

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](#).

In Memory and Appreciation of Dr. C. Paul Perry



All of us at the NVA were saddened by the recent death of pelvic pain pioneer, Dr. C. Paul Perry. He was an ardent spokesperson for improving the medical care of women with chronic pelvic pain and founded both the C. Paul Perry Pelvic Pain Center in Birmingham, Alabama and the International Pelvic Pain Society. During his career, Dr. Perry authored numerous medical journal articles and taught continuing medical education courses on advanced laparoscopy, hysteroscopy and the treatment of chronic pelvic pain. He was a fellow of the American College of Obstetricians and Gynecologists and a consulting editor for the College's medical journal, *Obstetrics & Gynecology*.

We will miss Dr. Perry both professionally and personally, and extend our deepest sympathy to his family. If you would like to send your condolences, you can do so on Dr. Perry's web page on the [CaringBridge site](#), or you can make a donation to the C. Paul Perry Memorial Education Fund on the [International Pelvic Pain Society's web site](#).

NVA Announces Career Award Recipient

In 2006, the NVA established the [Dr. Stanley C. Marinoff Vulvodynia Career Development Award](#) in recognition of Dr. Marinoff's invaluable contributions to the field of vulvodynia. The award is given annually to a junior faculty member who demonstrates a serious clinical or research interest in vulvodynia. The NVA is pleased to announce that the 2008 recipient of the award is Beri Ridgeway, MD, who is currently completing a fellowship in female pelvic medicine and reconstructive surgery at The Cleveland Clinic in Ohio.



Antidepressants and anticonvulsants are often the first-line medicines used to treat vulvodynia, but randomized placebo-controlled trials to determine the efficacy of these medications are scarce. With her NVA award and matching funds from The Cleveland Clinic, Dr. Ridgeway will investigate the efficacy of the anticonvulsant pregabalin (Lyrica) in the treatment of vulvodynia. Pregabalin has been shown to be effective in the treatment of other chronic pain disorders such as post-herpetic neuralgia, diabetic neuropathy and fibromyalgia. Dr. Ridgeway's primary objective is to determine whether, and to what extent, pregabalin relieves pain in women suffering from either generalized vulvodynia or vulvar vestibulitis syndrome. In addition, she will assess the medication's tolerability and its effect on quality of life. Dr. Ridgeway's aim is to add to the growing body of evidence-based literature on treatment efficacy, so women and their health care providers can make more informed treatment decisions.

For additional information on the Career Development Award and/or to read summaries of previous recipients' projects, please visit NVA's [web site](#).

NVA Reaches Thousands of Providers at National Conferences



In January 2008, the NVA received a generous grant from the Doris Bernstein Family Foundation. The grant was earmarked for education of the medical community and has enabled us to attend more national health care conferences in 2008 than ever before. In early May, Doris Bernstein and Neill Gillman worked with executive directors Phyllis Mate and Chris Veasley in the NVA exhibit booth at

the *American College of Obstetricians and Gynecologists* (ACOG) annual meeting. For the first time, vulvodynia and related disorders received a substantial amount of attention at the ACOG meeting. In addition to two full-day postgraduate courses on advances in vulvovaginal disorders and chronic pelvic pain, taught by Drs. Hope Haefner, Libby Edwards, Fred Howard and others, an additional 12 clinical seminars, posters, presentations and meetings focused on vulvodynia and related disorders. Hundreds of providers learned about the diagnosis and treatment of vulvodynia and hundreds more visited the NVA's exhibit booth seeking educational materials for themselves and their patients.

Highlights of the ACOG meeting included a seminar on the evaluation and non-surgical management of vulvar pain syndromes, given by Colleen Kennedy, MD, University of Iowa assistant professor of obstetrics and gynecology. Dr. Kennedy also presented a poster, with colleagues Drs. Susan Wing and Catherine Bradley, summarizing some of their findings from a recent NIH-funded study investigating the relationship between vulvodynia and bowel or bladder symptoms. In brief, the study showed that women with pelvic organ prolapse are more likely to report vulvar

burning, pain and painful intercourse compared to controls, and that urinary symptoms were associated with all vulvar symptoms, including burning, pain, itching, painful intercourse and vaginal discharge.

Denniz Zolnoun, MD, University of North Carolina assistant professor of obstetrics and gynecology and NIH vulvodynia grant recipient, and her colleagues also presented a poster summarizing findings from an NVA-funded project entitled, *Trends in Pharmacy Compounding for Women's Health in North Carolina: A Focus on Vulvodynia*. They administered a survey to two hundred compounding pharmacies to establish the prevalence of using compounded medications for women's health conditions and to identify trends in compounding practices for vulvodynia. The survey revealed that women's health disorders were the third leading reason for requesting compounded medications, with 13 percent used specifically for vulvar pain. The most common medication used for vulvar pain was lidocaine, followed by estradiol and testosterone. The research team concluded that compounding pharmacies play a critical role in providing medications that are not commercially available for disorders such as vulvodynia. They will make this data available to advocacy efforts aimed at making sure compounding pharmacies are able to continue to customize their medications for vulvodynia and other women's health conditions.

Dr. Michael Krychman, medical director of sexual medicine at the Southern California Center for Sexual Health in Newport Beach, California, gave a presentation on emerging trends in treating female sexual disorders (FSD). In brief, compounded topical medications, such as estradiol, testosterone and gabapentin are being used more frequently with reported success. In addition to the use of various oral and topical medications, clinicians are encouraging a multidisciplinary approach to treating FSD that incorporates alternative therapies, such as meditation and acupuncture. Finally, he stressed the importance of including physical therapy into the treatment regimen. Dr. Gary Ventolini, chair of the department of obstetrics and gynecology at Wright State University Boonshoft School of Medicine in Dayton, Ohio, presented findings from a recent study he conducted with Drs. Sheela Barhan and Janice Duke. The study evaluated a standardized, step-wise protocol for diagnosing and treating vulvodynia. After receiving a vulvovaginal culture and treatment for bacterial and fungal infection, women who still experienced vulvar pain were advised to modify their diet. If they didn't respond to dietary modification, they were given a tricyclic antidepressant, and if they still experienced pain, gabapentin was added to the treatment regimen. Of the 74 women who participated, 81 percent achieved painless sexual intercourse with one or more of these therapeutic options.

In late May, NVA hosted an exhibit booth at the annual meeting of the [American College of Nurse Midwives](#) for the first time. The conference was attended by 1500 clinicians specializing in women's health care. We extend our thanks to local NVA participants, Patricia Onorato, Cinzia Cloke, Emily Gleason, Carrie Thompson and Jennifer Bingham for volunteering their time to speak with health care providers and distribute informational packets. The conference held a full-day workshop, *Vulvovaginal Disorders: Unveiling What You Need to Know to Care for Women with Itching, Burning, Unusual Discharge or Vulvar Pain*, taught by Ione Bissonnette, CNM, MSN, Patricia Degroot, MD, and Diana Parks Forbes, NP and Alisa Pascale, NP. Many providers commented on how valuable the workshop was for them. The conference also included a women's health exposition. This gave the NVA the unique opportunity to educate the public about vulvodynia and offer assistance to anyone who suffered from the condition.

At the end of June, NVA exhibited at the annual meeting of the [American Academy of Nurse Practitioners](#) in Washington, DC, attended by 3200 nurse practitioners. Judi Lenehan, NVA's director of support services, Harriet O'Connor, NVA board member and Christina Chew, local volunteer, disseminated information and spoke with hundreds of nurse practitioners who visited NVA's booth eager for information. Many of them approached the booth saying, "Vulvodynia. I have many patients and this is a *real* problem. Give me one of everything you have."

This September, NVA will exhibit at [PainWeek 2008](#) in Las Vegas, Nevada, where NVA research grant recipient, Dr. Andrea Rapkin, professor of obstetrics and gynecology at UCLA, will give a presentation on vulvodynia and other urogenital pain disorders.

Recent NIH and NVA Vulvodynia Grants

In May 2008, the National Institute of Child Health and Human Development awarded a third research grant to University of Michigan co-investigators Barbara Reed, MD, professor of family medicine, and Hope Haefner, MD, professor of obstetrics and gynecology and co-director of the Center for Vulvar Diseases. This grant will fund a five-year project investigating the role of genetic factors and hormone use in the development of vulvodynia.

Over the past decade, research on a number of chronic pain syndromes has found that subtle variations in certain genes can make an individual highly sensitive to pain and more susceptible to developing a chronic pain disorder. For example, by analyzing slight differences in the gene that produces a certain enzyme (COMT), researchers can predict the risk of developing temporomandibular joint disorder. In recent years, studies on vulvodynia have also identified a number of genetic variations that lead to immunological changes in some women with vulvar vestibulitis syndrome (VVS).

Reed and Haefner expect to find an increased prevalence in one or more pain-associated genetic variations in women with vulvodynia. They will also study the influence of previous and current exogenous hormone use on the risk of vulvodynia onset and persistence. Prior studies have found an association between vulvodynia and/or vulvar sensitivity and hormonal exposure, such as oral contraceptive use or hormone therapy, but findings in this area have been inconsistent.

To date, most vulvodynia research has used a cross-sectional design, in which data is collected at a single point in time, and study participants have typically been women referred to vulvodynia specialty clinics. Consequently, little is known about the natural history of vulvodynia and risk factors associated with its occurrence, persistence and resolution in the general population of women. In contrast, Reed and Haefner's new study will use a longitudinal design and a geographically-defined population-based group of 2,500 women.

The specific aims of this study are to: (i) assess the prevalence, incidence, persistence and remission rates of vulvodynia, with clinical confirmation and DNA analysis, and (ii) determine the association between pain-related genetic variations and hormonal influences, singly and in combination, and the incidence, persistence and remission of vulvodynia. This comprehensive study should substantially

contribute to our understanding of the combined role of genetic factors and hormone exposure in the onset, maintenance and remission of vulvodynia, facilitating future studies on pathophysiology, treatment and prevention.

NVA Awards Two Research Grants

In December 2007, NVA awarded a research grant for the study of pelvic floor muscle function in women with VVS. The recipients of this award were Dr. Linda McLean, associate professor in the school of rehabilitation therapy, and Dr. Caroline Pukall, assistant professor of psychology, both of Queen's University in Ontario, Canada. Their study objectives are to determine whether, when compared to a control group, women with VVS demonstrate: (i) heightened activity of the superficial pelvic floor muscles in response to vestibular pressure and/ or stretching of the introitus, or vaginal opening; (ii) heightened activity of the deep pelvic floor muscles in response to introital pressure; (iii) anticipatory reactions of the superficial and/or deep pelvic floor muscles in response to introital pressure or stretching; and (iv) heightened activity of remote muscles (biceps and trapezius muscles) in anticipation of, or in response to, introital pressure or stretching. This study is the first to investigate possible differences in the tonic and reactive contractility of pelvic floor muscles in women with VVS and to differentiate superficial and deep pelvic floor muscle response in this group of women. The results are expected to shed light on the etiology and/or maintenance of the disorder and contribute to future clinical assessment and management of women with VVS. If the data reveal significant differences between superficial and deep pelvic floor muscle response in VVS patients, the investigators plan to seek funding to do the same study with women who have generalized vulvodynia.

NVA also awarded a grant to vulvodynia pioneer William Ledger, MD, chairman emeritus of the department of obstetrics and gynecology at New York Presbyterian Hospital, and Steven Witkin, PhD, director of the division of immunology and infectious diseases in the department of obstetrics and gynecology at Weill Medical College of Cornell University. Ledger and Witkin's long-term research collaboration and numerous publications have shown that women with VVS can be differentiated into subgroups based on: (i) the presence or absence of variations in specific genes involved in the immune response, (ii) the relative production of pro- and anti-inflammatory cytokines, (iii) an allergic response to seminal fluid, and (iv) whether or not symptoms began with the first attempt at sexual intercourse.

One of Ledger and Witkin's major research findings is that some women with VVS exhibit genetic variations that increase their capacity to initiate inflammation and reduce their ability to terminate inflammation. Specifically, they show a deficiency in Interleukin- 1 receptor antagonist production, which increases susceptibility to inflammation, coupled with an increase in Interleukin-1-beta production, which reduces the ability to terminate inflammation. With their NVA grant, Ledger and Witkin will apply this novel research finding to the treatment of women with VVS. They will (i) investigate whether women with VVS benefit from treatment with Anakinra, an Interleukin- 1 receptor antagonist that is already being used to treat rheumatoid arthritis, an inflammatory condition, and (ii) try to predict which patients, based on their genetic makeup, would benefit from this treatment.

Make a Research Donation

The NVA recently issued its annual request for research proposals from the medical community. We are committed to funding studies that will increase our knowledge base and lead to the development of effective vulvodynia treatments. Please make a tax-deductible contribution to the NVA Medical Research Fund [online](#) or by contacting NVA's administrator, Gigi Brecheen, at gigi@nva.org or 301-949-5114.

Increased Media Coverage Continues

As we reported in the [April issue](#), media coverage on vulvodynia is on the rise, largely due to the launch of the first [National Institutes of Health Vulvodynia Awareness Campaign](#).

An article in Self Magazine's April issue featuring one woman's 15-year struggle with vulvodynia led many readers to respond. The editor wrote in the June issue, "We received more letters about 'I May Never Have Sex with My Husband Again' than any other story in the issue." Self printed several of the letters, including this one from Mary Pietrucha of Chicago:

I was so glad to see an article about vulvodynia. I finally found a specialist who properly diagnosed me with the condition after months of agony. We have started a combination of treatments that seems to be working. I found the National Vulvodynia Association to be very helpful, as well as The V Book (Bantam) by Elizabeth Stewart, MD. Sex is slowly becoming something I enjoy again. Women cannot allow pain to control their life. We need to be proactive about our health.

In late April, California-based physical therapy specialist, Stephanie Prendergast, was interviewed for a segment on chronic pelvic pain and physical therapy on the Maria Sanchez Radio Show. Click [here](#) to listen to the interview.

Also in April, EmpowHer.com, a new women's online health community, included a series for audio files that answer frequently asked questions about vulvodynia by NVA research grant recipient, Dr. Caroline Pukall. Click [here](#) to view a list of the questions that were asked and listen to Dr. Pukall's reply.

Several printed articles were published in May and June, including [No Fem-Agra](#) by Shari Rudavsky, a medical writer for the Indianapolis Star Newspaper. The biggest publicity of the spring was the inclusion of Heather Morgan Shott's article, [Vaginal Problems that Affect Your Sex Life](#), in WebMD Magazine, a bimonthly publication distributed to most clinicians in the US and read by millions of patients in waiting rooms.

In addition, the following articles appeared online: [A Surgical Solution for Sexual Pain that Felt Like Shards of Glass](#) (health.com); [The Pain Down There](#) (SheKnows.com) and, [A \(Chronic\) Pain the Vadge](#) (feministing.com).

National Treatment Trial Currently Enrolling Patients

If you suffer from vaginal pain you may qualify to participate in a clinical research study.

This study is currently taking place only in the United States and 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 be continuing to have periods
- You must be in a steady relationship for more than 6 months and having vaginal intercourse
- You must be willing to abstain from intercourse for 2 weeks
- You must use effective contraception
- You must be in general good health

To find out more about the study and locate a participating physician, please refer to the below listings and contact their office directly to talk to the study nurse about the study and if you may qualify.

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

Study Sites

Montgomery, AL

Montgomery Women's Health Associates, PC
Contact: Muray Marshall
334-281-1191; mmarshall@montgomerywomenshealth.com

Chandler, AZ

Star W Research
Contact: Stephanie Wells
480-732-7405; swells@womenshealtharizona.com

Phoenix, AZ

Precision Trials, LLC
Contact: Debbie Romesburg
602-931-4507 x 225; DebbieR@PrecisionTrials.com

Searcy, AR

Searcy Medical Center
Contact: Cindy Savinsky
501-278-2800 x 6789; csavinsky@researchsolutionscorp.com

San Diego, CA

San Diego Clinical Research Center
Contact: Kellie Harden
858-793-7220; kellieharden@hotmail.com

Lakewood, CO

Physicians' Research Options
Contact: Victoria Webb
303-985-9100; Victoria.Webb@proslc.com

Clearwater, FL

Women's Medical Research Group, LLC
Contact: Nina Zaniefski
727-724-9730; ninaz@xxresearch.com

Hudson, FL

Clinical Research of Tampa Bay, Inc.
Contact: Linda Queen
352-263-3462; lqueen@tampabayrr.com

Largo, FL

Innovative Research of West FL, Inc.
Contact: Marianne Segal
727-584-6368; hm4hands@aol.com

Tampa, FL

Insignia Clinical Research
Contact: Holly Ruhlig
813-739-1174; hrhlig@tbwc.com

West Palm Beach, FL

Comprehensive Clinical Trials, LLC
Contact: Val Allen
561-478-3177; vallen@cctlc.net

Atlanta, GA

Atlanta Women's Research Inst.
Contact: Crystal Smith
678-867-9410; crystals@awhg1.com

Roswell, GA

Atlanta North Gynecology, PC
Contact: Randi Baill
770-992-2691; Researchrn1@aol.com

Boise, ID

The Woman's Clinic
Contact: Amanda Cambra
208-947-9805; cambraa@slrhc.org

Idaho Falls, ID

Rosemark Women Care Specialists
Contact: Lisa Clark
208-557-2927; lclark@rosemark.net

Champaign, IL

Women's Health Practice
Contact: Jan Dedrick
217-356-3736 x 370; Jan.Dedrick@womenshealthpractice.com

Grand Rapids, MI

Female Pelvic Medicine & Urogynecology Institute of Michigan
Contact: Beth Rogers
616-742-5614; rogersbv@gvgobgyn.com

South Bend, IN

Northern Indiana Women's Health Research
Contact: Terri Stoll
574-280-3946; www.niwhr.com

Paw Paw, MI

Women's Health Care Specialists, PC
Contact: Michelle Padley
269-657-6189; whcsresearch2@yahoo.com

Brooklyn, NY

BoroPark Ob-Gyn
Contact: Lena Basilio
718-216-0667; lbasilio@premresearch.net

New Bern, NC

Eastern Carolina Women's Center
Contact: Amanda Corman
252-633-3942 x 485; ccrc@womensctr.com

Winston-Salem, NC

Carolina Medical Trials
Contact: Amanda Moore
336-794-0149; akikermooore@bellsouth.net

Winston-Salem, NC

Lyndhurst Clinical Research
Contact: Lisa Cumming
336-354-1076; research@lyndhurstgyn.com

Englewood, OH

HWC Women's Research Center
Contact: Heather Groff
937-771-5103; hgroff@hwcwrc.com

Gallipolis, OH

Holzer Clinic
Contact: Laurie Wayland
740-441-3990; lwayland@holzerclinic.com

West Reading, PA

Advanced Clinical Concepts
Contact: Jan Petrie
610-929-9484; aclinical@advancedclinicalconcepts.com

Simpsonville, SC

Hillcrest Clinical Research
Contact: Becky
864-962-5146; becky@hillcrest-cr.com

Chattanooga, TN

Southeastern Clinical Research

Contact: Kim Norwood
423-778-6947; kimsnorwood@msn.com

Jackson, TN

The Jackson Clinic
Contact: Patient Recruitment
800-685-7633; study.info@scresearch.net

Memphis, TN

Adams Patterson Gynecology & Obstetrics
Contact: Patient Recruitment
901-255-2254; study.info@scresearch.net

Memphis, TN

Research Memphis Associates, LLC
Contact: Regina Bernard
901-507-2248; rbernard@wccmemphis.com

Austin, TX

Professional Quality Research
Contact: Teddy Brose
512-374-0677; tbrose@pqrinc.com

Corpus Christi, TX

Advanced Research Associates
Contact: Bonnie Gutierrez
361-906-9178; info@araresearch.com

Houston, TX

The Women's Hospital of Texas
Contact: Nelda Fraga
713-790-8500; Nelda.Fraga@hclhealthcare.com

Sandy, UT

Physicians Research Options
Contact: Peggy Genebach
801-352-9228; genebach@proslc.com

Salt Lake City, UT

Salt Lake Research
Contact: Christy Christiansen
801-288-9778; cchristiansen@saltlakeresearch.com