

The *NVA Update*, a bimonthly publication of the National Vulvodynia Association, provides information on recent advances in medical research funding, publicity and Capitol Hill efforts. Previous issues can be viewed on [NVA's web site](#). In addition to news articles, the NVA's printed newsletter, *NVA News*, contains articles on the diagnosis and treatment of vulvodynia by medical experts. To subscribe, visit [NVA's web site](#).

Vulvar Specialist Shares Important Lesson with Colleagues

by Christin Veasley



Whenever someone asks me if I know Dr. Hope Haefner, professor of obstetrics and gynecology and co-director of the Center for Vulvar Diseases at the University of Michigan, I say, "Hope is one of the most empathic, down-to-earth physicians I've ever known. I would want her to be my doctor." When I listened to her lecture on medical ethics and humanism at a major medical conference last May, I learned exactly why the words *empathic* and *kind* come to mind when I think of her.

Although I've known for some time that Hope dealt with health challenges early in her life, I didn't know many details or to what extent it had affected her personally or professionally. In her lecture, *Exploring Illness Through the Patient: A Sensory Journey in Ethics, Humanism and Professionalism*, she took the audience, composed mainly of medical professionals, through an exploratory journey to help them remember why they decided to practice medicine - to help people. She emphasized that we are *all* patients at some point in our lives - real, whole people that need to be treated as such and not reduced to simply body parts.

To start, Hope shared that she was diagnosed with ovarian cancer at the age of nine. Her doctors told her parents it was unlikely she would survive, but that she needed a complete hysterectomy, or removal of her uterus and ovaries. Hope's parents decided that it was in her best interest not to tell her about her cancer diagnosis and hysterectomy. Instead, they said that she had her appendix removed. In the months following, she underwent numerous radiation treatments, but didn't question them because of her young age and what she refers to as the "growing silence" between her parents and herself.

A few months before the 5-year mark, the time her parents had been waiting for to disclose that she *had previously been diagnosed with cancer* and was "cured," Hope started vomiting. In the emergency room, her physician inadvertently told 14-year-old Hope of her previous cancer and hysterectomy. In the lecture, she described the feelings that accompanied this revelation. Before she had an opportunity to talk with

her family, however, she suffered a catastrophic reaction to an intravenous fluid replacement treatment, for dehydration, that contained an incorrect amount of potassium. Her heart stopped beating and she was resuscitated in front of her family. Once she regained consciousness, the doctors discovered that she had a bowel obstruction, caused by the previous surgery and radiation exposure, and she underwent immediate surgery to release the adhesions. Thankfully, the cancer had not returned.

She described the depression and difficulties she experienced during her adolescence, because she felt different from her friends, and then fast-forwarded several years to the time she was an ob-gyn resident caring for a baby with the herpes virus in the neonatal intensive care unit (NICU). In the NICU, she smelled what she described as a 'sweet-unpleasant' odor and asked the nurse if she smelled it also, but she didn't. Exhausted after being on call for many hours, she dismissed it and headed home. While driving, she smelled it again and thought that it was strange, but didn't think too much of it. By the time she got home, Hope had a horrific headache and decided to lie down, but on the way to her bedroom, she started vomiting and passed out. Her husband found her minutes later and rushed her to the hospital. What had happened? Hope had contracted herpes encephalitis from the baby, and as a result, experienced a series of seizures. When she woke up in the hospital, she couldn't remember her husband's name, what year it was, or the name of the President.

In the months following, Hope underwent exhaustive therapy to regain her memory and described how instrumental her neurologist and her husband had been in her recovery. Her husband, a surgical resident, sat with her day after day, helping her to recall surgical procedures and the names of the instruments. After several months, she returned to the hospital to complete her residency, but her recovery was far from over. Her memory loss forced her to come up with intuitive methods to make up for lost time.

Hope then described what she considers one of the most rewarding moments in her career. Her neurologist, who had seen her at her very worst and played such a vital role in her recovery, came into the hospital with his wife who was in labor. Because of everything she had been through, Hope momentarily doubted her abilities, but she quickly recovered her confidence, and with her neurologist's faith in her, she felt blessed to deliver their baby.

The audience was awestruck by her story and struggled to hold back the tears. She then disclosed that she dedicated her career to treating women who suffer from chronic conditions because of the many health challenges she faced earlier in her life. Hope's contributions to the field of vulvar disease and the advancement of patient care have been truly remarkable. In recognition of her exemplary dedication, NVA would like to make our readers aware of health conditions that Hope considers very deserving of our attention.

Please share the following information on ovarian cancer and encephalitis with others.

Ovarian Cancer

Ovarian cancer is the fifth leading cause of cancer deaths in women and the leading cause of death from gynecological malignancy. There is no specific test to diagnose ovarian cancer in an early stage, although scientists are working on it. In the US, one of every 40 to 60 women will develop ovarian cancer in her lifetime. It occurs infrequently in children and older women are at highest risk. The most frequently reported symptoms

are bloating, pelvic or abdominal pain, difficulty eating or feeling full quickly, and urinary symptoms (urgency or frequency). Women or girls who have these symptoms almost daily for more than a few weeks should see their gynecologist, since prompt medical evaluation can lead to detection at the earliest stage of the disease. Early stage diagnosis is associated with an improved prognosis. For additional information, please visit www.ovariancancer.org or www.cancer.org. To learn more about how to help children with ovarian or other cancers, please visit www.wish.org or www.candlelighters.org.

Encephalitis

Encephalitis begins as an infection and subsequently causes inflammation of the brain. It differs from meningitis, which is an inflammation of the layers that cover the brain. Encephalitis is commonly caused by a viral infection, such as the herpes simplex virus (the virus that causes cold sores). Viruses that cause the measles, mumps, and chickenpox, as well as the Arboviruses (viruses spread by mosquitoes and ticks), can also cause encephalitis. Although viruses are the most common source of infection, bacteria, fungi and parasites can also be sources. The illness resembles the flu and usually lasts for two to three weeks. Symptoms of encephalitis include fever, headache, light sensitivity, weakness and seizures. Encephalitis varies from mild to life-threatening and can even cause death in some cases. Most people with a mild case can fully recover. Even though it is possible for those with severe cases to make a full recovery, they may suffer permanent damage to their nervous system. For additional information, please visit www.encephalitis.info or <http://www.emedicine.com/emerg/TOPIC247.HTM>

Vulvodynia Specialists Educate Hundreds at National Pain Meeting

NVA staff just returned from Las Vegas, Nevada, where 700 health care providers gathered for PainWeek 2008. PainWeek is a medical conference held each September (National Pain Awareness Month) to educate frontline clinicians about recent developments in pain management.

This year, vulvodynia was covered in several seminars, including those given by Ursula Wesselmann, MD, member of NVA's medical advisory board and professor of anesthesiology at the University of Alabama in Birmingham, and Andrea Rapkin, MD, an NVA research grant recipient and professor of obstetrics and gynecology at the University of California in Los Angeles.

Several other patient advocacy organizations accompanied NVA in the exhibit hall, including the [Interstitial Cystitis Association](http://www.interstitialcystitis.org), [National Fibromyalgia Research Association](http://www.nationalfibromyalgia.org), [American Headache Society](http://www.americanheadachesociety.org) and the [Trigeminal Neuralgia Association](http://www.trigeminalneuralgia.org).

PainWeek is the sixth medical conference that NVA has attended since January 2008, thanks to a generous donation from NVA supporter, Ms. Doris Bernstein. Hundreds of health care providers stopped by our exhibit booth to learn more about vulvodynia and pick up educational materials. All of the courses presented at PainWeek 2008 will be available for viewing online in the coming months at www.painweek.org.



Top Photo: Dr. Andrea Rapkin during her lecture on women's urogenital pain disorders.

Bottom Photo: NVA's Christin Veasley giving information to an attendee at our exhibit booth.

Vulvodynia Receives Prominent Media Coverage

Vulvodynia continued to receive prominent media coverage this summer. As you read the news articles summarized below, please take a few minutes to post your comments on the web sites and send a brief e-mail to the journalists and editors. Thank them for covering the condition and let them know that vulvodynia is an important topic that you want to hear more about in the future.



Just last week, vulvodynia received prominent coverage in US News & World Report magazine, with more than 2 million weekly readers. In the article titled, [Coping with 5 Common Sex Problems](#), NVA donor Michele G. (pictured to the right) candidly described vulvodynia's impact on her life and shared information on the treatments that have helped to alleviate her pain. Dr. Jennifer Gunter, director of pelvic pain and vulvovaginal disorders at Kaiser Permanente San Francisco Medical Center, also contributed to the article. She proposed that vulvodynia is a complex pain disorder and discussed the importance of early diagnosis and intervention.

Also this month, health.com featured the story of NVA's co-founder and executive director, Phyllis Mate (pictured to the left). In the article titled, [A Longtime Vulvodynia Patient Finally Gets Help From a Pain Specialist](#), Phyllis discussed the therapies that helped her regain her quality of life, specifically the important role that pain specialists can play in treating vulvodynia. The Orange County Register, a daily newspaper published in Santa Ana, California, also published an article on female sexual dysfunction this month. The author of the article, [Women Don't Have to 'Grin and Bear' Sexual Dysfunction](#), interviewed four Orange County medical providers who specialize in treating women who suffer from sexual disorders.



Over the course of the summer, two women, both freelance journalists and vulvodynia sufferers, published first-person accounts of their experience with vulvodynia in online magazines. Amber Adrian contributed an article to Tango magazine, titled [Allergic to Sex](#), which describes her two-year journey to proper diagnosis and successful treatment. Long-time NVA supporter Anika Fajardo, authored an article for Savvy Women's magazine titled, [Vulvodynia: When Love Hurts](#), summarizing vulvodynia's symptoms, diagnosis and treatment. The article also provided self-help tips and recommended additional resources for information and support.

In July, [Issues for Your Tissues](#), a women's health radio show in Austin, Texas, also covered vulvodynia. Katie Vitale, the program's host, interviewed physical therapist

Kimberlee Sullivan and vulvodynia patient Sharon Hernandez. During the broadcast, Ms. Sullivan discussed the important role that physical therapy often plays in the successful treatment of vulvodynia and made several recommendations for patients including the use of pain and food diaries and getting regular exercise, if possible. Sharon described the isolation and frustration she experienced while seeking a proper diagnosis and effective treatment, the disorder's toll on her overall physical and emotional health, and the difficulty she experienced trying to communicate her "invisible" pain to others. To listen to the broadcast, click [here](#).

The NVA extends its appreciation to Michele, Sharon, Amber and Anika for publicly sharing their experience with vulvodynia to help other women. NVA also thanks the journalists and editors of these articles for helping to raise awareness of this long-neglected condition.

Vulvodynia, NVA Featured in New Online Advocacy Toolkit

Purdue Pharma LP recently launched the second edition of their advocacy toolkit, [In the Face of Pain](#). The toolkit features information on a variety of pain conditions, including vulvodynia. In the *Advocacy Voices* section, dozens of advocates, pain patients and health care professionals shared their thoughts on pain advocacy, including NVA's Christin Veasley. She said, "If each of us does just a little, our efforts will ultimately make a big difference in the fight against pain. No allocation of time is too small. Simple acts, such as writing a letter to your elected official, offering a listening ear to a person in pain, or volunteering your talent to community advocacy groups, mean so much."

This free, online toolkit enables users to create personalized documents or presentations to use in their advocacy efforts, e.g., meetings with elected officials or educational presentations. Users can download their documents to their computer to update, print and share with others. To access the toolkit, click [here](#). For information on vulvodynia, start by looking under the heading 'Resources and Materials.' From there, you are a few simple clicks away from dozens of pain-related quotes, facts and resources.

EmpowHER.com Invites Women to Submit Articles

The NVA has joined forces with EmpowHER.com to raise awareness of vulvodynia. EmpowHER was recently selected as one of Google News' elite women's health sites.

The site has already posted audio and videotaped responses to *frequently asked questions* about vulvodynia and is now interested in expanding its coverage of the condition by including short, easy-to-read articles written by women with vulvodynia.

If you interested in contributing, please email a 300-400 word article to Tina Tran (tina@empowher.com). If you prefer, you can submit anonymously or under a web user name.

Ideas for articles include:

- Learning about your diagnosis;
- Tips for other women who have been diagnosed; and
- How to advocate for yourself.

Vulvodynia Studies Seeking Participants

University of Pittsburgh

Researchers at the University of Pittsburgh are conducting a study of a medicine for chronic vulvar pain (*vulvodynia*). The study requires 2 visits totaling approximately 1 hour. You must be 18 years of age or older and experiencing pain in the vulva with no known cause for at least 2 months. You will be reimbursed \$100 for completing all parts of this study. For more information, please call or email Dr. Glenn Updike, 412-641-1498 or gupdike@mail.magee.edu.

National Clinical Trial

If you suffer from vaginal pain you may qualify to participate in a clinical research study. This study is currently taking place in the United States and Canada. Participation will last approximately 18 weeks and will require approximately 8 visits to the doctor's office.

The following are requirements to be considered for the study:

- You must be 18-50 years of age
- You must continue to have menstrual periods or at least one functioning ovary
- You must be in a steady relationship for more than 6 months where vaginal intercourse is desired
- You must be willing to abstain from intercourse for 2 weeks
- You must use effective contraception
- You must be in general good health

If you qualify, you may receive study-related medication, study-related lab tests, study-related exams and compensation for your time and travel.

To find out more about the study and locate a participating physician, please click on the links below:

[US Sites](#)

[Canadian Sites](#)

Additional Studies

Information on other studies that are currently recruiting participants can be viewed on [NVA's web site](#) and ClinicalTrials.gov.