

## Vulvar Pain Resulting from Orthopedic Causes

**By Deborah Coady, MD, and Nancy Fish, MSW, MPH**

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The pelvis is enclosed by a mantle of bones and joints, any of which may be the source of sexual pain. The lumbar spine (at about waist level), the sacrum, the coccyx (tailbone), and the top of the hip bones form the back of the pelvis. The front of the pelvis is held together by the pubic bone, while the side of the pelvis is formed by pubic bones and the hip joint (see illustrations on pages 8 and 9).

If any of these structures is out of alignment, vulvar or pelvic pain can be the result. Tears or injuries in the joints and bones also can inflame the surround-

ing tissues, often irritating the nerves leading to the vagina and vulva. As with other types of sexual pain, we get a cascade of effects: bone or joint injury or misalignment affects muscles and tissues, which in turn affects nerves. Problems that began outside the vulva ultimately end up causing sexual pain.

### **What's Going On: The Biology**

When any portion of our skeleton is injured, the effects radiate outward to our other bones and

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## NICHD Hosts Vulvodynia Researchers

**I**n July 2011, the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), with support from the Office of Research on Women's Health (ORWH), convened its third vulvodynia workshop, *Vulvodynia: A Chronic Pain Condition – Setting a Research Agenda*. At the conference, NICHD hosted seventy scientists, clinicians and members of organizations and agencies interested in the condition, with the overall goal of developing a strategic plan for advancing vulvodynia research.

Building on the 2003 NIH workshop, *Vulvodynia: Toward Understanding a Pain Syndrome*, this meeting

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joints—as well as attached muscles and connective tissue, and then our nerves. Ultimately, we're looking at both the musculoskeletal system and the nervous system as pathways for sexual pain. Let's zero in on the specific areas of the musculoskeletal system and the types of injuries that are most likely to create sexual pain.

### The Back

The nerves that supply the vulva and vagina with motor and sensory signals leave the spine from the lumbar and sacral areas as nerve roots. As a result, any problem in this part of the spine can cause sexual pain—including injuries, scoliosis, osteoarthritis, bulging disks, cysts (fluid-filled sacs arising from the small vertebral joints), or tumors. And because these nerves supply the muscles and allow muscle function, injuries here can also cause muscle changes

in the pelvis, which in turn can lead to pain.

### The Hips

Since the hip and pelvis share many of the same muscles, and since these muscles affect pelvic and vulvar nerves, it makes sense that sexual pain can result from hip disorders. If you've injured your hip, you've made subtle but important changes in your gait and movement to compensate for discomfort, hip instability, and mechanical impairment. This creates problems in your muscles—which may tighten, shorten, stretch, or weaken to keep your core and pelvis stable. The central nervous system subconsciously “recruits” these muscles to do this job, even though it may be inappropriate for them to behave this way. The fascia and other connective tissues are also tightened, or shortened, adding to the imbalance and discomfort. And these structures in turn pinch, press, stretch, or otherwise irritate your pelvic nerves, which send pain signals to the brain.

Here are some specific ways that hip injuries might cause sexual pain:

### *Labrum Tears*

The hip labrum is a horseshoe-shaped ring of dense connective tissue that attaches to the bony rim of the hip socket to deepen, reinforce, and stabilize the socket, and to seal and protect the joint. Tears in this tissue (called “labrum tears”) cause Femoroacetabular Impingement (see below) and also force the pelvic floor muscles to compensate by tensing and shortening, putting pressure on the pudendal nerve and thus causing sexual pain.

### *Femoroacetabular Impingement (FAI)*

This is a common condition with two possible causes. In one, the ball (the head of the femur) rubs against or collides with the hip socket (the “acetabu-

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The National Vulvodynia Association is a nonprofit organization that strives to improve women's lives through education, support, advocacy and research funding. The NVA is not a medical authority and strongly recommends that you consult your own health care provider regarding any course of treatment or medication.

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lum”). When the ball and socket rub against each other, they create a bump (a “callus”) that limits the hip’s range of motion, especially with regard to your leg’s ability to flex and rotate inward. Alternately, an outgrowth or bump on the acetabular rim might limit leg flexion and outward rotation.

Either way, we’re usually looking at a vicious circle, in which these bumps create even more friction and therefore may get bigger, causing ever-greater instability and inflammation in the hip joint—and ultimately, a permanent loss of cartilage. If your cartilage is rubbed away, you’re at risk for osteoarthritis. Meanwhile, the bumps or calluses throw your muscles out of balance, make movement more difficult, and frequently lead to nerve irritation and pain.

### Other Orthopedic Causes

Back and hip disorders are the most common orthopedic causes of sexual pain. But a number of other, often severe conditions may also give rise to this pain. Unfortunately, most doctors are not aware of how common these conditions are among women, and how often they may lead to sexual pain.

#### *Coccydynia: Pain in the Tailbone*

This type of pain is due either to a congenital abnormality or (more often) to an acute or chronic injury that causes the tailbone to deviate—right, left, forward, or back—rather than extending straight down. The displacement causes pressure on branches of the pudendal nerve and also pulls on the pelvic floor muscles, causing muscle imbalance—which pulls even more on the coccyx, causing more pain. When you have coccydynia, deep penetration can cause excruciating pain and can also make your condition much worse.

#### *Sacroiliac Joint Problems*

The sacroiliac joints hold your back and pelvic

bones together. When they’re unstable—as they are in many women, due to laxity in the ligaments holding the joint together—you can suffer from pelvic floor pain. Often these joints are themselves affected by movement disorders arising from hip labrum tears and FAI. Remember, the pelvis is tightly interconnected and operates as one working unit. Tightness and discomfort in the pelvic floor may be due to the pelvic muscles’ compensating for instability in the sacroiliac joints. So if a sacroiliac joint is distressed, you may feel pain anytime your pelvis moves—and particularly during the regular pelvic movement involved in sex.

#### *Pubic-Bone Conditions*

The pubic bone is vulnerable to low-grade injury in sports and other activities, and that leads to inflammation—which may spread to the pelvis, the bladder, and even the clitoris, causing sexual pain. In addition, the adductor muscles of the legs originate at the pubic bone, and if they and their tendons are injured (they may tear and swell), pu-

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## **Christin Veasley Named NVA Executive Director**

In June 2011, after 15 years as Executive Director, Phyllis Mate retired, and the NVA Board appointed Christin Veasley, formerly our Associate Executive Director, to the position. Phyllis remains President of the Board and will continue to work closely with Chris, as they have done in the past. “Since Chris started working with us in 2000 she has been an invaluable asset to the NVA, and we are confident that she is the best person for the position.” said Mate. ■

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bic bone inflammation may follow. Pain from this inflammatory condition may also relay to the groin, clitoris, and urethra during sexual activity.

The front of the pelvic bones is held together in

### Definition and Types of Vulvodynia

Many different terms have been used to describe vulvodynia. As a result, confusion among patients and medical professionals is common. To encourage consensus and clarify terms used in this newsletter, we have provided a brief summary of the most current definitions and classification. For more detailed information, please visit [http://learnprovider.nva.org/historical\\_overview.htm](http://learnprovider.nva.org/historical_overview.htm) and [http://learnprovider.nva.org/terminology\\_classification.html](http://learnprovider.nva.org/terminology_classification.html).

Vulvodynia is *chronic (more than three to six months) vulvar pain without an identifiable cause*. The location, constancy and severity of the pain vary among women. The two main subtypes of vulvodynia, which sometimes co-exist, are:

#### Provoked Vestibulodynia (PVD)

(Previously: *Vulvar Vestibulitis Syndrome*)

Women with PVD have pain limited to the vestibule, the area surrounding the opening of the vagina, that occurs during/after touch or pressure, e.g., with intercourse, tampon insertion and/or prolonged sitting. PVD is further classified as *primary (pain since the first attempt at vaginal penetration)* or *secondary (pain that starts after a period of pain-free vaginal penetration)*.

#### Generalized Unprovoked Vulvodynia (GV)

(Previously: *Dysesthetic or Essential Vulvodynia*)

Women with GV have spontaneous pain in multiple areas of the vulva. It is relatively constant, but there can be some periods of symptom relief. Activities that apply pressure to the vulva, such as prolonged sitting or simply wearing pants, typically exacerbate symptoms.

the midline by a joint called the pubic symphysis, which opens markedly with pregnancy and childbirth. Sometimes it opens too much and becomes weak and unstable, causing significant postpartum pain in response to movement—pain that might continue for months or even years if inflammation continues. This is called Osteitis Pubis.

### Iliopsoas Conjoined Tendon Pain and Bursitis

The long psoas muscle is a major core and hip stabilizer and flexor that runs behind the pelvic organs and combines with the iliacus muscle in the pelvis to form the iliopsoas conjoined tendon, as seen in illustrations on pages 8 and 9. These muscles and their tendon connect the front of the bones of the spine to the hip bones. Injuries, hip disorders, and back problems can cause this structure to become inflamed, tight, or shortened—making it unable to do its work easily.

As with other pelvic conditions, an inflamed iliopsoas conjoined tendon can affect related nerves, such as the genitofemoral, which supplies part of the vulva's sensation. When disordered, this nerve transmits pain signals to the brain during sex. In addition, psoas muscle pain can be confused with endometriosis pain, since it has a similar location in the pelvis.

Other vulnerable areas around the iliopsoas conjoined tendon are bursas—fluid-filled sacs that work to counteract tension and friction at joints and tendons. If they become inflamed, however, bursas around the iliopsoas conjoined tendon or at the outer hip can create severe pain in the groin and vulva—this is called bursitis.

### Ischial-Tuberosity Problems

The ischial tuberosities—the “sit bones”—are the

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# NVA Funds Three New Research Studies

Since the creation of NVA's Medical Research Fund in 1997, we have awarded nearly \$1 million to 40 vulvodynia research projects. In recent years, thanks to our donors' generosity, half of our annual budget has been spent on medical research and we now solicit funding applications twice a year. The NVA Executive Board recently approved grants for the three projects summarized below.

## ***Vulvar Pain in the Brain***

Irv Binik, PhD, professor of psychology at McGill University in Montréal, Québec, was awarded an NVA grant to investigate brain activity and anatomy in women with primary and secondary Provoked Vestibulodynia (PVD). According to Dr. Binik, the study of PVD has been focused on peripheral mechanisms underlying chronic vulvar pain (e.g., dysfunction of peripheral vulvar nerves, tissue inflammation), with little attention paid to abnormal pain processing in the spinal cord and brain. Using functional magnetic resonance imaging (fMRI), Dr. Binik will compare brain activity during the application of painful and non-painful stimuli applied to the vestibule in women with PVD and pain-free controls. Brain imaging techniques will be used to correlate clinical PVD pain characteristics with vulvar pain-related brain activity, grey matter density, and axonal (white matter) organization. In addition to adding to our understanding of pathological pain processing in PVD, Dr. Binik proposes that a detailed analysis of brain activity and anatomy will aid in the identification of imaging biomarkers, which could be used to identify PVD subtypes, as well as novel therapeutic targets based on specific structural and anatomical abnormalities.

## ***Discovery Proteomics to Study Vulvodynia Pathogenesis***

Colin MacNeill, MD, assistant professor of obstet-

rics and gynecology, and Joanna Floros, PhD, professor of obstetrics and gynecology and pediatrics, both of the Pennsylvania State University College of Medicine in Hershey, will use their NVA grant, along with matching funds from their institution, to conduct the first proteomics study of vulvodynia. The study goals are two-fold. First, the doctors will compare vestibular fluid samples from healthy control women and women with vulvodynia to identify protein types and concentrations that may be abnormal in affected women. Next, the doctors will use this information to identify the underlying pathways and mechanisms that may be involved in the pathogenesis of vulvodynia. Data derived from this study will help to identify women who may be at risk of developing the condition as well as new therapeutic targets and biomarkers that could be useful in the diagnosis and/or subtyping of women with vulvodynia.

## ***Establishing a Mast Cell-Dependent Model of Vulvar Pain***

Devavani Chatterjea, PhD, assistant professor of biology at Macalester College in St. Paul, Minnesota, was awarded a grant to develop an animal model of chronic vulvar pain. Previous studies show that mast cells, which play a critical role in the body's immunological response, may contribute to the initiation and/or maintenance of vulvodynia in a subgroup of women. To determine the role of mast cells in the disorder's pathophysiology, Dr. Chatterjea and her group will establish a mast cell-specific mouse model of inflammatory pain. This model will add to our understanding of specific mast cell-related mechanisms responsible for triggering/maintaining vulvar pain, and also aid in the discovery of novel treatments.

To read summaries of other NVA-funded studies, please visit [www.nva.org/research\\_fund.html](http://www.nva.org/research_fund.html). ■



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bottommost bones of the pelvis. We put a lot of pressure on them with long hours of sitting (which our bodies are not designed to do), and they're vulnerable to chronic injury from falls and other traumas—including those caused by long-distance biking and other vigorous activities. Hip disorders can also involve the ligaments inserting into the sit bones. Since the pudendal nerve runs right behind the bones and ligaments, inflammation here can create significant pudendal nerve irritation, and thus sexual pain.

### *Osteoarthritis*

Osteoarthritis is a common inflammation of joints. Pain and stiffness from osteoarthritis may limit movement in parts of your body that are involved in sexual activity, such as your hips, back, neck, and

hands. It may be the most frequent cause of sexual pain, especially as we get older.

### **Diagnosis: The Tests You Need**

Diagnosing orthopedic injuries and disorders is often relatively straightforward, but what is not so clear is the link between these problems and sexual pain. Fortunately, a much better understanding of the links between hip and back and pelvic floor is emerging, and more doctors are beginning to see that fixing the “unhappy” hip or back does often reduce sexual pain, or even make it go away. But unfortunately, curing orthopedic pain is not a quick fix, because it takes time to get your core strong and in balance again. For these often somewhat mysterious or confusing orthopedic conditions, your physician should be working with a team of experts, since no single physician can know or do it all.

### **Symptoms of Orthopedic Problems**

Clitoral or deep rectal pain and/or itching when sitting

Deep, sharp pain in the vagina during penetration, usually on one side

Stiffness in the legs, back, and/or hips in sexual positions

Uncomfortable clicking of the hip, back, or groin when moving

In certain positions, sharp, radiating pain to the outer thigh, sometimes down to the knee, foot, groin, or buttock

Inability to sleep on a particular side due to pain

### The Basics

Your doctor's first step should be to take a detailed history from you. This is always an important part of diagnosing sexual pain, but it is particularly so with orthopedic causes, since a certain amount of detective work is needed to identify the initial injury. In fact, taking a good history may be more important than any test. Often, orthopedic pain does not seem to stem from any trauma. However, sports or other injuries can suggest orthopedic problems, as can lifestyle—such as a pattern of prolonged sitting, dancing, or other types of vigorous or repetitive movements. Infancy and early-childhood hip problems are also risk factors for adult hip problems. Hip discomfort at any time, present or past, might also be clues to orthopedic problems.

A detailed physical exam will also be very helpful. Your doctor should observe your gait, as a high percentage of women with orthopedic problems walk with a mild intermittent limp. Have your doctor

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evaluate your hips and back in standing position as he or she looks for tenderness, asymmetry, deformity, and scoliosis (curvature of the spine).

### Diagnosing Hip Injuries

We have at our disposal a number of physical-exam maneuvers to see if the hips are “unhappy.” The easiest of these include: the FABER (Flexion, ABduction, External Rotation) test, used to identify decreased rotation or pain when the hip rotates outward; the flexion–internal rotation–adduction impingement test, used to identify decreased rotation or pain when the hip rotates inward; and palpation of the greater trochanter (the outer part of the hip), which looks for tenderness and bursa problems.

Your doctor should also conduct a careful pelvic exam, with special attention to the hip-related anatomy. During the vaginal and rectal exams, your doctor should assess the obturator internus muscle, a primary hip rotator. We have found that this muscle bears a lot of strain when the hip is weak, unstable, or impinged and off-balance. It attaches to the other pelvic floor muscles and may greatly affect them. When we examine the obturator internus, hip and potential pelvic floor problems are often indicated by the following symptoms: tenderness, tension, tight bands; an increase in resting tone; asymmetry between right and left sides; or hypertrophy (overgrowth) or atrophy (shrinking).

Your physician should also test the pudendal nerve at the sacrospinous ligament complex at the ischial spine (see this landmark in illustration on page 8). When touched gently with an examining finger, a distressed nerve will respond with pain, often radiating to or referred to another part of the pelvis—or even to the hip or buttocks.

If your history and your response to this type of pelvic exam suggest hip problems, your doctor may proceed to imaging studies: x-rays, ultrasounds,

MRIs, or CT scans (though we try to avoid the latter because of radiation). Your doctor may choose a

### **Symptoms of Back Disorders**

Numbness in the vagina during penetration

Bladder and bowel problems

Burning pain that worsens in certain sexual positions

Sciatic pain, which radiates down the back of a leg

Tingling sensations in the groin or lower abdomen (if nerve roots from higher up are involved)

### **Symptoms of a Hip Problem**

Insidious pain in the front part of the hip and in the lower quadrant of your abdomen, as well as groin pain, which may radiate to the thigh or knee

Decreased range of hip motion as a result of pain and/or impingement

Dull or sharp, constant or intermittent pain in the hip, often with clicking, pinching, and/or locking

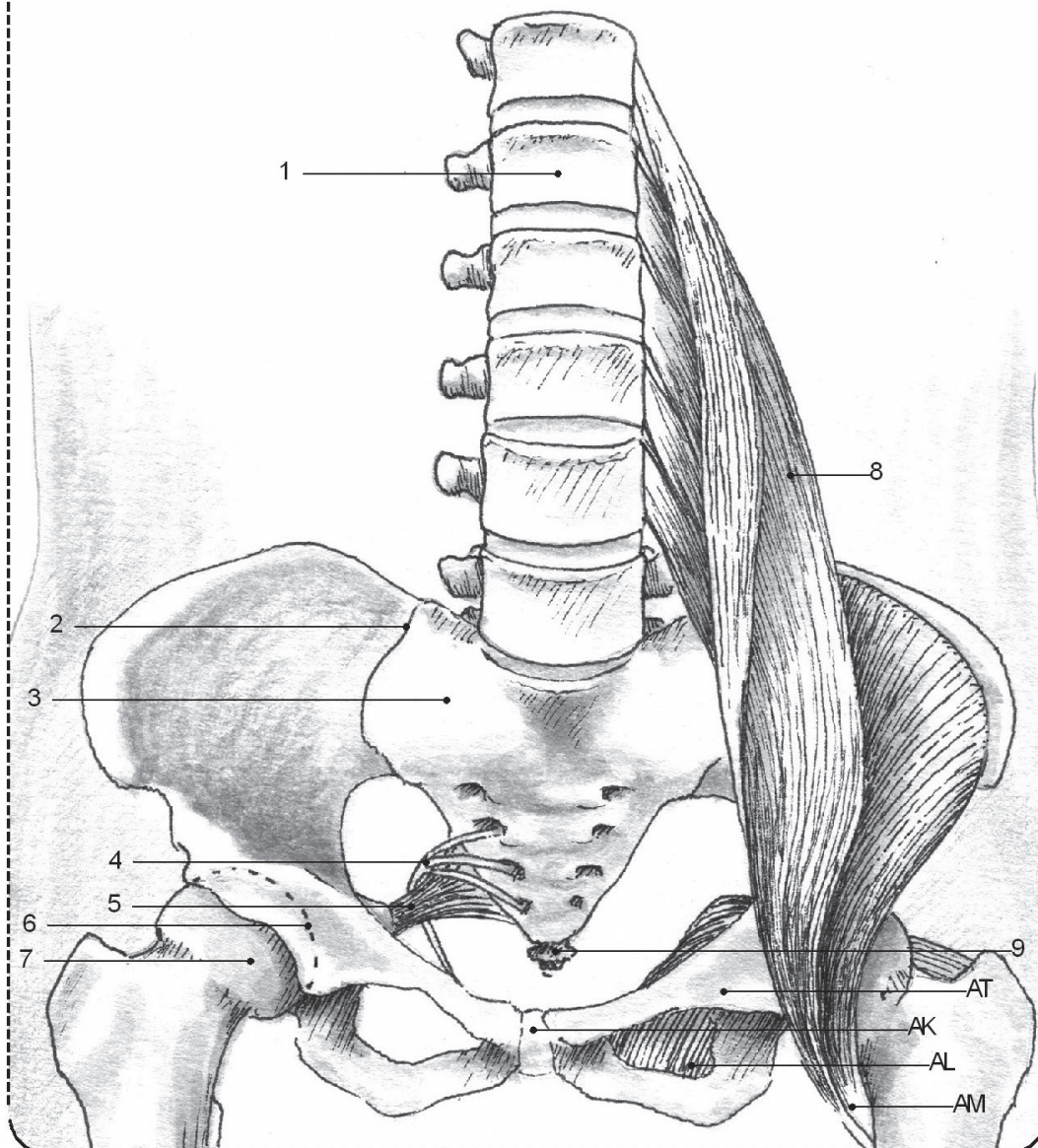
Pain that gets worse with activity, with prolonged sitting, when rising from a seated position, or when climbing stairs

Very weak gluteal muscles

*See ORTHOPEDIC, page 9*

## PELVIC ORTHOPEDIC STRUCTURES

- |                          |                              |
|--------------------------|------------------------------|
| 1 Lumbar spine           | 8 Psoas muscle               |
| 2 Sacroiliac joint       | 9 Coccyx                     |
| 3 Sacrum                 | AT Pubic bone                |
| 4 Pudendal nerve         | AK Pubic symphysis           |
| 5 Sacrospinous ligament  | AL Obturator internus muscle |
| 6 Acetabulum             | AM Iliopsoas tendon          |
| 7 Head of the femur bone |                              |





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study based on what's available in your community. However, MRIs are the most helpful, since the soft tissues surrounding the bones and joints are easily seen on the new high-resolution scans. They may show signs of labrum tears, impingement, inflammation, or swelling in the tissues around the hip joint. The newer scans can also image the obturator internus muscles and reveal the course of the pelvic floor nerves. Abnormalities here help prove the link between your hip and sexual pain.

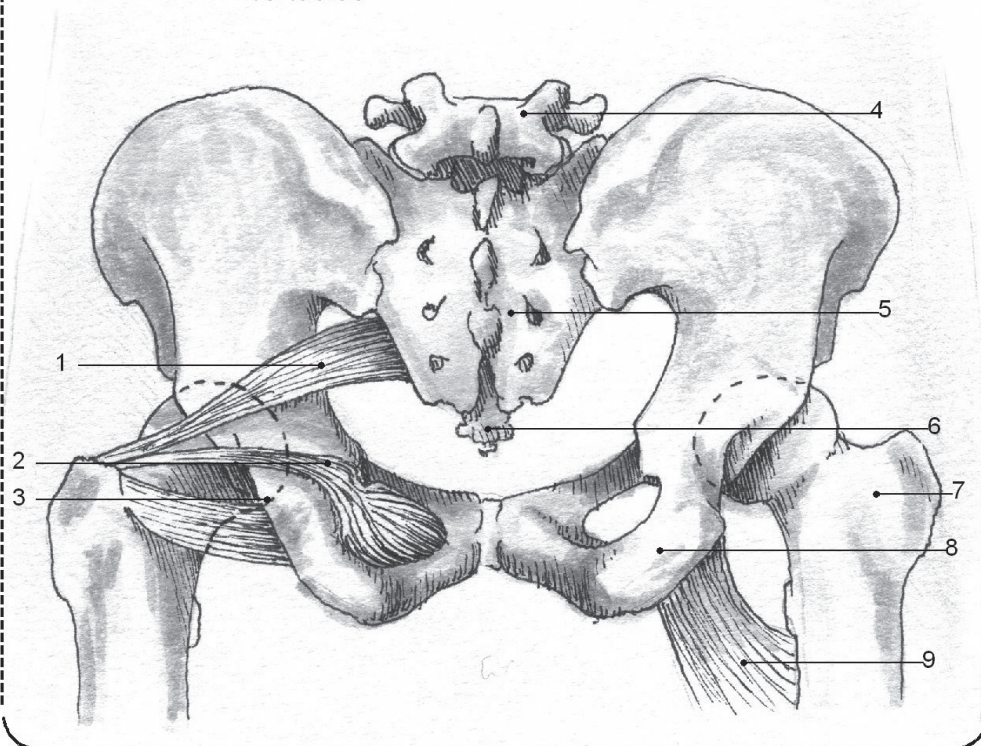
### Diagnostic Injections

Specialists will often recommend a diagnostic intra-articular hip injection or injections into inflamed tendons or muscles. Using x-ray or ultrasound guidance to pinpoint the correct location in your pelvis, a specialist will administer an injection combining numbing and anti-inflammatory medications.

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### BACK VIEW OF PELVIS

- |                             |                      |
|-----------------------------|----------------------|
| 1 Piriformis muscle         | 5 Sacrum             |
| 2 Obturator internus muscle | 6 Coccyx             |
| 3 Hip joint                 | 7 Femur bone         |
| 4 Fifth lumbar vertebrae    | 8 Ischial tuberosity |
|                             | 9 Adductor muscles   |



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# NVA Helps Establish Vulvar Pain Clinics

With a generous donation from Dr. Stanley C. Marinoff, NVA previously funded the establishment of vulvar pain clinics in Michigan, Wisconsin, New Jersey and Tennessee. This summer we awarded funding to three more health care providers to support clinics in Texas, Connecticut and Ecuador.

Anuja Vyas, MD, assistant professor of obstetrics and gynecology at Baylor College of Medicine in Houston is using her NVA award, along with matching funds from her institution, to establish specialized multidisciplinary vulvar pain clinics within her hospital and outpatient center. She credits her interest and expertise in this area to two mentors, Dr. Dale Brown, Jr., and the late Dr. Raymond Kaufman, who provided care to women with vulvar disorders in the Houston area. Dr. Vyas will focus on medical student and resident training that will help expand the number of educated skilled providers who can appropriately diagnose and treat women with chronic vulvar pain. "With these clinics, we can train residents who will take their accumulated knowledge and serve women in the communities where they establish practices," says Dr. Vyas. She will also educate women who suffer from vulvodynia, as well as those visiting the clinics for other reasons, and contribute to scientific research on the disorder. The hospital-based clinic opened in July 2011 and the outpatient clinic will open in summer 2012. For more information, please visit [www.baylorclinic.com/services-specialties/obstetrics/vulvovaginal-health-clinic.cfm](http://www.baylorclinic.com/services-specialties/obstetrics/vulvovaginal-health-clinic.cfm) or call 713-798-7500.

Elizabeth Jensen, CNM, APN, DNP, completed her doctorate in nursing with a specialty focus in vulvology under the mentorship of Dr. Benson Horowitz. With her NVA grant and matching funds from S.H.E. Medical Associates in Hartford, Connecticut, Dr. Jensen is establishing a vulvar pain clinic in Hartford and will eventually expand services to S.H.E. offices in Avon, Enfield, South Windsor and Marlborough.

Dr. Jensen recently completed a national survey of advanced practice nurses and believes that educating nurses in this subspecialty could significantly increase access to care for women with vulvodynia. She will use survey results to guide the development of educational programs for them. "Our primary goal is to become a renowned referral center for women with vulvodynia. We also want to increase the number of knowledgeable providers in this area of the country, diagnose and treat women in fewer provider visits, provide educational outreach services to women in need and contribute to the current level of knowledge about vulvodynia through research," states Dr. Jensen. For more information on the Hartford clinic, please call 860-236-5431.

With an NVA award and matching funds from the Runajambi Institute, Mario Maldonado, MD, will establish the first vulvar pain clinic in the Andes. *Clinica del Dolor Femenino* (Clinic for Vulvar Pain) will provide interdisciplinary and culturally adapted care to an ethnically and culturally diverse underserved population in the Ecuador highlands, many of whom live on less than two dollars per day. The low-cost, self-sustained clinic will also foster collaboration on international comparative multisite clinical vulvodynia research. The clinic is scheduled to open in December 2011. For additional information, please visit: [www.estedolor.com/vulvodinia/](http://www.estedolor.com/vulvodinia/).

Medical professionals who are interested in developing vulvar pain clinics may submit an application for a *Dr. Stanley C. Marinoff Vulvodynia Career Development Award*. Applications for the January 2012 awards are due in October. For more information on this funding mechanism, or to request an application, please visit [www.nva.org/career\\_development\\_award.html](http://www.nva.org/career_development_award.html) or contact Christin Veasley by phone (401-398-0830) or email ([chris@nva.org](mailto:chris@nva.org)). ■

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# NVA Receives Second Grant to Expand Treatment Registry

Prior to 1997, when the National Vulvodynia Association (NVA) started awarding pilot grants, almost no serious vulvodynia research effort existed. Since then we have made grants totaling nearly \$1 million and funded 40 pilot studies. The National Institutes of Health began funding vulvodynia research in 2000, but in the last 11 years it has spent less on vulvodynia research than on most other medical

conditions it supports. Vulvodynia ranks 226<sup>th</sup> out of 229 conditions it funds according to its *Estimates of Funding for Various Research, Condition and Disease Categories (RCDC)*.

Because of this lack of research funding, our understanding of the disorder's etiology and the underlying mechanisms that both trigger and maintain the disorder remain inadequate. This has impeded the development of diagnostic and treatment guidelines that are based on *scientific evidence* rather than clinical opinion, and perpetuates the haphazard medical treatment of women suffering with the condition. Scientific data needed to inform health care providers of appropriate effective medical management of vulvodynia is still lacking, and women are forced to experiment with a laundry list of therapies for months or years before they find one or more treatments that help reduce the severity of their painful symptoms.

In an effort to remedy this situation, two years ago NVA funded the first national multi-center Vulvodynia Treatment Registry. After initiating treatment, registry investigators follow women for at least 12 months to gather data to help determine which therapies are effective for different vulvodynia subtypes, identify factors that predict treatment success and guide the development of large controlled trials of promising therapies.

In 2010 with the continued support of the Registry's original donor, and a generous grant from The Patty Brisben Foundation for Women's Sexual Health ([www.pattybrisbenfoundation.com](http://www.pattybrisbenfoundation.com)), NVA expanded the registry project from three to seven data collection sites in Florida, Arkansas, California, Colorado, Ohio and Washington DC, with plans to add sites in Baltimore and Fort Lauderdale this fall.

*See TREATMENT REGISTRY, page 14*

## **To speak with a Registry Coordinator about participating, contact:**

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# IOM Releases Landmark Report on Chronic Pain

On March 23, 2010, President Obama signed into law the Patient Protection and Affordable Care Act. In addition to laying the groundwork for significant health insurance reform, the Act includes provisions that promise to stimulate long overdue advancements in the treatment of pain disorders. As part of this Act, Congress mandated the Department of Health and Human Services to commission an Institute of Medicine (IOM) study of the current state of prevention and treatment of chronic pain care in the U.S.

To deal with this complex issue, the IOM assembled a committee that included experts in all aspects of pain research and management and individuals suffering from chronic pain. Ursula Wesselmann, MD, PhD, professor of anesthesiology at the University of Alabama in Birmingham and NVA medical-scientific advisory board member, served on the diverse 19 member committee. Individuals were provided the opportunity to testify before the committee and the IOM also solicited public comment through its web site. NVA submitted written testimony that communicated the urgent need for *all* initiatives resulting from the IOM study to include vulvodynia. In addition, 300 women with vulvodynia and medical professionals who treat vulvar pain disorders submitted public comments, which resulted in the inclusion of vulvodynia in multiple sections of the report.

On June 29, 2011, the IOM convened a press conference and public briefing in Washington, DC, and released its landmark report titled, *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. (To view or download the report, visit [www.nap.edu/catalog.php?record\\_id=13172](http://www.nap.edu/catalog.php?record_id=13172).) For the first time, Federal agencies alerted Congress and the American public to the enormity of this growing public

health crisis. Without accounting for chronic pain in children, military personnel or those living in long-term care facilities, the report estimates that 116 million Americans suffer from chronic pain and that it costs \$635 billion each year in medical treatment and lost productivity.

The report calls for a coordinated national effort to transform how our society understands and approaches pain management. Its findings and recommendations are broken down into four major areas – public health, medical treatment, education and research. The report also provides a blueprint for implementing the committee’s recommendations, assigning tasks to all Federal agencies, private and public organizations, health care providers, medical professional and patient advocacy organizations, private insurers and academic institutions.

The following excerpt from the report, authored by co-chairs Philip Pizzo, MD, dean of the Stanford University School of Medicine, and Noreen Clark, PhD, director of the Center for Managing Chronic Disease at the University of Michigan illustrates the committee’s profound understanding of the individual and societal experience of chronic pain, as well as the historic importance and implications of their work.

“Protection from and relief of pain and suffering are a fundamental feature of the human contract we make as parents, partners, children, family, friends, and community members, as well as a cardinal underpinning of the art and science of healing. Pain is part of the human condition; at some point, for short or long periods of time, we all experience pain and suffer its consequences. While pain can serve as a warning to protect us from further harm,

*See IOM REPORT, page 13*



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## IOM Report

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it also can contribute to severe and even relentless suffering, surpassing its underlying cause to become a disease in its own domains and dimensions. We all may share common accountings of pain, but in reality, our experiences with pain are deeply personal, filtered through the lens of our unique biology, the society and community in which we were born and live, the personalities and styles of coping we have developed, and the manner in which our life journey has been enjoined with health and disease.

“It also became clear that when pain could be ascribed to an underlying disease, such as cancer, it was accepted as real and treated with concern. The validation of disease made the pain socially acceptable, not shunned by the health care system or by families and communities. However, when as a pediatric oncologist one of us also experienced chronic pain in a family member whose underlying disease was less well defined, the cultural perception of and response to the pain by the health care community was dramatically different. Reactions ranged from care and compassion to judgmental opinions that lacked compassion and sometimes devolved into blaming or personalization of responsibility. The lack of a defined disease made the symptoms of pain and suffering less acceptable and more ascribed to over-reaction, emotional instability, or worse. Because the pain could not be seen or measured “objectively” or interpreted within the context of the known, it was more likely to be dismissed, diminished, or avoided. The irony is that this pain and suffering, just like that of the patient with a known disease, could be life dominant—a disease in its own right.

“This is not to say that the medical community is uncaring and unwilling to help people with pain. But health care providers are subject to bias, limitations in knowledge, and differences in the systems in which they work. They are eager for new solutions and new insights, particularly with respect to chronic

pain when a defined cause is lacking. Unfortunately, many health care providers lack a comprehensive perspective on pain and not infrequently interpret the suffering of others through their own personal lens. Misjudgment or failure to understand the nature and depths of pain can be associated with serious consequences—more pain and more suffering—for individuals and our society.

“Our committee recognizes the need for a transformed understanding of pain. We believe pain arises in the nervous system but represents a complex and evolving interplay of biological, behavioral, environmental, and societal factors that go beyond simple explanation. Knowledge of pain needs to be enriched from the molecular and genetic to the cellular, neural network, and systems levels. It is necessary to understand how the settings and surroundings in which pain occurs and is experienced have an impact on its biology. The committee recognizes the need for new tools and metrics with which to define, diagnose, and monitor pain and its consequences, as well as for new approaches to treatment and prevention that are likely to result from novel and more interdisciplinary approaches to research. We see a need for better ways to develop, evaluate, and make available new approaches to pain management more rapidly and expeditiously. We also see the importance of approaching the individual within the broader domain of cultural diversity and of recognizing the subpopulations that are most affected by chronic pain and develop strategies to address their needs. We believe it is necessary to understand better the link between acute and chronic pain and find ways to break that link. We recognize the need to develop ever more informed health care professionals, working individually and in teams, in rural and urban settings, to address pain in the communities they serve. We believe it is necessary

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to understand better the true impact of pain on the workforce, our families, and the broader population and seek ways to lessen that impact. Meeting these challenges will require a cultural transformation in the way pain is perceived and managed on both the personal and societal levels.

“The committee worked diligently to develop this report in an objective manner based on evidence. In doing so, we became acutely aware of the limitations of existing knowledge and the data on which it is based. **We learned from our deliberations that there is crisis in the impact of and response to pain in America. Individually and collectively, we have a moral imperative to address this crisis. It is our hope that this report will help stimulate a concerted response to this crisis.**”

Over 1,500 media outlets featured stories on the IOM report and its major findings, helping to raise the public’s awareness of this issue. The NVA is now working in coordination with other patient advocacy and medical professional organizations that serve chronic pain sufferers as well as medical professionals who treat chronic pain to encourage the United States Senate Committee on Health, Education, Labor and Pensions to convene a hearing on the issue by the end of 2011. Additionally, NVA Executive Director Christin Veasley was invited by Secretary of Health and Human Services Kathleen Sebelius, to serve on the Interagency Pain Research Coordinating Committee of the National Institutes of Health, which will begin work in October 2011. In addition to coordinating Federal agency activities related to pain, the committee will develop a summary of advances in pain care research supported or conducted by Federal agencies and identify critical gaps in basic and clinical research on the symptoms and causes of pain. It will also make recommendations to ensure that: i) the activities of the NIH and other Federal agencies to eliminate unneces-

sary duplication of effort, ii) information on pain care is widely disseminated and available to those in need, and iii) potential partnerships between public and private entities to expand collaborative cross-cutting research are identified and utilized when appropriate. We look forward to keeping you abreast of developments with these new Federal initiatives and are optimistic that these initial steps will translate into meaningful changes in treatment for those suffering from chronic pain. ■

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## Treatment Registry

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We are pleased to announce that The Patty Brisben Foundation for Women’s Sexual Health has awarded NVA a second grant to expand the Registry project to include both peri- and postmenopausal women. This is very important because the majority of current vulvodynia research *excludes* women over the age of 45. Additionally, the Foundation’s support will enable registry providers to collect DNA samples from women and correlate genetic findings to the numerous biological measures obtained throughout the project. NVA anticipates that this data will aid in the identification of: i) vulvodynia biomarkers; ii) potential treatments for vulvodynia subtypes; iii) potential genetic treatment targets; and iv) women who may be at risk of developing the condition.

The registry is open to women aged 18 or older. It does not provide free medical care or treatment. **Participation is voluntary, does not include any experimentation and will not change your treatment recommendation.** To learn more, visit: [www.nva.org/treatmentregistry.html](http://www.nva.org/treatmentregistry.html). *Health care providers who would like to obtain registry flyers to distribute to their patients should contact Lilia Portilla at the Orlando site (see box on page 11).* ■

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## Orthopedic

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In particular, this approach can offer remarkable relief for hip labrum tears and FAI, as well as for associated vulvar and vaginal pain. Although the pain relief may not occur for one or two weeks, any reduction in pain suggests that your hip is indeed involved in your sexual pain. The contrary, however, is not true. If you undergo a diagnostic injection and receive no relief from pain, you may still have an orthopedic disorder, but your pain may be the result of changes in the surrounding muscles, fascia, and nerves.

Specialists can use similar injections to test for lower-back problems too. These may include: “facet joint injections” into areas where one vertebra connects to the next; injections into the muscles that surround the spine and that may be pulling on the disks or squeezing down on nerves; epidural injections; and spinal nerve blocks. For coccydynia, injections into and around the coccyx may be helpful diagnostic tools. Diagnostic injections are also available for such structures as ligaments and tendons attaching to pelvic bones and joints—including the adductors, iliopsoas conjoined tendon, gluteal muscles, sacroiliac joint and surrounding ligaments, sacrotuberous ligament, ischial tuberosity, and pubic bone.

### **Treatment: What You Can Expect**

Sometimes an orthopedic problem requires a rapid or extreme response, as in the case of one of our patients who was found to have a lumbar spine fracture. You are far more likely to have several treatment options, and you should begin with the least invasive, progressing to more complicated treatments only if you have to. You should try to avoid abnormal movements in order to reduce inflammation and muscle imbalance. For example, if you have a hip problem, you need to avoid prolonged sitting, moving your legs to extreme positions, and stressful repetitive motions. For back problems, avoid lifting, unbalanced bending, and poor posture. For

coccyx and sit-bone pain, avoid sitting, and use a padded seat cushion if you must. Anti-inflammatory medications such as ibuprofen and naproxen will help your joints heal, along with the surrounding muscles, ligaments, tendons, and cartilage. Topical anti-inflammatory or lidocaine skin patches can also be helpful. In some cases, oral muscle relaxants can keep muscles from overworking and going into painful spasm. Pain medications might also help you to walk more normally, removing the strain on the problem area.

Whatever other types of pain relief you employ, your mainstay of treatment for most orthopedic problems is almost certainly physical therapy. Make sure your physical therapist understands how to rehabilitate both your orthopedic problem and your pelvic floor. Your treatment goals include: normalizing your pelvic floor muscles; mobilizing the fascia, other connective tissue, and even skin of the hips and lower back; strengthening the hip and core muscles, including the gluteal muscles, which often become extremely weak; relaxing the obturator internus and piriformis muscles, taking pressure off pelvic nerves; and fixing gait and movement abnormalities – all the way down to your feet.

Moving up the scale to more invasive treatments, the injections discussed in the diagnosis section can also be helpful as treatments. Other treatment options are cold laser, ultrasound, dry needling, and trigger-point injections to muscles in pain or spasm due to imbalance. If none of these approaches succeed, you might consider surgical options.

### **Potential Breakthroughs: Looking Ahead**

The future is very, very hopeful for healing orthopedic problems causing sexual pain, as research is advancing rapidly to devise less-invasive means to

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## NICHD

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approached vulvodynia as a chronic pain syndrome rather than a gynecological disorder, bringing together a wide array of scientists and clinicians in the neuroscience field and exploring the underlying mechanisms of chronic pain. In addition to stimulating new ideas that will enhance ongoing vulvodynia research, NICHD aimed to encourage investigators working on chronic pain to expand their focus and include vulvodynia in their studies.

The NICHD viewed this meeting as *one* important step in expanding NIH-funded research on vulvodynia. In his opening remarks, NICHD Director Dr. Alan Guttmacher noted, “The importance of this topic is evident by the fact that both myself and our Deputy Director will be present for the entire conference, which is rare.” He promised that the NICHD directors and staff would be listening very carefully to the presentations and general discussion, as well as recommendations that stem from the meeting. In her opening statement, ORWH Director Dr. Vivian Pinn pledged the continued involvement and support of her office: “We look forward to working with NICHD and other NIH Institutes to advance vulvodynia knowledge and awareness. We commit our continued collaboration and support to finding answers that you are seeking and that we need.”

The meeting featured a mixture of presentations, general discussion and breakout sessions. In addition to serving on the planning committee, NVA Executive Director Christin Veasley led one of the five breakout sessions on communication and education. Other breakout group topics included the pathophysiology of pain, diagnosis and management of vulvodynia, vulvodynia treatment and medication issues and public-private partnerships to expand vulvodynia research. The meeting ended with a presentation of the recommendations from each of the five breakout group leaders and general discussion by the meeting attendees.

NICHD’s science writers are in the process of drafting a white paper that will include a summary of the presentations, breakout sessions and strategic research plan. Upon completion, the paper will be posted on NICHD’s web site for public comment. NVA will circulate an e-mail announcement at that time so that our patient, clinical and scientific communities can review the document and submit comments. (You can sign up to receive e-mail correspondence from the NVA at [www.nva.org/email\\_newsletter.html](http://www.nva.org/email_newsletter.html).)

NICHD’s goal for this workshop was to stimulate scientific discussion and facilitate more research that will improve the lives of women who suffer from vulvodynia. We are hopeful that the NICHD’s renewed commitment to studying this long neglected disorder will transform this strategic research plan into the answers that sufferers need. ■

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## Orthopedic

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treat these problems. Physical therapy techniques are improving; the individuality of our bodies is being recognized; and new substances to optimize healing are being studied.

*[Editor’s Note: This book will be available in November 2011. Help the NVA raise funds for medical research by pre-ordering the book from Amazon through NVA’s web site. Just click on the book cover located at [www.nva.org/book\\_list.html](http://www.nva.org/book_list.html), proceed with your purchase and Amazon will donate a percentage of your purchase price to the NVA. Additionally, the authors are generously donating a percentage of the book sale proceeds to the NVA.]* ■