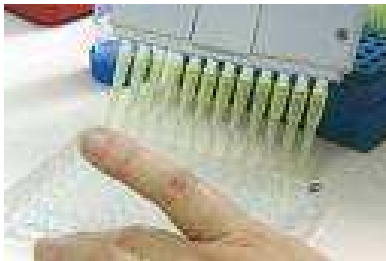


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The *NVA Update*, a bimonthly publication of the National Vulvodynia Association, provides information on recent progress in medical research funding, raising awareness of vulvodynia and Capitol Hill efforts. Previous issues can be viewed on [NVA's 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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## Please Donate to NVA's Research Fundraiser



Since 2006, NVA has awarded \$435,000 to fund medical research, because it is the fastest route to discovering the cause of vulvodynia and developing effective treatments. Your generous support has helped NVA to fund 20 research studies, the creation of three vulvar pain clinics and the first-ever *Vulvodynia Treatment Registry*. This Treatment Registry will help us determine which treatments are effective and why some women benefit from a particular treatment, while others do not. As a result of this wide-scale project, women and their health care providers will be better-equipped to make individualized treatment decisions.

Recently, NVA issued its *2009 Request for Research Proposals* and we expect to receive many deserving applications in July. **Please help us continue to fund the *Vulvodynia Treatment Registry* and other important research projects by making a tax-deductible donation to NVA's Medical Research Fund – 100% of your donation will be used to fund research.** To donate online through our secure web site, visit [www.nva.org/join-donate\\_renew.htm](http://www.nva.org/join-donate_renew.htm). Alternately, you can mail a check to: NVA Research Fund, PO Box 4491, Silver Spring, MD, 20914. Thank you!

## NVA Funds Five New Research Studies

The continued generosity of our donors has allowed NVA to award five new research grants and fund the creation of a vulvar pain clinic. NVA grants are an essential source of funding for clinicians and scientists, many of whom ultimately use their pilot data to secure large-scale grants from institutions such as the National Institutes of Health. Following are summaries of several recently funded studies.

### NVA-Funded Research



In January, NVA awarded a research grant to Maureen Basha, PhD, assistant professor in the department of pharmacology and physiology at Drexel University College of Medicine, Philadelphia. In collaboration with Susan Kellogg-Spadt, CRNP, PhD, director of vulvar and sexual medicine at the Pelvic and Sexual Institute, Graduate Hospital, Philadelphia, and Kristene Whitmore, MD, medical director of the Pelvic and Sexual Institute and chair of urology at Drexel University School of Medicine, Dr. Basha will study the influence of the ovarian hormones, estrogen, progesterone and testosterone, on vulvar sensory processing in women with and without vulvar vestibulitis syndrome, i.e., VVS or provoked vestibulodynia. There is a growing body of research evidence indicating that ovarian hormones play a role in pain modulation. The goals of this project are to determine: (i) changes in vulvar and non-vulvar sensory processing across the menstrual cycle; (ii) the impact of oral contraceptives on vulvar and non-vulvar sensory processing; and (iii) how ovarian hormone levels contribute to altered vulvar pain thresholds in women with vulvodynia. The results of this study will provide further insight into the role of ovarian hormones in causing and/or maintaining vulvodynia.

Nina Bohm-Starke, PhD, obstetrician/gynecologist and senior consultant of the vulvar open care unit at Danderyd Hospital in Sweden, also received an NVA grant, matched by her institution. She will investigate whether certain genetic variations are associated with general pain hypersensitivity in women with VVS. Recent studies have found that women with VVS also have lower pain thresholds than controls in non-vulvar body sites (e.g., arm, leg), suggesting altered pain processing in the central nervous system. Furthermore, some studies show a significant percentage of women with VVS suffer from more than one pain condition, i.e., they also have fibromyalgia, interstitial cystitis, temporomandibular joint/muscle disorders, and/or irritable bowel syndrome. This has led researchers to propose that some women with VVS may be genetically predisposed to develop pain conditions. In VVS patients and controls, Dr. Bohm-Starke will investigate alterations in several genes that are involved in pain modulation and inflammation. This study aims to (i) increase our knowledge of the underlying mechanisms in VVS, and (ii) identify a subgroup of women with VVS at risk of developing other pain conditions.



Andrea Nackley, PhD, assistant professor of pharmacology, and Denniz Zolnoun, MD, associate professor of obstetrics and gynecology and director of the Vulvar Pain Clinic, both of the University of North Carolina – Chapel Hill, were awarded an NVA grant to investigate possible common mechanisms in vulvodynia and temporomandibular joint/muscle disorders (TMD). In their proposal, Drs. Nackley (left photo) and Zolnoun (right photo) note that little is known about the cause(s) and factors that maintain these disorders and conventional treatments provide limited pain relief. Recent studies have demonstrated that persistent pain conditions occurring in isolation may result from *local* increases in peripheral nerve activity and proinflammatory cytokines (substances that trigger inflammation). Alternately, pain conditions occurring in concert may result from changes in both the central nervous system's processing of pain and *circulating* proinflammatory cytokines.

Drs. Nackley and Zolnoun hypothesize that vulvodynia and TMD share common central pathophysiology and will compare pain sensitivity and circulating cytokines in four groups: women with vulvodynia, women with TMD, women with concurrent vulvodynia/TMD and healthy controls. This study aims to provide: (i) a better understanding of the key mechanisms that drive vulvodynia and TMD, (ii) more accurate differentiation of distinct subgroups of vulvodynia and TMD patients, and (iii) the development of new therapeutic strategies tailored to these subgroups. Their ultimate goal is to uncover the underlying mechanisms and perpetuating factors for each subgroup and utilize treatments that target those factors.



In March, Theodore Fellenbaum, MD, director of the Mid-Michigan Vulvar Care & Colposcopy Center in Flint, was awarded a grant that was matched by Genesys Medical Regional Center, Grand Blanc, Michigan. The goal of this study is to test the effectiveness of a potential new treatment for VVS. Dr. Fellenbaum will clinically test the proposed link between mast cells, which play a key role in the inflammatory process, and the development of VVS. When triggered, mast cells degranulate, releasing toxic substances, such as histamine and cytokines, into the surrounding tissue. Mast cell degranulation may lead to an increase in nerve growth factor (a molecule that stimulates the growth of certain sensory nerves) and excessive hypersensitivity of the nerve fibers in the vestibule. This hypersensitivity may account for the pain of vulvar vestibulitis. In this study, Dr. Fellenbaum is investigating the action of an oral medication that reduces mast cell degranulation to see whether it alleviates VVS pain. He will compare the degree of pain relief reported by women taking this oral medication to that of two other groups of women being treated with topical medications.



Robert Moldwin, MD, director of the Pelvic Pain Center at the Smith Institute of Urology, Long Island Jewish Medical Center, New York, and medical student Amin Herati (right photo), were awarded a grant to investigate myofascial trigger points in women with vulvodynia. Women suffering from myofascial dysfunction have multiple trigger points, or hyperirritable spots of taut skeletal muscle, throughout their bodies. When active, trigger points cause pain and other symptoms. Although patients with chronic pelvic and urogenital pain can have trigger points in their pelvic floor muscles, very little is known about their prevalence and distribution. The goal of this study is to determine whether the locations or pattern of pelvic trigger points differ among three pelvic pain disorders – vulvodynia, interstitial cystitis (painful bladder syndrome)

and chronic prostatitis. If distinct trigger point patterns can be identified for vulvodynia and interstitial cystitis, clinicians could add trigger point evaluation to the diagnostic workup of women presenting with pelvic pain and be better-equipped to differentiate vulvodynia from interstitial cystitis.



### **Dr. Stanley C. Marinoff Vulvodynia Career Development Award**



E. Cristian Campian, MD, a urogynecology and pelvic reconstructive surgery fellow at Saint Thomas Health Services in Nashville, Tennessee and Yaniv Farajun, MD, a third-year medical resident at Western Galilee Hospital in Israel, are the 2009 recipients of the *Dr. Stanley C. Marinoff Vulvodynia Career Development Award*. Dr. Campian (left photo) will use his NVA award, matched by Baptist Hospital in Nashville, to establish a multidisciplinary vulvar pain clinic at Saint Thomas Health Services Center for Pelvic Health, the largest pelvic pain clinic in the area. In addition to improving women's access to specialized clinicians in the region, Dr. Campian's long-term goal is to collaborate with other vulvar pain centers in applying for research funding from the National Institutes of Health. In an effort to promote earlier diagnosis and timely treatment, he also intends to lecture on vulvar pain to primary care physicians. Women interested in making an appointment at this new vulvar pain clinic can call 615-284-4664 or visit: [www.centerforpelvichealth.org](http://www.centerforpelvichealth.org).

Dr. Farajun (right photo) will use his NVA award, matched by the Chief Scientist Fund of the Israeli Ministry of Health, to evaluate the effectiveness of an anticoagulant drug, enoxaparin, in treating VVS. Enoxaparin, a form of the drug heparin, inhibits the action of the enzyme heparanase. In a prior study, Dr. Jacob Bornstein found that heparanase was present in the vestibular tissue of women with VVS, but not in the control group. Dr. Farajun proposes that heparanase, which is released by mast cells, may play a role in the etiology of the condition, degrading the vestibular tissue and allowing nerve fibers that sense pain to penetrate the skin's surface. In the current study, participants will self-administer daily injections of enoxaparin into the abdomen, which will inhibit heparanase action and also exert an anti-inflammatory effect. This study will add to our understanding of the etiology of VVS and test a potential new treatment for the condition.



### **NVA's 2009 Mid-Year Report**

We are pleased to provide you with a summary of our recent accomplishments:

#### **Vulvodynia Treatment Registry**

In January, NVA requested research proposals from the medical and scientific communities to develop and implement a Vulvodynia Treatment Registry. We received several excellent applications and the grant recipients will be announced in July. The primary goal of the registry is to determine which vulvodynia treatments are effective. It should also clarify some of the differences between women who benefit from a certain treatment and those who do not, adding to our understanding of the underlying mechanisms responsible for the initiation and maintenance of vulvodynia.

## **Online Tutorials for Patients and Health Care Professionals**

NVA received a grant from [The Patty Brisben Foundation](#) to develop a novel online teaching program for women with vulvodynia. The goals of this comprehensive tutorial, which will launch in mid-June, are to empower women to make educated decisions about their health care and build strong partnerships with their health care providers. The self-guided tutorial covers gynecological anatomy and physiology, diagnosis and treatment of vulvodynia, coping with chronic pain and sexual/relationship issues. The Brisben grant will also fund a revision of our online tutorial for health care professionals (<http://learn.nva.org>) and extend its accreditation until 2011. The updated version will be online in October 2009. This tutorial is the only online vulvodynia course offering continuing education credit for health care providers.

## **Medical Research Grants**

NVA is strongly committed to accelerating [vulvodynia research](#). In the first six months of 2009, we funded five new research projects. (See previous article.) Our *2009 Request for Research Proposals* was issued in May and applications are due in July. If we receive a positive response to our summer fundraising appeal, we plan to fund at least two new studies this fall.

## **Dr. Stanley C. Marinoff Vulvodynia Career Development Award**

In 2006, the NVA created the [Dr. Stanley C. Marinoff Vulvodynia Career Development Award](#) to encourage interested medical professionals to pursue a clinical or academic interest in vulvodynia. The ultimate goal of this program is to increase the number of knowledgeable clinicians and scientists in the field. The 2009 *Award* recipients are Drs. E. Cristian Campian and Yaniv Farajun. (See previous article.) NVA will issue its next call for proposals in September and the next round of awards will be announced in early 2010.

## **Advancing Research at the National Institutes of Health (NIH)**

The [National Institute of Child Health and Human Development](#) (NICHD), which is the NIH Institute that administers vulvodynia grants, received an additional \$300 million through the [American Recovery and Reinvestment Act of 2009](#). To ensure that a portion of these funds will be used for vulvodynia research, the NVA met with NICHD director, Dr. Duane Alexander, in March. During the meeting, Dr. Alexander stated that he has listed vulvodynia as a 'high-priority' area of research. Eighteen excellent vulvodynia proposals were submitted to NICHD in late April and they are currently being reviewed. Several researchers were able to use pilot data collected with NVA grants in their recent NIH applications, greatly increasing their likelihood of success. NVA is optimistic that NIH will fund new vulvodynia research projects this fall. We will continue to meet with Dr. Alexander to ensure that vulvodynia remains a high priority area of research at the Institute.

## **Capitol Hill Efforts**

In March, NVA met with staff in the offices of [Senator Tom Harkin](#) (D-IA) and Representatives [Nita Lowey](#) (D-NY), [Tammy Baldwin](#) (D-WI) and [Lois Capps](#) (D-CA). NVA subsequently collaborated with Senator Harkin and Rep. Lowey to submit strong language on vulvodynia for Congress' FY2010 Appropriations Report, directing the NICHD to utilize all available mechanisms to increase federal funding of vulvodynia research.

## **Overlapping Conditions Alliance**

In March, NVA and five other non-profit organizations announced the formation of [The Overlapping Conditions Alliance](#). Since a significant percentage of women with vulvodynia report suffering from more than one pain condition, NVA is working cooperatively with these other non-profits to advocate for increased federal research funding on co-existing conditions. In addition to NVA, the organizations represented in the Alliance are: [Endometriosis Association](#); [Chronic Fatigue and Immune Deficiency Association of America](#); [International Foundation for Functional Gastrointestinal Disorders](#); [Interstitial Cystitis Association](#); and [The TMJ Association](#).

## Vulvodynia Researcher Receives Pfizer Award



The NVA extends its congratulations to Dr. Caroline Pukall, assistant professor of psychology, Queen's University, Ontario, Canada, who recently received [Pfizer's 2009 Neuropathic Pain Research Award](#). The main goal of her three-year study, *Vulvodynia: A neuropathic pain condition?* is to investigate whether two vulvodynia subtypes, provoked vestibulodynia (aka vulvar vestibulitis syndrome) and generalized vulvodynia, are neuropathic pain conditions. She will do this by conducting sensory tests in both subtypes and using established screening tools that assess neuropathic pain. The results of this study will help to improve diagnosis and treatment of vulvodynia.

## Vulvodynia Publicity

Since our [last e-update in April](#), vulvodynia has been featured on a national talk show, Detroit's local news and in several online articles.

In May, Dr. Debby Herbenick, associate director of the Center for Sexual Health Promotion, Indiana University, and NVA donor Alison Boteler were interviewed on the Tyra Banks Show, [Married Virgins](#), which draws over two million viewers. While the show primarily featured women suffering from [vaginismus](#), Alison discussed her history of vulvodynia and the methods she's used to treat her painful symptoms. Dr. Herbenick cited NVA as a leading source of information and health care provider referrals. As a result, the number of visitors to NVA's web site doubled during the week of the broadcast.

Also in May, Lisa Van, a young wife and mother, was interviewed on Detroit's local news. In the segment, [Pain in a Private Place](#), Lisa discussed her journey to find help for her pain and hope for better years ahead. Donna Carrico, nurse practitioner at Beaumont Hospital in Michigan, was also interviewed and discussed the frequent misdiagnosis that women with vulvodynia experience.

Vulvodynia was also featured in several online articles. The Parenting.com article, [12 Ways to Make Your Love Life Sizzle Again](#), discussed many reasons, including vulvodynia, why women with children lose interest in sex. Sexual health researcher, Dr. Jennifer Gunter, briefly covered vulvodynia in her Examiner.com article on interstitial cystitis, [Understanding Painful Bladder Syndrome](#). Earlier this month, Judy McGuire, published a Q&A on Seattleweekly.com, [The Injured Clam](#), in which she answered a question from a woman who had recently undergone surgery for vulvar vestibulitis syndrome.

## Sign National Pain Care Policy Act Petition



The [American Pain Foundation](#) recently announced a new video by Casey Matthews, a 19 year-old student from southern California, whose mother has suffered from chronic pain for as long as he can remember. As part of a political science class project, Casey made a video and started a petition in an effort to change how pain is managed in the US. To date, over 3300 people have signed the petition, which will be delivered to the US Senate to encourage the passage of the 2009 [National Pain Care Policy Act](#). To watch the video and sign the petition, click [here](#). You can also [take action](#) by contacting your Senators and requesting that they co-sponsor this Act.

## NVA Cost-of-Illness Survey Needs Your Participation

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 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 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 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**

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

### **UCLA (Los Angeles, California)**

Subject: Treatment of Vaginal Pain with Injection of Numbing Medicine.

Contact: Andrea Rapkin, MD and John McDonald, MD (Principle Investigators)  
For further information, call 310-825-6963

Requirements: Women between the ages of 18-65 with a diagnosis of vulvodynia, who are not currently pregnant and do not intend on becoming pregnant in the next 3 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 this disorder. Pelvic muscle evaluation and psychological questionnaires are included. The study will last up to 7 months and includes 3-5 treatment sessions, a 2-month follow-up visit, and a phone call 2 months after the follow-up visit to assess progress.

### **St. Cloud State University (St. Cloud, Minnesota)**

Subject: The Process of Receiving a Diagnosis of Vulvar Vestibulitis Syndrome.

Contact: Log in to the study's [web site](#) and read the consent form. If you want to participate, "sign" the form by submitting it through the submit button. Alternately, you can send an e-mail to Jennifer Connor - [jjconnor@stcloudstate.edu](mailto:jjconnor@stcloudstate.edu)

Requirements: You must have access to a computer, be able to read English, and have a diagnosis of vulvar vestibulitis syndrome (aka provoked vestibulodynia). Participants will complete an online questionnaire regarding when and where they received a diagnosis, as well as the efficiency of the process. Participants will also be asked about personal characteristics. The online session should take only 15-20 minutes.

### **Doctoral Dissertation Study (Philadelphia, PA)**

Subject: Vulvar Vestibulitis Syndrome: The Challenges of Connecting to Positive Sexual Health.

Contact: Jennifer Foust, MS, LPC  
Doctoral Candidate, Widener University  
215-922-5683 ext. 4

Requirements: This study is a dissertation project conducted by a doctoral candidate in human sexuality education at Widener University. Participants must be diagnosed with VVS, 20-40 years of age, reside in the Philadelphia area, and have received moderately successful or successful treatment of the physical symptoms of VVS. Participants will take part in a 90-minute focus group to discuss the effects of VVS on their sexuality. Participants will be compensated \$25 by the researcher for being in the focus group. When you call, please indicate that you would like to be a research participant.