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NVA News

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Is Vulvar Vestibulitis Associated with HPV?

By Jacob Bornstein, M.D., M.P.A.

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I first became interested in exploring the association between vestibulitis and the human papilloma virus (HPV) because several studies that investigated this possible association produced contradictory results. After I completed a fellowship at Baylor College of Medicine in Houston, Texas, my research laboratory began working on various molecular tests to detect DNA from the human papilloma virus – an extremely sensitive and accurate method for detection of the virus.

I am sure that the readers of *NVA News* need no explanation of the nature of vestibulitis, the major cause of dyspareunia. However, a few introductory remarks about HPV are necessary. HPV is an extremely important virus, as it is now regarded as the cause of cervical cancer and of some types of vulvar and vaginal cancer. In recent years the mechanism by which the virus leads to cervical cancer has been, for the most part, determined. We now know that two of the genes present in the human papilloma virus can, under certain circumstances, produce proteins called onco-proteins, which are capable of destroying the p53 protein, which happens to be an important defense mechanism of the cell against becoming cancerous. These types of HPV are therefore referred to as oncogenic. Hence, we now realize that detection of the oncogenic types of HPV in a patient is an important warning signal that warrants special evaluation and follow up, even in the absence of cervical cancer or precancer.

HPV has long been known to also cause other, non-malignant genital conditions, such as condylomata

See HPV, page 3

NVA Fundraiser Raises $30,000 for Research

Hundreds of donors contributed to our fall 2000 research fund-raising campaign, and as a result, the NVA has awarded two $15,000 grants to researchers from Cornell University and the University of Rochester. Both groups of researchers have been involved in the treatment and study of vulvar pain conditions for many years and will be expanding on research findings from their recent investigations into the causes of Vulvar Vestibulitis Syndrome.

The first grant recipients, Steven Witkin, Ph.D., and William Ledger, M.D., are researchers at Cornell University's Weill Medical College in New York City. Dr. Ledger is the former chairman and currently Professor Emeritus in the Department of Obstetrics and Gynecology and Dr. Witkin is a professor in the Department of Obstetrics and Gynecology, as well as the director of the Division of Immunology and Infectious Disease. Previous research from this team has shown that a high percentage of women with vulvar vestibulitis have a polymorphism (small change) in a gene that is responsible for terminating inflammation (interleukin-1 receptor antagonist). (*See NVA News, Spring 2000*)

See RESEARCH, page 10

LETTER TO THE EDITOR

Dear Editor:

On a recent trip to Washington, D.C., I had the pleasure of meeting Phyllis Mate and Harriet O'Connor. In addition to being founders of the NVA, they continue to volunteer countless hours consulting with medical professionals, accumulating resource materials, and promoting research on vulvodynia.

I know firsthand the trauma of coping with vulvodynia, and I remember too well how desperate I was when I first connected with the NVA. By that time, like most of us, I had seen eight doctors who had no answers for me. After spending thousands of dollars on doctors, the best investment I made in my own care was joining the NVA and purchasing the back issues of the newsletters. Because of the NVA and a doctor who was willing to read the newsletters, I have experienced what I consider to be a miracle in my life. Today I am living successfully with vulvodynia. There were days that I doubted this would ever happen. Do I still have bad days? Indeed. But I also have many good ones.

I continue to support the NVA because I want to pass along the benefits I've received. Unfortunately, there will always be women out there who need the same help that I did. I believe in the mission of the NVA and the people behind it. We owe Phyllis and Harriet tremendous thanks for rising above their own personal challenges to reach out to the rest of us. They are wonderful role models who volunteer their time to give far more then they receive. May they hear the echoes of the applause from the women and families who have benefited from their vision and dedication.

Sincerely,
Jane Elmer,
Plain, Wisconsin

Dear Jane:
We're fulfilling our promise to print your letter. Your appreciation is our reward. Thanks so much for your kind words.
Sincerely,
Phyllis and Harriet

Dear Editor:
After two years, I still have not had positive results with the low-oxalate diet and calcium citrate. Do you know of any scientific research on the success of this approach for vulvodynia?
S.M.

Editor's Note: To date, there have not been any controlled studies on the effectiveness of this approach in the treatment of vulvar pain. Recent research did not find a significant difference between urinary oxalate levels in vulvodynia patients and control women (See Baggish, M. Am. J. Obstet. Gynecol 1997; 177:507-11). ■

Vulvar Health Awareness Month Established

In March 2001, Vulvar Health Awareness Month (VHAM) was celebrated in the United States and many other countries including the United Kingdom, Australia and Canada. VHAM was initiated in the United States by Debby Herbenick of the US Vulvar Health Initiative, as part of an ongoing effort to promote the importance of regular vulvar self-examinations, to inform the public about treatment of vulvar disorders, and to generate research on prevention and treatment. One of Herbenick's goals is to eliminate the stigma attached to vulvar disorders so that women will feel comfortable seeking medical help.

As part of VHAM, physicians and other healthcare experts in several cities gave presentations on vulvar health at lectures organized by volunteers. Among those participating were Richard Marvel, M.D., University of Maryland; Thomas Julian, M.D., and Janice Singles, Psy.D., University of Wisconsin; and Barbara Anderson, Ph.D., Ohio State University. Allan Gordon, M.D., director of Toronto's Wasser Pain Management Centre, and Gordon Davis, M.D., director of the Arizona Vulvar Clinic in Phoenix have also been instrumental in their support of the awareness campaign and plan to be involved in future events. The US Vulvar Health Awareness Initiative has developed into a year-round campaign, and March will continue to be recognized as Vulvar Health Awareness Month every year until the campaign's goals are met. For more information, visit www.vulvarhealth.org or write to US Vulvar Health Awareness Initiative, PO Box 6762, Bloomington, IN 47404 (please enclose a self-addressed stamped envelope for a reply). ■

HPV

(from page 1)

acuminata, the small sexually-transmitted genital warts that may spread over the vulva, vagina and cervix. In all of the above conditions, the lesions caused by HPV are not painful. Consequently, until a few years ago, no one considered that there might be an association between HPV and vestibulitis – a painful condition of the vulvar vestibule.

As the cause of vulvar vestibulitis has never been determined, many hypotheses have been raised over the years suggesting a possible infectious etiology for this condition. In the past, for example, Candida albicans ("thrush" – a fungal infection) was implicated as a causative agent. However, HPV was not considered a candidate until the classic study by Horowitz (1989) showing that vestibulitis associated with histopathologic evidence of HPV infection responded favorably to the anti-viral substance, Interferon. There is a problem with this diagnostic process however; it is very difficult to confirm a diagnosis of HPV infection by histopathologic means, because this type of diagnosis of HPV infection is far from being sensitive or specific. Therefore, since HPV infection cannot be diagnosed accurately by histopathologic techniques (i.e., microscopy), and since HPV cannot be isolated and grown in culture, the only satisfactory way of diagnosing HPV infection is by using molecular techniques to detect fragments of DNA that belong to the virus.

Indeed, the initial molecular studies did demonstrate the presence of human papilloma virus DNA in a high percentage of specimens of vulvar vestibulitis, suggesting that HPV was the cause of the syndrome. Table 1 (see p. 8) summarizes the studies on detection of HPV-DNA in cases of vestibulitis. These studies showed contradictory results, with HPV detection rates ranging from 5.3 percent to 100 percent. Therefore, in order to draw any conclusion from these data, one must analyze the various articles in depth, and eliminate those in which there was inadequate specimen collection or some other faulty technique.

We suggest that about half the cases with severe vulvar vestibulitis may be caused by HPV infection.

The first published study by Turner and Marinoff (1988), documented HPV-DNA in 100 percent (seven of seven) of vulvar vestibulitis cases, using a technique called southern blot analysis. Southern blot is a molecular test that was once considered the gold standard of HPV testing.

In the second study by Umpierre et al (1991), the technique used for HPV detection was PCR – polymerase chain reaction. This technique is now considered a more sensitive HPV-DNA detection method. It became available once the appropriate technology for

See HPV, page 4

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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 practittioner to determine which course of treatment or medication is appropriate for you.

HPV

(from page 3)

multiplication of small DNA fragments became available. This study found HPV-DNA in specimens from 11 of 13 women with vestibulitis.

While these two papers strongly support the role of HPV in vestibulitis, the third study by Wilkinson et al (1993), also using PCR for HPV detection, found a low rate of HPV infection in vestibulitis specimens. In this study, of 21 specimens with adequate DNA, HPV was identified in only three instances (14.3 percent). However, the technique used may have been inadequate for its purpose; the specimens tested were not fresh frozen but rather fixed in paraffin blocks, and the ages of the patients ranged from 20 to 72 years, casting doubt on the diagnosis of vulvar vestibulitis, as this disease usually affects young women. In addition, the severity of the vestibulitis in these patients was not specified and could have been very mild. Furthermore, the technique could have missed the detection of some HPV types, as they checked only for specific types of HPV.

Bazin et al (1994) performed a larger analysis, based on 57 women with vestibulitis. Fresh tissues were obtained, but HPV was detected by PCR in only three cases (5.3 percent). However, a problematic issue in this study was that the PCR products were not evaluated directly after the PCR technique, but rather after one more test named hybridization, which detects only a few of the more than 100 HPV types.

We therefore believe that the studies by Wilkinson and Bazin, showing a "low rate" of HPV presence, were not convincing. There were several flaws in these studies, including the fact that they searched only for specific HPV types, and did not take into account the possibility that vulvar vestibulitis may be associated with other HPV types, or with an as yet un-sequenced HPV type. Nevertheless, these publications led some of the experts to believe that vestibulitis was not associated with HPV infection.

However, two large-scale studies, also quoted in the table, do lend support to the possible association of HPV infection and vestibulitis. The first study was conducted by our group (Bornstein et al, 1996). In this study we carried out PCR determination of HPV on 86 women with severe vestibulitis who had undergone perineoplasty, including surgical removal of the sensitive vestibule. These patients were compared with a group of control patients, comprised of 25 age-matched patients without dyspareunia, undergoing vaginal operations for various benign causes or undergoing repair of an episiotomy following childbirth. This study found HPV in 46 cases (54 percent) of patients diagnosed with severe vestibulitis. Only one woman of the 25 asymptomatic controls (4 percent) had HPV-DNA in the vestibule. The difference was highly significant. We repeated HPV testing of vestibulitis in two other studies, and found similar HPV detection rates.

The recent study by Morin et al (2000) also supports our results showing that HPV is detectable in 54 percent of women with severe vestibulitis. Using PCR, these authors found an HPV infection rate of 50 percent in a group of patients with vulvar vestibulitis. The group included patients with severe vestibulitis of short duration, i.e., three to six months.

I believe that these latter two studies deserve careful consideration. An infection rate of 50 percent with HPV – a sexually transmitted virus – in women with vestibulitis is significant, especially if one considers that the dyspareunia associated with vestibulitis causes the patients to refrain from frequent, promiscuous intercourse.

Based on these considerations, we suggest that about half the cases with severe vulvar vestibulitis may be caused by HPV infection, and that studies which found low HPV infection rates either tested patients with milder forms of vestibulitis or used techniques that were inadequate.

That conclusion leads to another issue. What is the significance (if any) of the presence of HPV in cases of vulvar vestibulitis? One implication, discussed in the study by Morin et al, is that the HPV infection rate rises with the severity of vestibulitis. Our group obtained similar findings when we studied a subgroup of patients with a severe form of vestibulitis that we named "Vestibulodynia." In these patients the vestibular pain never goes away, i.e, they report constant vestibular pain apart from the exacerbation of pain during intercourse. These women were six years older than those with "pure" vestibulitis, their HPV infection rate was higher, and in 64 percent surgery failed to cure the problem. The reason for the association of

See HPV, page 8

Chronic Vulvar Pain and Sexual Functioning

An interview with Irv Binik, Ph.D and Sophie Bergeron, Ph.D

Dr. Binik is a professor of psychology at McGill University and the director of the Sex and Couple Therapy Service of the Royal Victoria Hospital, Montreal, Canada. Dr. Bergeron is a clinical psychologist and assistant professor of sexology at the Université du Québec à Montréal.

How would you describe the type of work you do?

Binik: My work consists primarily of research and teaching. My major research interest is trying to understand the different types of pain women experience during sexual intercourse. I spend about 20 percent of my time with clients or in clinically related activities.

Bergeron: My professional activities focus on research and teaching, but I also have a part-time private practice specializing in the treatment of dyspareunia and vaginismus. My research interest is mainly in the area of vulvodynia, more specifically the evaluation of treatments for vulvar vestibulitis.

Can you give a brief overview of "normal" sexual functioning?

We try to avoid the word "normal" when discussing the sexuality of both women and men. Our working definition of a "normal" sex life is one that is satisfying to the individual or couple. This varies dramatically for individuals, depending on age, background, partner, sexual orientation, gender identity and a host of other factors. We are opposed to telling anyone that they should be having sex more or less frequently based on "what everyone else is doing."

Despite the enormous number of popular surveys, we haven't had good statistics about frequency of sexual activity and sexual satisfaction until very recently. Currently, our best source of information is a representative survey of North American men and women ages 18-59 that was carried out by Laumann and colleagues (1994). This survey has been published in two forms, a detailed academic report entitled *The Social Organization of Sexual Behavior* and a more popular version, *Sex in America*. According to this recent survey, women in the 25-29 age group report engaging in sexual intercourse an average of 7.5 times per month. By comparison, in one of our studies we found that women with vulvar vestibulitis in the same age range report engaging in intercourse about 4 times per month.

Based on this recent survey, how satisfied are women in the general population with the quality of their sexual lives?

According to Laumann's survey, about 40 percent of North American women are extremely satisfied, both physically and emotionally, with their sex lives. Regarding the other 60 percent, there are many factors that impact on sexual satisfaction; for example, physical or psychological conditions that interfere with sexual functioning (in the woman or her partner), relationship difficulties, stress, etc. Considering the widespread prevalence of these factors in many women's daily lives, it is not surprising that 60 percent of respondents were not extremely satisfied with their sex lives.

What is the accepted definition of sexual dysfunction?

The accepted definition of sexual dysfunction comes from the *Diagnostic and Statistical Manual of the American Psychiatric Association*. It defines sexual dysfunction as interference with typical aspects of the sexual response cycle, i.e. desire, arousal, or orgasm. There is a separate category entitled "sexual pain," i.e., genital pain which interferes with sexual intercourse. Although problems such as vulvodynia and vulvar vestibulitis are not specifically mentioned in this classification, they would typically be included as such. Our view is that that the various types of vulvodynia should not be considered sexual dysfunctions, but rather genital pain syndromes that interfere with sexuality. As we have said many times, "the pain is not sexual — the sex is painful". This distinction has important implications for treatment and research.

How would you describe the sexual problems experienced by women with vulvar vestibulitis?

In cases of vulvar vestibulitis, the most significant problem is pain

See SEXUAL FUNCTION, page 6

Sexual Function

(from page 5)

during vaginal penetration. The pain, usually limited to the vestibule, is typically described with adjectives suggesting burning or cutting sensations. These women may also feel deeper vaginal or pelvic pain that may be unrelated to the vulvodynia.

After a few repeated experiences of pain, fear of pain or any pain-eliciting activity usually develops, and this is often followed by some degree of avoidance of sexual activity. From a sexual point of view, the expectation or experience of repeated pain during intercourse may lead to interference with orgasm, reduced arousal and/or diminished desire. For example, one of our studies (Meana et al., 1997) showed that women with vulvar vestibulitis reported significantly lower levels of desire and arousal as well as significantly fewer episodes of intercourse. They also reported being less successful at achieving orgasm through oral stimulation and sexual intercourse.

Another response reported by these women is the contraction of the vaginal muscles in response to the pain, a condition known as vaginismus. These contractions can make vaginal penetration impossible. We don't know the proportion of women with vulvodynia who suffer from this problem. Although all the responses we have discussed can be termed sexual dysfunction, they are, in our view, natural psychological/physical responses to the experience of pain paired with penetration.

Do women with dysesthetic vulvodynia experience the same sexual problems as women with vulvar vestibulitis?

The sexual problems experienced by women with vulvar pain are quite variable and there are no studies that differentiate between the responses of women with vulvar vestibulitis or dysesthetic vulvodynia. Our clinical experience suggests that women with dysesthetic vulvodynia are generally more emotionally distressed than women with vulvar vestibulitis since their pain occurs even when there is no direct stimulation of the genital area. In many women with dysesthetic vulvodynia, the pain not only interferes with their sex lives; it may also affect their ability to engage in other important daily activities such as walking or sitting.

Pain medications such as tricyclic antidepressants and anticonvulsants are often prescribed for the treatment of vulvodynia. Do these medications affect sexual functioning?

Some individuals treated with tricyclics such as amitryptiline (Elavil) have reported experiencing less sexual desire and more difficulty reaching orgasm. However, these women were taking antidepressants as a treatment for depression which typically requires much higher doses than those used in the treatment of vulvodynia. So we don't know if the smaller doses prescribed for vulvodynia have any sexual side effects at all. As for the newer anticonvulsants that are now being prescribed in the treatment of vulvodynia, e.g., Neurontin, no studies have been conducted to date to evaluate their side effects on patients' sexual functioning.

What kind of psychological therapy do you think is the most helpful to vulvar pain sufferers?

We generally recommend the use of cognitive-behavioral pain control techniques to reduce or eliminate pain. These include pain monitoring, relaxation, education about vulvar pain and its impact on sexuality, distraction techniques, coping strategies such as learning to diminish catastrophic thinking, and other methods to help decrease the fear of pain and penetration. Apart from the obvious goal of reducing vulvar pain, this therapy focuses on helping women to conceptualize their pain as a multidimensional problem influenced by many factors — their thoughts, emotions, behaviors and couple interactions — all factors over which they have some degree of control. Also, we typically recommend pelvic floor physical therapy, including biofeedback, to deal with any muscular components of the pain. We have been experimenting with other methods of pain control such as hypnosis and acupuncture. As the pain lessens, we typically use sex therapy techniques to try to "rehabilitate" aspects of the sexual response cycle that have been negatively affected. If all attempts to control the pain without surgery fail, then we recommend a vestibulectomy, but only for women with vulvar vestibulitis.

When you see clients with sexual problems, do you usually see them with a partner? How can partners help?

It is often a good idea to see a woman with her partner since having him actively involved in the therapy is an advantage. This affords the partner an opportunity to learn more about vulvodynia, which is a key factor in providing support. The partner can also partici-

See SEXUAL FUNCTION, page 7

(from page 6)

pate in some homework exercises aimed at reducing the fear of pain and the fear of penetration. Finally, involvement can give the partner an outlet for his emotional suffering in this frustrating situation. A partner's participation is not necessary, however, and we do see women alone and in women's groups. Some women do not have partners or do not wish to get involved with someone before eliminating their pain.

In our treatment study, cognitive-behavioral therapy was carried out in a group format; six to eight women per group met once a week for 10 sessions. We found this group format to be very popular because all the women suffered from similar problems and provided each other with a lot of emotional support.

Does the length of time a woman has suffered from vulvar pain affect the outcome of sex therapy?
Our treatment study suggests that the duration of pain has no impact on the outcome of treatment.

Most women with chronic vulvar pain learn to avoid sexual intimacy. Can this response be reversed after the pain is reduced?
One of the difficulties with all chronic pain is that after the pain has been reduced or eliminated, some of the associated disability still remains. This is as true of back pain and resuming work as it is of vulvodynia and sexual intercourse. For some, the resumption of sexual activity happens immediately and effortlessly; for others, a gradual re-learning process is necessary to break the association between sex and pain. Some vulvar pain patients may need to see a sex therapist to facilitate the re-learning process.

In our treatment study, which focused on severe cases of vulvar vestibulitis, we found that general sexual functioning seemed to improve after undergoing either a behavioral or surgical pain-reduction intervention. However, frequency of intercourse did not increase significantly after completion of treatment, and still had not increased at a two and a half year follow-up of study participants. This may indicate that sexual counselling should be recommended more often to help improve the sex lives of women whose vulvar pain has diminished or disappeared. It may also mean that women who have suffered from vulvar vestibulitis for a number of years have had to modify their sexual activities to take the focus off intercourse; once the pain disappears, they may not feel the need to engage in intercourse more often than they used to when they had pain.

Do you have any advice for women who have been recently diagnosed with vulvar vestibulitis or dysesthetic vulvodynia?
Our basic advice is not to give up. Although we have a lot to learn about treating chronic vulvar pain, persistence does seem to pay off. There are a number of available treatments and although we can't predict in advance which treatment will help which woman, many patients have been helped.

What were the results of your study that compared treatments for vulvar vestibulitis?
Our study compared three treatments for vulvar vestibulitis: 1) a combination of group cognitive-behavioral pain management and sex therapy, 2) pelvic floor biofeedback, and 3) vestibulectomy (surgery). In this treatment study, we found that group cognitive-behavioral therapy resulted in an average 38 percent reduction of pain, and either totally eliminated or significantly reduced the pain in 40 percent of the participants. Biofeedback produced very similar results. Vestibulectomy had the highest success rate, in that 70 percent of participants reported either a complete elimination or substantial reduction of pain during intercourse.

Based on our clinical experience, however, we have seen that some women are not interested in undergoing an invasive intervention. For these women, we have found that a combination of treatment approaches — for example, cognitive-behavioral therapy AND physical therapy/biofeedback — increases the chance of a successful outcome.

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HPV

(from page 4)

HPV with the more severe cases of vestibulitis has not been elucidated. Possibly, the virus itself increases the sensitivity of the tissue, or perhaps persistence in the tissue is a hallmark of a defective immune response of a particular individual.

Another possible implication of the association of HPV and vestibulitis is that therapy with antiviral agents may be appropriate for patients with vestibulitis. Treatment of vestibulitis with Interferon – an antiviral substance – has yielded variable results. Perhaps, if interferon treatment were used only in women with HPV-positive vestibulitis, a more successful outcome would be obtained. Other anti-HPV agents that are currently being researched, such as the Imiquimod (Aldara) derivatives, may also warrant therapeutic trials in vestibulitis patients.

This review would not be complete without mentioning that in our 1996 study, we also investigated the role of two other viruses in vulvar vestibulitis – Herpes simplex virus (HSV) and Cytomegalovirus (CMV). The reason for performing the analysis was that HSV is associated with painful vulvar lesions and CMV infection is a common genital infection as well. However, the findings did not indicate that these two viruses play any role in vulvar vestibulitis syndrome.

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See HPV, page 9

Table 1:

Detection of HPV DNA in vulvar vestibulitis: a literature review

Author (year)	Detection Method	Total No. Specimens	No. with sufficient DNA	No. HPV positive cases (% cases with sufficient DNA)
Turner (1988)	Southern blot	7	7	7 (100)
Umpierre (1991)	PCR	13	13	11 (85)
Wilkinson (1993)	PCR	31	21	3 (14.3)
Bazin (1994)	PCR	57	57	3 (5.3)
Bornstein (1996)	PCR	89	86	46 (54)
Morin (2000)	PCR			(50%) in severe cases lasting < 6 months

HPV

(from page 8)

virus integration site into the human genome is present in vulvar vestibulitis. *Eur J Obstet Gynecol* 2000; 89:173-176.

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Vulvodynia Gains National Attention

On Valentine's Day 2001, Jennifer Berman, M.D., and Laura Berman, Ph.D., appeared on the Oprah show to discuss *For Women Only*, their new book on female sexuality. The Bermans gave reasons why so many women lack sexual desire and suggested possible solutions for women who want to reclaim their sex lives. After the interview, a member of the audience asked a question about pain after intercourse, leading the doctors into a discussion of vulvodynia. The Bermans acknowledged that painful intercourse is a common female sexual problem and promoted the NVA as an excellent resource on the subject. (If you would like to watch a short clip from the February 14th broadcast of the Oprah show or learn more about the topics discussed, visit http://www.oprah.com/tows/pastshows/tows_past_20010214.html.)

Immediately following the show, Oprah's producers established a link from oprah.com to the NVA's web site (www.nva.org), and within one week, our web site received more than 10,000 hits (we normally receive about 4,000 hits per month). "The response to the Oprah show has been overwhelming," said NVA Executive Director Phyllis Mate. "It just goes to prove that there are thousands of women suffering with these conditions, even though they're not aware that there's a name and diagnostic category for them." Subsequently, the NVA has been in contact with the producers of this segment, sending information on vulvodynia and suggesting topics for a future show. If you would like to e-mail the Oprah show about your experience as a vulvar pain patient, you can do so by visiting http://www.oprah.com/email/reach/email_reach_fromu.html.

A few months earlier, Christin Veasley, the NVA's Director of Research and Development, was featured on Oxygen media, a cable station devoted to women's issues. She appeared on a women's health program with two sex therapists, Leonore Tiefer, Ph.D., and Janell Carroll, Ph.D., to discuss the topic of female sexual dysfunction. Christin was interviewed about her experience as a vulvar pain patient and discussed the impact of her pain syndrome on her sexuality. The reaction to the show was so positive that the producer asked Christin to consider participating in another program on female sexuality later this year. ■

NVA To Exhibit at ACOG's Annual Meeting

For the first time, the NVA will exhibit and staff a booth at the annual meeting of the American College of Obstetricians and Gynecologists (ACOG), April 28th thru May 2nd 2001 in Chicago. This is one of the largest medical conferences in the US, drawing more than 5,000 attendees across the US and Canada. Our intention is to distribute information on vulvodynia to thousands of health care professionals and to give this women's health issue a visible presence at the conference. We'd like to thank our longstanding benefactor, Mona Schlossberg, for her generous donation that has made our participation possible.

Research

(from page 1)

With the NVA's research grant, Drs. Witkin and Ledger will now analyze the potential role of the gene responsible for initiating the inflammatory response (interleukin-1). Research studies on individuals with other chronic inflammatory disorders have shown that the most prolonged inflammation occurs in individuals with specific alterations in BOTH the interleukin-1 and interleukin-1 receptor antagonist genes. The proposed study will involve testing at least 50 women with vulvar vestibulitis and an equal number of control women over a one-year period. With the data from their new study, Drs. Witkin and Ledger hope to formulate novel treatments for vulvar vestibulitis based on correcting the immune imbalance.

The second recipient, David Foster, M.D., is the medical director of Obstetrics and Gynecologic Ambulatory Care at the University of Rochester Medical Center. He is the author of several articles and chapters on vulvar pain and has treated many vulvodynia patients. Dr. Foster has proposed that Vulvar Vestibulitis Syndrome may be characterized as a neuro-inflammatory condition with a mix of genetic and environmental attributes. With a previous NVA grant, Dr. Foster completed preliminary studies on the relationship of cytokines (pro-inflammatory substances) and Substance P (a neurotransmitter) in vulvar vestibulitis patients and asymptomatic controls.

The study found an inverse relationship between cytokines and Substance P in tissue samples of vulvar vestibulitis patients, depending on the vulvar region sampled. In certain tissue samples from vestibulitis patients, higher than control levels of pro-inflammatory cytokines were associated with lower than control levels of Substance P. Utilizing two independent assays, low substance P levels were found both in the nerve endings and in the tissues surrounding the nerves. Assuming that this finding is correct, it suggests that therapeutic blockade of pro-inflammatory cytokines may be a more effective treatment than therapeutic blockade of Substance P in vulvar vestibulitis patients.

Dr. Foster has continued this line of research utilizing tissue cultures and molecular techniques. He has discovered by culturing the fibroblast (a type of cell that produces scar) that the fibroblast acts in a peculiar way immunologically in vulvar vestibulitis patients. Fibroblasts taken from the precise area of pain exhibit vastly different cell behavior than those taken only one inch away from the site of pain, i.e., immunologically, they behave very "aggressively" in the area of vestibulitis pain. In asymptomatic women, fibroblasts do not exhibit this difference between vulvar sites. With the current NVA grant, Dr. Foster's team will study the mechanism of this difference by testing for genetic differences in cytokine genes as well as melanin genes and relating the genetic findings to observations in cell culture. Dr Foster proposes that the identification of certain inflammatory substances released from the relevant fibroblast cells, for example, COX-2, may prove to be a good target for drug therapy.

The NVA has established a permanent Research Fund and continues to accept donations for this purpose. If you would like to make a donation to be used solely for research funding, please contact Phyllis Mate at 301-299-0775 or mate@nva.org. ■

Survey Participation on the Internet

If you are interested in helping to generate much needed information on vulvar pain disorders, please visit these internet sites and complete these short surveys:
http://www.vulvodynia.com/survey1.htm
http://www.newshe.com/survey.shtml

Thank You!

We would like to express our appreciation to Enterprise Rent-A-Car (www.enterprise.com) and the Cora and John Davis Foundation for their recent donations to the NVA.

The Support Corner

Wisconsin Support Group Forum

On March 17, 2001, the Wisconsin support group sponsored a forum in Madison to focus attention on vulvar disorders. Thomas Julian, M.D., professor in the obstetrics and gynecology department, University of Wisconsin Hospital, delivered an in-depth presentation on vulvar dermatology. Following his lecture, a panel of four vulvodynia support group members shared their stories, frustrations and hope for the future.

In addition to hosting this event, the Wisconsin group also worked on a public awareness campaign that was two-fold. The group members distributed NVA brochures, with a specially tailored insert for Wisconsin residents, to physicians and clinics statewide. Secondly, they sent press releases and letters to the editor to more than 50 media sources in the state. The letter, provided by NVA Executive Director Phyllis Mate, emphasized the need for the medical community and the public to recognize vulvodynia as a serious women's health issue.

New Jersey Support Group Meetings

Monmouth Medical Center (MMC) in Long Branch, New Jersey, (mid coast shore area) will be sponsoring the Shore Vulvodynia Support Group meetings. They will be held on the first Tuesday of each month between 7 and 9 PM at the hospital. In addition to providing emotional support, these meetings are an opportunity to share information and listen to presentations by healthcare professionals. The support group is trying to create awareness of vulvar disorders in the community. Anyone interested in attending these free meetings can register through MMC at 732-923-6990.

For more information, you can contact Suzanne Novak @732-988-8725 or Ellen L. Johnson @732-531-0272, or visit their web site at http://www.geocities.com/svsg_newjersey/.

Editor's Note: We would like to feature The Support Corner in future newsletter issues. If you are interested in publicizing information on vulvodynia support programs or publicity initiatives in your area, please e-mail your submission to mate@nva.org or mail it to Newsletter Editor, PO Box 4491, Silver Spring, MD 20914. ■

Back Issues Available To Subscribers

If you would like to purchase back issues of the newsletter, please visit our web site, www.nva.org, or call 410-686-7011, request a resource list and we'll mail one to you. Alternately, you may request a resource list by writing to:

NVA Newsletters
P.O. Box 4491
Silver Spring, MD 20914

Send Us Your E-mail Address

The NVA would like to be able to establish communication with our supporters by e-mail. This will help us notify you about breaking news such as the recent Oprah show during which her guests discussed vulvodynia. Eventually, if we collect enough e-mail addresses, we hope to offer an e-mail version of the newsletter that would be available to you the same day it's printed. You can be assured that we will not divulge your e-mail address to anyone outside of the NVA.

If you are interested in receiving e-mail communications from the NVA, please send an e-mail to list@nva.org. Please send your e-mail from the e-mail address that you want us to use for communicating with you, and simply type the word SUBSCRIBE in the subject line. See you in cyberspace!

THE NVA NEEDS YOUR CONTRIBUTION

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

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Address_____

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Phone (H)_____ **(O)**_____

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

- ❑ **$35** ❑ **$50** ❑ **$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.

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