N National
V Vulvodynia
A Association

NVA News

Volume V, Issue I

Winter 1999

Demographic Profile of Vulvodynia Patients

By Leslie Ann Sadownik, M.D.

Leslie Ann Sadownik, M.D., FRCSC, is a clinical instructor in the Department of Obstetrics and Gynecology of Vancouver Hospital, University of British Columbia, Vancouver, Canada.

Introduction

More than 1,000 women per year are seen in the Vancouver Hospital Department of Gynecology's Vulvar Disease Clinic. Approximately one third of these patients present with chronic vulvar complaints such as burning, itching, pain or dyspareunia. In 1983, the International Society for the Study of Vulvar Disease defined vulvodynia as chronic vulvar discomfort, especially that characterized by the patient's complaint of burning, stinging, irritation or rawness. Subsets of vulvodynia have been described in the medical literature; they include vulvar dermatoses, cyclic candidiasis, pudendal neuralgia and vulvar vestibulitis. Demographic profiles of vulvar vestibulitis patients have been previously published in the literature. Few studies, however, have commented on the demographic and clinical profile of a large population of vulvodynia patients inclusive of all subgroups of vulvodynia. The purpose of this study was to characterize the demographic and clinical details of a Canadian population of vulvodynia patients.

Methodology

All my new patients over a two year period (1996-1998) were asked to complete a questionnaire (modified from the National Vulvodynia Association Patient Survey) at their first visit. The initial patient assessment included the taking of a medical and sexual history, with or without a physical examination. Physical examination consisted of colposcopic examination of external and internal genitalia, if possible, Q-tip touch test, speculum exam, if possible, and microscopic examination of vaginal discharge.

See DEMOGRAPHICS, page 3

Vulvodynia Story on CBS Special

BODY HUMAN 2000: LOVE, SEX, and THE MIRACLE OF BIRTH, a television special utilizing state-of-the-art photography while exploring the mysteries of human sexuality and procreation, will be broadcast Wednesday, April 7th, 10 p.m. ET/PT on the CBS Television Network. One of the show's segments features an NVA member who suffered from severe vulvar pain for several years until she underwent surgery at the University of North Carolina Hospital.

This broadcast is the first prime-time television coverage of vulvodynia and the NVA hopes that it will raise public awareness of the disorder. Please encourage your gynecologist, family physician, relatives and friends to watch the show.

INSIDE

LETTERS TO THE EDITOR

Dear Editor:

I am a 33-year-old mother of a healthy three-year-old. I have had vulvar vestibulitis since the latter part of 1992. I was lucky to be diagnosed very quickly after my symptoms began. I was started on Zovirax and xylocaine, followed by tricyclic antidepressants. I did not experience any measurable improvement and wanted to become pregnant, so I tapered off the medication and tried the low-oxalate diet and calcium citrate. At first I was diligent in following the diet, but when I became pregnant three months later, I returned to my usual diet.

My child was born in March 1996. She was delivered vaginally and I experienced a third degree tear which healed very well. After the six week recovery period, sexual relations with my husband became easy and nearly pain-free. But as the months went on, the pain increased until sexual intercourse was once again something I avoided. When it was time for my yearly gynecological examination, I found a doctor who specialized in treating vulvodynia patients. During the internal exam he noticed that my pelvic floor muscles were very tense. It made sense that this was one cause of my pain, because after my muscles were stretched by childbirth, intercourse had become much easier.

In July 1997, I contacted biofeedback expert Dr. Howard Glazer. He categorized my condition as "secondary pure vulvar vestibulitis" because I only felt pain upon contact with outside pressure. He told me there was a good chance that retraining my muscles would grant me some relief. I ordered a home biofeedback training kit and started the exercises. Through biofeedback I became aware of the tension in my pelvic floor muscles and learned how to relax them. I did exercises to strengthen my muscles as well.

Now it is 18 months later and I am pain-free. I stopped the biofeedback exercises in January 1998. I do not follow any special diet or take any medication. I give full credit to Dr. Glazer's treatment and hope that others will experience the same success that I did.

K.G.

Dear Editor:

Six years ago I developed severe vulvar pain in the space of an hour. After visiting several doctors, I was told that I had essential vulvodynia or pudendal neuralgia. I was in my early fifties and on hormone replacement therapy. Initially, 25 mg. of desipramine was prescribed for pain relief. Over the next three months, the dosage was increased to 100 mg. daily. I experienced some pain relief, but started having some anticholinergic side effects—dry mouth and constipation. My doctor and I decided to gradually increase the dosage to see if I could become totally pain-free. At 175 mg. of desipramine, my pain completely disappeared. The constipation and dry mouth persisted, but were tolerable. I also experienced dry eyes occasionally, which I treated with artificial tears.

Three years later, my doctor and I decided to try reducing the dosage; at 125 mg. I started to experience significant pain. This was frightening and intolerable, so the desipramine was increased to 175 mg. again. Constipation continues to be a problem, but I manage it with Metamucil, stool softeners, a laxative pill, extra fluid, and raw fruits and vegetables. My quality of life is great as long as I remain on medication. Eventually I will attempt to reduce the dosage again, but for the time being I'm happy to have my life back.

N.H.

Dear Editor:

I am 27 years old and never thought I would have to deal with the physical and mental anguish of having vulvar vestibulitis syndrome (VVS). Like many sufferers, I went to countless doctors who misdiagnosed me with all kinds of infections. Frustrated, depressed and confused, I finally was diagnosed with vulvar vestibulitis one year ago. My fiancee and I were struggling to cope with my condition, so we postponed our wedding without setting another date. I never

(See LETTERS , page 11)

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

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

Editor:
Phyllis Mate

Layout:
Andrea Hall

Contributors:
Harriet O'Connor
Chris Sanders

Demographics

(from page 1)

Highlights of Results

A total of 196 questionnaires were completed. The average age of respondents was 37, with a range from 19-87 years. A post-secondary level of education was reported by 73 percent of respondents. Marital status was reported as 53 percent married, 36 percent single, 6 percent separated, 4 percent widowed and 2 percent divorced. Half (52 percent) of the patients were nulligravida, i.e, had never given birth. Average age of first sexual intercourse was 18.5 years. The number of respondents who indicated having had sex without consenting to the activity was 8 percent. Patients reported consulting family physicians (90 percent), gynecologists (80 percent), alternative medicine care givers (14 percent), dermatologists (10 percent) and other specialists (10 percent). More than half (58 percent) of the patients reported seeing at least two different types of physicians for their problem.

A past history of yeast vulvovaginitis was reported by 69 percent of patients.

Symptoms: The average duration of symptoms was 32 months. (Range 2 - >99 months.) Seventy percent of patients reported constant symptoms. Vulvar symptoms included vulvar burning (55 percent), vulvar pain (51 percent) vulvar itching (43 percent), abnormal vaginal discharge (26 percent) and physical lesions on the vulva (15 percent). Sexual concerns included superficial pain with intercourse (60 percent), post-coital pain (42 percent), diminished sexual interest (33 percent), partner having difficulty penetrating the vagina (28 percent), diminished sexual arousal (26 percent), deep pain with intercourse (20 percent), and problems with sexual orgasm (26 percent). Some patients reported associated bladder (23 percent) or bowel (15 percent) problems.

Interventions: The most common treatments tried were topical anti-yeast medications (54 percent), topical steroids (48 percent), anti-yeast pills (33 percent) and estrogen cream (30 percent). Respondents stated that 70 percent of the time these interventions did not relieve their symptoms or made them worse.

See DEMOGRAPHICS , page 4

Demographics

(from page 3)

Past Medical History: A past history of yeast vulvovaginitis was reported by 69 percent of patients. Almost all patients (99 percent) reported other health problems, including pelvic pain, bladder dysfunction and bowel difficulties.

Physical Limitations Secondary to Vulvodynia: The most common physical activities limited by a patient's vulvar pain included sexual intercourse (90 percent), clothing choices (37 percent), sitting (33 percent) and walking (30 percent).

Emotional Aspects of Vulvodynia: A majority of patients reported often or always avoiding sexual intimacy (63 percent). However, 82 percent reported rarely or only sometimes fearing that they would lose their significant other. More than half (57 percent) felt hopeful that they would get better and only 19 percent felt that no one believed they were in pain. Almost half (49 percent) were often or always angry about having chronic vulvar pain.

Physical Examination: Gross appearance of the vulvar anatomy and vulvar skin (pigmentation, skin thickness, and physical lesions) was normal in 78 percent of the patients examined. In most cases, positive physical findings were isolated to pain on palpating the posterior (66 percent) and anterior (47 percent) vestibule. Inflammation of the posterior vestibule was noted in 30 percent of patients and of the anterior vestibule in 21 percent. Inspection of vaginal mucosa and discharge revealed few abnormalities, affecting less than 10 percent of patients.

Discussion

Vulvodynia affects patients of all ages. Of note was the surprisingly high percentage of patients with post-secondary education. Furthermore, given that the average age of patients was 37 years, a significant portion were unmarried and had never given birth.

Clearly, these patients had access to the Canadian health care system. They were seen by many different specialists and tried numerous treatments. Respondents reported that more than 70 percent of the time these interventions did not relieve their symptoms or made them worse. No single treatment, or combination of treatments, was perceived as consistently improving symptoms. As reported elsewhere in the literature, although the majority (69 percent) of these patients reported a history of yeast infections, evidence of active yeast infection was rare upon physical examination.

There was a strong association between chronic vulvar pain and sexual dysfunction. The incidence of sexual abuse, defined as nonconsensual intercourse, was not greater than expected in the general population. (The number of respondents to this question dropped from 196 to 170, so this could be an underestimate.) Patients reported problems in all phases of the sexual response cycle. The data on sexual functioning corroborates previous studies which found that a high percentage (>50 percent) of vulvar vestibulitis patients report sexual problems.

Furthermore, vulvodynia was often associated with pelvic pain, bowel problems and bladder dysfunction. Almost all patients disclosed health problems other than vulvodynia. A majority (62 percent) reported that they had undergone some type of surgery. Approximately 10 percent of patients suspected they had another chronic pain condition. This supports other studies that have found that half of vulvar vestibulitis patients also report chronic nongenital pain, particularly in the abdominal and/or pelvic area.

Similar to other chronic pain conditions (headaches, low back pain), the patient's pain seemed out of proportion to the physical findings. Positive physical findings were most often limited to inflammation in the vestibule and reported pain on palpation of the vestibule. As might be expected, the chronic pain resulted in physical limitations and emotional reactions.

See DEMOGRAPHICS, page 7

Becoming Pregnant With Vulvodynia

Questions and Answers with Scot Hutchison, M.D.

Ob/Gyn Fertility Specialist, Reproductive Health Center, Tucson, Arizona

Q: If a woman can only engage in sexual intercourse a few times a month, what methods can she use to maximize her chance of conception?

A: The main emphasis of the following methods is to detect ovulation. In order to become pregnant, a woman should have sexual intercourse directly before ovulation occurs. The most popular method for detecting ovulation involves the use of an ovulation kit which can be purchased at any drugstore. The kit includes test sticks which the woman holds under her urine stream. These sticks react to the surge in luteinizing hormone which occurs immediately prior to ovulation. The day the test turns positive, indicating a surge in luteinizing hormone, is the best time to have intercourse. A positive result means that ovulation will occur within 24 to 36 hours. One kit contains five ovulation sticks and costs about twenty-five dollars. For most women, five sticks should be a sufficient amount for one month's use.

An alternative method is to record basal metabolic temperature by taking a rectal temperature reading daily. This is a retrospective method of detecting ovulation, because once the basal temperature has risen, ovulation has already occurred. To use this technique, you have to record basal temperature during one menstrual cycle prior to the month of planned conception, to determine on which day of the cycle ovulation occurred. If a woman's cycle is regular, there is an excellent chance that she will ovulate on the same day of her cycle the following month. To increase her chance of conception, sexual intercourse should take place on that day.

Alternately, a woman can try to pinpoint ovulation by watching for a distinct type of cervical/vaginal discharge. When the discharge is watery, stretchy and clear, it indicates that ovulation is about to occur and the timing is right to have sexual intercourse.

Q: When attempting sexual intercourse, are there lubricant products that should be avoided?

A: Yes. Any lubricant containing an ingredient called chlorohexadine should be avoided because this chemical is toxic to sperm. For example, KY Jelly contains this ingredient. Good products to use are conventional olive oil or Astroglide, a lubricant that does not contain chlorohexadine. Whichever lubricant you choose, use it sparingly in all circumstances.

Q: What procedures can women use to become pregnant when sexual intercourse is not possible?

A: The best way for a woman to conceive when intercourse is not possible is to use artificial insemination around the time of ovulation. This can be performed by the couple themselves or with the help of a fertility specialist. If a couple wants to attempt self-insemination, the partner ejaculates into a container, the woman lies down and elevates her hips by placing a pillow under them, and then the semen is poured into the vagina. It is necessary to understand that the semen not only has to enter the vagina, but must reach the cervix and travel into the uterus for conception to occur. This can be difficult to achieve without a physician's assistance.

Q: How is artificial insemination done in a doctor's office?

A: Most importantly, there is a narrow window of time each month within which artificial insemination must be performed. It has to take place on the day of ovulation. There are two possible methods of artificial insemination, one of which is referred to as "capping." Initially, the woman's partner ejaculates into a specimen container. Afterwards, the semen is poured into a cap that fits onto the woman's cervix. Then the cap containing the semen is placed on the cervix where it remains for about 12 hours.

(See PREGNANCY, page 6)

Pregnancy

(from page 5)

The second procedure also requires the woman's partner to ejaculate into a container, following which the semen specimen is "washed," removing everything except the sperm. Then a narrow catheter is threaded through the woman's vagina into her uterus, and the sperm is injected through the catheter into the uterus.

The typical cost of insemination in a doctor's office is $200-$300 per menstrual cycle. Depending on the specifics of your insurance coverage, the cost of this procedure may or may not be covered.

If a woman does not become pregnant after undergoing artificial insemination for three cycles, the vulvodynia diagnosis is no longer relevant, i.e., there is a significant fertility problem other than the inability to engage in frequent sexual relations. In this instance, the woman becomes a standard fertility patient and various fertility therapies or *in vitro* fertilization may be attempted.

Q. Can you describe the *in vitro* fertilization procedure?

A: In preparation for *in vitro* fertilization, a woman follows a two-month protocol, taking birth control pills or a high dose progestin for the cycle before attempted conception. When menses begins, drugs are injected to induce the growth of multiple follicles. Then the eggs are removed through the vagina with technological aids. Some of the eggs are fertilized with the partner's sperm in a petri dish; within 48 hours cell division occurs and the fertilized embryos are implanted in the uterus. The remaining embryos are frozen for future use. *In vitro* fertilization typically costs between $6,000 and $10,000.

Q: Women with vulvodynia often are prescribed tricyclic antidepressants such as Elavil or anticonvulsants such as Neurontin. Is there concern regarding the use of these medications during pregnancy?

A: As a general rule, physicians recommend terminating these medications at the time of the last menses before attempted conception. These medications should be avoided during the first trimester of pregnancy, because it is the most critical period for preventing birth defects. This is a cautionary measure; some of these medications have not been studied in great detail with regard to their effect on the developing fetus. If a woman can refrain from taking any kind of medication until the end of the first trimester, pain treatment options can then be discussed with her physician.

Although they are not as effective pain modulators as the tricyclic antidepressants, the selective serotonin reuptake inhibitors (e.g., Paxil and Zoloft) are considered safe to take during pregnancy. Narcotics also are considered relatively safe, although high doses may cause the child to be born addicted. This is an important issue to consider when making a decision whether to use narcotics throughout pregnancy. Injections of corticosteroids into the vulva or the application of topical creams such as Estrace and Lidocaine also are acceptable vulvodynia treatments during pregnancy.

Q: Is it advisable for vulvodynia patients to have Caesarean sections instead of vaginal deliveries?

A: Women with vulvodynia should talk to their physicians about the option of a Caesarean section. If there is an increased risk of vulvar trauma (e.g., a tear, episiotomy, or delayed second stage of labor) during vaginal birth, a Caesarean section may be advisable. If there is a low risk of vulvar trauma, vaginal deliveries do not necessarily exacerbate vulvodynia symptoms. During the course of labor, the woman and her physician should make this decision depending on individual circumstances.

Q. What suggestion do you have for women who would like to have children but do not want to attempt pregnancy?

If a woman does not want to attempt pregnancy herself, surrogate motherhood and adoption are options. For surrogacy purposes, a woman's eggs are removed as they would be for *in vitro* fertilization. The eggs are then fertilized with

See PREGNANCY, page 7

Pregnancy

(from page 6)

her partner's sperm and transferred into a surrogate mother. After birth, the child is returned to the genetic parents. There are very intricate legal issues involved with this method of childbirth and it is outlawed in some states. The cost of surrogate pregnancy ranges from $20,000 to $40,000 and it is not covered by insurance.

Adoption can be pursued through either a public or private agency. Using a public agency typically costs about $20,000 less than private adoption, but there are other important issues to consider. For example, in some cases of public adoption, the biological parents may obtain visitation rights. For more information on alternative methods of conception, ask your gynecologist or family physician for a referral to a fertility specialist or contact the following organizations:

American Surrogacy Center
Marietta, GA
www.surrogacy.com

American Society for Reproductive Medicine
1209 Montgomery Highway
Birmingham, AL 35216-2809
205-978-5000
asrm@asrm.org
www.asrm.org

American College of Obstetricians and Gynecologists
409 12th Street, S.W.
P.O. Box 96920
Washington, D.C. 20090-6920
www.acog.org

Editor's Note: *If you would like to share your experience in becoming pregnant (anonymously if you prefer), please send your story to Chris Sanders, NVA News, P.O. Box 4491, Silver Spring, MD 20914.* ■

SUPPORT THE NVA

Did you know that you can make a donation to the NVA using appreciated securities, including publicly traded or privately held stock and mutual funds?

The appeal of this method of giving is that the donor is entitled to take a charitable deduction for the full current value of appreciated securities held longer than one year, and is able to avoid paying the capital gains tax that would be due if the securities were sold.

If you have any questions about making this type of donation, please contact NVA Executive Director Phyllis Mate at 301-299-0775 or via e-mail (matenva@graphcom.com).

Demographics

(from page 4)

Conclusions

In general, the vulvodynia patients seen through the Vancouver Hospital Vulvar Disease Clinic were extremely well-educated and sought help from multiple physicians and different medical specialties. Despite numerous consultations and interventions, the health care provided was not perceived as helpful for their condition.

Vulvodynia is associated with sexual dysfunction; therefore all patients should have a sexual history taken and be offered sexual counseling where appropriate. This population of vulvodynia patients exhibited many health problems, including other chronic pain conditions, and many would probably be best helped using a multidisciplinary approach.

References

1. McKay, M. Vulvodynia diagnostic patterns. Dermatol Clin 1992; 10:423-33.

2. Schover, L.R., Youngs, D.D, Cannata, R. Psychosexual aspects of the evaluation and management of vulvar vestibulitis. Am J Obstet Gynecol 1992;167:630-6.

3. Van Lankvoid, J., Weijenborg, P., Ter Kuile, M. Psychological profiles of and sexual function in women with vulvar vestibulitis and their partners. Obstet Gynecol 1996;88:65-9. ■

An Overview of Interstitial Cystitis

By Lucretia Perilli, ICA Communications Associate

A significant number of vulvodynia patients suffer from interstitial cystitis (IC), a chronic, painful inflammatory condition of the bladder wall. There are approximately 700,000 people in the United States diagnosed with IC. As is the case with vulvodynia, the condition is under-diagnosed, and there may be as many as 1.5 million people affected. The average age of onset is 40 years, but IC can strike anyone at any age, including children and teenagers (25 percent of the patient population is under the age of 30.) Ninety percent of IC patients are women, although recent studies have suggested that some men diagnosed with nonbacterial prostatitis may actually have IC. Currently there is no cure for IC, but many treatment options are available.

Symptoms

IC symptoms include bladder pain, suprapubic pain or pressure, urinary urgency and frequency (up to 50 times a day, in severe cases), and waking numerous times at night to urinate. Symptoms range from mild to severe. Patients may also experience urethral, vaginal, penile and/or rectal pain, and pain that radiates down the thighs. Sexual intercourse may be very painful. IC symptoms may be exacerbated by stress, but IC is not a psychosomatic disorder.

Some IC patients report muscle and joint pain, vulvar pain, migraines, allergic reactions and gastrointestinal problems, as well as the more common symptoms. It appears that IC has a yet unexplained association with certain chronic diseases and pain syndromes such as vulvodynia, fibromyalgia, irritable bowel syndrome and Sjogren's syndrome. In one study (Urology, May 1997 supplement), 2,400 IC patients were surveyed; 12.2 percent had vulvodynia and 26.4 percent had vulvodynia symptoms, although they had not been diagnosed.

Interstitial cystitis is a devastating condition that can affect every aspect of a person's life. The constant need to urinate disrupts sleep and makes travel and other normal activities difficult. Studies have shown that the quality of life of IC patients is equal to that of patients on kidney dialysis, whose suffering is widely recognized.

Causes

Numerous causes for IC have been suggested, and there may be multiple precipitating factors. Suspected causes include bacterial or viral agents that have yet to be identified in the laboratory; defects in the bladder lining (the so-called "leaky bladder syndrome)"; toxic substances in the urine; bladder irritation caused by substances such as histamine released into the bladder wall by mast cells; bladder-specific autoimmune dysfunction; and a sensory nerve disorder. To date, none of these possible causative factors have been proven or disproven.

Diagnosis

Because of the lack of an IC-specific marker, diagnosis is not straightforward. In spite of advances in understanding the disease, it still takes some patients up to five years to obtain a diagnosis. An IC diagnosis is made by:

1. Symptom history.
2. Urine culture to rule out bacterial infection.
3. Physical examination to rule out other causes of pelvic or vulvar pain, such as sexually transmitted disease, endometriosis or vulvodynia.
4. Examining the inside of the bladder with a special instru-

(See INTERSTITIAL CYSTITIS, page 9)

Interstitial Cystitis

(from page 8)

ment known as a cystoscope. This procedure should be done under general or regional anesthesia because the signs of IC may not be seen during a simple office cystoscopy. A cystoscopy performed during an office visit can be very painful as well.

Because of the lack of an IC-specific marker, diagnosis is not straightforward.

Analysis of the national IC Database Study revealed that when patients' bladders were overdistended (stretched with water) under general anesthesia, 90 percent of IC patients had some cracks and bleeding from the bladder wall, characterized as "glomerulations," and 11 percent had ulcers or "Hunner's patches." In general, a biopsy of the bladder wall is not necessary for the diagnosis of IC, but it may be helpful in ruling out bladder cancer. (IC is not associated with bladder cancer.) Other conditions that should be ruled out before an IC diagnosis is made are kidney disease, bladder calculi (stones), tuberculosis and radiation cystitis.

Treatments

During the past decade, the range of treatment options for IC has expanded. For mild cases, changes in diet, stress reduction and "bladder retraining" (instituting a pattern of urinating less frequently) are often sufficient to bring symptoms under control. For more symptomatic patients, a number of treatments have been helpful. One of these treatments, hydrodistention, is performed with either general or regional anesthesia. In this procedure, the bladder is stretched by filling it with water. As mentioned above, this is one of the diagnostic tests for IC, but it also can be therapeutic.

Many oral medications are used to treat IC. Elmiron is the only oral medication approved specifically for the treatment of IC. Tricyclic antidepressants are often helpful because they have anti-pain properties in addition to their anticholinergic properties. Antihistamines such as hydroxyzine (Atarax, Vistaril) also may be useful, especially for those IC patients who have allergies. Other oral medications that may be helpful include nonsteroidal anti-inflammatory drugs (NSAIDS), antispasmodics, muscle relaxants, and if pain is severe, opioid analgesics.

Bladder instillations are sometimes used to control IC symptoms. DMSO (dimethyl sulfoxide) is an anti-inflammatory agent that is instilled directly into the bladder. It can be mixed with other agents such as bicarbonate, steroids and local anesthetics to create a "bladder cocktail."

There are several other types of treatments for IC. Transcutaneous electrical nerve stimulation (TENS), a standard treatment for muscle pain, may help reduce bladder pain as well. Acupuncture and acupressure, massage, body work, yoga, biofeedback, myofascial release (techniques that help to relax the pelvic floor muscles), stress reduction, visualization and moderate exercise regimes have all been found useful by some patients.

Surgery that diverts urine to an exterior collection bag or constructs an interior reservoir to collect urine, is reserved for the most severe cases (less than 5 percent of the patient population) when all other treatments fail. There are potentially serious complications from surgery, and in some cases, even surgery may not relieve IC pain.

Currently, two experimental treatments for IC are being tested. A surgically implanted device, the Sacral Nerve Stimulation Implant, recently approved by the U.S. Food and Drug Administration for urge incontinence, is undergoing

(See INTERSTITIAL CYSTITIS, page 11)

A Lesson For All of Us

by Chris Sanders

In the December 7, 1998 issue of *People* magazine, the cover story titled "After the Tears" featured Michael J. Fox's battle with Parkinson's Disease, a diagnosis that, until then, Fox had only shared with a tight circle of family and friends. During the interview, Fox made the following insightful observation. "It's not that I had a deep dark secret. It was just my thing to deal with. But this box I had put everything into kind of expanded to a point where it was difficult to lug around. What's in the box isn't inhibiting me. It's the box itself. I think I can help people by talking. I want to help myself and my family."

Can vulvodynia sufferers learn something from Fox's approach to dealing with Parkinson's? Yes, he lives with a different kind of illness and a different set of symptoms. However, there is a common thread - the feeling that one's condition has to be kept secret. Sometimes it is not the actual diagnosis or symptoms that affect us the most. Often it can be trying to keep the diagnosis in a box that is the most detrimental - trying to deal with the pain on one's own and concealing it from family, friends and coworkers is, in itself, inhibiting. Yes, it did take Michael J. Fox seven years to start talking publicly about his illness. You and I know all too well how difficult it is to take that first step. But as Fox learned, you can help yourself and your family more than you know, by "opening your box"and talking about your experience.

"...I'd like to stop it (Parkinson's) from its logical conclusion, but I'm grateful," Fox said. "It's made me stronger. A million times wiser. And more compassionate. I've realized that I'm vulnerable. The end of the story is you die. We all die. So, accepting that, the issue becomes one of quality of life. The biggest thing is that I can be in this situation and still love life as much as I do. Life is great. Sometimes, though, you just have to put up with a little more crap."

None of us has asked to live with vulvodynia, but hasn't it made you more grateful? Grateful for things you took for granted before? A loving partner? Your child's health? Pain-free days? Hasn't your experience made you stronger, wiser and more compassionate?

At the end of the journey we all die, with or without a diagnosis of vulvodynia, Parkinson's or any other medical disorder. The issue facing all of us is maintaining our quality of life. How do you want to spend the rest of your life? Do you want to spend it in fear, running from what you have to deal with? Or do you want to confront your condition and work towards managing it in a way that provides the best possible quality of life? What I've learned from Michael J. Fox is that you can still enjoy life even though you have a serious medical condition. I think that's a lesson for all of us. ■

Interstitial Cystitis

(from page 9)

testing for use in IC patients.A promising bladder instillation treatment, BCG (bacillus Calmette-Guerin), is currently in the clinical trial phase and not yet approved by the FDA. It appears to work by boosting the immune system.

The ICA

The Interstitial Cystitis Association (ICA) was established in 1984 to provide information and support to the thousands of patients who suffer from this debilitating disease, and to promote research. The ICA has been instrumental in dramatically increasing awareness in both the public and medical communities, and in stimulating research at the National Institutes of Health (NIH). Over the past decade, some of the funding earmarked for IC research at the NIH has been used to establish a database of IC patients. Researchers are now working toward tailoring treatments to different subgroups of the patient population. For more information about IC, contact:

ICA
51 Monroe Street, Suite 1402
Rockville, MD 20850
1-800-HELP-ICA
http://www.ichelp.org ■

Letters to the Editor

(from page 2)

felt so alone. No one understood what I was going through.

After it was determined that I had VVS, I thought there would be a light at the end of the tunnel. Many painful treatments later, I became completely discouraged. Eventually I found and joined the NVA. The newsletter helped me immensely. I spoke to my support group leader and realized that I wasn't alone! I even learned that there were women whose symptoms were worse than mine. I called specialists from California to Maryland, and flew to Washington, D.C. to see Dr. Stanley Marinoff. After a physical examination, he suggested surgery as an option. He told me that the surgery success rate was high for patients with my particular symptoms. I thought about it for a few weeks and then returned to D.C. to undergo surgery. I was very frightened because I felt that if it didn't work out, my relationship with my fiancee probably wouldn't last.

Well, I had the surgery 6 months ago. It was very uncomfortable for a few weeks, but it wasn't painful. I had endured even more pain from my symptoms and other treatments. If you're wondering if the surgery was successful..... I was married on January 16, 1999!

D.W. ■

Treating Vulvodynia With Aldara?

The NVA would like to obtain information on the use of Aldara in the treatment of vulvodynia. This medication is <u>not</u> a standard treatment for vulvodynia.

If you have tried Aldara for this purpose, please write to: Harriet O'Connor, NVA, P.O. Box 4491, Silver Spring, MD 20914, or call the NVA office at 301-299-0775.

If you get voice mail, mention that you are calling about Aldara, and leave your name, phone number and the best time to call you. Thank you.

Moving?

Please send your change of address to the NVA:

P.O. Box 4491
Silver Spring, MD
20914-4491

Newsletters are sent by bulk mail and are not forwarded by the USPS. For every piece of returned mail, the NVA pays a first class postage fee.

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.

N
V
A

NATIONAL VULVODYNIA ASSOCIATION

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