

NVA UPDATE

February 2008

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The following e-newsletter is adapted from the winter 2007/2008 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 at the bottom of this newsletter. If you are not a current NVA donor, you can subscribe to the full printed version of this newsletter on [NVA's web site](#). Please direct any comments, including a desire to unsubscribe to chris@nva.org.

NVA Year-End Review

NVA gained more ground this past year than ever before in its mission to fund research, educate the medical community and promote public awareness of vulvodynia. We thank everyone who made a donation for contributing to the following accomplishments.

NVA's Success on Capitol Hill

In spring 2007, NVA successfully launched its third consecutive national advocacy campaign. NVA supporters met with a majority of the Senators serving on the Health Appropriations Subcommittee and Representative Nancy Pelosi (D-CA), the first female Speaker of the House. In addition, thousands of advocates sent letters and e-mails describing how vulvodynia impacts their lives to more than 400 Congressional representatives.

NVA staff targeted key members of Congress serving on health-related committees that oversee NIH appropriations. As a result of this effort, strong [language on vulvodynia](#) was included in both the House and Senate 2008 NIH Appropriations reports. After NVA's meeting with Rep. Lois Capps (D-CA), co-chair of the women's issues caucus, and Rep. Tammy Baldwin (D-WI), co-chair of the task force on women's health, Capps and Baldwin appealed to Rep. Steve Israel (D-NY), co-chair of the cancer caucus, to include vulvodynia in an upcoming gynecological cancer briefing. Rep. Israel agreed and NVA became an active participant in the planning of the September 25th gynecological disorders briefing (see *NVA Joins Forces with Gynecologic Cancer Activists* below). Rep. Patrick Kennedy (D-RI), from Ms. Veasley's home state, attended the briefing to show his support for women's health; Rep. Kennedy and Ms. Veasley are now discussing the possibility of a Rhode Island women's health forum in 2008. NVA also took the lead in encouraging joint meetings with the Interstitial Cystitis Association and Senator Barbara Boxer (D-CA), to discuss the inclusion of urogynecological disorders in a women's health bill that Sen. Boxer and other female Senators plan to introduce in 2008.

NVA has been lobbying for vulvodynia research funding and a national vulvodynia public awareness campaign for many years. Two years ago, Congress included language in the NIH Appropriations report directing the NIH to develop a [National Vulvodynia Awareness Campaign](#), in coordination with the NVA. On October 24th, after more than a year of planning, the NIH Office of Research on Women's Health (ORWH) launched the campaign at

the National Press Club in Washington, DC (see *NIH Launches Vulvodynia Awareness Campaign* below).

Online Tutorial for Healthcare Professionals

As a result of generous support from [The Patty Brisben Foundation](#), NVA was able to revise and update its online tutorial for healthcare professionals (<http://learn.nva.org>) and add CME/CE accreditation to the program. It is the first online vulvodynia course to offer continuing education credits.

Medical Research Grants

As a result of successful fund-raising appeals, NVA has awarded more medical research grants this year than ever before. Until 2004, NVA was only able to fund one study per year, but since then, we've *doubled* the number of grants awarded each year. In 2007 alone, NVA awarded nine new grants. Several of NVA's prior grant recipients have used their pilot data to obtain multi-million dollar NIH funding. Detailed summaries of all these studies can be viewed on [NVA's web site](#).

Dr. Stanley C. Marinoff Career Development Award

In 2006, NVA created the [Dr. Stanley C. Marinoff Vulvodynia Career Development Award](#) to encourage interested faculty to pursue a clinical and/or academic interest in vulvodynia. The award provides seed money to conduct medical research, write a publication, or develop a vulvar pain clinic. The ultimate goal of this program is to increase the number of knowledgeable and qualified clinicians and scientists in the vulvodynia field. For the second consecutive year, NVA solicited applications from the medical/scientific community and received several excellent proposals. NVA will announce an award recipient in early 2008.

Other Outreach Activities

The NVA exhibited at the 2007 national healthcare conferences of the American Pain Society and the American Academy of Nurse Practitioners. NVA staff and volunteers disseminated hundreds of educational packets and answered health care providers' questions.

In November, NVA began working on an economic impact, or cost of illness, survey with a social worker from the Walter Reed Army Medical Center. The survey will estimate both the direct and indirect costs of vulvodynia, including costs associated with medical appointments, prescription medications, over-the-counter remedies and time lost to work. Information gathered in this survey will aid NVA in its future Capitol Hill efforts.

Because of the many exciting developments in 2007, vulvodynia and the NVA were featured in a variety of [media venues](#), including Redbook, Health and Prevention magazines, Canada's Globe & Mail Newspaper, CNN Headline News, ABC's hit television series, *Private Practice*, and multiple health websites (see *Media Coverage on the Rise* below).

Ongoing Programs

In addition to the initiatives described above, NVA maintains several ongoing programs and activities including, but not limited to, the following.

NVA has published 41 issues of its printed newsletter, [NVA News](#), containing detailed articles by medical experts on the diagnosis and treatment of vulvodynia; the newsletter also features other articles relevant to women with vulvodynia, such as maintaining sexual intimacy, managing pregnancy and childbirth, and coping with chronic pain. Our newsletter is distributed to patients and health care providers, as well as other important contacts, including members of Congress and NIH administrators.

First published in 2004, the demand for NVA's self-help guide, [I Have Vulvodynia... What Do I Need to Know?](#), continues to grow. This educational guide provides detailed information on vulvovaginal self-care, diagnosis and treatment of vulvodynia, and coping strategies. It is available to women who contact us directly and to health care providers who order copies for their patients.

NVA has disseminated 26 issues of its electronic newsletter, [NVA Research Update](#), to the medical and scientific community. This quarterly newsletter summarizes recent medical journal publications and includes periodic updates on upcoming conferences and research funding opportunities.

In an effort to keep members informed about recent advances in research, publicity and Capitol Hill efforts, NVA sends its electronic newsletter, [NVA Update](#), to patients, their family and friends, and other interested parties. These updates include 'action alerts,' which notify NVA contacts that their participation is needed at a certain time.

Since its inception, NVA has developed and maintained an [international support network](#) as a resource for patients in need. Our network provides phone and e-mail support in many areas, and monthly support group meetings in some locations. Currently, we have about 100 support leaders in place in the United States, Canada and several other countries.

NIH Launches Vulvodynia Awareness Campaign

After years of urging US Senators and Representatives to help NVA educate the public about vulvodynia, Congress mandated the National Institutes of Health (NIH) to develop the first [National Vulvodynia Awareness Campaign](#). This campaign targets primary health care professionals and the general public, as well as vulvodynia patients.

On October 24, 2007, after more than a year of preparation, Vivian Pinn, MD, director of the NIH Office of Research on Women's Health launched the campaign at the National Press Club in Washington, DC. The press conference was attended by representatives from more than [30 partnering organizations and government agencies](#). The diverse group of partnering organizations includes the National Women's Health Resource Center, the American College of Obstetricians and Gynecologists, the Society for Women's Health Research, the Center for Disease Control, the National Black Nurses Association and the National Hispanic Health Association.

Dr. Pinn outlined the goals of the outreach campaign and introduced the panel of eight speakers. Among the speakers were Hope Haefner, MD, director of the University of Michigan's Center for Vulvar Diseases; Bernard Harlow, PhD, chair of the University of Minnesota's Division of Epidemiology and Community Health; Candace Brown, PharmD, MSN, professor of pharmacy, psychiatry and obstetrics and gynecology at the University of Tennessee Medical School; and Christin Veasley, NVA's Associate Executive Director. Dr. Harlow presented the findings of the NIH-funded vulvodynia prevalence study, and Drs. Haefner and Brown described vulvodynia's symptoms, diagnosis and treatment. The emotional high point of the event was Christin Veasley's first-hand account of her eight year struggle with vulvodynia. You can [read Ms. Veasley's speech](#) or [watch a videocast](#) of the press conference on ORWH's web site.

The NVA, the NIH Office of Research on Women's Health and the National Women's Health Resource Center have been leading the publicity campaign by contacting editors and writers at popular magazines, newspapers, and health and news websites. Following the launch

event, for example, many internet sites, such as everydayhealth.com and earthtimes.org featured articles on vulvodynia and Dr. Laura Berman discussed chronic vulvar pain on her Yahoo health blog, [The Art of Intimacy](#). Reporter Darla Carter wrote an article on vulvodynia for the [Louisville Courier Journal](#) and Denise Oliviera, a New York journalist and NVA member, wrote an excellent piece for the [New York City Independent Media Center](#). One of NVA's strongest proponents for the past 10 years has been Phyllis Greenberger, MSW, president of the Society for Women's Health Research (SWHR). Shortly after the campaign launch, Dr. Jennifer Wider of the SWHR wrote an article on vulvodynia for [HealthNewsDigest.com](#), which was subsequently picked up by numerous web sites, including Science Daily, AHN and MedHeadlines. In December, Dr. Pinn focused her monthly PodCast, *Pinn Point on Women's Health*, on vulvodynia. You can [download the PodCast](#) or [read the transcript](#) on ORWH's web site.

If you would like to receive a press kit on vulvodynia, please e-mail aprilb@esi-dc.com. You can order the *Vulvodynia Awareness Campaign* information packet [online](#) or by contacting the NIH Resource Center at 1-800-370-2943 or the National Women's Health Resource Center at www.healthywomen.org or 1-877-986-9472.

NVA's Christin Veasley Speaks at National Press Club

Below is her speech given at the launch of the NIH Vulvodynia Awareness Campaign.

On behalf of the millions of women who suffer from this life-altering pain condition, I would like to thank Dr. Vivian Pinn, director of the NIH Office of Research on Women's Health, for her exemplary effort in planning this long-deserved public awareness campaign. Thirty years ago, women reached a milestone when they started openly discussing menstrual issues; twenty years ago, it was breast cancer, and ten years ago, menopause. Sadly, however, women still feel too embarrassed to reveal they have vulvodynia or other vulvovaginal disorders, which is the reason why this campaign is so important.

I stand before you as both a representative of the National Vulvodynia Association and as a former vulvodynia sufferer. My vulvar pain came on suddenly when I was 18 years old. I thought, like most of us, that I would visit the doctor, get a prescription and feel better in a few days. I only wish that were the case! The pain was relentless and I kept going back... and going back... and when my provider finally told me that I had vulvodynia, my reply to her was very similar to that of HBO's *Sex and the City* character Carrie Bradshaw. When her friend Charlotte disclosed that she had vulvodynia, Carrie incredulously asked, "Vulvo-what-ia?" I thought, "What in the world is vulvodynia? Is that even a word?" I couldn't even pronounce it. What I learned about vulvodynia at 18 was that: (i) it is a chronic pain condition; (ii) the medical community didn't know what causes it; and (iii) there was no cure. I had absolutely NO idea what I was up against in the months and years ahead. At the time, I was a full-time pre-med college student and worked part-time at a restaurant. My genital area was burning all the time, like someone was pouring acid into an open cut on my skin. I couldn't wear pants or sit through a one-hour class. I vividly remember having pain so intense in the middle of my physics final that I had to get up and turn in a half-complete exam. I couldn't stay seated or concentrate because of the pain. Can you imagine having pain that severe and then your doctor dismisses it by saying, "Have a little wine before intercourse." Even today, women with vulvodynia hear this from some doctors!

Having a name for my condition was half the battle. I could focus on solving the problem instead of seeking a diagnosis. After my provider said she couldn't help me, I did what the majority of women still have to do today – I became my own educator. I went to the

medical library and requested every vulvodynia article ever published. I searched the University hospital for a physician who was a little bit knowledgeable about the condition. By far the most valuable thing I did was contact the NVA. I scoured all of the back issues of their newsletter and volunteered to be a support leader. At a time when I was desperate and had no hope, NVA helped me regain control of my life and find the treatment that would enable me to have the family I dreamed of having someday. It took time, however. Because there were no studies on which treatments worked, it took years of trial and error until I found one that was successful. Even though it took seven years, I feel very fortunate, because the majority of women with vulvodynia live with some degree of pain their entire lives. The type of vulvodynia I had – vulvar vestibulitis – was treatable with surgery. It's been eight years since the surgery which eliminated my pain and afforded me the gift of two beautiful daughters.

When NVA surveyed 2000 women with vulvodynia, 75 percent reported discomfort discussing the condition with even their closest female friends. Feeling embarrassed keeps women silent. It took me years to confide in close friends and family. I still remember the very first time I spoke to another sufferer on the phone. The comfort that conversation provided me was immeasurable. To speak to another woman who knew what I was going through was life-changing for me. That is what a big part of this campaign is about – reaching out to women who don't know what's wrong with their bodies – to let them know they're not alone, there are treatments and there is hope.

In the NIH press kit, there are profiles of eight selfless women who have overcome their hesitation to speak publicly about having vulvodynia for a greater purpose – to raise awareness of this condition. They are of different ethnic backgrounds and range in age from 20 to 60. But they all share a common experience – every day they struggle to cope with vulvar pain and its consequences on their quality of life. With your help, their stories will be told. Ghandi said, "We must become the change we want to see." These courageous women are doing just that. (Read their stories [here](#).)

NVA Joins Forces with Gynecologic Cancer Activists

To raise Congressional awareness of gynecological cancer and pain disorders, the US House of Representatives' Cancer and Women's Issues Caucuses organized a briefing held September 25, 2007. The briefing was hosted by Representative Steve Israel (D-NY), co-chair of the Cancer Caucus.

Emmy-nominated actress Fran Drescher described her personal experience overcoming uterine cancer and the creation of the Cancer Schmancer Movement. Sherry Salway Black, executive director of the Ovarian Cancer National Alliance, discussed her battle with ovarian cancer and Dr. Richard Schlegel, chair of the pathology department at Georgetown University Medical Center, gave an overview of cervical cancer and his work on the new HPV vaccine. NVA's associate executive director, Christin Veasley, focused her presentation on vulvodynia, specifically addressing the problem of misdiagnosis, the stigma associated with having a chronic vulvovaginal disorder and the lack of research on treatments. She closed by outlining what Congress can do to help women with gynecologic pain disorders. You can read NVA's presentation [here](#).

NVA Funds Record Number of Research Studies

In the early years, NVA was able to fund only one pilot research study each year. As the organization has grown, we have focused more and more on raising money specifically for research grants. The result is that we have been able to double the number of research grants awarded every year since 2004. *This past year, NVA was able to award nine research grants for studies on vulvar vestibulitis or generalized vulvodynia.* This article will describe all studies NVA funded between July and December 2007. Summaries of studies funded earlier in the year, and in previous years, can be viewed on [NVA's website](#).

Multilevel Nerve Blocks in the Treatment of Generalized Vulvodynia

In the summer of 2007, a grant was awarded to a multidisciplinary team at the UCLA School of Medicine to study the efficacy of multilevel nerve blocks in women with generalized vulvodynia. With this grant, gynecologist Dr. Andrea Rapkin and anesthesiologist Dr. John McDonald will use the same series of nerve blocks that produced successful outcomes in their earlier study with vulvar vestibulitis patients. Their hypothesis is that generalized vulvodynia involves abnormalities in the nervous system that can be effectively treated with local anesthetic nerve blocks. The study requires multiple treatment sessions. During each visit, a patient receives three nerve blocks administered at different levels of the nervous system: a caudal (spinal) block, bilateral pudendal block and a vulvar block targeting the perineal branch of the pudendal nerve. Patients will receive up to five treatment sessions, two to three weeks apart, and be followed for 12 months after their last treatment.

Compounding Pharmacy Trends in Women's Health

Given the lack of consensus guidelines and specific medications for the treatment of vulvodynia, many practitioners rely on independent compounding pharmacies to formulate topical medications for their patients. Compounding pharmacies are in jeopardy because a bill recently introduced in Congress, The Safe Drug Compounding Act of 2007, would authorize federal regulation of their practices. Therefore, NVA provided modest funding to Denniz Zolnoun, MD, assistant professor at the University of North Carolina-Chapel Hill School of Medicine, who proposed to conduct and analyze a survey of the practice trends in compounding pharmacies. Although the importance of compounded medications in treating vulvodynia is commonly acknowledged by specialists in the field, this survey will provide the objective data needed to empower advocates representing women's health interests. One of the study's main goals is to gather information on medications made by these pharmacies that are critical to the treatment of women with vulvodynia. Zolnoun distributed a questionnaire to more than 450 compounding pharmacies and will analyze the survey data to: (1) demonstrate the importance of compounding pharmacies in the provision of women's health services; (2) establish the prevalence of medications compounded for vulvodynia, and (3) identify the types and combinations of medications these pharmacies make for the treatment of vulvodynia.

Hormonal Influences in the Etiology of Vulvar Vestibulitis

This past fall, NVA awarded a grant to Catherine Leclair, MD, director of the vulvar health program, and Terry Morgan, MD, PhD, assistant professor of pathology, both of Oregon Health and Science University. Dr. Leclair was the 2006 recipient of NVA's first *Dr. Stanley C. Marinoff Vulvodynia Career Development Award*. With this award, LeClair began investigating possible hormonal influences in the etiology of vulvar vestibulitis.

With their current NVA grant, Drs. Leclair and Morgan will continue their study of the underlying mechanism responsible for the increase in nerve fiber density in the vestibules of women with VVS. They will also investigate whether a mild chronic inflammation involving

mast cells (cells involved in inflammatory and allergic reactions) plays a role in the initiation and/or perpetuation of VVS.

Recent research has shown that women with VVS have a reduced number of estrogen receptors in their vestibular tissue. According to Leclair and Morgan, one consequence of this decrease may be an upregulation of epidermal growth factor receptor (EGFR). (Upregulation means that a cell increases the number of receptors to a certain hormone or neurotransmitter to improve its sensitivity to this molecule.) LeClair and Morgan hypothesize that abnormal estrogen receptor down-regulation and/or androgen receptor up-regulation may lead to an increase in EGFR expression and the cascade of events culminating in VVS. Their long term goal is to determine the underlying mechanisms responsible for the initiation of vestibulitis and develop treatment strategies that will eliminate the need for surgery.

Genetic Predisposition in Vestibulodynia (Vulvar Vestibulitis)

Longtime clinical researcher, Jacob Bornstein, MD, chief of the department of obstetrics and gynecology at Western Galilee Hospital, Nahariya, Israel, and associate professor, Rappaport Faculty of Medicine, Hateron, Haifa, received his first NVA research grant. In this study, Dr. Bornstein and genetics researcher, Dr. Tzipora Falik, are investigating associations between vestibulodynia and genes that transcribe proteins, which either have been found, or are thought to be involved in, the abnormal tissue changes seen in this disorder. Specifically, they will study a number of polymorphisms (variations) of three genes coding for molecules involved in the breakdown of vestibular mast cells and increased vestibular nerve fiber growth: heparanase, vanilloid receptor-1 (TRPV1), and nerve growth factor (NGF). The subjects for this pilot study are women suffering from severe vulvar vestibulitis who have experienced pain since their first episode of sexual intercourse. This study is an important exploratory component of a larger-scale study that will help delineate genetic susceptibility to vestibulodynia, or vulvar vestibulitis, ultimately paving the way for individualized treatment.

Research Grants Awarded in December 2007

Because the quality of last year's research proposals was outstanding, NVA made a special fundraising appeal to its donors in November 2007. The response was so successful that NVA was able to award two additional research grants in late December. Drs. Linda McLean and Caroline Pukall, of Queen's University in Kingston, Ontario, received a grant to study pelvic floor muscle function in women with vulvodynia, and Dr. William Ledger, a pioneer in the treatment of vulvodynia and chairman emeritus of the department of obstetrics and gynecology at New York Presbyterian Hospital, was awarded a grant to further his study of vulvar vestibulitis. Based on the findings of his collaborative work with Dr. Steven Witkin at Cornell University's Weill Medical College, Dr. Ledger will test a novel treatment for vulvar vestibulitis patients. We will include summaries of these studies in our next newsletter.

Media Coverage of Vulvodynia on the Rise

A prime-time television show, a cable talk show, the country's most influential newspaper and two popular women's magazines have all tackled the subject of vulvodynia in the last six months!

In October, NVA approached renowned health columnist, Jane Brody, to write an article on vulvodynia. Our conversations in the months following led to the article, [*New Insights into*](#)

[Genital Pain in Women](#), that appeared in the January 29, 2008 edition of The New York Times. In addition to the paper's daily circulation of 1.1 million, Ms. Brody's column appears in nearly one hundred other newspapers around the world. In the weeks following, the NVA and Ms. Brody have been flooded with letters from grateful readers. One reader wrote, "Having chronic pain is terrible, but not being believed is unbearable. Thanks for sending me this wonderful reminder that I am not alone, and I am not imaging this condition."

On October 10th, ABC's new hit show viewed by more than 12 million, [Private Practice](#), dealt with vulvodynia by featuring a character suffering from a combination of vaginismus and vulvar vestibulitis. The show accurately portrayed some of the symptoms of vestibulitis, but depicted an unrealistic "quick fix" for the condition. NVA issued a [media release](#) on the show's inaccurate depiction of the condition.

On November 5th, Dr. Debby Herbenick, associate director of the Center for Sexual Health Promotion at Indiana University (and longtime NVA supporter), was a guest on The Tyra Banks Show. Watched by more than 2 million people every week, the show, [What's Up Down There?](#), covered "everything vulva and vagina," including vulvovaginal anatomy, self-examination, vulvar pain and other conditions that affect genital health. Vulvar pain was only briefly addressed, but the show sent a very powerful message to viewers – *that women should no longer feel embarrassed to discuss their genital health.*

This past fall, vulvodynia was included in two excellent magazine articles on women's health. NVA's Christin Veasley was interviewed for the *Redbook* September 2007 article titled, [Your \(Very Personal\) Health at 20, 30, 40 and 50](#). This article dealt with painful sexual intercourse and eleven health conditions, including pelvic prolapse, yeast infection, bacterial infection and incontinence. *Prevention* magazine's November 2007 issue also contained an informative article titled, [Help for Intimate Pain](#). In addition to its discussion of vulvodynia, the article covered endometriosis, interstitial cystitis, pelvic floor tension myalgia and pelvic congestion syndrome.

Combined, the above articles and television shows have reached tens of millions of people. Currently, NVA is helping writers prepare articles that will appear in popular magazines and health web sites this spring and summer.

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Support the NVA

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 [NVA's web site](#).