

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

Update on NIH *Vulvodynia Awareness Campaign*

In October 2007, the National Institutes of Health launched the first-ever [Vulvodynia Awareness Campaign](#) at the National Press Club in Washington, DC. The NIH has since posted a [video](#) of the conference that can be viewed online or, if you prefer, you can read a transcript of NVA's presentation [here](#). This campaign was spearheaded by the NIH Office of Research Women's Health (ORWH) in consultation with NVA, and was joined by over [30 government agencies and health organizations](#). As part of the campaign, a diverse group of courageous [women with vulvodynia](#), ranging in age from 25 - 60, have come forward to share their stories with the media in the hope of raising public awareness of the condition. NVA is pleased to report that since the launch of the campaign, vulvodynia has been the focus of numerous print articles and TV interviews, greatly increasing the public's awareness of the condition. In addition, this past December, ORWH Director, Dr. Vivian 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.

In March, NVA met with Dr. Pinn and her staff to discuss the progress of the campaign and goals for 2008. They were pleased to report that next to their home page, the vulvodynia campaign web page is the most frequently visited section of their web site, attracting nearly 2000 monthly visitors. In addition, hundreds of people have downloaded the campaign materials from the site each month. Currently, Dr. Pinn and her staff are working on a mass mailing to **3,700 community health centers** supporter by the US Health Resources and Services Administration. These centers, which are community-based and consumer-run, provide quality primary health care services to medically underserved communities and vulnerable populations with limited access to health care. These include low income populations, the uninsured, individuals with limited English proficiency, migrant and seasonal farm workers, and families experiencing homelessness or living in public housing.

Both ORWH and NVA are very enthusiastic about the campaign and its outreach. We will continue to update you on the campaign's progress throughout the year.

NVA Inundated at Women's Health Congress

In January, NVA received a generous grant from the family foundation of committed NVA donor, Ms. Doris Bernstein. The grant, earmarked for health care provider education, will enable the organization to attend more national health care conferences in 2008 than in previous years combined! In March, NVA exhibited at a women's health conference, [Women's Health 2008: The 16th Annual Congress](#) in Williamsburg, Virginia. NVA Medical Advisory Board Member and assistant professor of obstetrics and gynecology at Harvard Medical School, Elizabeth Stewart, MD, was one of the three speakers opening the conference. Her lecture, *The V Word: An Update in Vulvovaginal Health*, was attended by all conference attendees. The next day, Dr. James Simon, clinical professor of obstetrics and gynecology at George Washington University Medical School, gave an insightful lecture on female sexual dysfunction. Following these presentations, NVA's exhibit booth was flooded with requests for information and we distributed hundreds of informational packets, returning home completely empty-handed. As a bonus for participating in the conference, the NVA was able to place a complimentary, full-page ad in the March 2008 issue of the *Journal of Women's Health*, distributed to 5,000-plus women's health specialists.

NVA will next head to New Orleans in early May to staff an exhibit booth at the annual clinical meeting of the [American College of Obstetricians and Gynecologists](#) (ACOG), attended by 3500 health care providers. We are pleased to report that, for the first time, the meeting will include seven symposia on vulvodynia and female sexual medicine, in addition to the day-long postgraduate course, *Advances in Vulvar and Vaginal Conditions*, taught by Drs. Hope Haefner, Libby Edwards and David Scott Miller.

Then in June, NVA will participate in two ground-breaking meetings on comorbid conditions, or conditions that often overlap with vulvodynia. The first meeting, [Can Studies of Comorbidities with Temporomandibular Joint and Muscle Disorders \(TMJD\) Reveal Common Mechanisms of Disease?](#), is being organized by the TMJ Association and co-sponsored by the National Institutes of Health. Its goal is to present scientific information on overlapping health conditions to determine common underlying mechanisms and novel targets for diagnosis and treatment. These conditions include vulvodynia, interstitial cystitis, headache, irritable bowel, endometriosis, fibromyalgia, chronic fatigue syndrome, rheumatoid arthritis and TMJD. In late June, the National Institute of Diabetes and Digestive and Kidney Diseases will host a meeting titled, [Defining the Urologic Chronic Pelvic Pain Syndromes](#). One of the meeting's goals is to present and discuss epidemiological research on multiple overlapping chronic pelvic pain conditions. Both meetings will include patient advocacy roundtables in which NVA will take part. We hope that these meetings will lead to additional NIH funding opportunities that will advance knowledge of common underlying mechanisms of these disorders, ultimately leading to improved treatment options and patient care.

Vulvodynia Media Coverage Still on the Rise

Media coverage of vulvodynia exponentially increased in 2007 and we're pleased to report that the trend is continuing! In February, vulvovaginal specialists Drs. Elizabeth Stewart and Andrew Goldstein were interviewed for a story on ABC's Healthcheck, [Painful Sex is Still a Painful Secret](#). The article featured the stories of

three women who suffered from dyspareunia (painful intercourse), vulvodynia and vaginismus. Also in February, a reader of Guam's daily newspaper, [The Pacific Daily News](#), submitted a question about his girlfriend's pain following intercourse and urination to Dr. Thomas Sheih, an obstetrician/gynecologist who answers readers' questions on issues related to vulvovaginal health. In his response, Dr. Sheih discusses vulvodynia/vestibulitis as a potential cause of her symptoms.

In March, NVA member Dana Pegg was interviewed on Health Talk with Dr. Manny on Fox News. In the interview, [Living with Vulvodynia – Is Your Vagina Depressed?](#), Dana discussed her journey with vulvodynia and how she currently manages her condition. Obstetrician/gynecologist Dr. Adelaide Nardone discussed vulvodynia's symptoms, potential cause(s) and its diagnosis. Dana ended the interview with valuable advice to fellow sufferers, "Women know their bodies better than anyone else, so they should listen to them and be vigilant."

The April issue of Self Magazine, with 5.2 million readers, features a first-person account of one woman's 15-year struggle with vulvodynia. In the article, [Secrets to a Happier, Closer Bond in Bed – A Woman's True Tale of Intimacy Lost and Found](#), the author describes her pain in the following way, "It feels as if the skin lining my vagina has been chemically burned, exposing the delicate tissue underneath. To have anything touch it is excruciating, never mind something that produces friction. Just thinking about it makes my eyes well up." Like many women, she was erroneously told time and time again that "everything looked fine" and that the cause of her pain was likely psychological. After years of misdiagnosis and pain, the obstetrician who delivered her first child referred her to a more experienced gynecologist. Finally she received a proper diagnosis, began treatment, and with the help of her supportive husband, has started on a path to healing. Also in April, the widely distributed Canadian Living Magazine published an article on a multidisciplinary approach to treating chronic pain entitled, [Coping with Chronic Pain](#). The article detailed the story of Kelly Corry, a 47 year-old woman who developed vulvodynia and interstitial cystitis 20 years ago, after suffering a miscarriage during her third pregnancy.

In an effort to raise the public's awareness of vulvodynia and reach isolated women suffering with vulvodynia, NVA is currently working with several journalists on future magazine and newspaper articles.

Oprah Winfrey Show Update

NVA just received word from the producers at The Oprah Winfrey Show that the vulvodynia segment taped in February 2008 will not air this season. The producers are still interested in airing it, but the next season doesn't start until fall 2008. When NVA receives confirmation of an air date, we will send out an e-mail announcement.

Spotlight on NVA Volunteers – College Campus Initiative

Much of NVA's work is done by dedicated volunteers across the country. One of our longtime and highly committed volunteers is Chicago-area support leader, Pam Fischer. In addition to her ongoing responsibilities, Pam recently led a special

vulvodynia project in her home state. Thank you Pam and Chicago area support group!

Data from the NIH-funded Harvard epidemiological study on vulvodynia indicated that vulvodynia's symptoms are most likely to appear between the ages of 18 and 25. As such, it is important that clinicians working at university student health centers be informed about vulvodynia and NVA services. Pam's group compiled contact information for student health centers at universities across Illinois and contacted each one to find out the appropriate person to whom this information should be sent. NVA then mailed each center informational packets on vulvodynia and NVA services. This effort will help educate young women about vulvodynia and ensure that they know how to find help. If you have a few hours to spare and would like to implement this important project in your home state, please contact NVA's administrator, Gigi Brecheen, at 301-949-5114 or gigi@nva.org. If you are interested in volunteering in another capacity, please visit [NVA's web site](#) to read more about the many ways you can help.

Upcoming Conferences

On May 30, 2008, the first annual [Women in Pain Conference: Gender Matters](#) will be held in Duarte, California. The conference is open to women in pain, their caregivers and healthcare professionals. Free registration will be offered to the first 50 women who register. To register and view additional information on the conference, click [here](#).

For those of us also affected by interstitial cystitis (IC), the Interstitial Cystitis Association (ICA) will host a regional forum in Tampa, Florida, on July 13, 2008. Speakers will include both national and local interstitial cystitis experts. The ICA anticipates an audience of up to 150 IC sufferers, family members and friends. Additional information will appear on the [ICA's web site](#) and in upcoming issues of Café ICA, the organization's electronic newsletter. Shortly, the ICA will release information on its second Regional Forum to be held in the Minneapolis area in late summer 2008.