

The *NVA Update*, a bimonthly publication of the National Vulvodynia Association, provides information on recent progress in medical research funding, raising awareness 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 vulvodynia experts on the diagnosis and treatment of vulvodynia. To subscribe, visit [NVA's web site](#).

The NVA's Year in Review: 2008

NVA continues to make progress on behalf of women with vulvodynia and what follows is a summary of our most important accomplishments in 2008.

Online Tutorial for Patients

NVA submitted a proposal and was awarded a grant from [The Patty Brisben Foundation](#) to develop an online educational tutorial for women with vulvodynia. The overall goal of this program is to empower women to advocate for their own health care and build a strong partnership with their health care providers. In addition to providing the most up to date clinical and research information, the tutorial will cover chronic pain and sexual intimacy issues, and give practical advice on coping with vulvodynia.

Online Tutorial for Healthcare Providers

A 2007 grant, also from The Patty Brisben Foundation, enabled NVA to update its [online healthcare professional tutorial](#) and add continuing medical education accreditation to the program, making participation more valuable for medical professionals. The response to the online tutorial has been very positive, with over 10,000 health care providers viewing it since January 2008.

Medical Research Grants

Reflecting our strong commitment to accelerating vulvodynia research, NVA allocated over 40 percent of last year's revenue to funding research and currently funds eight vulvodynia studies. Our 2008 year-end appeal raised over \$25,000 for research, which is now \$50,000 because a committed supporter matched every donation. With this positive response, we can award at least two new research grants in early 2009. Several prior grant recipients have used pilot data from NVA-funded studies to secure multi-million dollar NIH funding. Detailed summaries of all NVA-funded research studies can be viewed on our [website](#).

Vulvodynia Registry

In December, the NVA received an exceptionally generous donation from a longtime supporter to facilitate the creation of a vulvodynia registry. This registry will contain a collection of data on the effectiveness of different treatments in women with vulvodynia. Women who participate in the project will provide researchers with biological specimens for analysis. The purpose of the registry is to help researchers determine (i) which treatments are effective for specific subtypes of vulvodynia and (ii) how women who respond to a specific treatment differ from those who do not. The ultimate goal of the project is to

generate individualized treatment guidelines for vulvodynia patients. In 2009, NVA plans to award a grant to a multidisciplinary team of clinicians and researchers to start developing the registry.

Dr. Stanley C. Marinoff Vulvodynia Career Development Award

In 2006, as a tribute to founding medical board member, Stanley C. Marinoff, MD, NVA created the [Dr. Stanley C. Marinoff Vulvodynia Career Development Award](#) to encourage medical professionals, early in their careers, to pursue a clinical or academic interest in vulvodynia. The award provides seed money to conduct medical research, write a publication, or develop/enhance a vulvar pain clinic. The goal of this program is to increase the number of knowledgeable and qualified clinicians and scientists in the field of vulvodynia. The 2008 recipient of this award, Beri Ridgeway, MD, is currently completing a fellowship in female pelvic medicine and reconstructive surgery at The Cleveland Clinic in Ohio. In her 12-month research project, Dr. Ridgeway is investigating the effectiveness of the anticonvulsant pregabalin (Lyrica) in the treatment of vulvodynia.

In late 2008, NVA received seven applications for the 2009 Career Development Award. Because there are several outstanding proposals this year, NVA plans to select two award recipients by March 2009.

Donor Funds Conference Exhibits

In January 2008, the NVA received a generous grant for health care provider education from Ms. Doris Bernstein's family foundation. This grant has enabled us to reach thousands of medical professionals by exhibiting at six national health care conferences this past year. Last March, NVA exhibited at a women's health conference, Women's Health 2008: The 16th Annual Congress, where NVA medical advisory board member, Elizabeth Stewart, MD, gave a lecture on vulvovaginal health. In May, the NVA exhibited at the American College of Obstetricians and Gynecologists' annual meeting in New Orleans, Louisiana, attended by 3,500 health care providers. For the first time, the meeting included *seven* symposia on vulvodynia and female sexual medicine, in addition to a day-long course on vulvodynia. Later in May, the NVA hosted a booth at the annual meeting of the American College of Nurse Midwives in Boston, Massachusetts. The conference, attended by 1,500 women's health clinicians, included a full-day workshop on vulvovaginal disorders and a women's health exposition for the public. In June, the NVA exhibited at the American Academy of Nurse Practitioners' annual meeting in Washington, DC, attended by 3,200 nurse practitioners. Lastly, this past September, NVA hosted a booth at *PainWeek 2008*, which included vulvodynia in several lectures on urogenital pain syndromes. Most of the pain meeting's attendees were primary care physicians, a group that we think it's important to educate about vulvodynia.

Success on Capitol Hill

In 2008, NVA made exceptional progress on Capitol Hill, convincing Senators and Representatives to increase pressure on the National Institutes of Health (NIH) to fund vulvodynia research. First, with the help of Senator Tom Harkin (D-IA), language on vulvodynia was again included in Congress' FY2009 NIH Appropriations Bill, strongly urging the NIH to substantially increase the amount of funding for vulvodynia research and create a specialized panel of experts to review future research applications on vulvodynia. In October, Reps. Lois Capps (D-CA), Nita Lowey (D-NY), and Tammy Baldwin (D-WI), and NVA's Christin Veasley, invited Duane Alexander, MD, the Director of the National Institute of Child Health and Human Development (NICHD), to Capitol Hill. Dr. Alexander was specifically asked to outline the steps NICHD will take in 2009 to increase funding of vulvodynia research. He committed to issuing a *Program Announcement with Special Review*, inviting members of the medical and scientific communities to submit vulvodynia

research proposals that will be scored by a panel of experts in the field. This type of announcement, which NICHD plans to release in spring 2009, publicizes that NICHD has a serious interest in fostering vulvodynia research. We are optimistic about this new funding opportunity. Coincidentally, the timing is excellent, because data from the nine studies NVA funded in 2007 will be analyzed in time for those researchers to submit NIH applications under the new Program Announcement. We immediately alerted our prior research grant recipients of this upcoming funding opportunity.

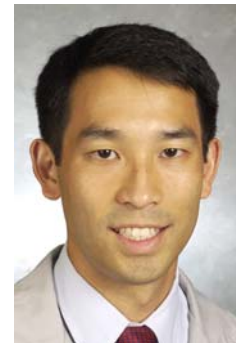
NVA continues to collaborate with the NIH Office of Research on Women's Health (ORWH) on the [National Vulvodynia Awareness Campaign](#). In early 2009, educational materials on vulvodynia will be mailed to thousands of health centers, including 3,700 government-supported rural and inner-city clinics, and 1,600 university student health centers. Additionally, ORWH, with the assistance of NVA, is planning a vulvodynia conference for medical professionals, to be held in fall 2009.

NIH Funds Vulvodynia and Pelvic Pain Research



In fall 2008, two researchers received multi-year grants from the National Institutes of Health (NIH) to continue their work on vulvodynia and pelvic pain. Melissa Farmer, a PhD candidate at McGill University and previous NVA research grant recipient, was awarded a 3-year predoctoral fellowship grant from the National Institute of Neurological Disorders and Stroke. With her award, Ms. Farmer will continue developing an animal model of vulvodynia. The overall goal of her research is to study the role of peripheral mechanisms and a genetic risk factor in the development of vulvodynia. Specifically, she will study whether (i) frequent vulvovaginal candidiasis (yeast) infections in mice are associated with changes in vulvar sensitivity; and (ii) whether chronic vulvovaginal infection increases sensory nerve fiber density and modifies local pain receptors. She will also investigate whether the melanocortin-1-receptor (MC1R) gene is involved in the development of vulvodynia, by testing mice that do not carry the MC1R gene.

In September 2008, the National Institute of Child Health and Human Development awarded a grant to Frank Tu, MD, MPH, assistant professor of obstetrics and gynecology at the North Shore University Health System in Illinois. Dr Tu, a pelvic pain specialist, received a 5-year *Patient-Oriented Research Career Development Award*. His long-term research goal is to identify modifiable disease mechanisms in urogenital pain syndromes. Dr. Tu's current project will test the hypothesis that patients suffering from painful bladder syndrome also show increased pelvic floor muscle sensitivity, by assessing these patients' pain thresholds when pressure is applied to pelvic floor muscles during a gynecological exam. The purpose of this research is to improve diagnosis and treatment of pelvic pain syndromes and related conditions such as vulvodynia, both of which are associated with increased pelvic floor muscle sensitivity. According to Dr. Tu, "Objective, valid measures of pelvic floor muscle dysfunction will allow for the rational application of mechanism-specific treatments, which would improve patient care and quality of life for millions of women."



NVA Welcomes New Support Services Director



After many years of dedicated service, Judi Lenehan is retiring from her position as NVA's director of support services. She continues to be a valued member of the NVA's executive board. We are pleased to welcome Rebecca Spell, MSW, to serve as our new support director. Rebecca, NVA's support leader in Durham, North Carolina, has extensive social work and counseling experience. She also serves as the executive director of the Western Wake Crisis Ministry, a nonprofit organization that provides much-needed services to those experiencing hardship in her community. Rebecca is excited to be on board and will use her professional expertise to benefit the women utilizing NVA's

support services network.

Vulvodynia Subject of Continued Media Interest

Vulvodynia and associated disorders continue to be a subject of media interest. After you read the articles summarized below, please take a few minutes to post your comments on their respective websites and send a brief e-mail to the author or editor. Please thank them for covering vulvodynia and let them know it's a topic you would like to read more about in the future.

In late October, the Office of Research on Women's Health (ORWH) broadcasted the fourteenth in a series of podcasts, "Pinn Point on Women's Health," hosted by ORWH Director, Vivian Pinn, MD. During the broadcast, Dr. Pinn discussed pelvic floor disorders (PFD) with Linda Brubaker, MD, professor of obstetrics, gynecology and urology at Loyola University. Dr. Brubaker described several of the most common pelvic floor disorders including urinary incontinence, pelvic organ prolapse and fecal incontinence. PFDs affect 25 percent of American women and become more common with aging. A "sisterhood of silence" surrounds these disorders, however, with many women hiding their condition from physicians and loved ones because of the attached stigma. Dr. Brubaker urged women to see their health care provider at the first sign of a pelvic floor disorder, stressing the importance of early intervention. For more information on PFDs, Dr. Brubaker encouraged listeners to visit the [Pelvic Floor Disorders Network web site](#). Visit ORWH's web site to [listen to the podcast](#) or [read the transcript](#).

Throughout December 2008, vulvodynia was covered in a variety of publications, including the Canadian newspaper *Globe and Mail*, which reaches 322,000 readers daily. Zoe Cormier's article titled [Dismissed and Undiagnosed](#), summarized one woman's search for a diagnosis and effective treatment. Regina Netto, a 38-year-old woman from Laval, Quebec, was tested for urinary tract infections and interstitial cystitis, and visited countless health care providers, all of whom concluded that nothing was wrong with her. The article also included interviews with several health care providers, including Toronto neurologist, Dr. Allan Gordon, and NVA medical advisory board member, Dr. Howard Glazer. They discussed the complexity of diagnosing vulvodynia and the value of a multidisciplinary treatment approach. Dr. Glazer also recommended that women continue to be sexually active (only in the absence of pain), because it can promote healthy blood flow to the genital area.

Also in December, Mary Buxton, a licensed social worker and certified sex therapist, was a featured blogger on [www.NurseBarb.com](#). Ms. Buxton's blogs, [Vulvar Pain](#) and [Vulvar Pain Part 2](#), provided an overview of vulvar pain and offered women practical advice on how to improve their physical and emotional well-being. Ms. Buxton discussed the benefits of a

multidisciplinary treatment approach that includes a health care provider, sex therapist, pelvic floor physical therapist and pain management specialist. She also recommended that women learn both cognitive and behavioral therapy techniques, such as modifying negative thoughts, using a pain diary and broadening their sexual practices. In addition to improving physical well-being, Ms. Buxton thinks this multi-faceted approach can help women successfully overcome the impact of vulvar pain on their relationships.

In mid-January, vulvodynia was covered in the Calgary Herald, which has more than 115,000 daily readers. In the article titled, [Treating V-Spot Pain](#), columnist Katherine Dedyna interviewed a University of British Columbia clinical research team that recently reported success in treating vulvodynia with acupuncture. In addition, the article sheds light on how challenging it is for most women to talk to their providers about vulvodynia and noted that many women visit as many as six doctors before receiving an accurate diagnosis.

The NVA would like to thank all the courageous women who share their stories in a public forum, as well as the journalists and editors who bring much-needed awareness to this neglected condition.

TMJ Association Announces New Online Forum

In an effort to raise awareness about the reality of living with temporomandibular joint and muscle disorders (TMJD), and to help patients, the TMJ Association recently launched an online forum. TMJD sufferers, and their loved ones, can visit the site to exchange information, share experiences and find mutual support. The forum contains a special section for women who suffer from both TMJD and vulvodynia. To learn more, please visit <http://forum.tmj.org>.

Participants Needed for Research Studies

Online Research Study

NVA supporter Alexandra Carmichael, a scientist and former vulvodynia sufferer, is conducting a vulvodynia study through the website she co-founded, [CureTogether](#). Specifically, she is gathering self-reported data on vulvodynia symptoms and treatments. Her goal is to discover associations that help to identify which treatments work best for which patients. With enough women participating, a genome-wide association (GWA) study, that locates genes or genetic regions associated with vulvodynia, can be conducted. Currently, 155 women have registered for the CureTogether survey and a total of 1,500 patients is required. Participation is entirely voluntary, anonymous and confidential. It involves registering at the website below and then rating symptoms and treatments. The survey takes 15-20 minutes to complete and women can see their results immediately. Registrants will be notified when the genetic study is set to begin and offered an opportunity to participate. If you are interested in learning more about the study or want to participate, please visit [CureTogether](#) or email Alexandra at alexandra@curetogether.com.

Beaumont Hospital (Royal Oak, Michigan)

Researchers at Beaumont Hospital are recruiting participants for a 16-week clinical trial investigating a novel treatment for vulvodynia, CC-10004. All study medication, exams, blood work, ECGs and questionnaires will be provided at no cost. Women must be between the ages of 18-69 years and have a reported history of vulvar pain for at least three months. To learn more about the study, please contact Karen Sherer, RN, Research Nurse Coordinator, at 248-551-3565.

University of Ottawa (Ontario, Canada)

Researchers from the University of Ottawa are recruiting participants for two studies. The first will investigate the sexual health of women with vaginismus and provoked vestibulodynia (aka vulvar vestibulitis syndrome). Women aged 18-44 years who have always had difficulty with vaginal penetration, or have had pain during at least half of all intercourse attempts, are invited to participate. Participation involves two visits to a University of Ottawa laboratory, completing a set of questionnaires and watching films clips. Women will be compensated for their time and receive information about treatment options. For additional information, please contact Rebecca Cherner by phone (613-562-5800, ext 2220) or e-mail (sexualhealth@uottawa.ca).

The second study involves participation in an online survey assessing the impact of vulvodynia on lesbian, bisexual and other sexual-minority women. In order to participate, women must be 18 years of age or older. Eligible participants will complete an anonymous and confidential online survey that includes questions pertaining to a woman's current vulvovaginal pain experience, gynecological history, sexual functioning and relationship satisfaction. The survey takes approximately 30 minutes to complete. If you are interested in participating, please visit the [University of Ottawa's Human Sexuality web site](#). For additional information, please call Heather Andruff, PhD, at 613-562-5800, ext 4449, or e-mail her at heather.andruff@uottawa.ca.

Summaries of additional research studies currently in need of participants can be viewed on [NVA's web site](#).