

## Treating Vulvodynia

*Questions and Answers With David C. Foster, M.D.*

*Dr. Foster is director of the division of general gynecology at Johns Hopkins Hospital in Baltimore, Md. and a member of the NVA Medical Advisory Board. He has published several recent articles on vulvar pain, and has worked extensively with vulvodynia patients.*

**NVA:** Do you think that vulvodynia is increasing in the population?

**DCF:** I think it is a hidden disorder that has existed for a long time. The first written records of painful intercourse were in Egyptian papyrus and the Talmud. Vulvodynia appears to have escalated in the last decade, but I think that's because more physicians are beginning to recognize the disorder.

**NVA:** Would you give us your definition of vulvodynia and vulvar vestibulitis?

**DCF:** Vulvodynia as defined by the ISSVD is adequate: chronic

vulvar pain lasting six months or longer and characterized by burning. It is a general vulvar pain and would encompass several defined disorders. Vulvar vestibulitis is a subgroup of vulvodynia. It is demonstrated by a very precise diagnostic evaluation, with allodynia (pain upon touch) localized to the vestibule.

**NVA:** Is inflammation required to make the diagnosis?

**DCF:** No, it is not necessary to make the diagnosis. I do think that vestibulitis has an associated change that can appear inflammatory at times. It is often intermittent. Erythema (redness) is

probably more a marker of vasomotor instability.

**NVA:** How would this occur?

**DCF:** Our hypothesis is that this vasomotor instability involves alterations in peripheral nerve activity in the vestibule. At this time there is a particular type of nerve called a capsaicin-sensitive sensory efferent. Efferent nerves carry impulses away from the brain and afferent nerves carry impulses to the brain. With "sensory efferent" nerves, conduction can go both to the brain and back to the tissue. This phenomenon, of having the nerve impulse return and change the state of the tissue, results in vasomotor

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## NVA forms support network

We are pleased to announce the formation of the NVA's nationwide support network. The creation of this network is an important part of our mission to improve the lives of women with vulvodynia. It will enable women with vulvodynia to communicate with each other, come together to share their experiences, and offer each other solace and hope. The support effort will be headed by Harriet O'Connor and Donna Wolf. Harriet, a member of the NVA's Executive Board, has a bachelor's degree in nursing from Georgetown University and leads the Washington, DC area support group. Donna, who has a master's in business administration from NYU, is the director of the 60 member New York Vulvodynia Support Association and oversees support groups in the New York City area.

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## LETTER FROM THE EXECUTIVE DIRECTOR

Dear Friends:

Greetings from sunny Sarasota, Florida, the new home of the NVA. Our address has changed to Post Office Box 19288, Sarasota, FL 34276-2288 and our new telephone number is (941) 927-8503. In addition to relocating, there have been several exciting developments since the last newsletter was published. First, we have joined the Coalition of Patient Advocates for Skin Disease Research, a group of organizations that work together to secure research funding for skin disorders. By working with other groups that share a common goal, the NVA can increase its impact in the political arena.

In other news, the NVA has been making headway in obtaining publicity for vulvodynia. In February, through the efforts of NVA member Cindy Price, news reports aired on the ABC affiliates in Chicago and New York. For this sensitive, in-depth coverage, we thank reporters Kathy Brock and Bertha Coombs. Meanwhile, in March, the American College of Obstetricians and Gynecologists (ACOG) announced the formation of the NVA in its monthly newsletter. This recent publicity has generated hundreds of inquiries from vulvodynia patients and health care practitioners. Interestingly, many of the doctors who contacted us commented that they treat numerous patients with the disorder, suggesting that vulvodynia is not as rare as previously thought.

Of course, our best bet at finding a cure lies in the area of research and we've been hard at work on that end as well. In early March, NVA Government Relations Director Fran Callanan and I made our first visit to Capitol Hill, where we briefed Congressional staff members on vulvodynia and emphasized the urgent need for research funding. I'd like to thank Fran, who previously worked on the Hill, for helping us to educate Congressional leaders about vulvodynia.

Turning to this issue of the NVA News, we think that you will find a number of interesting articles and columns. On page 1, Dr. David Foster, director of the division of general gynecology at Johns Hopkins Hospital, answers questions about possible causes of vulvodynia and provides us with a look at a new experimental treatment. See page 7 for Harriet O'Connor's article on getting the most out of your health insurance coverage. And on page 1, Donna Wolf, coordinator of support groups in the New York City area, discusses the formation of the NVA support network.

We thank you for the complimentary letters we have received in response to the last newsletter and the formation of the NVA. So many talented and energetic people at the NVA are volunteering enormous amounts of time to ensure that women with vulvodynia receive the help they so desperately need. We rely entirely on the financial contributions of individuals to cover our operational costs. If you can afford to donate additional money to the NVA, we assure you that it will be put to good use.

If you have any suggestions that you would like to make, please don't hesitate to call us. There is no limit to what we can accomplish if we all work together.

Jacqueline J. Smith  
Executive Director

## Foster (From P. I)

instability. The vasomotor instability is mediated by various neurotransmitters — nerve proteins. These nerve proteins can produce an active change in the blood vessels and affect the inflammatory response in the vulvar area. What we are seeing in these particular nerve endings is both a response in the brain (pain) and a local response in the tissue. This inflammatory effect commonly produces a burning sensation. Our hypothesis is that the disorder is localized in this

specific type of nerve ending. There is a great deal of support for this concept, especially in the lower urinary tract.

**NVA:** How does this relate to vestibulitis?

**DCF:** This has significance because the lower urinary tract and the vestibule are derived

**NVA:** Some people experience an increase in pain over time. Are more and more nerve endings involved? If so, how does this happen?

**DCF:** I think that this occurs probably because of a summation of other insults to the area.

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**"Our hypothesis is that the disorder is localized in this specific type of nerve ending."**

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The National Vulvodynia Association does not engage in the practice of medicine. It is not a medical authority, nor does it claim to have medical knowledge. In all cases, the NVA recommends that you consult your own health care practitioner regarding any course of treatment or medication.

from the same embryological tissue — endoderm. This area is known as the urogenital sinus. This region of the body has a particularly large collection of capsaicin-sensitive sensory efferent "C" fibers. Our hypothesis is that the pathology initiates some sort of irritation or trauma which ultimately goes on to produce an abnormality of "C" fiber function.

**NVA:** Could you give an example of this phenomenon?

**DCF:** "C" fibers are free nerve endings that are "polymodal" (can respond to a myriad of stimulants) and can "summate" (one stimulant can add to the effect of another stimulant). The irritation due to sexual intercourse combined with an infection could summate, resulting in the aggravation of the nerve ending. I do think there is a genetic component involved because the hypersensitivity of vestibulitis doesn't occur in most patients.

**NVA:** What types of insults?

**DCF:** In the past we have seen chemical or laser cautery to the vulva, which has been used, theoretically, for pain caused by the human papillomavirus (HPV). At this time we are fairly certain that HPV does not cause the pain, but we are also suspicious that some treatments may actually aggravate vulvodynia. We are concerned that many chemicals used to treat yeast or infection can exacerbate vulvodynia, because they can also produce a secondary inflammatory response.

**NVA:** Have you used any new type of treatment?

**DCF:** We are doing a little work with capsaicin, a "C" fiber neurotoxin. It is an extract of hot chili peppers and produces a burning sensation. There will be capsaicin analogues coming out that may produce the same effect on the "C" fibers and not have

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## Foster (From P. 3)

the burning side effect. They are not on the market yet.

**NVA:** How does capsaicin work?

**DCF:** Capsaicin works by causing the "C" fiber to fire. The very immediate response is an increase in neurotransmitters at the skin level. Once capsaicin is used for an extended period of time, these "C" fibers start to regress and physically begin to disappear.

**NVA:** At this point do you stop capsaicin?

**DCF:** Yes, and we would hope for normal regrowth of nerves, or at least an extended period of relief. If you can also remove a specific insulting agent at this point, there is a much better chance for a cure.

They would basically alter the communication between the nerve and the surrounding areas, and they would reduce the number of receptors available to transmit the pain signal.

**NVA:** Isn't that what the tricyclics do?

**DCF:** Yes, but in a non-specific way. Tricyclics block the reuptake of norepinephrine; once it is blocked, norepinephrine becomes reduced, leaving the nerve with altered neurotransmitters. What we are working towards is something that could be applied topically that would specifically block the neurotransmitters without having the side effects of the tricyclics.

nerves that are primarily sensory, such as the iliohypogastric and iliohypogastric nerves. These can be blocked with few side effects. But the pudendal nerve is different because it has a significant motor component.

**NVA:** Could immediate, aggressive treatment of vulvodynia pain cause the symptoms to disappear?

**DCF:** Some people seem to have had this experience. We really do see a continuum of this disorder. It progresses to a dystrophic change in the skin. Ultimately there will be changes in blood flow and changes in inflammatory response in the skin. The skin becomes more friable, more easily injured and less elastic. This is the end result of the neuralgia.

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"The active research looking at neurotransmitters and neuroproteins will probably be a very fruitful area for developing new products that would block the chronic pain."

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**NVA:** Are there any other new developments in treatment?

**DCF:** The active research looking at neurotransmitters and neuroproteins will probably be a very fruitful area for developing new products that would block the chronic pain. The goal would be to develop analogues of certain neurotransmitters that would "down regulate" the receptors. These analogues, which look like neuropeptides but don't act like them, might be a way of treating the disorder.

**NVA:** If this is a neurological problem, why can't nerve blocks be used?

**DCF:** Nerve blocks are used for chronic pain. There are many effects of nerve blocks other than pain relief. The higher the block, the more diffuse the area that is affected. If you block the pudendal nerve higher up, you will get loss of rectal sphincter control and loss of bladder sphincter control. I think that for pain in the vestibule, the use of nerve blocks is limited. There are some

**NVA:** If you have a patient on tricyclics will that skin change still occur?

**DCF:** It depends upon whether the vulvodynia or vestibulitis gets under control.

**NVA:** Is it correct to say that the tricyclics, such as desipramine, block the nerve impulses to a large degree?

**DCF:** Tricyclics block the epinephrine component of the neurotransmitters. I think there are a number of neurotransmitters we are dealing with — substances such as neurokinin, bradykinin and histamine. Many of these factors may not be totally blocked by desipramine, but desipramine does a good job of blocking the epinephrine component.

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## Support (From P. I)

Since vulvodynia is rarely recognized by doctors, women with vulvar pain usually suffer for years before receiving a proper diagnosis, and the process often leaves them feeling isolated and depressed. Some women have difficulty discussing vulvodynia with others who don't understand the devastating impact of this illness. The opportunity to speak with other women who suffer from the disorder can alleviate this emotional isolation. Members of the New York City and Washington, D.C. support groups say that they find the exchange of ideas, feelings, and information to be extremely helpful and often uplifting.

The NVA Support Network will promote communication between interested members in various ways. Telephone and correspondence networks will be instituted in each state, to allow members to speak with or write to fellow sufferers in their geographic region. If there is enough interest in a given area, we will also form support groups so members can meet in person on a regular basis. Support group formats may vary month to month, ranging from general discussion to lectures by guest speakers.

We believe that the success of the support network will ultimately depend on you, our members. This will be your network, and we are counting on your enthusiasm, compassion and talent to make it work. We understand that many of you do not have the time, or don't feel well enough, to take on added responsibilities. But we also know that some of you are ready and able to get

involved in helping others and yourselves. If you are interested in being part of this effort, we are looking for women in each state to serve as Volunteer Support

Coordinators. If you would like to learn more about this, please write to Harriet O'Connor at the NVA address. We look forward to hearing from you!

## NVA visits Capitol Hill

In early March the NVA's Executive Director, Jacqueline Smith, and Government Affairs Director, Fran Callanan, paid their first visit to Capitol Hill, as part of a drive to obtain additional federal money for research on vulvodynia. They visited the offices of Senators Barbara Mikulski, Charles Robb and John Warner, and Representatives Connie Morella, Jim Moran, and Steny Hoyer. Senator Mikulski and Representative Hoyer are members of the Senate and House Appropriations Committees, which oversee funding for the National Institutes of Health (NIH).

Currently there is only one federally-funded study on treatment of vulvodynia, being conducted at the NIH by Dr. Maria Chanco Turner, a member of the NVA's medical advisory board. The subject of this controlled research is the effect of desipramine, a tricyclic antidepressant, on vulvodynia pain.

The greatest difficulty in obtaining funding for vulvodynia research is the lack of data on its prevalence among the U.S. population. Smith and Callanan explained the need for this data to the congressional staff. "We believe strongly that prevalence studies will demonstrate that vulvodynia is not such a rare disorder," said Smith.

Of the six congressional aides with whom Smith and Callanan met, only one had previously heard of vulvodynia. "We described the suffering that this disorder causes its victims and everyone listened sympathetically. Senator Mikulski's aide was especially interested and said that she would bring the issue to the Senator's attention," said Callanan. In a follow-up letter to Smith, Mikulski called the statistics on vulvodynia "quite startling" and urged the NVA to keep in touch with her on this matter.

Smith concluded from the visit to Capitol Hill that there is a great need to educate public officials about vulvodynia. "Congress won't allocate funding for a disorder they know nothing about, so it is our job to let them know just how devastating the condition can be and how many women it potentially affects," said Smith. NVA Board member Harriet O'Connor will return to Capitol Hill in late June to represent the NVA as a member of the Coalition of Patient Advocates for Skin Disease Research.

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# Empower Yourself

Many of us who suffer from vulvodynia have had the experience of consulting doctor after doctor, looking for answers and finding few. All too often, when our doctors could not discover the physical cause of our pain, we were told that the problem must be psychological. Still others of us were misdiagnosed and treated for ailments we may never have had. Without a proper diagnosis, treatments rarely helped and sometimes made things worse. Unfortunately, these types of experiences

lives. In this issue, we will focus on mutual aid self-help groups, commonly known as support groups; these groups can meet in person, over telephone lines or through computer bulletin boards.

A lot of women, myself included, have found that taking positive steps to change our mental and/or physical condition, can negate feelings of helplessness. One way to achieve this is to talk with women who suffer from the same disorder, share methods of

to give these women comfort, reassurance and hope. In the process I have also received the same. I have made new friends whom I will remain close to long after we are all pain-free. And I have even had some fun along the way. As a group we have learned that occasionally we can laugh together in the face of our problems. It may sound like a cliché, but sometimes laughter really is the best medicine.

By contributing to the direction of group meetings, sharing the benefit of my own experience, and pulling people together for a common purpose, I believe that I have become a stronger person. I have increased my level of self-confidence and regained a sense of power over my life and my health. But not everyone has to take a leadership role in order to benefit from involvement in a group. One member of my support group was very depressed when she began attending meetings. She had tried a few treatments without success, and had resigned herself to the "fact" that nothing would ever help her. She told me months later that she didn't know where she found the motivation to come to her first meeting. But she continued to attend, and although she said little during these sessions, she became very involved in administrative functions. At the same time, her attitude began to change. She no longer felt as depressed and hopeless about her situation.

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"It is one of the most beautiful compensations of this life that no man can seriously help another without helping himself."

*Ralph Waldo Emerson*

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can have severe emotional side effects. They can create a sense of helplessness, victimization, and loss of control over our lives, feelings which can lead not only to depression, but to a lack of effort to seek or adhere to treatment. Yet many vulvodynia sufferers have found ways to take back control, and in so doing, they have fought depression successfully and found the energy to tackle the challenges presented by this difficult condition. Consequently, we are introducing this Empower Yourself column as a regular feature of the NVA News, in order to share some of the ways in which fellow sufferers have improved the quality of their

copings, and channel our frustrations into constructive action. In support groups, members work together to decide what issues and goals the group will focus on. Participation in this kind of group tends to create a sense of personal responsibility and enhance self-esteem.

Ralph Waldo Emerson said, "It is one of the most beautiful compensations of this life that no man can seriously help another without helping himself." Based upon my own experience leading a vulvodynia support group, I have found this statement to be true. Over the past two years I have spoken to many women with vulvodynia, and attempted



## GETTING THE MOST OUT OF YOUR HEALTH INSURANCE

Health insurance generally covers the major costs of an illness. In the diagnosis and treatment of vulvodynia, however, women usually see several physicians before they even receive an accurate diagnosis. After being diagnosed, many women try several treatments before finding the most effective one, a process that can be very expensive for the insurance company and the patient. The following will highlight various measures you can take to secure expert treatment at a known cost.

In order to calculate your financial responsibility for medical treatment, call your physician's office in advance to discuss the charges for a work-up, office visits and tests. If the physician participates in your health care plan, this generally means that he or she accepts a negotiated fee directly from the insurer, and you pay a predetermined percentage. For a non-participating physician, call your insurance company to determine the maximum amount that they will pay for each visit or procedure, so that you can calculate your cost.

It is important for you to understand the information contained in your physician's statement of services. Each medical disorder has a universal diagnostic code number, an ICD-9 code, which is used by all insurance companies. When you submit a claim, the person who processes it simply enters the codes into a computer to determine the company's payout. This person has little or no discretion to grant you coverage. At the present time, vulvodynia does not have an ICD-9 code, so your physician may check off multiple diagnoses. Ask your physician's office for an explanation of the various code numbers and medical terms listed on your statement. This knowledge can help you negotiate with your insurance carrier if necessary.

If some charge is not covered, almost all companies have an appeal process to allow for individual circumstances, so don't hesitate to call the insurer to find out what recourse is available. Most companies have either a local or an 800 telephone number. If they want additional information, provide it in writing and keep copies of all correspondence. If you do need to appeal a claim, it will be evaluated by a supervisor, possibly a doctor or nurse, who has discretion, experience, and knowledge of medical problems. Because vulvodynia is a little-known and misunderstood disorder, the insurance carrier may respond to some education. You're likely to obtain the best results if you have a positive attitude and are courteous in your approach.

Your physician's help is essential to a successful appeal. Ask him/her to write a letter to the insurance company explaining that your condition is complicated and requires follow-up. If at all possible, provide your physician with relevant medical articles to include with this letter. Remember to keep a copy of the letter for your files.

If you are in an HMO, look for a physician who has experience in the treatment of vulvodynia. If none exist, seek out a physician who seems to understand the pain you are suffering. Ask if he/she would be willing to consult with outside experts and investigate current treatment protocols. In this way the HMO physician may be able to provide you with appropriate care. Share resources you have discovered, such as articles from medical journals, lecture notes, the NVA newsletter, etc. Some HMOs do allow members to be referred to outside specialists. If yours does, your HMO physician may be more willing to provide a referral if you identify an appropriate specialist.

Good Luck!

## Foster (From P. 4)

**NVA:** Have you had success in using the tricyclics?

**DCF:** I have been quite successful with the tricyclics. I am presently looking at my patients and estimating the success rate.

**NVA:** At what dosage of desipramine do patients generally respond?

**DCF:** It is probably between 125 mg. and 200 mg. daily. I have seen some people respond after taking only 50 mg. daily.

**NVA:** Do most people tolerate desipramine?

**DCF:** I think there are people who have pre-existing problems that make desipramine difficult to tolerate. A good example is mitral valve prolapse, a common disorder in women that can have an associated arrhythmia problem. With desipramine, we know the initial response is actually more of a sympathetic response — increased heart rate, nervousness, flushing, and other cardiac side effects. These sympathetic effects do seem to abate over time. The anticholinergic effects, such as dryness of mouth and constipation, seem to persist.

**NVA:** If patients become completely asymptomatic, do you wean them off the tricyclic and are there any risks involved?

**DCF:** I have a number of patients who have come off the tricyclics and been cured. For some women the pain returns when they stop the drug. The risk is the same as with any type of treatment for vulvodynia. If there are repeated traumatic episodes such as extended bike-riding, a large episiotomy, laser

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## READER TO READER

### How I Deal With the Pain

Telling anyone that I have vulvodynia is very difficult and time-consuming because I have to explain to people exactly what it is. It seems that even doctors haven't heard about it, so sometimes I feel it is not worth the effort of explanation.

I, like the previous reader, tell mainly my closest friends and family. Since I work in a clinic, many of my co-workers and the physicians I work with are very supportive and make talking about it a little easier. They are as frustrated as I am that there is no cure. Although they are supportive and very caring, they can't begin to imagine what it is like to deal with the pain every day. I usually describe the pain as similar to a severe yeast infection or urinary tract infection. People are amazed at how I live with daily pain, but I believe you just learn to live with it because you have no choice. For me, it is important that vulvodynia not interrupt my daily work life, but this can be very difficult when the pain is excruciating. With the hope that some day a cure will be found, I find the strength to keep going — even on days when I feel like giving up.

I am fortunate to have a very supportive husband and if it weren't for that, I'm not sure I could be so optimistic about hoping for a cure and eventually having a normal life again. My husband encourages me almost daily, especially when I am down. He has never once doubted that my pain is real and is always considerate as to how I feel. He also understands how painful intimacy can be for me and accepts for now our unusual sex life.

Sometimes I feel that this illness has brought my husband and I closer together, not only because of what we've endured together, but also because many times we are limited to just "cuddling" and offering each other reassurance. It is still difficult for me, at times, to overcome my feelings of inadequacy as a wife and lover. I tell my support group members that sex does not make a marriage, but it sure can be an important and fun part of it. I think that when you have something like this to "test" your love for each other, you realize what a good marriage you really have. I'm sure that having vulvodynia has been equally difficult for other women, and I believe for a cure to be found, we must overcome our embarrassment and let everyone know that this disease is real and that more research needs to be done. If we can increase public awareness, fewer women will have to suffer in silence, like so many have in the past.

**Next issue:** When my vulvodynia flares up, I lose perspective and get depressed. How do other women cope with this?



## Foster (From P. 8)

surgery of the vulva, bad infection, profuse sweating, or wearing synthetic underwear, the pain may return.

**NVA:** When do you recommend surgery?

**DCF:** I think that a patient should exhaust medical treatment, including a low-oxalate diet and interferon, before she has surgery. In cases where a patient has enough scarring that she suffers trauma every time she has sexual intercourse, surgery is indicated.

**NVA:** What is the long-term response to surgery?

**DCF:** We did a study of 93 patients who had surgery (perineoplasty) four to eight years previously. The results were as follows: 55 percent fully asymptomatic; 33 percent considerably better; 8 percent unchanged; and 4 percent somewhat worse after surgery.

**NVA:** How localized do the symptoms have to be to have a perineoplasty?

**DCF:** I feel that patients' symptoms should be localized in the vestibule for surgery to be really effective. Patients with more generalized pudendal neuralgia are more difficult to treat. Some of them will do well with a nerve block.

**NVA:** What do you suggest when a woman wants to get pregnant but is taking a tricyclic?

**DCF:** Many women who have used these medications for depression have become pregnant. Fetal anomalies are not a major concern with the tricyclics. Getting pregnant while taking a

tricyclic would not be a reason to terminate the pregnancy. The FDA has not approved these drugs for use during pregnancy, but some women would not be able to tolerate intercourse without the drugs.

**NVA:** Has treating women with vulvodynia given you a different perspective on chronic pain?

**DCF:** It is necessary to understand chronic pain from both medical and psychological perspectives. The physician needs to deal with the whole patient because so many of the issues of vulvodynia concern sexuality and interpersonal relationships. I was a psychology major in college and that has been very helpful. This condition causes trauma to the psycho-

gist, dermatologist, urologist, neurologist, pain-management specialist, and psychologist.

**NVA:** Is the human papillomavirus (HPV) or the herpes virus related to vulvodynia?

**DCF:** We looked at 31 patients who came with a previous diagnosis of HPV. We did a polymerase chain reaction, a specific test for HPV, on each patient; we found only one with HPV. HPV is being terribly overdiagnosed. Herpes is a more problematic issue. I am not sure we know at this point where herpes fits into this problem. My concern is that we may indeed be having a herpetic type of infection smoldering in the sacral ganglion. This infection would be without visible lesions.

"The physician needs to deal with the whole patient because so many of the issues of vulvodynia concern sexuality and interpersonal relationships."

social and psychosexual existence of the patient, but it is surely not a psychogenic problem.

**NVA:** What would you envision as an optimal treatment setting?

**DCF:** For early types of vulvodynia, I think primary practitioners who understand the pathology can treat the disorder. But patients who have a long-standing problem would benefit from being seen in a multidisciplinary setting. Such a setting would include a gynecolo-

**NVA:** Many women equate the development of vulvodynia with recurrent yeast infections. Do you see a connection?

**DCF:** The early response of "C" fibers is an itching phenomenon which can mistakenly be interpreted as a yeast infection. Patients are often treated with an antifungal without microscopic diagnosis. Frequently they have a history of yeast infections. We have not been able to show any definitive connection.

## BOOK REVIEW

### Taking Charge: Overcoming the Challenges of Long Term Illness

*by Irene Pollin, M.S.W. & Susan K. Golant, Published by Times Books ISDN 0-8129-2258-1*

Although this well-written book does not address vulvodynia specifically, its advice regarding chronic illness management is extremely relevant to a vulvodynia patient and her loved ones. Mrs. Pollin, who conducted twenty years of research and works in family counseling, speaks from experience due to the loss of her two children to congenital heart defects.

Initially the book addresses the "new reality" of being diagnosed with a chronic condition, and secondly, it presents coping mechanisms for the eight fears associated with chronic pain sufferers.

The authors begin by providing statistics on the number of long-

term illness sufferers in the United States. While disturbing at first, the reader is comforted to know that she/he is not alone. For example, 37 million Americans live with arthritis, another invisible chronic illness for which there is no cure.

The book delivers sound advice for coping with your illness, dealing with changing family dynamics, and forging effective doctor-patient relationships. This section is recommended for you *and* any caregivers or family members who want to help you through the challenge of pain.

"If your spouse is reluctant to express emotions, don't push. Nevertheless you can still explain that even though you understand his or her restraint, you need to cope by confronting your feelings. You may feel disappointed that your closest ally doesn't commu-

nicate the way you do, but don't underestimate your spouse's feelings. Even though the means of expression differ, they may be as strong as yours. Aware of this disparity, you can seek help from support groups, friends, and other extended family members."

The eight fears which the authors help the reader master include: fear of loss of control, fear of loss of self-image, fear of dependency, fear of stigma, fear of abandonment, fear of expressing anger, fear of isolation, and fear of death. Each chapter ends with a list of key points to remember and actions to take.

Ms. Pollin concludes with a message of hope, but it would be fair to say that the entire book is hopeful for those who are willing to take charge.

## America On-Line Support Group

A support group for vulvar pain sufferers is active on America Online. At the Main Menu go to Clubs and Interests. The click on "Health and Fitness." From there, double-click on "Better Health and Medical Forum." Click on "Message Center." Click on "List Categories." Highlight the line "For Men or Women Only " and click on "List Topics." Highlight the line "Vaginal Pain" and click on "List Messages." We have a number of NVA members online, including one of our executive board members who reads messages here frequently. You can also e-mail us at [MGMNVA@AOL.COM](mailto:MGMNVA@AOL.COM).

# VULVODYNIA MAKES HEADLINES

## Television, Medical Reports Bolster Awareness

Vulvodynia has been the subject of recent news reports, both on television and in print, thanks largely to the NVA's effort to increase public awareness of this disorder. This coverage has included special reports on local ABC-TV affiliates in Chicago and New York, an article in *Woman's Day* magazine, and a synopsis in the March newsletter of the 35,000 member American College of Obstetricians and Gynecologists (ACOG).

The most comprehensive coverage was a two-part story entitled

"Silent Suffering," which aired during the February 26/27th 10 p.m. WLS-TV Eyewitness News program in Chicago. Cindy Price, a Washington, D.C. NVA member and former Eyewitness News intern, was responsible for generating the station's interest in the subject. The broadcast featured the personal experiences of several women who suffer from vulvodynia, and included an interview with NVA Director Jacqueline Smith. To round out the coverage, anchorwoman Kathy Brock gave a basic description of the disorder, listed possible causes, and advised viewers on where to turn for more information.

Once word of the pending Chicago story leaked out, the station's New York City affiliate, WABC-TV, decided to do a segment on vulvodynia as well. Bertha Coombs' New York story, entitled "Private Pain," appeared on the 11 p.m. Eyewitness News show on February 28th. Among the women interviewed was New York City vulvodynia support group leader Donna Wolf.

Response to the television reports has been overwhelming, especially in Chicago where Eyewitness News staff had to set up a hotline to handle the heavy volume of calls. "Hundreds of women telephoned the station after the broadcast, and within hours, the NVA phone was ringing off the hook," commented Jacqueline Smith.

The popular print media is also beginning to pay more attention to vulvodynia. The May 16th issue of *Woman's Day*, a magazine with a circulation of 4.7 million, featured an article entitled, "Diseases Doctors Miss." This article, which covered eight illnesses that doctors often misdiagnose, opened with Jacqueline Smith's personal story and described a few treatments for vulvodynia. Another disorder that the article reviewed was interstitial cystitis, a bladder condition that some vulvodynia patients suffer from as well.

The NVA has received many inquiries from concerned medical practitioners who read about the organization in the ACOG newsletter. Most of these doctors are looking for better ways to treat patients suffering from chronic vulvar pain. "Thanks to the ACOG coverage, information on vulvodynia is slowly getting into the hands of doctors, where it is needed most," said Smith.

If you have media contacts and would like to help educate the public on vulvodynia, please write to Marjorie MacArthur c/o the NVA.

### Empower (From P.6)

She resumed her search for effective treatments, and with the help of her doctors, eventually discovered a treatment combination which substantially alleviated her pain. When I asked her which came first, her mental or her physical improvement, she was unequivocal. She firmly believed that her active participation in the group enabled her to overcome her depression, and gave her the hope and confidence she needed to find help for herself.

For more information on how you can get involved with a support group, see page 1 of this newsletter.

— Donna Wolf

# THE NVA NEEDS YOUR CONTRIBUTION

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

Name \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

Phone (H) \_\_\_\_\_ (O) \_\_\_\_\_

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

☐ \$35      ☐ \$50      ☐ \$100      ☐ Other \$ \_\_\_\_\_

☐ 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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NATIONAL VULVODYNIA ASSOCIATION

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