

NVA UPDATE

February 2007

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The following e-newsletter is adapted from the winter 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 on the bottom of this page. To subscribe to the full printed version of this newsletter, please visit <http://www.nva.org/join-splash.htm>

Please direct any comments, including a desire to unsubscribe, to chris@nva.org.

NVA Awards Record Number of Research Grants

Our summer 2006 research fundraiser was so successful that, this past fall, NVA funded three new vulvodynia research studies, in addition to supporting two ongoing studies from 2005. Because a huge number of scientists are competing for limited National Institutes of Health (NIH) funding, applicants find it advantageous to submit a sizable amount of preliminary data with their applications. Consequently, NVA's research grants can often play a critical role in helping scientists secure substantial long-term funding from the NIH.

Colin MacNeill, MD, associate professor of obstetrics and gynecology, Penn State Milton S. Hershey Medical Center, stated in his NVA research proposal that, "One key focus of vulvodynia research is understanding its pathophysiology, that is, the determination of cellular mechanisms by which chronic inflammation is initiated, and the genetic variants that encode proteins participating in this process." He proposes that, "an understanding of inflammatory mechanisms is an essential first step in designing effective therapies for vulvodynia and the paucity of such an understanding hampers design of effective treatments." Dr. MacNeill was awarded an NVA grant to determine the role of two collectins (proteins), Surfactant Protein-A (SP-A) and Surfactant Protein-D (SP-D), members of a family of innate immune pattern recognition proteins (immune system proteins that recognize disease-causing organisms), in regulating vulvovaginal inflammation. Surfactant proteins are produced in the vaginal and vestibular mucosa, as well as elsewhere in the body, and may play an important role in preventing vulvovaginal infection. Dr. MacNeill hypothesizes that polymorphisms (gene variants) that code for these proteins may be responsible for initiating or maintaining the early inflammatory process in vulvar vestibulitis syndrome (VVS). In this study, he will test this hypothesis by measuring levels of surfactant proteins in vestibular tissue and testing for eleven polymorphisms in VVS patients and controls. In early 2007, Dr. MacNeill plans to include this data in a research application to the NIH.

Yitzchak Binik, PhD, professor of psychology at McGill University, was awarded an NVA grant to investigate the relationship between chronic Candida infection and VVS in an animal model. Many women with VVS report previous recurrent episodes of vulvovaginal Candida infection. This association has led some researchers to propose that chronic Candida infection, in which there is continued irritation of the vulvovaginal mucosa, may lead to the abnormal pain transmission experienced by women with VVS. In the present study, Dr. Binik will evaluate whether chronic Candida infection results in lowered vulvar pain thresholds and reduced mating behavior in mice. In addition, he will determine if the immunological profile associated with chronic Candida infection is similar to the immunological profile in VVS. Dr. Binik's goal is to use an animal model to pursue novel therapeutic interventions for women with vulvar pain.

Lori Boardman, MD, associate professor of obstetrics and gynecology at Brown University, Women and Infants' Hospital, was awarded a grant to conduct a Phase I study of the safety and tolerance of a novel topical treatment for VVS. Once this safety study is completed, she will submit the data in a research

proposal to the NIH. This proposal will be to perform a multi-center, randomized, placebo-controlled clinical trial investigating the efficacy of this topical treatment.

Given the state of knowledge in the vulvodynia field, almost all of the research proposals submitted to NVA aim to investigate the cause(s) or treatments of vulvar vestibulitis syndrome. It should be emphasized, however, that many clinicians and researchers have suggested that the results of VVS studies also are relevant to our understanding of generalized (or dysesthetic) vulvodynia.

The members of the NVA executive board would like to express their appreciation to everyone who contributed to the success of the 2006 research fund-raiser. They would also like to thank the medical advisory board members and other vulvodynia experts who generously donated their time to review and score this year's research grant proposals. If you missed the opportunity and would like to make a donation to our 2007 Medical Research Fund, please contact Chris Veasley at chris@nva.org or Gigi Brecheen at gigi@nva.org or 301-949-5114.

(Editor's Note: Thanks to the overwhelming generosity of individuals contacted in late November, the NVA Board has just awarded its first 2007 research grant to Dr. Steven Witkin of Weill Medical College of Cornell University. A summary of his research project will appear in our next newsletter.)

NVA Honors Executive Director's 10-Year Anniversary

In late October, co-workers and NVA Board members surprised Phyllis Mate, NVA's volunteer executive director, with a reception honoring her years of dedication to women with vulvodynia. The introductory speaker, Dr. Stanley Marinoff, NVA's first medical advisor and former director of the Center for Vulvovaginal Disorders in Washington, DC, spoke of NVA's remarkable growth under Phyllis' leadership. "Ten years ago this was a small group serving patients, but with Phyllis' vision, NVA has made an impact on Capitol Hill, convincing legislators to support NIH funding of research on the causes and treatments of vulvodynia." In addition, he noted that NVA raises funds to award grants for much-needed pilot studies and vulvar pain clinics.

NVA Treasurer, Maurice Kreindler, read a touching letter from Mona Schlossberg, who, in 1994, recognized the need to give women with vulvodynia a collective voice and generously donated the funds to create NVA. Mona wrote of Phyllis' commitment to educating the medical community. "She has led a successful campaign to raise awareness of vulvodynia among health care professionals. I have witnessed this in my own interactions with doctors. Finally, vulvodynia is out of the dark."

NVA co-founder Marjorie Veiga spoke of Phyllis' multi-tasking ability. "The executive director must supervise employees and volunteers, raise funds, and oversee all programs for patients and health care providers. At the same time, Phyllis burns the midnight oil editing our respected newsletter, read by thousands of physicians and patients in nine countries. She does this as a volunteer, sometimes working 60 hours a week."

Christin Veasley, director of professional programs, gave the evening's final tribute. She recalled Phyllis' kindness when she first contacted NVA as a teenager, shortly after being diagnosed with vulvodynia. "At a time when I had no hope, she answered the phone and provided the resources and support I need to take back my life and go on to have the family I wanted." She described working closely with Phyllis for the past seven years, noting, "In a career where burn-out is common, she has shown me how to persevere and not get discouraged." Chris finished by turning to Phyllis and expressing the gratitude of women with vulvodynia, "Tonight, we honor you and all that you have sacrificed to make our lives better."

With co-founders Harriet O'Connor, Marjorie Veiga, and Rhonda Brunell, Chris presented the honoree with a crystal vase inscribed, "In grateful appreciation of Phyllis Mate for ten years of exceptional service and dedication to the National Vulvodynia Association. Her vision, compassion and resolve have improved the lives of countless women with vulvodynia." Upon accepting the award, Phyllis warmly acknowledged NVA staff members Chris Veasley, Gigi Brecheen, Judi Lenehan, and former support

director, Harriet O'Connor, saying, "If it hadn't been for their help, I would have found a way to retire five years ago." Describing the journey from a small support group to an international patient advocacy organization, she reflected, "It's been enormously gratifying to see how the NVA's growth and influence led, not only to the first NIH vulvodynia conferences, but to federal funding of vulvodynia research." Phyllis characterized the success NVA has experienced during her tenure as a real-life example of the philosopher Johann Wolfgang von Goethe's aphorism, At the moment of commitment, the universe conspires to assist you. We're grateful she made that commitment.

ACOG Publishes Committee Opinion on Vulvodynia

In October 2006, the American College of Obstetricians and Gynecologists (ACOG), published a Committee Opinion on Vulvodynia in its clinical journal, *Obstetrics & Gynecology*, distributed to its 51,000 members. The Opinion will be included in the annual ACOG desk reference, a big step forward in educating all gynecologists about vulvodynia. NVA wishes to thank Ralph Hale, MD, ACOG's executive vice-president, for supporting educational initiatives that will heighten the profile of vulvodynia in the medical community, and recognizes the commitment of the late John Gibbons Jr, MD, who enthusiastically promoted this initiative.

Concurrent with the above publication, the NVA and the NIH Office of Research on Women's Health (ORWH) issued a joint media release. ORWH Director Vivian Pinn, MD, stated in the release, "Data from a recent NIH-funded study, conducted by Drs. Bernard Harlow and Elizabeth Stewart of Harvard University, show that 13 million women may suffer from vulvodynia during their lifetime. The data clearly demonstrate the need for continuing research on vulvodynia and for raising awareness about this condition among both women and their health care providers."

Vulvodynia in the Media

In just the first month of 2007, vulvodynia was featured in several media venues. On January 24th, vulvodynia was the topic of CNN's Headline News 5-minute health segment, *Seeking Solutions with Suzanne* (Comcast cable subscribers). You can view additional information on the broadcast at: <http://www.suzanne.tv/show.asp?sid=511>. Canada's largest newspaper 'The Globe and Mail,' which circulates to 1.3 million people, included vulvodynia in a women's health article. Christin Veasley, NVA's director of research and professional programs, was interviewed on a new radio program called, "Sex Talk with Andrea Adams-Miller," at Indiana's Bowling Green University. On November 27th, Voices in the Family host, Dan Gottlieb, PhD, featured vulvodynia on a show about women and healthcare. In addition to interviewing a vulvodynia patient, Dr. Gottlieb was joined by Dr. Karen Bowles, an internal medicine physician, Phyllis Greenberger, MSW, President of the Society for Women's Health Research, and Deborah Kotz, senior health editor at US News & World Report. If you would like to listen to the program, you can do so from this website: <http://www.whyy.org/91FM/voices200611.html>

The March issues of Health, Pilates Style Magazine and Canadian Health (on the stands in mid-February) will also include articles on vulvodynia, so be sure to pick up a copy when you're out!

We'll share more details about these efforts in the spring issue of the NVA News. In the interim, if you have any ideas, media contacts and/or information on programs that you think should cover vulvodynia, please contact NVA's communication director, Marjorie Veiga at mveiga@cox.net.

NVA Updates Healthcare Provider Referral Database

In an effort to assist women in making informed choices about their treatment, the NVA has expanded the information contained in its healthcare provider referral database. All practitioners listed in our referral database have been surveyed and expressed an interest in treating women with vulvodynia. This

database has always contained providers' contact information and area of specialization and now also includes:

- the average number of vulvodynia patients the provider treats each month
- type of practice, e.g., private practice, hospital out-patient clinic
- additional specialty information, including whether the provider practices obstetrics
- if available, an address or link to the practitioner's web site, containing more detailed information on his/her practice
- the percentage of the practice devoted to treating patients with either vulvar disorders or chronic pain
- whether a practitioner is currently involved in either clinical or basic science research related to vulvodynia.

If you are a current NVA donor and would like to receive an updated list of healthcare providers in your state, please contact NVA's administrator, Gigi Brecheen, at gigi@nva.org or 301-949-5114. The updated list will be emailed to you, or mailed if you do not have computer access. If you are not a current NVA donor, additional information on how to obtain this and other NVA services can be viewed here: <http://www.nva.org/join-splash.htm>

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Sex Therapy in the Treatment of Vulvodynia by Stephanie Buehler, PsyD, CST and Christine Seeberger, MA
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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: <http://www.nva.org/join-splash.htm>