
The *NVA Update*, a publication of the National Vulvodynia Association, provides information on recent progress in medical research funding, raising awareness of vulvodynia and Capitol Hill efforts. Previous issues can be viewed on [NVA's web site](http://www.nva.org). The NVA's printed newsletter, *NVA News*, contains articles by vulvovaginal experts on the diagnosis and treatment of vulvodynia. To subscribe, visit [NVA's web site](http://www.nva.org).

NVA Launches First Online Learning Program for Women with Vulvodynia



Thanks to the generous support of [The Patty Brisben Foundation](http://www.pattybrisbenfoundation.org), in June 2009, the NVA announced the release of the first online tutorial for women with vulvodynia – [Everything You Need to Know About Vulvodynia](http://www.learnpatient.nva.org). This comprehensive, self-guided learning program aims to empower women to make educated decisions about their health care, build strong partnerships with their health care providers and improve their quality of life. The tutorial covers gynecologic and pelvic anatomy/physiology, diagnosis and treatment of vulvodynia, coping with chronic pain, and practical advice on sexual/relationship issues. If you want to view it, visit: <http://learnpatient.nva.org>. Health care providers who wish to obtain program flyers for distribution to patients should send an email to gigi@nva.org or call 301-949-5114.

NVA Attends Vagina Monologues to Benefit Boston Vulvovaginal Center

On September 29th, Elizabeth Stewart, MD, and Diana Parks Forbes, NP, hosted a special production of The Vagina Monologues to benefit the Vulvovaginal Service at Harvard Vanguard Medical Associates. [Dr. Stewart](#) is the Director of the Vulvovaginal Service, author of [The V Book](#) and a longtime member of [NVA's medical advisory board](#) and [Ms. Parks Forbes](#) is a nurse practitioner specializing in the treatment of vulvovaginal disorders. Among the 300 attendees was Lynette Margesson, a vulvar dermatologist who has a private practice in New Hampshire and collaborates with Dr. Stewart at Vanguard. With additional funding, Dr. Stewart intends to establish a Vulvovaginal Center of Excellence at Harvard that would include a multi-disciplinary team of providers specializing in gynecology, vulvar dermatology, physical therapy and couples counseling, among other disciplines. Dr. Stewart and Ms. Parks Forbes are developing educational programs for medical students, residents and other health care providers who want to learn more about treating vulvovaginal disorders. The NVA extends its gratitude to Dr. Stewart and Ms. Parks Forbes for their dedication to this area of women's health.



Left to right: Diana Parks Forbes, Dr. Elizabeth Stewart, Dr. Lynette Margesson, Christin Veasley

NVA Funds First Vulvodynia Treatment Registry

Thanks to the generosity of a longtime donor, we are pleased to announce that NVA has awarded a \$50,000 grant to Drs. Georgine Lamvu, Denniz Zolnoun and Lori Boardman to develop and implement the first-ever Vulvodynia Treatment Registry. The purpose of this multi-site registry, launched in September 2009, is to gather data on the efficacy of different treatments for vulvodynia. These treatments include, but are not limited to, topical medications (e.g., lidocaine, gabapentin); oral "pain-blocking" medications (e.g., anticonvulsants, tricyclic antidepressants and muscle relaxants); physical therapy; and surgery for vulvar vestibulitis

(aka Provoked Vestibulodynia). Women receiving medical care at the University of North Carolina, University of Central Florida and Florida Hospital will be eligible to participate.

Once enrolled, participants will undergo a thorough medical evaluation and tests to assess vestibular skin and pelvic muscle sensitivity. They will also complete several questionnaires on pain, sexual function and quality of life. All tests and questionnaires will be administered multiple times during a two-year period to assess long-term benefits of treatment. In addition, the investigators hope that data collected through the registry will clarify why only some women benefit from a particular treatment and identify factors that can predict treatment success. Additionally, the registry's findings will be used to guide the development of controlled studies on treatment efficacy.

About the Investigators



[Georgine Lamvu, MD, MPH](#), associate professor of obstetrics and gynecology at Florida State University, directs the gynecology unit at Florida Hospital in Orlando and supervises the hospital's surgical outcome database. Additionally, she serves as Director of the Florida Hospital Chronic Pelvic Pain Clinic, which provides medical care to 2000 women with chronic pelvic or urogenital pain disorders annually. Dr. Lamvu completed her fellowship in advanced laparoscopy and pelvic pain at the University of North Carolina, where she supervised the chronic pelvic pain database evaluating surgical and medical outcomes in women with chronic pelvic pain. Her research and clinical expertise will make her an exceptional Director of the Registry project.



[Denniz Zolnoun, MD, MPH](#), assistant professor of obstetrics and gynecology and Director of the Vulvar Pain Clinic at the University of North Carolina, Chapel Hill, provides medical care to many women with vulvodynia. In 2003, she was the recipient of the prestigious BIRCIWH Scholarship (Building Interdisciplinary Research Careers in Women's Health). In 2006, she received a five-year grant from the National Institutes of Health to refine diagnostic criteria for vulvar vestibulitis syndrome by studying vulvar skin and pelvic muscle sensitivity. Her research and clinical expertise make her well-qualified to serve as an advisor on muscle and skin measurements, as well as data collection.



[Lori Boardman, MD, ScM](#), is a professor of obstetrics and gynecology at the University of Central Florida College of Medicine in Orlando. Her clinical practice is located within the University's Student Health Services, which is used by 9,000 women annually. Dr. Boardman previously served as the Director of the Vulvar and Colposcopy Clinics at Women & Infants Hospital in Providence, Rhode Island. She was also a recipient of the Mentored Investigator Award in Women's Health from the National Institutes of Health. Dr. Boardman will serve as advisor in research methodology and data analysis. Her clinical expertise will also be invaluable to the project.

Vulvodynia on Primetime Television, Satellite Radio and More

On August 7th, millions tuned in to watch 20/20's *Medical Mysteries* featuring a segment on painful sexual intercourse.

[Dr. Timothy Johnson](#), ABC's chief medical editor, discussed the diagnosis and treatment of painful intercourse with [Andrew Goldstein, MD](#), director of the Center for Vulvovaginal Disorders in Washington, DC, and [Amy Stein](#), a New York-based physical therapist specializing in the treatment of urogynecological pain disorders. He also interviewed three women for the segment: Sara Fontaine and Allison Nugent, two young women who described living with the pain condition, and Christin Veasley, NVA's associate executive director, who was diagnosed with vulvar vestibulitis when she was in college.



During her interview, Sara said she visited 15 doctors in search of a diagnosis and underwent treatments for conditions she didn't have. Allison remarked that, "Dealing with a chronic pain condition is difficult no matter what, but handling it when nobody can tell you what it is, or how to treat it, is just beyond the pale."

All the women discussed the pain condition's impact on their relationship with their partners. "All the results were coming back negative and my husband just assumed that it was him – that I wasn't attracted to him anymore," recalled Sara. Allison felt that her pain not only affected her husband, but made her doubt herself, saying, "Part of what makes you a woman is having female sexual organs, and when they're not working properly, it's an assault on your ego as a woman." Allison also disclosed that her pain problem put tremendous stress on her marriage, which ultimately ended in divorce. On a heartening note, Chris and her husband Melvin (pictured) said that they decided to get married even though they were unable to have sex for the first five years of their relationship. Melvin admitted that he had struggled with the decision to marry, but ultimately concluded that, "Sex is an important part of a relationship, but it's not *the* most important part." They have been married for nine years and have two lovely daughters.



After the show, hundreds of viewers posted online comments on the 20/20 web site or wrote to NVA. Many expressed disappointment that the show did not identify the women's medical conditions as vulvodynia or vulvar vestibulitis. Some viewers thought that more details on physical therapy and the surgical treatment were needed. For example, the show did not specify that pelvic floor muscle rehabilitation usually requires visiting a physical therapist several times a week for many months, nor did it mention that women who undergo surgery may need up to one year to experience significant relief. Others remarked that featuring three women whose pain was greatly improved or cured did not portray the reality of many women who do not find relief and continue to suffer from this chronic condition.

The show concluded, however, with Allison's helpful advice for women suffering from any condition that causes painful sex. "It's important to seek treatment and talk to your doctor about it, but if he/she doesn't think you have a physical problem, you should find a vulvovaginal expert who does understand," she stated. NVA applauds Sara, Allison, Chris and Melvin for having the courage to share their personal stories on national television.

Following the show, ABC affiliates in Denver and Memphis covered the topic on their local news and [video of the segment](#) was posted on 20/20's website. The producers also posted a [10-minute video](#) of Ms. Stein demonstrating pelvic floor muscle stretches, a [questionnaire](#) that differentiates sources of painful sex and a link to the NVA's web site. NVA issued a [press release](#) expressing appreciation of ABC for bringing this rarely-discussed condition out of the shadows, but emphasized that vulvodynia's impact reaches far beyond the bedroom. The release, distributed to thousands of health reporters and editors, stated that millions of vulvar pain sufferers do not find adequate relief and that research on treatments is lacking.

ABC's The Doctors



On August 28th, [Dr. Lisa Masterson](#) of ABC's [The Doctors](#) interviewed Sheila, a woman experiencing painful sex for several years. During the short segment, [Surprising Solutions You Never Knew About](#), Sheila said that although she has a successful marriage, sex produces excruciating pain and makes her feel like "less than a woman." Similar to many vulvodynia sufferers, Sheila visited five doctors before consulting Dr. Masterson, who suspected that Sheila suffered from vulvodynia and took a biopsy of the painful tissue to rule out other causes, such as a dermatological disorder. Dr. Masterson reassured Sheila and millions of viewers that vulvodynia is "not all in a woman's head" and that it is a very real and painful medical condition. She also noted that many women, including her patients, are embarrassed to discuss painful sex with their health care providers. Sheila expressed her appreciation to Dr. Masterson, saying that "within 30 minutes, she asked more questions than anyone else has in five years."

Oprah & Friends Radio - All Things Gyno



On August 10th, sex therapist [Dr. Laura Berman's satellite radio show](#) covered several gynecological disorders with [Elizabeth Gunther Stewart, MD](#), a Harvard University vulvovaginal specialist and NVA medical advisory board member, [Elizabeth Stewart, MD](#), a Mayo Clinic obstetrician/gynecologist, and [Judith Florendo, PT](#), a Chicago-based physical therapist specializing in pelvic floor muscle dysfunction. During the two-hour program, *All Things Gyno*, Mayo Clinic's Dr. Stewart gave an overview of uterine fibroids and Harvard's Dr. Stewart answered listeners' questions about vulvo-vaginal conditions, clarifying the difference between dermatological disease, vulvodynia, vaginismus and pudendal neuralgia. Ms. Florendo discussed the important role of physical therapy in the treatment of vulvovaginal pain conditions and told women what to expect during their initial evaluation and subsequent treatment sessions. We extend our appreciation to Dr. Berman for covering vulvodynia on her show and to both Dr. Elizabeth Stewarts and Ms. Florendo for their dedication to treating women with gynecological and pelvic pain conditions.

Vulvodynia Matters Hosts Boston-area Educational Forum

On October 1st, Patricia Onorato, NVA's longtime Boston-area support leader, hosted an educational forum for women with vulvar pain and their family members and friends. This was the first event hosted by the newly formed non-profit organization – [Vulvodynia Matters](#). Patricia and her sister Mary, along with Cinzia Cloke, founded this organization in 2008 to provide support to women in the area and to educate patients, providers and the public about vulvodynia. [Lynette Margesson, MD](#), adjunct assistant professor of obstetrics and gynecology and medicine (dermatology) at Dartmouth Medical School, was the guest speaker. She discussed the diagnosis and treatment of chronic vulvar pain, provided a comprehensive overview of how the body and brain process chronic pain, and described techniques woman can use to break the pain cycle. The event was attended by more than 60 women, their family members, and local health care providers.



Left to right: Kate Stenson-Lunt, Dr. Lynette Margesson, Christin Veasley, Patricia Onorato, Mary Onorato, Dr. Peter Pacik, Dr. Elizabeth Stewart, Cinzia Cloke, Carmen Pepicelli

ACPA Releases Consumer Pain Treatment Guide

The [American Chronic Pain Association](#) recently announced the release of a new online program – [Consumer Guide to Pain Medications and Treatments](#). The Guide aims to help chronic pain sufferers better understand their treatment options, equipping them to make treatment decisions *with* their medical providers. Sections include: Pain Types, Talking to Your Professionals, Medications Used to Manage Chronic Pain, Making Your Medication Decision and Medication Safety, among others. To view the Guide, visit the [ACPA's web site](#).

2010 NIH Appropriations Report



This past summer, NVA worked with Senator Tom Harkin's (D-IA) office to include strong language on vulvodynia in the [2010 National Institutes of Health \(NIH\) Appropriations Bill](#). Three sections of the report included language on vulvodynia, i.e., those addressing the National Institute of Child Health and Human Development, National Institute of Diabetes and Digestive and Kidney Disease, and the Office of the Director. Additionally, Congress sent a clear message to NIH about the need to increase federal funding of chronic pain research in general. The 2010 language follows:

[NIH Office of the Director](#)

Vulvodynia - The Committee calls upon the [Office of Research on Women's Health](#) (ORWH) to allocate sufficient additional resources to the [educational outreach campaign on vulvodynia](#), launched in 2007, to ensure that materials are more widely disseminated to the public, patient, and medical communities, as well as federally funded health centers and college health clinics. The Committee also notes that five years have passed since the last NIH vulvodynia conference, and requests that the ORWH convene, with the support of relevant institutes and centers, a research conference on vulvodynia in fiscal year 2010.

Overlapping Chronic Disorders - The Committee notes that millions of Americans suffer with one or more of the following chronic disorders: chronic fatigue syndrome, endometriosis, fibromyalgia, headache, interstitial cystitis, irritable bowel syndrome, temporomandibular joint and muscle disorders and vulvodynia. A growing body of evidence demonstrates that these conditions frequently co-exist or overlap, yet all are poorly understood. Progress in treating these prevalent, life-altering disorders has been hindered by their complex genetics and heterogeneous etiologies; however, studying related or clinically overlapping chronic conditions can yield unique biological insight into the mechanisms underlying common disease. The Committee calls upon the Director to coordinate, with all relevant institutes and centers, a trans-NIH research initiative in fiscal year 2010 that will support studies aimed at identifying common etiological pathways, with the goal of identifying potential therapeutic targets. The Committee also requests that the Director hold a conference in fiscal year 2010 that will bring together a wide range of basic and clinical researchers from multiple specialties, as well as professional and patient advocacy organizations, to present and discuss the latest scientific discoveries and develop future research recommendations. The Committee requests an update on progress made in this area in the fiscal year 2011 congressional budget justification.

Pain Research - The Committee is disappointed with the pace at which NIH is expanding and improving pain research, in general, and in particular with the slow startup of the Pain Progress Review Group. The Committee urges the NIH to invigorate the [NIH Pain Consortium](#) and focus its efforts on identifying and filling important gaps in the pain research agenda, not simply showcasing the relatively small amount of work currently being done in this area. The Committee also urges the NIH to work with the Departments of Defense and Veterans Affairs to coordinate their respective research efforts on pain conditions afflicting troops returning from the current conflicts in Iraq and Afghanistan.

[National Institute of Child Health and Human Development \(NICHD\)](#)

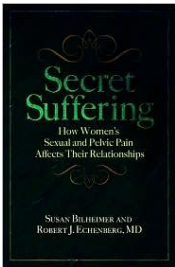
Vulvodynia - The Committee remains concerned with the lack of progress in expanding research efforts on vulvodynia in recent years, and it strongly urges that the NICHD employ a full range of award mechanisms to substantially increase the number of awards for vulvodynia studies in fiscal year 2010. In addition, new research indicates that chronic vulvovaginal pain is also highly prevalent in the adolescent population and has been documented in children as young as 4 years of age; therefore, the Committee urges that consideration be given to collecting data on vulvodynia and related pain conditions in the [National Children's Study](#). The Committee notes the lack of vulvodynia experts on peer-review panels and again encourages the Director to work with the Center for Scientific Review and other institutes and centers to ensure their adequate representation. The Committee also calls upon the Institute to continue efforts with the Office of Research on Women's Health on the [vulvodynia educational campaign](#). Finally, the Committee notes that vulvodynia coexists with other persistent pain conditions, including interstitial cystitis, fibromyalgia, temporomandibular joint and muscles disorders, irritable bowel syndrome, endometriosis, and chronic fatigue syndrome. The Committee calls upon the NICHD to collaborate with the Office of the Director on a trans-NIH research initiative that will support studies aimed at identifying common etiological pathways among these disorders, with the goal of developing therapeutic targets.

[National Institute of Diabetes and Digestive and Kidney Disease \(NIDDK\)](#)

Pelvic Pain - The Committee recognizes that there is a growing population of patients with chronic pelvic pain, chronic prostatitis and urogenital pain, and it urges the NIDDK to collaborate with the ORWH, [National Institute of Allergy and Infectious Diseases](#), [National Institute of Arthritis and Musculoskeletal and Skin Diseases](#), [National Institute of Neurological Disorders and Stroke](#), and NICHD to establish a dedicated center for research and education on urologic/urogenital chronic pelvic pain and chronic prostatitis syndromes that will focus specifically on interstitial cystitis and vulvodynia, and related co-morbid disorders.

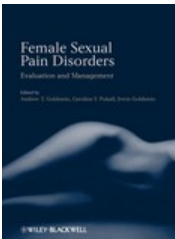
New Books

Did you know that you can help the NVA fund medical research by shopping online at Amazon? If you are interested in purchasing any of the books below, please visit the [NVA's web site](#) first, click on the book cover, and a percentage of your total purchase price will be donated to NVA at no extra cost to you!



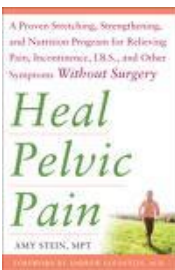
Secret Suffering: How Women's Sexual & Pelvic Pain Affects Their Relationships Susan Bilheimer and Robert J. Echenberg, MD

[Secret Suffering](#) explains how pelvic and sexual pain affects the lives of women and their partners. Susan shares her experiences as a patient who has traveled the painful and frustrating road of living with an illness that is dismissed and not taken seriously. Dr. Echenberg shares decades of expertise as a chronic pelvic pain specialist.



Female Sexual Pain Disorders: Evaluation and Management Andrew T. Goldstein, MD, Caroline Pukall, PhD and Irwin Goldstein, MD

[Female Sexual Pain Disorders](#) empowers women's healthcare professionals to help women overcome painful intercourse. It provides practical guidelines for health care professionals to differentiate the causes of sexual pain and describes multidisciplinary treatments for managing it. All book proceeds will be donated to the International Society for the Study of Women's Sexual Health.



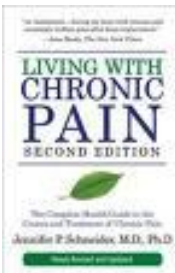
Heal Pelvic Pain Amy Stein, MPT

[Heal Pelvic Pain](#) provides information on a stretching, muscle-strengthening and massage program that women can do at home to help alleviate their pelvic floor muscle pain. In addition, Ms. Stein provides suggestions for reducing stress and building core strength.



100 Questions and Answers About Women's Sexual Wellness and Vitality A Practical Guide for the Woman Seeking Sexual Fulfillment Michael L. Krychman, MD

In [100 Questions and Answers](#), Dr. Krychman, sexual medicine specialist, provides answers to 100 of the most common questions women and their partners ask about sexual health. He also provides practical advice on complex problems and suggestions for improving your sexual function through lifestyle changes, medication and therapy.



Living with Chronic Pain (Second Edition) Jennifer P. Schneider, MD, PhD

[Living with Chronic Pain](#) is an excellent resource for anyone suffering from debilitating chronic pain. This updated second edition provides the latest information about medications, treatments and research. Chronic pain specialist Dr. Jennifer Schneider takes the reader through the process of choosing a pain specialist that is best for her and describes steps that the pain sufferer can take to regain her quality of life.



Because It Feels Good: A Woman's Guide to Sexual Pleasure and Satisfaction Debby Herbenick, PhD

In [Because It Feels Good](#), Dr. Herbenick advises women on how to make sex fun and satisfying. From enlightening lessons on female anatomy to the complicated issue of libido, the book informs women about every aspect of sexual function, with the goal of helping women to achieve the sex lives they deserve.

Participate in Research



There are many opportunities for women with vulvodynia to participate in scientific research studies. For a complete list of studies that are currently recruiting participants, please visit the [NVA's web site](#).

Treatment of Vaginal Pain with Injection of Numbing Medicine (University of CA – Los Angeles)

Women aged 18-65 with a diagnosis of vulvodynia, who are not currently pregnant and do not intend on becoming pregnant in the next 3 months, may be interested in a UCLA study to see if vaginal and lower back nerve blocks (injection of local anesthetic medicine) are helpful in treating this disorder. Pelvic muscle evaluation and psychological questionnaires are included. The study will last up to 7 months and includes 3-5 treatment sessions, a 2-month follow-up visit, and a phone call to assess progress 2 months after the follow-up visit. For further information, call 310-825-6963. (Principle Investigators – Drs. Andrea Rapkin and John McDonald.)

Pregabalin (Lyrica) for the Treatment of Vulvodynia (Cleveland Clinic, Ohio)

Eligible participants must be age 18 or older and have been diagnosed with vulvodynia (generalized vulvodynia or vulvar vestibulitis). Participants must practice reliable form of birth control defined as sterilization, hormonal contraception, abstinence or IUD. Women must not have contraindication to pregabalin or history of prior use of the medication. The study will last approximately 11 weeks and participants must be able to attend five follow-up visits during that time. The study drug, tests, procedures and visits will be provided at no cost. For additional information, contact Linda McElrath, RN by phone – 216-445-2494. (Principle Investigator – Beri Ridgeway, MD)

A Clinical Trial of CC-10004 for the Treatment of Vulvodynia (Beaumont Hospital, Michigan)

This is a 16-week drug trial. All study medication, exams, blood work, ECGs and questionnaires will be provided at no cost. Women must be between the ages of 18-69 and have a reported history of vulvar pain for at least three months. For additional information, please contact Karen Sherer, RN, by phone (248-551-3565). (Principle Investigator – Kenneth Peters, MD)

Online Diagnosis Survey (St. Cloud State University, Minnesota)

If you have computer access, are able to read English and have a diagnosis of vulvar vestibulitis syndrome (aka provoked vestibulodynia), you may be eligible to participate in the study. Women will complete an online questionnaire regarding their diagnosis and the efficiency of the process. The online session takes approximately 15 to 20 minutes. To participate, log in to the study's [web site](#), read the consent form, and "sign" the form by selecting the submit button. Or you can send an email to Dr. Jennifer Connor (jjconnor@stcloudstate.edu).

Online Coping Survey

For her doctoral dissertation, Erica Hamilton is studying coping efforts among women with chronic pelvic pain. If you are 18 or older and have suffered with any form of chronic pelvic pain (e.g., vulvodynia, endometriosis) for at least 6 months and have access to a private internet connection, you may be eligible to participate in the study. Participation lasts five to six weeks and involves completing an electronic demographic form, participating in two phone interviews and tracking symptoms over the course of a full menstrual cycle (or 30 days if you are not menstruating). The first phone interview is expected to last approximately two hours. Women are then asked to complete a short electronic form each day for the duration of the tracking period (5-15 minutes per day). The form asks questions about pain intensity, daily challenges related to the pain, and daily coping efforts. The second phone interview is expected to last between 30 and 60 minutes. Participants will be compensated with a \$50 gift certificate. For additional information, or to participate, contact Erica Hamilton, MA, PhDc, by email (ericahamilt@gmail.com).

Online Pain Characteristics Survey

If you are 18 or older and have access to a private internet connection, you may be eligible to participate. Women, with and without vulvodynia, and their partners, will complete an online vulvodynia survey. To participate, visit <http://vulvodynia-pelvicpainsupport.com> and click on the appropriate link. For additional information, contact Dr. Clark by email (drlauraclark@vulvodynia-pelvicpainsupport.com).