

Dysesthetic Vulvodynia and Sexual Intimacy

With Susan Kellogg-Spadt, Ph.D., CRNP and Loretta Sernekos, Ph.D.

This is Part 2 of a two-part series on vulvodynia and sexual intimacy. Dr. Kellogg-Spadt is the Director of Sexual Medicine at the Pelvic Floor Institute in Philadelphia, Pennsylvania, where she is a nurse practitioner specializing in vulvodynia and female sexual dysfunction. Loretta Sernekos, Ph.D., a writer who focuses on women's health issues, is one of Dr. Kellogg-Spadt's patients.

LS: Could you briefly describe the typical patient with dysesthetic vulvodynia (DV)?

SKS: There are two general categories of DV patients we see in this practice. Not every patient fits into these categories, however, and some women have attributes of both categories. Nonetheless, two types of patients can generally be discerned. Women in the first group are typically over 60 years of age and report intense genital and/or anal burning pain that increases with sitting or other postural changes. Ninety percent of the time, these women do not present with a sexual concern. Rather, they complain of incessant pain that dramatically affects their activities of daily living (ADLs). They can have pain anywhere from the clitoris to the rectum, although the distribution of

their pain tends to be low in the vulva and may include their upper thighs and gluteal fold. In these women, a light stroke with a Q-Tip on the perineum or in the groin area can evoke intense pain. Most of these women tell us they simply want to be able to sit and/or wear clothing that doesn't hurt their genitals.

LS: What is the significance of their being over 60?

SKS: Women over 60 are more inclined to have altered pelvic floor tone, an increased chance of osteoporosis and changes in skeletal integrity. They are also more likely to have herniated disks, sacroiliac dysfunction or nerve compression issues.

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Vulvodynia: Advice for the Newly Diagnosed Woman

By Amy Kaler, Ph.D.

Dr. Kaler is an assistant professor in the Department of Sociology at the University of Alberta in Edmonton, Alberta. She performs research in the sociology of gender, specializing in sexuality, health and reproduction.

Since 2002, I have been studying the ways in which long-term vulvodynia affects women's lives. This ongoing study is sociological rather than medical, focusing on how vulvar pain impacts women's self-image, their relationships with others and their life plans. The study has two arms: 1) open-ended in-person interviews with volunteers, and 2) an interactive website for women who want to participate, but whom are unable to meet with me in person because of distance constraints. The response to this project has been tremendous. This summary of some preliminary results is my way of thanking NVA members who have assisted me through their participation, as well as a way of introducing the project to women who might want to participate.

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LS: How would you describe the second group of DV patients?

SKS: There is a small cadre of patients in their 30s and 40s who complain predominantly of clitoral and/or labia minora allodynia (pain due to a stimulus, such as touch, that would not normally provoke pain) and/or hyperesthesia (heightened sensitivity and pain response to even very light touch). These patients may also have pain on the labia majora and in the groin folds. Some women only have clitoral pain (sometimes called clitorodinia), a more localized type of dysesthesia. Pain is frequently described as a burning or pinching sensation, or it can manifest as throbbing, deep aching or stabbing. During an examination, even a very light touch along the edges of the labia minora and/or clitoral hood evokes pain. These women tend to not have as much difficulty with the act of sitting itself, but more so with prolonged sitting or with a forward lean motion, which can affect their ability to

do certain tasks or jobs. They may also have difficulty wearing tight or even fitted clothing. In general, the intensity of their pain is lower than the women in the first group, and its distribution tends to be higher on the vulva.

LS: How does DV impact women in their daily lives?

SKS: Although some aspects of sexuality may be impacted, very basic ADLs like dressing and sitting — and all that follows, such as eating meals, driving a car and employment — can be dramatically impacted. That is clearly the primary concern of these patients, and although sex may be an issue, it is not always the first concern these women present with. Remember that this is a constant, rather than sporadic, disorder. So the primary goal of DV patients is to get rid of the pain or at least get a break from it. Many of the older women with DV who come to this practice are unable to sit for any length of time. They describe their sit bones (ischial tuberosities) as being “on fire.” And women in both groups may have to drastically alter their dressing habits because of the discomfort that clothing brings. With these types of basic activities being impacted, the first priority is often normalizing daily life, with a second priority being sexual matters.

The first goal of the provider and the patient is to reduce daily pain to a tolerable level. This is best accomplished through the efforts of a multidisciplinary team, including a vulvar specialist, a pain specialist, a neurologist and a physical therapist. Many women respond to anti-convulsants such as Neurontin and elevated doses of tricyclic antidepressants, such as Elavil or Pamelor. Other women respond to a combination selective serotonin reuptake inhibitor (SSRI) known as Effexor. We might also recommend Lidocaine and other topical nerve-quieting compounds. If the pain is so severe that it requires opioid-type analgesia, a consultation with a pain specialist is very valuable.

LS: How do women with DV maintain intimacy? Are most of them able to have intercourse?

SKS: Most DV patients can have intercourse, as long as sexual positions are carefully chosen to avoid

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NVA News

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

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irritating or stimulating the area(s) of allodynia and/or hyperesthesia. After appropriate medical therapy has resulted in manageable pain levels, they often express interest in being intimate. But it's not uncommon for DV patients to have great fear that sexual contact will aggravate their painful sensations. They are less concerned about being able to orgasm; absence of pain is their primary goal. They don't necessarily expect the focus of pain to return to a focus of pleasure initially. Only after they've had successful sexual play, over a prolonged amount of time, do women express interest in pursuing clitoral stimulation or other forms of intimacy.

LS: I can relate to that fear! During a recent flare, I was convinced at first that it must have started because of some intense sexual activity — and perhaps it did. Eventually, I said, "I can't live my life in fear." I remembered that I've had many pleasurable sexual experiences that did not lead to a flare, and that sometimes my flares seem to come from nowhere. But for a while I was concerned that I had "turned the pain back on."

SKS: Clearly, the biggest hurdle for DV patients is to use the sexual areas of their bodies for sexual intimacy again, without up-regulating their nervous system. I've heard women say, "I'm thrilled that my pain is at a manageable level now. I don't care if I ever have sex [or sexual pleasure] again." And that is absolutely their prerogative; they should never be pushed to do something they are not comfortable doing. A woman doesn't know if any given interlude will be the one that causes a flare; that is the essence of nerve pain. But if a woman is willing to try having sexual pleasure again, it is critical that she has a plan, including "rescue" medications, so that if those intense nerve pathways get reactivated, she has some degree of assuredness that it will be a short-lasting flare. For example, she may temporarily increase her Neurontin or Elavil. She may need to take a painkiller, use an ice pack, or rely on topical numbing agents.

LS: Having pain that can be terrible has made me realize that I need to accept intimacy where and when I find it. For me, it's important to maintain intimacy through physical touch even when I don't feel well; touch is so healing and it maintains a sense of bonding with my husband. It doesn't have to be what is

commonly thought of as sexual touching. Other types of touching, such as kissing, caressing, hugging, stroking, massaging, etc., can be very sensual, without in any way "alarming" the nervous system.

SKS: Yes. Loving touch can evoke a healing nervous system response by releasing endorphins and other pain-reducing substances. The same nervous system that can cause so much pain can be calmed by the healing power of touch and intimacy. But I think women with DV worry that the intimate touch might lead to something painful or that they will be seen as a "tease" if they take things only so far. Here is where a therapist or a pain specialist can help. She or he can frame DV as a nerve disorder, not a "sexual problem." In this framework, the therapist can mediate certain conversations between the woman and her partner. For example, a woman might say something like, "I think that my nerve pain is finally under control, but I am very concerned that any touch in that area will start a flare. For the next few months, I would like to touch you and hold you and be with you in a non-intercourse way. I cannot emotionally or physically risk waking up those nerves and feeling more pain. I'd like to move on, but want to take small steps toward being fully sexual again." That's a really hard conversation to have with a partner and it may be best said in the presence of a therapist or a health-care provider.

SKS: Loretta, you are one of my DV patients who have made a very healthy transition in terms of your sexuality. Could you share your story so that our readers may learn from your journey?

LS: I'd be happy to share my story in the hope that I may spark an idea or provide "food for thought" for other DV patients. Vulvar pain initially had a large impact on my sexuality, because it made intercourse impossible. As we discussed in our previous article (See *NVA News*, summer 2003), having my vagina taken away as a focus of sexuality was ultimately liberating, because it forced my husband and me to rethink what "normal" sex meant for us, it slowed us down, and it took the emphasis away from strictly genital sensual pleasure. But as my pain progressed from only penetrative pain to hyperesthesia near my

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clitoris, as well as clitorodysnia, it made me stretch my mind and my imagination even further. At first, being unable to tolerate any clitoral stimulation filled me with a mixture of rage and grief and a sense that I had been robbed.

SKS: What was the next step for you? How did you replace that sense of being robbed with a sense that you could do something about your situation?

LS: I drew on the thinking and reading about sex that I had previously done, only this time, I expanded my boundaries. I did a lot of reading about female orgasms. Other than an awareness of G Spot orgasms, I did not know that there are so many ways to have an orgasm, not all of which are clitorally-centered or as physically intense as clitoral orgasms. Some are much less genitally physical in nature and less intense, but still very pleasurable. And that's when the light bulb lit up over my head. I said, "If the clitoris is off-limits, we can do other things."

I read more, looking for ideas I might be able to use or adapt for my own purposes. My thinking was also influenced by readings on sexuality and disability. These readings were very inspiring and made me realize that if someone is determined to have sexual pleasure, they can find it; they can make it happen!

SKS: Can you give us some examples?

LS: Disabled people write of being sexually intimate despite having breathing tubes, urine collection bags and spastic limbs, to give just a few examples. Some quadriplegics, without any sensation in the genitals, are able to have orgasms. These people describe being sexually intimate with loving partners and having great, satisfying relationships.

SKS: By educating yourself about various forms of sexual expression and the experiences of others, it seems you began to expand your ideas of what intimacy can be.

LS: Exactly. But that only became apparent to me over a period of time, after I thought about the meaning of sexual intimacy in a broader sense and combined that thinking with my past experience of vulvar pain. I realized that if I put my mind in a receptive

mode and just allowed things to happen, together with my husband I might be able to redefine sexual pleasure. I must stress how important it is to have good communication with your partner, either between the two of you, or with the help of a third party. It's also very important for the partner to be patient, and for the woman to be patient with herself. Ultimately, having DV, and especially clitoral pain, expanded my sexual horizons in some unexpected ways.

SKS: You developed a sort of continuum of intimate and orgasmic activity that you can employ at any given time, depending on how you are feeling. Could this work for other women with vulvar pain?

LS: Definitely. The key aspect of the continuum is that it provides a range of options for pleasure. Always being able to attain some level of sexual/sensual pleasure helps me maintain a positive body image and balances the sense of the body as the site of pain with a sense of the body as the site of pleasure. If you think of the first point on that continuum as loving, intimate touch, it's a great place to start. No matter how much pain I am in, loving touch is always welcome and soothing. If my pain is bad enough, mustering the energy for genital sex may be beyond my strength or arousal and stimulation may be impossible. So it's OK to simply enjoy being caressed sometimes.

If a woman feels ready to move on to the next step, she could try sensual touch that includes physical arousal (even intercourse if she is able), as long as it is clear to her partner that no attempt at orgasm will be made. That way, she can enjoy those pleasurable sensations and feel-good chemistry, and see that she can feel pleasure without getting her pain reactivated.

The next point on the continuum would be to attempt some sort of orgasmic pleasure, perhaps by exploring what I call whole-body orgasms. These orgasms are a bit difficult to describe; they are a feeling of intense pleasure and energy surging through the body, but don't usually involve the typical contracting and muscle tensing, and do not require any genital stimulation.

If a woman is feeling well enough to try a more physical orgasm, she could explore orgasms obtained

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through stimulation of body parts other than the sex organs. Our bodies are wonderful creations, with multiple centers of pleasure. Practically any area of the body you can think of can be a source of arousal, once you let go of the idea that genitals are the sole area for sexual pleasure. Breast stimulation or stroking/caressing of the ears, neck and feet are examples—you are limited only by your and your partner's imagination. The orgasms that arise from these activities can be intensely pleasurable (even if they feel somewhat different than a clitoral orgasm). My advice to women exploring this option would be first, take your time and be patient; and second, keep an open mind and go with whatever happens—don't set a lot of expectations and preconceptions about the sensations you "should" feel.

Another possibility, particularly for women who cannot tolerate direct clitoral stimulation, is G Spot orgasms. The G Spot is a very sensitive area inside the vagina, on the upper part, about two inches from the pubic bone. Gentle stroking of this area can feel very pleasurable and may result in intense orgasms. These are similar to clitoral orgasms, but slightly different. Another area that can result in great pleasure is the "U Spot", which is just below the urethral opening. Although some women enjoy U Spot stimulation, others may find it is too close to their urethra or clitoral area and is beyond their comfort level.

If a clitoral orgasm is desired, some women with clitoral/dysesthetic pain can try to indirectly stimulate the clitoris. For example, using a gentle vibrator near the clitoris, on the hair-bearing areas, the outer lips or even the groin or perineum, may provide enough stimulation for a clitoral orgasm, without actually stimulating any painful areas directly. Sometimes, gently massaging the labia majora together can also produce a clitoral orgasm.

Finally, if a woman feels well enough, physically and emotionally, she can attempt direct clitoral stimulation with or without intercourse. By using the gradual approach to pleasuring I have outlined, a woman and her partner can experiment, knowing they can stop whenever sensations get painful and/or too intense.

SKS: These are great points. I also think it's important to initially keep the duration of stimulation as

short as possible, so as to minimize the possibility of initiating a flare, and slowly build sexual confidence.

LS: A warm bath before sexual activity can help keep the duration of stimulation short, because it increases blood flow to the genitals and allows orgasm to happen more quickly. A gentle vibrator can also permit more rapid orgasm.

SKS: Thank you so much for sharing the story of your journey with our readers.

LS: My pleasure. As I am fond of saying, it is possible to have DV and still have a wonderful sex life, albeit a different one than before — maybe an even better one.

Suggested Readings:

Anand, Margo. *The Art of Sexual Ecstasy: The Path of Sacred Sexuality for Western Lovers*. New York: Jeremy P. Tarcher/Putnam, 1989. [Whole-body orgasms]

Chalker, Rebecca. *The Clitoral Truth: The Secret World At Your Fingertips*. New York: Seven Stories Press, 2000. [Extensive discussion of the G Spot and female ejaculation]

Douglass, Marcia and Lisa Douglass. *The Sex You Want: A Lover's Guide to Women's Sexual Pleasure*. New York: Marlowe & Company, 2002. [Section on urethral eroticism and the U Spot.]

Heart, Mikaya. *When the Earth Moves: Women and Orgasm*. Berkeley, CA: Celestial Arts, 1998. [Discussion of several types of female orgasm]

Klein, Marty and Riki Robbins. *Let Me Count the Ways: Discovering Great Sex Without Intercourse*. New York: Jeremy P. Tarcher/Putnam, 1998.

Kroll, Ken and Erica Levy Klein. *Enabling Romance: A Guide to Love, Sex, and Relationships for the Disabled (and the People Who Care About Them)*. Horsham, PA: No Limits Communications, 2001.

Ladas, Alice Kahn, Beverly Whipple and John D. Perry. *The G Spot And Other Discoveries About Human Sexuality*. New York: Holt, Rinehart and Winston, 1982. ■

Newly Diagnosed

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The primary aim of the study is to discover what women learn from the experience of living with vulvodynia. On the website and in all in-person interviews, I ask women what they have learned that they would like to pass on to a woman who has just been diagnosed. Because the NVA newsletter is often the first point of contact for women who have just learned that they have vulvodynia, I thought it would be appropriate to present a preliminary analysis of responses to this question.

The themes below are drawn from the first fifty respondents to the interactive web survey. Their responses to the question "If you could give advice to a young woman who has just been told that she has vulvodynia, what would you tell her?" were compiled and then coded for thematic content with the use of the Ethnograph software package. After coding, the themes were ranked from most prevalent to least prevalent. Below are the five most prevalent themes.

1. *"Be strong, be patient, have hope."*

The most common theme was the importance of **personal strength** in living with vulvodynia. Personal strength was defined as both persistence in searching for a way to alleviate the pain and the courage to assert oneself and insist that others take the pain seriously. Indeed, the single most common piece of advice mentioned by nearly every respondent was that women with vulvodynia should "never give up." Personal strength was considered necessary both to avoid sinking into despair and to handle the challenges posed by an ailment with no fixed treatment or cure, the very existence of which is sometimes doubted by doctors and others.

2. *"Find a supportive, knowledgeable doctor and don't hesitate to share what you have learned about new treatment options."*

The second most common theme was the importance of developing a **supportive, but not unquestioning, relationship with a doctor**. Finding the right personal fit with a doctor was considered crucial – but it was regarded as equally important for women not to settle for a doctor who is uninformed or fixated on one mode of treatment to the exclusion of others. Family doctors, or even some gynecologists, were generally not considered helpful in dealing with a condition as

poorly understood as vulvodynia. One respondent said she would advise women with vulvodynia who are searching for a doctor to rely on the recommendations of others with vulvodynia. Two other respondents mentioned the importance of checking to see whether a particular doctor belonged to a professional association which dealt with vulvodynia. The importance of finding a doctor who respects his or her patient's priorities and knowledge about her own condition was often stressed, and women were advised to balance their own knowledge of what was happening to their bodies with their physician's general knowledge about vulvodynia.

3. *"Do your own research, research, research."*

The third most common theme was the importance of **learning as much as possible** about vulvodynia. Respondents said they would advise other women to check out online medical databases and medical libraries and to take on the responsibility for learning as much about vulvodynia as possible, especially with respect to emerging treatments. (Two respondents cautioned that in the midst of research, women should remember there is no "one size fits all" treatment for vulvodynia, and what works for one person may not work for another). Being informed about vulvodynia was seen as an aspect of personal strength – as one respondent said, "information is power" – and also as an aspect of building a good relationship with doctors, because an informed patient and an informed doctor can converse on the same level.

4. *"You are not alone. Stay connected with other women with this health issue."*

The fourth most common theme was to **seek out other women with vulvodynia**. Because vulvodynia is a little-known condition which often brings on feelings of shame or embarrassment, many women identified isolation as one of the biggest threats to their emotional well-being. Connecting with other women, whether over the internet, by phone or in person, was recommended as a way not only to share medical information but also to lessen embarrassment or stigma. (Interestingly, many responses from the in-person interviews associated with this project expressed some ambivalence about the value of interacting with others

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Extended Lidocaine Use May Ease Vestibulitis Pain

By Kathleen Nelson

Women with vulvar vestibulitis may have a new treatment option to help alleviate daily and intercourse-related pain. Consistent use of 5 percent lidocaine ointment over many weeks reduced pain in some women according to a preliminary study that appeared in the July 2003 issue of *Obstetrics and Gynecology*.

Denniz Zolnoun, MD, assistant professor of obstetrics and gynecology at University of North Carolina School of Medicine in Chapel Hill, reported treatment results on the effectiveness of topical lidocaine in reducing vestibulitis pain in 61 study participants with vulvar vestibulitis. Lidocaine, a topical anesthetic that numbs and blocks pain signals in nerve endings when applied to the skin, has been used occasionally by some vestibulitis patients to make intercourse tolerable. The drug was used differently in this study, however. Rather than sporadic application for acute symptoms, study participants inserted a lidocaine-soaked cotton ball into the vagina and left it in place for 8 to 10 hours per night over an average of seven weeks.

Although many vestibulitis patients experience pain primarily with sexual intercourse or tampon insertion, some experience pain more frequently throughout the day. Therefore, the study assessed both daily pain and pain during intercourse. To obtain a baseline, the study began with subjects rating their pain on a scale from one to 100, with 100 representing the most severe pain. The average age of the women was 30 years and most were Caucasian. The majority had seen other doctors and tried other treatments before participating in the study.

After approximately seven weeks of overnight use of lidocaine, pain ratings on both measures dropped significantly. The average daily pain rating before treatment was 27 out of 100; afterwards, the rating dropped to about 17 points. At the beginning of the study, the average rating of intercourse-related pain was 76, much higher than the average daily pain rating. After seven weeks of lidocaine use, pain with intercourse plummeted to an average of 37. Whereas only 36 percent of women in the study were able to have intercourse during the month before treatment, 76 percent reported that they were able to have intercourse after lidocaine therapy.

A new role for lidocaine?

"As gynecologists, we consider lidocaine to be superficial numbing medication, but prolonged exposure to lidocaine functions differently than simple numbing on diseased skin," said Zolnoun. She believes the medication has different effects depending upon whether it is used occasionally before intercourse, or religiously for 8 to 10 hours a day for several weeks.

"Even if occasional lidocaine users are able to have pain-free intercourse using the drug as a numbing agent, many have [skin] irritation the day after," Zolnoun said. Longer-term use appears to function differently, shutting down the pain receptors.

Zolnoun noted several other encouraging findings in her study. Even women who had occasionally used lidocaine before intercourse in the past and did not experience pain relief, were just as likely to experience pain relief with extended use as women who had never tried it before. Also, treatment was equally effective in women who had suffered from vulvar vestibulitis for many years. Women with endometriosis, or whose symptoms began after childbirth, also exhibited positive treatment results.

The ins and outs of lidocaine application

Vulvar vestibulitis pain is typically felt at the site of the vestibular glands, two glands at the entrance to the vagina. The glands are located in a circular area of tissue known as the vestibule, which surrounds the entrance to the vagina. "It takes a fair amount of education on the provider's part to teach women to place the lidocaine correctly" said Zolnoun. "The vestibule is a tiny space in front of the hymen that some gynecologists are still not clear about," she added. Zolnoun trains her patients to apply the ointment by using a mirror to clearly identify the vestibule. Patients apply the lidocaine ointment in and around the vestibule, then coat a cotton ball with the ointment and place it in the center of the vestibule.

The pain of vulvar vestibulitis also makes application difficult. With sore vulvar skin, opening the labia to apply the ointment can be excruciating. Sometimes

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women reach the right spot with the lidocaine-soaked cotton ball, but it hurts so much that they push it deeper into the vagina, bypassing the vestibular glands, said Zolnoun. Placing the cotton ball in the vestibule inevitably results in a twinge of pain when the vestibular glands are pushed inward, similar to what happens during intercourse. The initial sensitivity should disappear within a few minutes, however, leaving the cotton ball to sit in place and saturate the glands with lidocaine over the next eight hours.

Lidocaine and nerve pain

Researchers don't yet understand exactly how lidocaine's pain-blocking abilities work on nerve fibers. In earlier studies, lidocaine reduced symptoms in patients with postherpetic neuralgia, a neuro-inflammatory disorder that causes a painful rash. Some researchers think that vulvar vestibulitis may also be neuro-inflammatory, i.e., nerves firing erroneously transmit a burning or painful sensation from the vestibular tissue. There are differences between the two disorders, however. Postherpetic neuralgia is neuropathic pain that starts at the level of the spinal cord, explains Zolnoun, while vestibulitis is thought to begin at the site of the vestibular tissue itself.

"Regardless, the same nerves that communicate the pain, called C-fibers, seem to transmit the burning sensation in both conditions," said Zolnoun. "So it's possible the same treatment, irrespective of where the nerve irritation is coming from, may work."

However, the lidocaine treatment did not work for everyone. Study subjects who had other diagnoses in addition to vulvar vestibulitis, such as infection or interstitial cystitis, and women who had undergone

vulvar surgery, did not have as much success with the treatment. Also, women with severe generalized pain characteristic of dysesthetic vulvodynia did not experience the same level of pain reduction.

Tips for interested patients

Regarding the treatment, Zolnoun said, "It is not harmful, costs about \$10 per tube, and is relatively simple to use." She had two additional suggestions for potential users. Earlier this year, 5 percent Xylocaine-brand ointment went off the market and some women reported burning for more than a minute with use of the generic 5 percent lidocaine ointment. To deal with this problem, Zolnoun recommends that generic lidocaine be compounded with petroleum jelly by a pharmacist, adding a little to the expense (it costs about \$30), but usually resulting in less sensitivity. Secondly, to avoid irritation, Zolnoun recommends using sterile, pure cotton balls, found at most pharmacies, rather than those used for cosmetics.

Only about half the women in the study returned six-month follow-up questionnaires, and of those, most still needed to use lidocaine periodically when their vulvar vestibulitis symptoms flared. This study had too few participants to determine whether some patients remain pain-free with long-term lidocaine use, said Zolnoun. She is designing a larger, more comprehensive study to build on her current findings.

If you would like to participate in a pilot study on lidocaine use, please contact Denniz A. Zolnoun, Department of Obstetrics and Gynecology, University of North Carolina School of Medicine, Chapel Hill, North Carolina 27599 or via e-mail at denniz_zolnoun@med.unc.edu. ■

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NVA Supports Pain Awareness Campaign

In November 2003, NVA's Christin Veasley participated in an important forum, *A Discussion on Pain in America*, co-sponsored by the Harvard School of Public Health and Research!America, a non-profit organization dedicated to making health research a higher national priority. The primary purpose of the forum was to generate discussion between pain clinicians, scientists and journalists to encourage the media to educate the public on the prevalence and treatment of chronic pain, as well as the status of pain research in the United States.

Mary Woolley, President of Research!America, presented a summary of the organization's September 2003 survey results on pain in America. According to the survey, more than 50 percent of Americans suffered from chronic or recurrent pain in the past year; if you also include individuals whose lives were impacted by chronic pain through relationships with a close family member or friend in chronic pain, the percentage affected rises to an astounding 75 percent! "This survey should serve as a wake-up call to all Americans, including our elected leaders, that chronic pain is a problem of epidemic proportions in our country," said Ms. Wooley.

As might be expected, the survey results confirmed that chronic pain can cause enormous upheaval in people's lives. Almost 40 percent of chronic pain sufferers reported that because of their pain it was necessary to make major life adjustments, such as taking disability leave from work, changing jobs, receiving help with daily activities or moving into housing that was easier to manage.

Judy Foreman, syndicated health columnist for the Boston Globe and author of two recent articles on pain, moderated a two-hour discussion at the end of the forum. Joining her were journalists Melanie Thernstrom, author of *Untying the Knot*, an expansive New York Times article on pain (August 2003) and an upcoming book, *Pain: The Disease*, and Michael Lasalandra, a medical writer at the Boston Herald. These journalists provided insight into the typical day of a media professional and discussed important issues in pain reporting in different media. They explained that overview articles on chronic pain are not generally published because "pain" itself is not con-

sidered an interesting subject, but that an article describing a controversy in pain management or presenting a new treatment for pain might be deemed newsworthy.

Earlier this year, Jane Elmer, NVA's support group leader in Wisconsin, participated in a meeting of the Partners for Understanding Pain, a consortium of more than 70 organizations committed to publicizing chronic pain issues. The goal of the meeting was for these organizations to share their resources and explore ways in which they can work together to promote pain awareness and improve the quality of life of chronic pain sufferers. Among topics addressed at the meeting were pain and the workplace, pain and the underserved (e.g., the elderly and the poor), pain in children, and women and pain. Elmer shared a historical perspective of vulvodynia, the challenges it presents to women and the need to better inform the medical community, policy makers and society at large.

Hope on the Horizon

The release of the Research!America survey results and the efforts of collaborative groups such as Partners for Understanding Pain, has begun to produce results. At the Harvard forum, Louis Sullivan, M.D., former Health and Human Services Secretary, described the creation of a comprehensive "virtual textbook" on pain, called TOP MED (Topics on Pain Medicine). TOP MED is web-based and self-directed, allowing medical students to study when and where it is convenient for them, and includes information on human and social costs of pain, neurobiology, patient evaluation, analgesics, and all types of pain. This textbook will be made available free of charge to medical students across the country in the fall of 2004. This initiative was a direct result of a recent survey performed by the Association of American Medical Colleges which revealed the shocking statistic that only three percent of medical schools offer a course on pain management!

For the first time on Capitol Hill, in the current Congressional session, a comprehensive, proactive

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Pain Awareness

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pain bill was introduced by Congress by Rep. Mike Rogers (R-MI). The "Pain Care Policy Act" (HR 1863) seeks to increase federal funding for pain treatment, education and research. This legislation would establish a White House Conference on Pain Care, authorize a National Center for Pain within the National Institutes of Health (NIH), and give the NIH authority to establish six regional pain centers. It also calls for allocation of \$60 million to improve pain-care training, educate pain patients, provide access to pain treatment for those in need and expand pain research. To follow the progress of this Congressional bill, log onto the American Pain Society (APS) web site at <http://www.ampainsoc.org/decadeofpain/> and click "Track the Progress of Pain Care Policy Act" on the right-hand side of the page.

To maintain the momentum, the American Pain Society recently launched *Time for Relief*, a television and radio public service advertising campaign, the goal of which is to increase public awareness of the plight of people in chronic pain. (To listen to these an-

nouncements, visit the APS website at <http://www.ampainsoc.org/decadeofpain/news/media.htm#pcv>.)

Purdue Pharma, L.P., the organizers of Partners for Understanding Pain, recently created and disseminated an advocacy toolkit, entitled "In the Face of Pain." The kit was designed to provide people with the necessary information and tools to advocate for awareness and understanding of pain issues, and to promote discussion of the social impact of the pain epidemic. To receive a copy of the toolkit, send an email to painadvocacycommunity@pharma.com. (The NVA's Christin Veasley is featured in the section entitled "Gender and Pain Management.")

(Editor's Note: Judy Foreman's articles on pain were published in the Boston Globe on November 4th and November 18th in her column, "Health Sense." To read these articles online, go to <http://www.boston.com/news/globe/> and search the archives on the right-hand side of the page.) ■

Newly Diagnosed

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with vulvodynia. Such contact could be inspiring and supportive but could at other times be emotionally draining.)

5. "Don't adopt the frame of mind that it will be fixed right away; instead, accept it as part of your life, keeping in mind that there will be good times as well as bad times."

Finally, the fifth most common theme was the importance of **learning to live with vulvodynia** rather than expecting a complete cure. Even though some cases of vulvodynia have been successfully cured, respondents said they would advise women to presently focus on management of their pain, rather than complete resolution of their symptoms. They also described the importance of finding a balance between optimism that one can be cured and accepting the possibility of enduring some degree of pain indefinitely. Most women stressed the importance of not letting the search for a cure dominate one's life, and

said they would tell others not to put their entire lives on hold until their vulvodynia has been resolved. In particular, respondents said they would tell newly diagnosed women that personal relationships need not be sacrificed to vulvodynia – as one respondent put it, she would tell newly diagnosed women to "look for a good man who will love you no matter what!" and many respondents attested that such men could indeed be found, though it might take patience to find them.

I'd like to express my appreciation to everyone who has participated in the study to date, and invite women to visit www.humanities.ualberta.ca/survey/vulvodynia.htm if they are interested in participating in this ongoing project. Individual responses are confidential. A summary of the project's results will be disseminated to the vulvodynia community through academic and professional channels, and will also, I hope, reach a wider audience via mainstream media.

(Dr Kaler would like to thank the Canadian Social Sciences and Humanities Research Council, the National Vulvodynia Association and vulvodynia.com for their assistance with this research.) ■

NVA Offers Patient Guide to Vulvodynia

The NVA, through a grant from Purdue Pharma L.P., is pleased to announce the publication of its new patient guide, *I Have Vulvodynia....What Do I Need to Know?*. Written primarily for recently diagnosed patients, the guide provides a comprehensive overview of vulvodynia from both gynecological and chronic pain perspectives. In addition to focusing on the treatment of vulvodynia, the guide features self-help tips and coping strategies for vulvodynia patients, as well as information on general gynecological health.

The guide will be available in March 2004 and will be sent free of charge to current NVA members who elect to receive it electronically in Adobe PDF format. To order it, send an e-mail to chris@nva.org with the phrase "patient guide" in the subject line, as well as your full name in the message.

If you would like to receive a printed copy instead, please send a \$5 check (to cover our printing, shipping and handling costs) to "NVA Patient Guide," PO Box

4491, Silver Spring, MD 20914-4491. Health care providers who wish to purchase multiple copies for their offices should contact Chris Veasley at chris@nva.org or 401-398-0830.

The NVA gratefully acknowledges Purdue Pharma L.P. for their support of this project through a grant from the Purdue Pharma Fund. ■

Stock Donation

Please consider making a gift of appreciated stock to NVA. You will not have to pay capital gains tax on your profit and will receive a tax deduction for the stock's full market value on the date of your gift. For further information, contact Chris Veasley via e-mail at chris@nva.org or 401-398-0830.

Research Participants Needed

Vulvodynia in Post-Menopausal Women

Researchers at Johns Hopkins Hospital in Baltimore, Maryland are looking for post-menopausal women to participate in a research study concerning the mechanisms of pain in vulvodynia, a chronic pain syndrome of the vulvar and vaginal area. You may be an appropriate candidate for this research study if you:

- are 45 or older;
- have been diagnosed with Vulvodynia for at least 6 months;
- have not had a menstrual period for at least 12 months; and
- have been on or off hormone replacement therapy (HRT) for at least 12 months.

Women who have had a hysterectomy are ineligible for this study. You will receive a stipend for parti-

cipation. For more information, call 410-614-4517 or e-mail women@bme.jhu.edu.

(Support: National Institutes of Health, National Vulvodynia Association; Principal Investigator: Ursula Wesselmann MD, Ph.D., Dept. of Neurology, Johns Hopkins Hospital.)

Dysesthetic Vulvodynia Treatment

Clinical gynecologist is seeking women with dysesthetic vulvodynia to test the efficacy of two medications not previously studied in the treatment of the disorder. To participate, you must not currently be taking a tricyclic antidepressant, SSRI or anticonvulsant medication; or have diabetes, heart disease or bipolar disorder. Please contact Andrew Goldstein, M.D., at 202-887-0568 for more information. ■

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.



NATIONAL VULVODYNIA ASSOCIATION
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