

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 on the diagnosis and treatment of vulvodynia written by vulvovaginal experts. To subscribe, visit [NVA's web site](#).

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### **Please Help the NVA Fund Research *Matching Donation Appeal***

This past summer, NVA received 14 excellent vulvodynia research proposals that have been reviewed by our medical advisory committee. Five proposals were recommended for immediate funding and we are appealing to you to help us fund them. **Your donation will go even further this year, because a longtime NVA supporter has volunteered to match every contribution of \$50 and above.**

In addition to awarding pilot research grants, NVA is working with members of Congress and the National Institutes of Health to obtain federal funding of vulvodynia research and implement awareness programs. Last week, NVA was awarded a grant from the Patty Brisben Foundation to develop an online tutorial for women suffering from vulvodynia. This new tutorial will complement our online medical professional tutorial that provides continuing education credit to doctors and other health care providers.

NVA staff and volunteers want all women with vulvodynia to be accurately diagnosed by the *first* health care provider they consult, to receive effective treatment and to resume a life that is pain-free. **Please help us move one step closer to reaching our goal by supporting vulvodynia research in whatever amount you can afford -- 100% of your donation is tax-deductible and will be used exclusively to fund medical 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.

### **Participants Needed for *Cost of Illness Survey***

The NVA is seeking US women diagnosed with either generalized vulvodynia or vulvar vestibulitis syndrome (aka vestibulodynia) to participate in a cost of illness survey that asks questions about lost work hours and out-of-pocket expenses related to having vulvodynia. From a cost of illness survey, analysts can calculate the financial impact of a particular health condition on our economy. It is invaluable for NVA to have this information to convince members of Congress of the great need to increase funding of vulvodynia research. **This survey requires only three hours of your time over the next six months.** With the use of a NVA-supplied calendar, you will keep track of your vulvodynia-

related expenses, such as prescription medications, doctor visits and over-the-counter remedies. Participants will anonymously log onto NVA's web site once every four weeks (for six months) to record expenses. Each time you log on, the survey will take 5 to 10 minutes to complete.

**Upon enrollment, participants will receive a complimentary copy of NVA's self-help guide. Upon completion, you will receive a complimentary one-year subscription to NVA's newsletter.** For additional information, or to participate, please visit <http://www.nva.org/costsurvey>.

## Help the NVA While Shopping Online

Now more than ever, smart shoppers are looking for ways to stretch every dollar. In these uncertain economic times, we all face difficult choices as we plan for special occasions, holiday gifts and charitable giving. Through partnerships set up by NVA, you can be sure that when you shop at Amazon.com or GoodShop.com, a portion of the money you spend will be sent to NVA. Now you can buy the things you need, save money on great deals and feel good knowing that you're supporting our cause! So instead of fighting those long lines, we encourage you to visit [www.nva.org](http://www.nva.org), click on the Amazon or GoodShop logo and do your holiday shopping. Thank you!

## Vivian Pinn, MD, Receives Top Honor



The NVA recognizes a staunch women's health advocate, Vivian W. Pinn, MD, director of the NIH Office of Research on Women's Health (ORWH). Her commitment to improving women's health and support of NVA's efforts have been instrumental in advancing vulvodynia research and awareness in the past decade. Fittingly, on November 1<sup>st</sup>, Dr. Pinn received the American Academy of Medical Colleges' Herbert W. Nickens Award, honoring her for making an outstanding contribution to promoting justice in medical education and health care.

As a young girl, Vivian helped to care for her grandparents and observed first-hand the healing power of medicine. It was the tragedy of her mother's misdiagnosis, however, that fueled Dr. Pinn's determination to make the health care system more responsive to women and minorities. When Dr. Pinn's mother presented with back pain, she was told that she had poor posture and her doctors overlooked the bone cancer that eventually took her life.

Dr. Pinn has spent the past 17 years working to legitimize overlooked and misunderstood women's health conditions. As ORWH director, she has successfully fulfilled the mandate to ensure that women are included as participants in NIH-funded clinical research. Her impact is far-reaching, having served in a vast number of leadership positions, such as US delegate to the World Health Assembly in Geneva. Whether she is reaching out to ensure the responsive and respectful treatment of patients, or to mentor young doctors, she always strives to improve the quality of health care. As a physician, teacher, mentor, and policy leader, she has taken patient-centered care to higher levels while at the same time helping to advance the careers of women and minority doctors.

## NVA Welcomes New Part-time Staff



### Erin Lapham

Erin, a sexuality educator certified by the American Association of Sexuality Educators, Counselors and Therapists, has been lecturing on women's health to thousands of women for the past six years. She has a Master's degree in Public Health with a concentration in sexuality education from Indiana University. While completing her degree she interned for the Kinsey Institute, researching Sex, Gender and Reproduction. Thrilled to be part of the NVA team, Erin is working on educational programs for women suffering from vulvodynia.

### Crystal Dade

Crystal began struggling with chronic vulvar pain at age 19 and it took her three years to finally receive a diagnosis of vulvodynia. With the help of the NVA, Crystal started her journey to finding relief. For several years, Crystal has served as the Calgary, Alberta NVA support leader, which she feels has helped her own recovery process. Crystal works on special NVA projects and is currently administering our cost of illness study. (See Cost of Illness Survey above.)



### Philip Kumler, PhD

Philip is now a retired chemistry professor, having taught for 30 years at SUNY-Fredonia. He holds a PhD in Organic Chemistry from the University of Rochester. Phil is currently investigating pain medications in various stages of development at pharmaceutical companies. He first became aware of the NVA while helping his wife gather information on vulvodynia. We are hopeful that his current investigation will help us promote interest in vulvodynia among pharmaceutical companies.

## Vulvodynia Publicity Takes Off

Vulvodynia and related conditions received considerable media coverage in fall 2008. As you read about the news articles summarized in this article, please take a few minutes to post your comments on their publications' websites and send a brief e-mail to the journalist and/or editor. Please thank them for covering vulvodynia and let them know that it's a topic you would like to hear more about in the future.

We were delighted to see vulvodynia covered in November's issue of Cosmopolitan magazine and December's issue of Glamour and Prevention magazines. Together, these publications reach millions of readers in over 100 countries, with articles translated into 34

languages! Glamour's featured an excellent article, [We're about to Make Sex Better for 66% of Women](#), which discussed the many reasons why the majority of women will experience painful intercourse at some point in their lives. A candidly written article by Katharine O'Connell, MD, assistant clinical professor of obstetrics and gynecology at Columbia University Medical Center, with an easy to follow algorithm titled, *When Does Sex Hurt*, helps women begin narrowing down the possible causes of their pain. In addition to vulvodynia, Dr. O'Connell discussed vaginal dryness, yeast infections, ovarian cysts, endometriosis, interstitial cystitis and pelvic congestion.

In early fall, vulvodynia received expansive coverage from Dr. Paul Donohue's nationally syndicated column, *To Your Good Health*, printed in 175 newspapers nationwide. In the article titled, [Vaginal Pain is Often Misdiagnosed](#), he answered a woman's question about coping with chronic vulvar pain, provided current information about treatment options and gave suggestions for finding support and more information. Following Dr. Donohue's article on vulvodynia, NVA's website received a substantial increase in hits.

In September, Personal Life Media covered vulvodynia on their [Sex, Love and Intimacy](#) radio program featuring Dr. Laura Brodzinsky, an assistant clinical professor of obstetrics and gynecology at Stanford Medical School who oversees the Stanford vulvodynia clinic. On the popular program, Dr. Brodzinsky and host Chip August talked very candidly and openly about vulvodynia. Listeners were encouraged to become their own health care advocate and to try and overcome any embarrassment they may have with their bodies.

[EmpowHer.com](#) featured several articles on vulvodynia in November, including one by Jennifer Gunter, MD, director of pelvic pain and vulvovaginal disorders at Kaiser Permanente San Francisco Medical Center. In the article titled *Understanding Vulvodynia*, Dr. Gunter discussed the prevalence of vulvodynia and described some common treatments. She informed women with vulvodynia that they are not alone and should find a knowledgeable health care provider to receive the help they deserve. The site also featured the stories of several vulvodynia sufferers, including NVA supporter Alexandra Carmichael. In her article titled, *Vulvodynia: My Tracks to a Cure*, Alexandra shared the trials and tribulations she experienced while trying to get a proper diagnosis and described the treatment she found that ultimately relieved her pain. Her experience led her to create the novel web site project [CureTogether](#).

A Harvard Women's Health Watch article titled, *Managing Common Vulvar Skin Conditions*, (November issue) asked the important question, "What have you done lately for the more sensitive skin of your vulva?" In the article, leading vulvovaginal experts, including Elizabeth Stewart, MD, assistant professor of obstetrics and gynecology at Harvard Medical School and NVA medical advisory board member, gave practical, up-to-date information on the various treatment options for vulvar problems, including yeast infection, eczema, and psoriasis, to name a few. The article also cautions women that self-treatment can lead to problems and recommends seeing a trained health care professional for a diagnosis.

A November 7<sup>th</sup> press release highlights the agonizing process women with a vulvodynia diagnosis can experience while trying to find the treatment they need. In [Once Again Women Have to Fight for Their Rights: This Time for Their Vaginal Health](#), the author emphasized how unfair it is that vulvodynia, a condition affecting as many as 16 percent of women, is still widely under-diagnosed and inappropriately treated. In an effort to bring much needed attention to women suffering from vulvodynia, a group of Polish women participating in an online community started an awareness campaign in November. This campaign is aimed primarily at women who silently suffer and don't realize that their

condition has a medical classification. For more information about this social action campaign, please visit [www.vulvodynia.pl](http://www.vulvodynia.pl).

### **Canadian Vulvodynia Clinic Open Its Doors**

With generous funding from the Leslie Diamond Foundation, plus resources provided by Vancouver Hospital, the Multidisciplinary Vulvodynia Program (MVP) opened its doors on October 21, 2008. The MVP is one of the first centers in Canada dedicated to treating women with chronic genital pain. Staffed with gynecologists, pelvic floor physiotherapists and psychologists working collaboratively, and a nurse clinician coordinating patients' care, the goal of the MVP is to provide evidence-based quality care all in one location. MVP also serves as a resource for community physicians treating women with vulvodynia, offering treatment guidelines that will ensure their patients receive high quality care. For more information about the Multidisciplinary Vulvodynia Program, visit [www.mvprogram.org](http://www.mvprogram.org).