National
Vulvodynia
Association

NVA News

Volume VIII, Issue II
Spring 2003

NIH Hosts Vulvodynia Research Conference

More than 200 hundred clinicians and research scientists from universities and hospitals in the US, Canada, Europe and Israel convened on April 14th and 15th at the National Institutes of Health (NIH) multidisciplinary research conference on vulvodynia. The purpose of the workshop was to present recent research on vulvodynia prevalence, causes and treatments, and to stimulate innovative research approaches to the study of vulvodynia.

In her opening remarks, honorary chair Florence Haseltine, MD, Director of the Center for Population Research at the National Institute of Child Health and Human Development (NICHD), noted the "increasing interest in vulvodynia since the last NIH workshop in 1997" and expressed a commitment to keep scientists updated on new developments. Dr. Phyllis Leppert, conference co-chair and chief of NICHD's Reproductive Sciences Branch of the Center for Population Research, voiced the expectation that the workshop would "stimulate a lot of new discussion and research."

Dr. Maria Turner of the National Cancer Institute, co-chair of this year's conference and organizer of the NIH's 1997 vulvodynia workshop, kicked off the scientific sessions by summarizing the highlights of the 1997 workshop. In addition to stimulating clinical, epidemiologic and basic science research on vulvodynia, she concluded that one of the major accomplishments of the 1997 workshop was the conceptualization of vulvodynia as a chronic regional pain syndrome. She referred to the scientific advances of the past six years and her hope that future research will help us better understand vulvodynia, and in doing so, provide more successful treatments.

Turner also pointed out a major problem currently facing researchers in the field: the task of differentiating the subsets of vulvodynia and establishing a consistent terminology. The lack of consistent terminology has been a source of confusion for

See NIH, page 3

Vulvodynia May Be A Highly Prevalent Disorder

The following press release was issued on April 14th 2003 by Brigham and Women's Hospital.

BOSTON – Researchers at Brigham and Women's Hospital (BWH) have found new evidence that both clinicians and the general public may have significantly underestimated the prevalence of a very debilitating and chronic vulvo-vaginal pain disorder known as vulvodynia. Women who suffer from vulvodynia experience chronic burning or sharp knifelike pain or pain on contact that occurs in the absence of infection or vaginal diseases. Often times, the unexplained pain results in an inability to exercise, have intercourse, and in extreme cases can cause women to be bedridden.

The study findings were presented at the National Institutes of Health (NIH) vulvodynia conference on April 14th and are outlined in the April issue of *The Journal of the American Medical Women's Association (JAMWA)*. In one of only a handful of studies to look at this syndrome, BWH researchers found that approximately 16 percent of respondents to a Boston-based population survey reported histories of chronic vulvar pain for at least three months or longer. Nearly seven percent of respondents

See PREVALENCE, page 9

LETTER FROM THE EXECUTIVE DIRECTOR

Dear Reader,

April 2003 was a landmark month in advancing the cause of vulvodynia sufferers. The National Institutes of Health (NIH) held its second vulvodynia research conference in six years and encouraged researchers to submit proposals for NIH funding. I'd like to express our appreciation to Drs. Florence Haseltine and Phyllis Leppert of the National Institute of Child Health and Human Development for sponsoring this conference. I especially want to thank Maria Turner, MD, of the National Cancer Institute, who chaired the 1997 vulvodynia workshop and co-chaired this year's conference. Maria was instrumental in launching both NIH conferences and has been a friend and advisor to the NVA since our inception.

Also in April, additional results from the NIH-funded vulvodynia prevalence study were released. According to the study, millions of women in the US may be affected by vulvodynia. (See Prevalence article on page 1.) NVA immediately sent out copies of the publication to major pharmaceutical companies and the media. This data will be very helpful in encouraging pharmaceutical companies to focus on developing treatments for chronic vulvar pain conditions.

NVA News
National Vulvodynia Association
P.O. Box 4491, Silver Spring, Md. 20914-4491
(301) 299-0775; FAX: (301) 299-3999
www.nva.org

The *NVA News* is published three times per year.

Editor: Phyllis Mate
Layout: Andrea Hall
Contributors: Catherine Clevenger;
Adrienne McAuley, PT; Christin Veasley

The National Vulvodynia Association is an educational, nonprofit organization founded to disseminate information on treatment options for vulvodynia. The NVA recommends that you consult your own health care practitioner to determine which course of treatment or medication is appropriate for you.

The night before the NIH conference, NVA held an "appreciation dinner" for many doctors who've written for our newsletter and been very supportive of our efforts to help patients and educate their colleagues in the medical community. The dinner was a great opportunity for our executive board members to develop personal relationships with several vulvodynia experts from across the country. In addition to our medical advisory board members (see page 5), Drs. Jessica Thomason, Martha Goetsch, Gae Rodke, Hope Haefner, Ronald Meltzer and Jacob Bornstein were among our welcome guests.

On the publicity front, I was recently interviewed by Leah Thayer, newsletter editor for the National Women's Health Network (NWHN), who wrote an article on how a small, patient-run volunteer organization like ours was able to accomplish so much in eight short years. I told Leah that individuals who suffer from an under-recognized health condition often become the most committed volunteers. For an "inside look" at how the NVA operates, this article will appear in the NWHN's May 2003 issue (www.womenshealthnetwork.org). Unfortunately, we are still without air dates for two important television shows that were originally scheduled for March but were pre-empted by network coverage of the war. ABC's 20/20 filmed a segment on female sexual dysfunction, in which a vulvar vestibulitis sufferer and Dr. Howard Glazer, author of the *Vulvodynia Survival Guide*, were interviewed. Of equal interest, the Discovery Channel's *Berman and Berman: For Women Only* will have *V Book* author Dr. Elizabeth Stewart as a guest on an upcoming show. When we receive air dates, we will disseminate the information to our regional contact leaders, but you may want to keep an eye out for these programs.

If you have any interest in serving as a regional contact leader for NVA, please contact our administrative assistant Rosemary Amiri (rose@nva.org). From time to time, we have to replace our support leaders and it would be helpful for us to know, in advance, if you might be interested in assuming this responsibility.

Wishing you an enjoyable and relaxing summer,

Phyllis Mate

Phyllis Mate

NIH

(from page 1)

researchers and clinicians, as well as patients. For example, unprovoked, chronic vulvar pain or "dysesthetic vulvodynia," is now referred to as "generalized vulvar dysesthesia" by some experts. Similarly, the condition widely known as "vulvar vestibulitis" is referred to by some as "localized vulvar dysesthesia." Turner hopes that the International Society for the Study of Vulvovaginal Disease will sort out the confusion shortly.

Prevalence

The next presentation, by Dr. Barbara Reed from the University of Michigan, was entitled, "The Voices of Vulvodynia." In preparation, Dr. Reed asked patients from her practice what they would like the NIH workshop to accomplish. Most patients expressed the hope that a cure or more effective treatments would be developed, but an equally urgent patient request was to "spread the word" about vulvodynia and its impact on a woman's life.

Reed presented the results of a Web-based vulvodynia prevalence survey she conducted at the University of Michigan. Of the 1,000 respondents, ages 18 to 69, 1.7 percent reported suffering from chronic vulvar pain (corresponding to 2.4 million women in the United States). Dr. Bernard Harlow, Harvard epidemiologist and co-investigator on an NIH-funded vulvodynia prevalence study, responded, "In comparison to data we've collected on a larger sample of women, the 1.7 percent estimate is probably an underestimate; however, even if it is anywhere near the true prevalence, we are dealing with a major public health problem." Reed's survey also confirmed that "patients still have to visit many doctors and wait a long time to receive an accurate diagnosis."

One of the conference highlights was the presentation of Harlow's long-awaited survey data based on a sample of 5,000 women, ages 18 to 64. Contrary to popular belief that vulvodynia does not affect many women, this vulvodynia prevalence survey found that 16 percent of women experience chronic vulvar burning, knife-like pain, or pain on contact for three months or longer at some point in their lives. Nearly seven percent of respondents were experiencing vulvar pain at the time of the survey. (See Prevalence article on page 1.)

Dr. Mary Margaret Chren of the University of California discussed the implications of Harlow's data, emphasizing the burden vulvodynia places on a woman's life. Chren's own survey of vulvodynia sufferers found that having vulvodynia negatively impacts on a women's quality of life more than having other health conditions or other types of vulvar conditions such as lichen sclerosus.

Related Disorders

The next portion of the conference featured basic science studies on pain disorders that may be related to vulvodynia, in an attempt to help the scientific community gain insight into possible underlying mechanisms of vulvodynia. These presentations included a discussion of neuropathic pain, chronic pelvic pain, and myofascial pain.

Neuropathic Pain

Pain expert, Dr. Marshall Devor of the Hebrew University of Jerusalem, began his presentation by differentiating normal or "nociceptive" pain vs. neuropathic pain. Nociceptive pain is experienced when your detection system is functioning normally; for example, you hit your thumb with a hammer and damage tissue, which causes pain in your thumb. If the pain detection system itself is damaged or malfunctioning, however, this results in neuropathic pain. For example, your thumb is not injured, but you experience pain because there's an injury in the nerve that serves the thumb.

Devor presented a working hypothesis of vulvodynia as a neuropathic pain state, speculating that chronic vulvar pain or dysesthesia (abnormal sensation) may result from a damaged, pinched or stretched pudendal nerve, rather than an abnormality in the vulvar tissue itself. The nerve injury site, or the sensory cells whose axons make up the nerve, may fire spontaneously giving rise to ongoing burning pain felt in the vulva, but not actually arising there. Furthermore, tactile allodynia (a state in which

See NIH, page 4

NIH

(from page 3)

non-painful touch produces pain) may occur due to central nervous system amplification of the sensory effects of light touch on the vulva. The amplification process, known as "central sensitization," is triggered by electrical impulses arising in the damaged pudendal nerve.

Similar to certain other nerves in the body, the pudendal nerve runs along a course that places it at risk for crush or stretch injury. There is also clinical evidence that supports the neuropathic pain hypothesis, i.e., some vulvodynia patients experience pain relief with traditional neuropathic pain treatments such as anticonvulsants, low doses of tricyclic antidepressants and topical anesthetics.

Devor then addressed the question of variability in pain experience, i.e., why some women experience vulvar pain and others do not. Obviously, not everyone has pudendal nerve injury, and even among those who do, there may be individual differences in pain expression and experience due to environmental factors such as family upbringing, ethnicity, culture, etc. In addition, there may be genetic factors that influence individual susceptibility to pain. He described recent animal research from his lab and others showing that certain breeds of animals are more susceptible to developing pain in the presence of neuropathy than others, and discussed ongoing efforts at identifying the gene(s) involved. Although there is little solid empirical evidence demonstrating a genetic predisposition to pain in humans, the possibility exists, and should de-stigmatize women who experience more pain than average through no fault of their own. Devor believes that this area is in need of further research.

Chronic Pelvic Pain

Dr. Ursula Wesselmann of Johns Hopkins University discussed the possible relationship between visceral pain and vulvodynia. Visceral pain originates from the internal organs of the digestive, respiratory or urogenital systems as well as the heart, spleen, etc. Wesselmann referred to a survey that asked people who were not experiencing pain to think about having pain in different parts of their bodies. According to the results, people rate having pain in the genital and reproductive organs as more disturbing than having pain in other parts of the body.

Chronic pelvic pain (CPP) is a common visceral pain syndrome that is unique in its presentation compared to other chronic pain conditions. The definition of CPP set forth by the American College of Obstetricians and Gynecologist is "pelvic pain in the same location for greater than 6 months." Due to the absence of objective, measurable findings, CPP is difficult to diagnose and differential diagnosis must include assessment of all pelvic organs.

So, what is the possible interplay between vulvodynia and CPP? Wesselmann investigated this question in a set of basic science experiments. In the first experiment, uterine inflammation was induced in rats and pain-related behavior was observed for one week. Afterwards, the pain-related behavior disappeared and the rats resumed their normal demeanor; on day nine, vaginal inflammation was induced in the same rats and they were sacrificed two hours later. The spinal cords of the rats were examined for evidence of pain transduction from the vagina and uterus to the brain. Wesselmann found evidence of pain transduction from the vagina and the uterus, even though the uterine-induced pain was previously resolved. From this finding, she hypothesizes that sensitivity of the vagina (and possibly the vulva) is heightened after a painful stimulus to the uterus (or other pelvic organ) has been endured. Clinical studies have shown that patients diagnosed with interstitial cystitis (a painful bladder condition) demonstrate increased sensitivity in the vaginal area compared to healthy controls, providing further evidence of Wesselmann's hypothesis that having a prior pelvic pain condition may sensitize adjacent genital structures and predispose the individual to experience genital pain at a later time.

Myofascial Pain

Dr. Jay Shah, from the NIH Clinical Center, gave a presentation on the possible relationship between myofascial pain and vulvodynia. He explained that pelvic organ disease, tense pelvic-floor holding

See NIH, page 6

NVA Meets With Women's Health Lobbyists

In January, NVA medical advisory board member, Dr. Stanley Marinoff, and NVA staff member, Christin Veasley, met with Phyllis Greenberger, MSW, president and CEO of the Society for Women's Health Research (SWHR), to discuss the ways in which SWHR might help the NVA increase awareness and funding for vulvodynia. The Society's legislative director, Roberta Biegel, and scientific director, Sherry Marts, PhD, were also present at the meeting. SWHR is the nation's only non-profit advocacy group whose sole mission is to improve the health of women through research. The Society plays a critical role in educating health care practitioners, scientists and consumers about advances that may help in the diagnosis, treatment and prevention of disease by sponsoring professional meetings, publishing reports and producing educational materials.

Marinoff and Veasley updated the group on the NVA's advocacy efforts and the current status of vulvodynia research funding at the National Institutes of Health. As a result, Greenberger agreed to run an article about vulvodynia in the June 2003 edition of the Society's newsletter. The print version of the newsletter is read by 5500 scientists, academics, Capitol Hill staff and consumers, and an electronic version is disseminated to an additional 7000 individuals. For more information on the SWHR's activities, please visit their website at www.womens-health.org. ■

Left to right: Roberta Biegel, SWHR director of government relations; Phyllis Greenberger, SWHR President & CEO; Chris Veasley, NVA director of professional programs; Sherry Marts, SWHR scientific director; Dr. Stanley Marinoff, NVA medical advisory board member.

NVA Medical Advisory Board Meeting

NVA's executive and medical advisory boards convened on the eve of the NIH conference. Among the subjects discussed were the analysis of NVA's patient survey data and medical board members' current research interests. The meeting was chaired by NVA executive director, Phyllis Mate, who summarized the organization's recent educational programs and other efforts to generate awareness and promote research. Staff member Chris Veasley described new projects directed at educating health care professionals about vulvodynia. Medical board members in attendance were Drs. Stanley Marinoff, Howard Glazer, Libby Edwards, Jerome Weiss, Elizabeth Stewart, Ursula Wesselmann, Paul Nyirjesy and Justin Wasserman. Also in attendance were executive board members Harriet O'Connor, Cathy Clevenger, Adrienne McAuley and Maurice Kreindler. ■

Left to right: Drs. Howard Glazer, Libby Edwards, Stanley Marinoff, Jerome Weiss, Elizabeth Stewart, Ursula Wesselmann, Paul Nyirjesy and Justin Wasserman. (Not pictured: Dr. David Foster)

NIH

(from page 4)

patterns, trauma and/or inflammation can overload the muscles of the pelvic floor, causing the development of myofascial trigger points, or hyperirritable bundles of fibers within a taut band of muscle that become "knotted," inelastic and unable to contract or relax. A trigger point can refer pain along that muscle or to surrounding muscles. The affected muscle(s) and fascia contract in a way that causes the surrounding muscle groups to compensate. These, in turn, may become so overloaded that they too develop trigger points and become dysfunctional, thereby spreading symptoms and creating a vicious cycle. The increased tenderness and tension in these muscles may refer pain into the lower back, abdomen or perineum, or may cause urethral, vaginal or anal symptoms. Shah stressed that when women present with these symptoms, myofascial dysfunction should be considered as a possible cause or contributor. Diagnosis requires a careful physical examination by an experienced practitioner, because there aren't any imaging tests or blood tests to diagnose myofascial trigger points.

In conclusion, both Wesselmann and Shah suggest that some cases of chronic vulvar pain may arise from related pelvic conditions, making it very important for healthcare providers to take a thorough medical history and examine antecedents to patients' current pain condition.

Etiology of Vulvar Vestibulitis

Dr. Nina Bohm-Starke, of the Karolinska Institutet in Stockholm, Sweden, presented data on the pathophysiology of vestibular tissue in vulvar vestibulitis syndrome (VVS). In the first set of studies, Bohm-Starke took biopsies of vestibular tissue from women with VVS and healthy controls, and found that the tissue from VVS patients contained significantly more nerve fiber endings compared to that of the control group.

In a second set of studies, she wanted to determine if the erythemous (reddened) areas present in the vestibules of VVS patients could represent vasodilation, or increased blood flow to those areas. Using Laser Doppler Perfusion Imaging, she scanned areas of the vestibule in VVS patients and healthy controls. In VVS patients, Bohm-Starke found a gradual increase in blood flow from the anterior to posterior part of the vestibule, i.e., from the area adjacent to the urethra to the opening of the vagina. She did not, however, find this difference in blood flow in the control group. In the first study, Bohm-Starke had stained VVS tissue samples containing the overabundance of nerve fiber endings to test for CGRP (calcitonin gene-related peptide) and obtained positive results. Consequently, she proposed that increased blood flow in the vestibules of VVS patients might be due to the release of CGRP (calcitonin gene-related peptide), a substance considered to be the major cause of vasodilation in neurogenic inflammation. In summary, Bohm-Starke's findings indicate ongoing inflammatory mechanisms in the vestibules of women with VVS.

Dr. David Foster of the University of Rochester also presented data on the role of inflammation in VVS. He pointed out that vestibular tissue is unique embryologically, similar to the tissue of the mouth, and that it is necessary to take its unique identity into account in trying to determine the cause of VVS. Recent work from his research lab has focused on the role that fibroblasts (cells that produce scar tissue) may play in the inflammatory process. His studies have shown that fibroblasts taken from the precise area of pain in VVS patients exhibit vastly different cell behavior than those taken only one inch away from the site of pain. In addition, Dr. Foster is examining the role of genetics on the inflammatory mechanisms in VVS pain.

Treatment

Dr. Elizabeth Stewart of Harvard University presented an overview of vulvodynia treatments, noting that clinicians often use multiple treatment approaches for vulvodynia because the cause is unknown and there are no *proven* effective treatments. To date, there have not been any placebo-controlled treatment studies and most of our information comes from studies with small numbers of subjects. Nevertheless, clinicians have found certain treatments to be helpful in some patients. Stewart covered the most widely used treatments: topical estrogen; topical anesthetics, e.g. Lidocaine;

See NIH, page 7

NIH

(from page 6)

tricyclic antidepressants, such as amitriptyline; and anti-convulsants, such as Neurontin. She also referred to promising pilot data compiled by Dr. David Foster on a combined central and peripheral treatment approach, employing the tricyclic antidepressant desipramine and the topical anesthetic Lidocaine. (Foster recently received an NIH grant to carry out a controlled study of this treatment regimen.)

Other recommended treatments, often used in combination with some of the above, are: biofeedback, to reduce resting pelvic floor muscle tension; physical therapy, such as pelvic floor exercise and myofascial release; and a low-oxalate diet/calcium citrate regimen. Stewart reviewed several surgery studies reporting significant success rates in VVS patients, and noted that surgical procedures vary and the extent of necessary tissue removal is unclear. She recommends that the procedure be tailored to fit each individual case. Stewart also discussed the use of interferon for VVS, pointing out that this treatment has had disappointing follow-up results. Experimental approaches, such as decompression of pudendal, ilio-inguinal and sacral nerve roots and the administration of pudendal nerve blocks were briefly mentioned. In closing, Stewart stated that treatment success will remain limited until the pathophysiology of vulvodynia is established, and that promising research avenues are being pursued.

Alternative Therapies

Dr. Hope Haefner of the University of Michigan pointed out that, in the general population, more visits are made to alternative therapists than to doctors. She listed numerous alternative therapies that have been tried in treating vulvodynia: hydrotherapy (e.g., rinsing, ice packs), magnetic therapy, aromatherapy, guided imagery, healing touch, homeopathy, hypnosis, reflexology, herbal medicines; meditation, yoga, and tai chi. In addition to the lack of research studies on many alternative therapies, Haefner cited the following concerns about natural products: minimal efficacy, lack of quality control, side effects and drug interactions. In closing, Haefner emphasized that research studies are needed to determine which alternative approaches might be helpful in the treatment of vulvodynia.

Surgical Treatment

In his review of surgical treatment for vulvar vestibulitis (VVS), Dr. Jacob Bornstein of the Carmel Medical Center in Haifa, Israel, listed the advantages of surgery as 1) having the highest success rate of treatments, 2) not requiring prolonged periods of treatment, 3) providing the best chance for complete recovery, and 4) resulting in minimal recurrence of symptoms. He remarked that even though more conservative treatments are available, surgery is not necessarily the "end of the road," i.e., other treatments may still be tried after surgery. Bornstein emphasized that some surgeries do not produce acceptable results because of failure to remove enough tissue. He acknowledged there is a small risk of complications from surgery and cautioned that it is not an appropriate option for everyone. The groups with the highest failure rates contain women who experience 1) primary dyspareunia (pain with intercourse experienced from the very first time of intercourse) or 2) constant vulvar pain plus dyspareunia.

Comparative Treatment Study

Dr. Sophie Bergeron, from the Universite du Quebec a Montreal, presented results from her recent study on the long-term outcome of three different treatment interventions for vulvar vestibulitis (VVS). Seventy-eight VVS patients were randomly assigned to one of three treatment groups: group cognitive-behavioral therapy, electromyographic biofeedback, or vestibulectomy. Patients were assessed at pre-treatment, post-treatment, 6-month and 2.5 year intervals following treatment, utilizing several measures including gynecological examinations, structured interviews, standard pain questionnaires, and measures of sexual functioning and psychological adjustment.

Dr. Bergeron found that all treatment groups reported significant reduction in pain at the 6-month follow-up, however, the vestibulectomy group reported greater reduction in pain than the other two groups. All groups improved on measures of psychological adjustment and sexual function, but frequency of intercourse remained markedly below

See NIH, page 8

NIH

(from page 7)

community sample norms. Compared to the 6-month follow-up, all groups reported significant improvement on most measures after 2.5 years, suggesting continued improvement over time.

The Bergeron study also attempted to identify factors that might predict treatment outcome at long-term follow-up. In the cognitive behavioral therapy group, patients reporting higher pre-treatment pain also reported higher pain at the 2.5-year follow-up. In the biofeedback group, higher pre-treatment pain ratings and lower confidence in treatment were associated with higher pain levels at follow-up. In the vestibulectomy group, more negative sexual attitudes were associated with higher pain levels at follow-up.

Dr. Bergeron concluded that current surgical and behavioral therapies are effective in reducing the pain of VVS, but do not significantly alter the associated sexual impairment in these patients. These results indicate that a multi-disciplinary approach to the treatment of vulvar vestibulitis may be necessary to relieve both the physical and sexual consequences of the disorder.

New Pain Drugs

Dr. Don Manning, Executive Director, Clinical Research and Development at Celgene Corporation, gave a comprehensive overview of the state of drug development for pain conditions. Although there are upwards of 70 compounds currently in development for the treatment of pain, Manning noted that many are merely new formulations of existing compounds that have been used to treat pain for decades. He posed the question, "What would be the ideal characteristics of the next generation of pain-relief agents?" He answered that they would 1) produce a significant level of pain relief, 2) exert an anti-inflammatory effect, 3) modulate the neural activity responsible for painful symptoms and 4) not be too sedating. Also, because chronic pain patients usually need to take medication for an extended period of time, the ideal drug would not have any long-term safety issues. Additionally, it would be fast-acting and not lead to the development of tolerance, i.e., requiring larger dosages over time to produce the same pain relief. Lastly, he observed that it may be preferable for certain drugs to operate systemically and for others to be administered locally, e.g., topical anesthetics. Manning also reviewed the categories of available pain relief medications and their mechanisms of action, as well as new pain medications in the drug development pipeline.

Questions in Need of Answers

In her presentation, Dr. Libby Edwards of Wake Forest University covered all the critical issues facing vulvodynia researchers today. She began by clarifying that vulvodynia is simply a descriptive term for certain symptoms, not a "disease," and proceeded to generate the following questions. Is vulvodynia a single entity with one cause? Are there easily identifiable, distinct subsets? Is vulvodynia associated with inflammation? If so, is it due to tissue damage or is it neurogenic? Does vulvodynia involve central or peripheral processing? Which treatments work for vulvodynia? Edwards' presentation made it clear that there are still more questions than answers and that further research is desperately needed.

Conclusion

Drs. Maria Turner and Phyllis Leppert wrapped up the conference and invited questions from the audience. Turner reviewed some of the research findings presented and reiterated that progress has been made since the 1997 workshop. Leppert, acknowledging the presenters' enthusiasm in performing research on vulvodynia, noted that the condition is clearly deserving of the NICHD's attention and encouraged participants to submit research proposals for funding consideration. She "challenged" the attendees to take the information and ideas from the conference and organize educational symposiums at their own institutions and establish research priorities.

Following the workshop, NICHD staff issued a press release on vulvodynia and began work on a brochure for vulvodynia patients. Drs. Leppert and Turner will supervise the write-up of the conference proceedings and submit commentaries to the *Journal of Obstetrics and Gynecology.* ■

Prevalence

(from page 1)

were experiencing the pain at the time of the survey. Contrary to earlier assumptions, white and African American women reported similar incidence rates. However, Hispanic women were shown to be 80 percent more likely to experience symptoms compared to the other groups.

"The magnitude of this problem is largely unknown," said Bernard Harlow, PhD, a researcher in BWH's Obstetrics and Gynecology Epidemiology Center. "Our study is the first to suggest that this disorder affects an ethnically diverse group of women and may be a much larger problem than we ever thought." Based on survey data, the researchers conservatively estimate that approximately five percent of all women will experience this condition before age 25, and it is likely that the true figures are much larger. The good news, according to Dr. Harlow, is that one piece of data strongly suggests clinicians may have a potential indicator of vulvodynia symptoms. Though further analysis is required, the study showed that women who experienced pain upon first tampon use were seven to eight times more likely to have chronic vulvar pain later in life.

"These findings are extremely important given the lack of understanding and education surrounding vulvo-vaginal care," said co-author, Dr. Elizabeth Stewart, MD, a nationally recognized vulvodynia expert. "We are hard pressed to dispel the myth that vulvo-vaginal pain is just in a woman's head, despite the 10 million doctor's office visits for this problem that occur every year. This research tells women they are not alone – according to the data, upwards of 14 million women may suffer from vulvodynia during their lifetime."

The population assessment, based on 4,915 questionnaires sent to women age 18 to 64 in diverse Boston-area communities, also revealed that many women are challenged when it comes to diagnosis. About 40 percent of women surveyed chose not to seek treatment, even when the symptoms limited intercourse. More than 60 percent of respondents who sought treatment saw three or more clinicians.

"I spent many years in severe pain, seeking help from doctor after doctor, thinking I was the only one in the world who suffered from this condition," said Phyllis Mate of Washington, D.C. "Eventually I found a doctor who put me in touch with a small group of vulvodynia patients in my area. We decided to help ourselves and other women by creating an organization dedicated to raising public awareness of this condition." Mate co-founded the National Vulvodynia Association in 1994.

"Considering that we have likely underestimated the prevalence of this condition, there is a significant need to learn more about vulvodynia and educate both women and clinicians," concluded Harlow. "Fortunately, with the support of the NIH, we are allocating more resources toward further research and ultimately providing better care for patients." ■

NVA Partners With Pain Organizations

Did you know that one out of every three people live with pain and that it's the number one cause of disability in the United States? In an effort to raise awareness of the enormous impact of pain on our society, the American Chronic Pain Association (ACPA) is spearheading a national education campaign titled *Partners for Understanding Pain.* The NVA, along with forty-four organizations has partnered with the ACPA campaign designating September as *Pain Awareness Month.* The goal of the initiative is to reach several key audiences - chronic pain sufferers, the media, health care professionals and legislators - to create a greater understanding and awareness of the impact on pain on our economy, as well as the personal lives of individuals. The September 2002 campaign began with radio appearances broadcast to more than 12 million listeners and the creation of a

See PAIN ORGANIZATIONS, page 11

Wisconsin group organizes day of advocacy

On March 15th, nearly 100 vulvodynia patients, family members and health care providers attended an open forum organized by the NVA's Madison, Wisconsin support group. Keynote speaker, state representative, Sheldon Wasserman, M.D., gynecologist and obstetrician at Columbia St. Mary's Medical Clinic in Milwaukee, agreed that spending more tax dollars on vulvodynia research is merited and urged the group to take action by organizing meetings, lobbying local legislators, and writing letters to elected officials in the state capital and Washington, D.C. He encouraged the group to bring vulvodynia to the attention of the newly-elected governor of Wisconsin, Jim Doyle. Accepting this challenge, several support group members have already arranged to meet with Doyle's policy analyst in early May and are setting up a meeting with Congresswoman Tammy Baldwin (D-WI).

The NVA is grateful to Jane Elmer, Caroline More and other support group members whose hard work contributed to making the event a success. Thanks to the efforts of Caroline, vulvodynia was also covered in the health segment of the local NBC affiliate's evening news, in three local Wisconsin newspapers and on Wisconsin Public Radio. If you are interested in putting together similar events in your area, please contact Chris Veasley at chris@nva.org or 301-299-0775.

New Jersey Group Spreads the Word

Dear Reader:
After living with a great deal of discomfort for over four months, and being misdiagnosed and treated for a yeast infection, I was diagnosed with vulvodynia about two years ago by a vulvar pain specialist. This began my quest to learn as much as I could about the condition. When I was first diagnosed, I didn't want to belong to a "support group," but then I realized that I needed to hear that I was not the only woman with vulvodynia. Reaching out for help was the best choice I ever made. I remember the relief I felt after speaking with the leaders of the NJ Shore support group who knew exactly what I was going through.

Since this group began, the members have taken on many positive initiatives. In my case, I used outreach skills I learned in social work to schedule health care providers, specializing in gynecology, pain management, psychology, physical therapy and biofeedback to speak at our support group meetings. Just recently, some of us decided that we needed to 'get the word out' about vulvodynia to more health care providers in our area, and we compiled a list of all the gynecologists in our area. With the help of the NVA, we put together educational packets and distributed them to nearly 100 local providers. Although we started with gynecologists, we also plan to distribute information to primary care providers, urologists and pain management specialists, and medical school faculty. We followed up by making phone calls to these providers and received very positive responses to our mailing.

I hope that you will consider doing similar outreach in your area. Even though we all lead very busy lives, this is so important and long overdue. If women all around the country participated in disseminating information to health care providers in their area, more of us would be spared the pain and suffering caused by misdiagnosis. We can make a difference!

Sheryl R in NJ

(Editor's Note: If you want information to distribute to providers in your area, contact Chris Veasley at chris@nva.org or 301-299-0775.) ■

Shop Amazon.com To Help NVA

If you plan to shop at Amazon.com:
First go to www.nva.org and click
on a book cover on our home page.
(You don't have to buy the book.)
Five percent of the proceeds from
your purchases will go to NVA.
Thank You!

Research Participants Needed

Vulvodynia Study

Researchers at Johns Hopkins Hospital are looking for women to participate in research studies concerning the mechanisms of pain in vulvodynia, a chronic pain syndrome of the vulvar and vaginal area. If you are at least 18 years old and if you have been *diagnosed with Vulvodynia for at least 6 months* you might be an appropriate candidate for these research studies. Women who are pregnant or had a hysterectomy are not eligible. (Support: National Institutes of Health, National Vulvodynia Association; Principal Investigator: Ursula Wesselmann, MD, Dept. of Neurology, Johns Hopkins Hospital.) Info: 410-614-4517; women@bme.jhu.edu

(Editor's Note: The portion of the above research specifically studying dysesthetic vulvodynia in post-menopausal women is supported by an NVA research grant to Dr.Wesselmann at Johns Hopkins University School of Medicine, Baltimore, Maryland. The NVA Research Fund is made possible by the generosity of our donors.)

Quality of Life Survey

Dr. Amy Kaler, a sociologist studying the impact of early-onset vulvodynia on women's lives, has created a web-based survey for women interested in contributing to this project. The survey consists of a series of open-ended questions about personal biography, self-image, relations with significant others, interaction with medical practitioners, life choices and expectations for the future. Respondents can answer in as much detail as they wish, and participation is anonymous. For more information, see www.humanities.ualberta.ca/survey/vulvodynia.htm. Any questions or comments should be directed to Dr Kaler at akaler@ualberta.ca. ■

Pain Organizations

(from page 9)

resource-rich Web site that was visited more than half-a-million times that month. Moving forward, the group plans to release media kits on selected subjects related to pain, such as 'The Cost of Pain' and 'Women and Pain.' To join the efforts of *Partners for Understanding Pain*, visit www.theacpa.org to print letters that can be sent to both local and national elected officials.

Also this past winter, the American Academy of Pain Medicine (AAPM) in cooperation with the National Pain Foundation launched a pain awareness campaign called *Untying the Knot.* (See www.painconnection.org). Comedian Jerry Lewis kicked off the campaign at the AAPM annual meeting last February in New Orleans, Louisiana. The NVA staffed an exhibit booth at the meeting, answering questions and disseminating educational materials about vulvodynia to interested health care professionals.

(Editor's Note: The next medical meeting the NVA will exhibit at is the American Physical Therapy Association annual conference, to be held in Washington, D.C. in June 2003.) ■

THE NVA NEEDS YOUR CONTRIBUTION

I WANT TO SUPPORT THE NVA AND RECEIVE MORE INFORMATION ON VULVODYNIA.

Name ______________________________

Address ______________________________

____

Phone (H) ____________________ **(O)** ____________________

E-Mail Address ______________________________

The NVA needs the support of everyone: patients, families, and health care providers.

☐**$40** ☐**$60** ☐**$100** ☐**Other $** __________

☐**$60 Health Care Professional**

☐**Yes, I would like to be contacted by other NVA supporters in my area.**

☐**No, I do not want to be contacted. Please keep my name confidential.**

Please send your check or money order, payable to NVA, together with your name, address and telephone number to: NVA, P.O. Box 4491, Silver Spring, Md. 20914-4491.

N
V
A

NATIONAL VULVODYNIA ASSOCIATION
P.O. Box 4491 ❖ Silver Spring, MD 20914-4491