislators serving on health-related committees, including the chair and ranking member of the Senate Health Appropriations Subcommittee,

Senators Tom Harkin (D-IA) and Arlen Specter (R-PA), respectively, and the ranking member of the Senate Health, Education, Labor and Pensions Committee, Senator Michael Enzi (R-WY). She also met with the co-chair of the House of Representatives' Women's Caucus, Representative Lois Capps (D-CA), and both co-chairs of the Task Force on Women's Health within the Caucus, Representatives Tammy Baldwin (D-WI) and Cathy McMorris-Rodgers (R-WA).

Several key issues were addressed at these meetings. NVA highlighted that, since 2003, funding of the NIH has failed to keep pace with the increasing cost of biomedical research, and in absolute terms, the value of NIH grants has eroded. Simply put, a grant that might have paid for \$100,000 of research costs in 2003 only buys \$88,000 worth in 2007. In addition, Chris pointed out that the number of applications submitted to NIH has increased dramatically during the past four years, whereas budget restraints have forced NIH to limit funding to only the top 15 percent of applicants. Consequently, NIH turns away many deserving scientists who struggle to secure funding elsewhere so they can reapply to NIH. Facing this situation, some scientists at the beginning of their careers decide to abandon research altogether.

NVA proposed that, to help remedy this situation, legislators should support at least a 6.7 percent increase in NIH funding in FY2008. We also advocated similar increases in 2009 and 2010, which would restore the purchasing power lost to NIH since 2003 and sustain our country's investment in biomedical research. In addition, NVA promoted the inclusion of stronger language on vulvodynia in the FY2008 Appropriations bill, directing NIH to allocate funds to support vulvodynia research. Finally, we asked legislators to co-sponsor or vote in favor of the National Pain Care Policy Act of 2007 when it is introduced in the US House and Senate later this year. Although the bill isn't vulvodynia-specific, it does address the larger umbrella issue of neglected and under-treated chronic pain conditions. Specifically, the Act would authorize an Institute of Medicine conference on pain, permanently establish an NIH Pain Consortium and focus national attention on the need for pain management.

In FY2006, Congress directed NIH to collaborate with NVA to develop and implement a national campaign to (i) raise the public's awareness of vulvodynia, (ii) provide resources for women suffering from the disorder and (iii) educate the medical community about the condition. After her Capitol Hill meetings, Chris was joined by Peter Reinecke, legislative advisor to NVA (and formerly Senator Harkin's chief of staff), to discuss the upcoming NIH vulvodynia awareness campaign with Vivian Pinn, MD, Director of the Office of Research on Women's Health, and several other NIH representatives. Dr. Pinn, a longtime champion of women's health, has been very supportive of NVA's goals for many years and is playing a key role in the planning of the NIH vulvodynia campaign to be launched later this year.

NVA's final advocacy week meeting was with Louis DePaolo, MD, Chief of the Reproductive Sciences Branch, National Institute of Child Health and Human Development (NICHD), to discuss the current status of vulvodynia research funding in the institute. NICHD is one of 27 institutes and centers at the NIH and vulvodynia research is funded primarily through this institute. Although NICHD has spent approximately \$1 million annually for vulvodynia research over the past seven years (a small amount by NIH standards), there has not been any increase in the annual level of funding. Several factors contribute to this funding freeze, including the increase in the overall number of applications submitted to NIH and continuing NIH budget cutbacks in recent years. We voiced our concern about the stagnant funding level and stressed the importance of ensuring that appropriate reviewers, i.e., scientists and clinicians knowledgeable about vulvodynia, are on the committees that score vulvodynia research applications. Dr. DePaolo invited a continuing, open dialogue with NVA and promised to work with his staff to find the best way to promote research efforts in the field.

The NVA greatly appreciates the efforts of those who volunteered their time to meet with, or write to, their elected officials. The participation of individuals across the US and Canada in this grassroots advocacy effort is critical to our future success.

## **NVA Continues to Award Record Number of Grants**

In December 2006, NVA's Executive Director made a special appeal to several longtime donors to help fund a research proposal by Steven Witkin, PhD, professor of immunology and director of the division of immunology and infectious diseases in the department of obstetrics and gynecology, Weill Medical College of Cornell University. Because of our donors' generous response, this past January the NVA awarded a grant to Dr. Witkin, one of the most dedicated and prolific researchers studying the etiology of Vulvar Vestibulitis Syndrome (VVS). Since 2000, Dr. Witkin has conducted numerous studies showing that some women with VVS exhibit polymorphisms (genetic variations) that make them more susceptible to developing the condition. His research demonstrates that women with VVS are more likely to exhibit a reduced capacity to 'turn-off' inflammation (IL-1ra gene polymorphism), an increased capacity to initiate inflammation (IL-1beta gene polymorphism) and a reduced capacity to combat *Candida albicans* infections (MBL gene polymorphism).

It has been difficult for researchers to identify the precise etiology of VVS, because women with the condition report a variety of events that initially trigger their symptoms, including vulvovaginal infection, childbirth, hormonal alteration and chemical and laser treatment. Dr. Witkin's recent proposal stated that, *regardless of the initial trigger*, VVS may be due to vestibular peripheral nerve damage caused by prolonged exposure to *reactive oxygen species* (ROS). These oxygen-containing molecules can be induced by a number of infectious or non-infectious insults and can damage nerve cells. Specifically, he suggests that ROS persistence, which increases susceptibility to nerve damage and maximizes regional sensitivity, may be the result of genetic variations that either reduce the ability to directly inactivate ROS or foster a prolongation of ROS production.

With the NVA grant, Dr. Witkin is comparing the DNA of VVS patients whose symptoms began after a specific event such as childbirth or vulvovaginal infection, to that of patients whose symptoms were not associated with an identifiable trigger. In addition, he will examine blood samples from both subgroups to measure their immune response to the yeast and hyphal forms of *Candida*. In summary, Dr. Witkin is seeking evidence of a unifying mechanism that would explain how VVS can result from multiple causes. The existence of a unifying mechanism would lead to (i) an improved ability to identify women at risk for developing VVS, (ii) the testing of potentially effective preventative strategies and (iii) the formulation of novel treatments.

In February 2007, NVA awarded a grant to Bernard Harlow, PhD, Mayo professor and division head, department of epidemiology and community health, University of Minnesota School of Public Health. In 2000, Dr. Harlow was the recipient of a five-year NIH grant to study the prevalence of vulvodynia and identify risk factors for developing the disorder. Among his key findings are that a large percentage of women who develop vulvodynia report severe pain and difficulty with first tampon use, and that some women who develop VVS exhibit an easily triggered pro-inflammatory immune response. Harlow hypothesizes that, in some women, vulvodynia is the consequence of a genetic predisposition that leads to an altered immuno-inflammatory response that may occur before the onset of menstruation.

With his recent NVA grant, Harlow examined vulvar tissue specimens from women with vulvodynia for specific altered immuno-inflammatory response markers. These tissue specimens, obtained under his earlier NIH-funded research, were analyzed for the presence of neurogenic proinflammatory mediators, cytokines and bactericidal proteins. Harlow's current laboratory findings, combined with his prior epidemiological data, will be submitted in a grant application to the NIH later this year.

### **NVA Funds New Vulvodynia Clinics**

In May 2006, the NVA created the Dr. Stanley C. Marinoff Vulvodynia Career Development Award to encourage interested faculty to pursue clinical or academic work in the vulvodynia field. The award provides seed money for pilot research, writing a medical article on vulvodynia or the creation of a vulvar pain clinic. One of the 2006 recipients of the Career Development Award was Gina Anderson, MD, assistant professor of obstetrics, gynecology and women's health at the New Jersey Medical School. Dr. Anderson used her grant to establish a vulvar pain clinic in Newark, New Jersey, a previously underserved community. Because lack of access to vulvodynia experts is a major problem experienced by

many vulvar pain patients, the NVA Board decided to allocate funding from our general operating budget toward the development of two additional vulvar pain clinics, one in Washington, DC, and another in Grand Blanc, Michigan.

Mary Kendell, MS, WHCNP, adjunct assistant professor of obstetrics and gynecology, George Washington University School of Medicine, Washington, DC, was awarded a grant to develop a curriculum to train and evaluate ob/gyn residents in the treatment of women with chronic vulvar pain. The educational component of the curriculum includes both print and web-based learning tools, as well as practical training of medical residents in standardized exam techniques and vulvar colposcopy. To promote and evaluate medical residents' competency, the George Washington University School of Medicine utilizes a state-of-the-art standardized patient testing center that allows its students and residents to hone their skills. In this controlled environment, faculty can observe and record resident/patient interactions and provide real time feedback to residents on their patient care, medical knowledge, interpersonal skills, professionalism and systems based practice. Ms. Kendell's initial goal is to develop a successful standardized curriculum that will improve medical residents' competence and level of comfort in evaluating and treating chronic vulvar pain disorders. Her ultimate goal is to establish a vulvodynia clinic at George Washington University School of Medicine.

Theodore Fellenbaum, MD, assistant program chair of obstetrics and gynecology, Genesys Regional Medical Center in Grand Blanc, Michigan, was awarded a grant to organize a community-based vulvodynia clinic that also promotes resident physician education. The Genesys Medical Center demonstrated its commitment to establishing this clinic by matching the amount of NVA's grant. Dr. Fellenbaum is collaborating with members of the Genesys obstetric & gynecologic residency program and the Genesys medical education department. The goals of this collaboration are to: (i) screen, diagnose and treat genital pain disorders of unknown etiology; (ii) provide previously unavailable training in genital pain for Genesys and other hospital ob/gyn resident physicians and medical students; (iii) provide lectures on vulvodynia to other medical disciplines; and (iv) establish a means for ongoing academic research on vulvodynia.

NVA would like to fund the opening of at least one new vulvodynia clinic each year. If you are a health care provider interested in starting a clinic, please contact Chris Veasley at [chris@nva.org](mailto:chris@nva.org). If you would like to make a donation to help us establish vulvodynia clinics, please contact Gigi Brecheen at [gigi@nva.org](mailto:gigi@nva.org) or 301-949-5114, or mail a check to NVA, PO Box 4491, Silver Spring, MD 20914. Thank you.

## Help Women with Vulvodynia

Private donations play a critical role in helping NVA staff and volunteers fulfill our mission. These donations enable us to create valuable resources for women suffering from vulvodynia, improve our support network, organize campaigns to increase federal research funding, open vulvar clinics and award pilot research grants. Over the past 10 years, NVA has awarded more than \$200,000 in research grants, enabling many recipients to obtain substantial, long-term NIH funding.

Ways you can give:

- **Credit Card Donation** on NVA's secure website, [www.nva.org](http://www.nva.org).
- **Monthly Giving** – If you bank online, you can set up an automatic monthly donation.
- **Workplace Giving** – Some employers will match all or part of a charitable contribution. Check with your employer's human resources or benefits office. You may also be able to give through payroll deductions.
- **Honor an Occasion** – If you make a gift in honor of a birthday or anniversary, NVA will acknowledge the gift to both you and the honoree. You may also choose to make a gift in honor or in memory of a loved one.
- **Online Shopping** – Before visiting Amazon.com, go to our home page, [www.nva.org](http://www.nva.org), and click on the Amazon link. NVA will receive 5% of your total purchase amount.

- **Appreciated Securities Donation** – You will receive a tax benefit by making a gift of appreciated securities. Contact Chris Veasley at [chris@nva.org](mailto:chris@nva.org) or 401-398-0830 for more information.
  - **Bequest** – To help ensure that our services continue in the future, please consider making a charitable bequest to the NVA in your will.
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### **Complete Table of Contents (NVA News: Spring 2007)**

Vulvodynia's Psychological Impact on the Partner by David C. Foster, MD, MPH, and Merrill B. Kotok, BSN, RNC

The Many Faces of Vestibular Pain by Andrew Goldstein, MD, FACOG

NVA Campaigns for Increased Research Funding

NVA Continues to Award Record Number of Grants

NVA Funds New Vulvodynia Clinics

Volunteers Take Center Stage in Publicity Efforts

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Founded in 1994, the NVA is a nonprofit organization dedicated to improving the lives of women who suffer from chronic vulvar pain. The NVA is one of the only organizations in the world that provides educational and supportive services to women suffering from vulvodynia as well as health care providers who treat vulvar disorders. The overwhelming majority of NVA's financial support comes from women who suffer from vulvodynia as well as their family members and friends. We need your support! Please consider joining the NVA or making a donation today! For more information, please visit: <http://www.nva.org/join-splash.htm>