

An Integrated Approach to Pelvic Pain

Physicians of all specialties can learn ways to manage overlapping conditions.

— Robert J. Echenberg, MD

Dr. Robert J. Echenberg is the founder of the Echenberg Institute for Pelvic and Sexual Pain in Bethlehem, Pennsylvania. Previously known as the Institute for Women in Pain, Dr. Echenberg's practice is one of the first privately owned multi-disciplinary practices exclusively specializing in assessment, diagnosis, and treatment of chronic pelvic pain (CPP). Since its inception in 2006, the Institute has treated more than 1,200 women and a growing number of men with pelvic and sexual pain disorders from 25 states and five countries.

A member of ICA's Medical Advisory Board, Dr. Echenberg is the author of the book Secret Suffering: How Women's Pelvic and Sexual Pain Affects Their Relationships. Dr. Echenberg spoke with ICA Update about IC and overlapping conditions, why education must come before medication, and ways in which the medical system must change to address the needs of patients with overlapping chronic inflammatory and pain conditions.



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Talk about how IC fits into the variety of overlapping conditions you treat.

I started this program in 2001 when asked to develop a nonsurgical approach to female pelvic pain through our department of obstetrics and gynecology. We knew that all over the country young women were receiving multiple invasive diagnostic and therapeutic procedures for persistent and otherwise unexplained painful symptoms in the pelvic region (between the belly button and mid thigh). I found early on that IC was a cornerstone, if not one of the most common triggers of pelvic pain.

There's a huge spectrum of pelvic pain patients, both male and female. Many conditions within the pelvic organs such as IC, endometriosis, and IBS are common organ or visceral generators of pain within the pelvis, but what I soon realized is that we were generally not even thinking of all the muscles, ligaments, and nerves that almost always contribute to the pain itself.

Much of the literature and my own experience since 2001 points to bladder pain syndromes being at least part of the picture of chronic pelvic, genital, and sexual pain about 80 to 85 percent of the time. That's a huge number, and chronic pelvic pain translates into tens of millions of individuals in the U.S. alone. Not only are multiple parts of the anatomic pelvis involved in persistent painful pelvic symptoms, but there are also many overlapping inflammatory issues and other pain syndromes commonly associated with CPP. These include migraine, fibromyalgia, TMJ, multiple chemical sensitivity syndrome, all the autoimmune disorders, and others. IC patients are among large numbers of people suffering not only pain, but also fatigue, sleep disorders, hypersensitivities, allergies, and other slowly disabling illnesses that plague our health care system.

What are the challenges of dealing with overlapping pelvic pain conditions?

The pelvic region is the busiest region of the body, both functionally and mechanically. We constantly use our pelvic region with all of the obvious bodily functions of elimination, reproduction, sexual pleasure—and we really can't do any

other activities without structurally using our pelvis as well. Plus the stats are astounding—estimates of up to 30 million women and an unknown number of men suffer from CPP in the U.S. alone. Because there are so many conditions that overlap within the pelvis and elsewhere in the body, the biggest challenge to our system itself is that we are not training pelvic pain specialists who look at the whole person and know how to “connect the dots” regarding pain management expertise.

The pelvis is divided up into six or seven different specialties, and if you link all the psychological effects and how the body predictably responds to cumulative injury and trauma, unfortunately few of those specialists are currently being taught 21st century pain science. Meanwhile, those trained in pain management commonly fall short in their training of any of the pelvic organ “triggers.” Patients themselves face the biggest challenge in their quest for someone who recognizes that so many of these overlapping illnesses are really connected.

Even when I’m looking at a complex pelvic pain patient and commonly finding through a detailed history and physical examination that their bladder and urethral inflammation is linked to their pelvic regional pain syndrome, it also becomes necessary for me to understand chronic pain science and what other overlapping organ systems may be involved. In the best of all worlds, these long-term sufferers would be best handled by a “team” of healthcare practitioners who would contribute to the total bio-psychosocial needs of that patient. Just treating their IC is not enough. Therefore I need to have in my toolbox knowledge and experience in diagnosing and treating irritable bowel syndrome, pelvic floor dysfunction, peripheral neuropathies in the pelvic region, vulvodynia, and vestibulodynia, persistent genital

arousal disorder, and also know when to refer to rheumatology, a sleep specialist, physiatrist, physical therapist, acupuncturist, and other mind/body practitioners.

We need a multidisciplinary, multi-organ system approach, and we need desperately to have many specialists—not just people working in the pelvic region—understand the processing of pain. That science has been exploding over the past several decades. I believe our biggest challenge remains in universally training all of our doctors and other practitioners about this science in order for it to trickle down into everyday practice. Worldwide, pain is the most costly part of the entire health care system. Here in the U.S., pain costs us more than diabetes, cardiovascular disease, and cancer combined.

What I have learned the most about “chronic pain” is that it should be looked at as its own disease. As opposed to “acute pain” and “acute inflammation,” which are our necessary companions for survival, chronic pain and inflammation are common pathologies unto themselves, and they no longer are protecting us and keeping us safe. These chronic disorders insidiously do incredible harm to such a high percentage of people throughout all parts of the world and cultures.

How do you use this knowledge of pain when treating IC and other pelvic pain symptoms?

We need practitioners who look at the whole picture.

I first review with each patient their life history of trauma and begin to explain chronic pain as a result of cumulative trauma and stress to the system that comes in all varieties. The pelvic region is not only the busiest part of the body, but it also takes a great deal of punishment over a lifetime. There is a nervous system memory and a lifetime muscle memory of every sensation and context of all that we have experienced. The mid-brain “chemically remembers” all of our physical, emotional, psychological, spiritual, financial, and sexual traumas and injuries and is always ready to remind us of them if it believes the body is in danger. At any moment, innumerable inputs from all of our senses and organs can trigger a memory of trauma and a cascade of events occur in a flash of time to place us in “fight or flight.” Chronic persistent pain comes from both messages from the periphery and how those messages are received in our central nervous system.

Many of our CPP patients know that stress and anxiety and their cycle of pain all go hand in hand. Most people date the onset of their pain issue to a specific event such as childbirth, an accident, a surgery, a bad relationship, or other memorable trauma. What we find is that when those events occurred the patient already had probably developed a very high pain tolerance and their body was simply waiting for one more trauma to throw them over the edge.

It is remarkably simple to explain this concept of “windup” of the nervous system and how it explodes with vengeance to most of our patients, and then they soon relate to this concept by their own experience. They also say that they have been further traumatized by the system itself because so many of their tests are “normal,” they “look healthy,” and more than a few have been labeled as “drug seekers” or just plain “crazy.” So there is also a huge component of stress, anger, and

frustration that women and men find themselves in on a daily basis while they are fighting their pelvic pain issues—family issues, work issues, partners or families that don't understand that these people have real pain and don't acknowledge it—all these make the struggle all the more difficult to endure.

It is always really gratifying to me to see that understanding of their pain actually begins to lower their pain, increase their confidence, decrease their fear and hopelessness, and they begin to see a purpose again in their lives. Along with medications, localized pelvic treatments, physical therapy, and dietary changes for all of these painful disorders, they begin to realize they actually have the key and the tools to start “turning the dial down” by retraining and rebooting their own brains in how those messages are received.

What's your approach to treating pelvic pain?

Because I do what I do, I get very complex patients. They've usually gone to multiple specialists and institutions seeking to get rid of their pain. I've had to accommodate more and more difficult and more and more complex overlapping disorders. I had to figure out a model of care that incorporated all the other aspects of their pain besides that generated by their IC.

I look at myself as a pain management doctor for the pelvic region. Pelvic pain can be looked at as a chronic regional pain syndrome (CRPS) because so many structures in the pelvic region are linked by the nervous system and how pain is processed by the brain.

Because I have developed a pain management approach, I look at IC as just one of the triggers—but a major one. Just treating the bladder will reduce some of the pain. But I also focus on the things in the textbooks and medical literature for pelvic pain in general. Since 2001, I have attended as many pain conferences as possible, have read

pain journals, been an active member of the International Pelvic Pain Society and have taken so many of those pioneering chronic pain concepts and applied them to my previous 35-plus years of Ob/Gyn experience and my working knowledge of pelvic anatomy and function. I also began listening to and believing the descriptions of pelvic, genital, and sexual pain told to me by over 1,200 severely suffering patients over this past decade. There are guidelines for IC and chronic pelvic pain from more than a few prominent organizations, such as the American and European Urological Associations. I have tried to put all of these concepts into action with each of our patients as a pain management practitioner. I have become facile with the use of peripheral nerve blocks throughout the pelvic region. I do simple bladder instillations, use Botox into the pelvic floor when necessary, and have learned a great deal about the appropriate use of medications for “turning the dial down.”

How do you start working with patients?

One of the keys of the success of my program is that I typically spend at least three hours with each new patient. I'm a proponent of education before medication—and before treatment. People need to be validated that their pain is real, and then learn how the pain is processed and how stress and their families not understanding them and the practitioners (who have been telling them that the pain just “couldn't be that severe because the tests are all normal”) have just made matters worse.

I am not naïve and I realize that hardly any other practicing physicians would be able to spend that amount of time with a first visit. I have chosen to do so because I want to show that this model of evaluation and care really works better than

what I knew as an Ob/Gyn over so many years. In the real world, the 15-20 percent of patients that have chronic pelvic pain could be given this education and begin their treatment regimen by well-trained physician extenders such as nurse practitioners or physician assistants. Perhaps one experienced gynecologist or urologist or GI doctor in a physician group practice could easily be trained to follow through with the procedures and work as a team using the most up to date science of pain management. This especially applies to IC/PBS, because it could be picked up by screening younger patients and treating them early in order to prevent the progression of pain that often follows lack of diagnosis and treatment in our current system.

In my practice, patients fill out a 14-15 page questionnaire before they come in—we don't give them the appointment until they fill it out. What we do during our first appointment is review the questionnaire. I quickly launch into a discussion of their symptoms and how the model of explaining pain may fit their individual experiences.

That model then makes sense to them, and soon they are recalling numbers of other events or experiences that they hadn't thought were related until that moment. Many cry with sadness or even relief that someone knowledgeable is actually listening and believing, sometimes for the first time in many years. The light bulbs often seem to light up.

Then we go into the examining room and do a very specialized exam. It's different from a standard gynecological or urological exam—it's more of a musculo-skeletal and neurological exam trying not to miss anything between the mid-abdomen, mid-back and the mid-thighs. We gently look at the genital area and demonstrate to them the external pain generators, often observing

obvious or subtle inflammatory or painful changes on the labia, clitoris, perineum, and vestibule that commonly have never been told to them before. We'll use a mirror so they and their partners understand that it's real inflammation and real sensitivity.

We then gently do internal exams, showing people that their pelvic floor is almost always tight, often more on one side than the other, then palpating the underside of the bladder and showing them that it's commonly their bladder that's been hurting in many cases. Just doing the exam is an educational process for patients. Many women then realize that it has been their bladder all along that was tender and painful with deeper sexual relations, and not their cervix, tipped uterus, ovaries or endometriosis, as so many have been told.

Sometimes I do a bladder instillation or pudendal or other peripheral nerve blocks for the genital area or other areas of the pelvis during that first visit. That reinforces the fact that they can be pain free in those locations and that their pain level can go down significantly. You can't just tell people you're going to help their pain—you have to show them that it is actually possible. These early treatments are simple, quick, safe, and go a long way to demonstrate that it is the bladder and nerves and muscle clenching that has been the cause of much of their pain—even though they may have had multiple surgeries and even hysterectomies for the same pain in the past.

How do you convince patients, many of whom have been suffering for years, that this approach can work?

I tell people we're just starting to understand the brain. It's going to take a couple of generations to understand how to turn that dial down completely. But it can be turned down significantly now.

When people get through that and they absorb it, it's often overwhelming. Most are skeptical that anything's going to work. When they understand that the dial can be turned down, even for short periods of time, their hope increases exponentially.

From the practitioner's standpoint, most of us really need to learn how to listen—how to be compassionate listeners and communicators, validate people's pain, and have a basic scientific knowledge as to why someone is in this chronic pain state to begin with.

What needs to be done to fix the system?

The system makes it very hard. There are lots of barriers that are obvious, and education has to be implemented at the basic core curricula. We need to start training gynecologists, urologists—anyone who works in the pelvic area—about pain itself. Not many programs teach the up-

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to-date neuroscience of pain processing. All the brain science and neuroscience should start seeping into the curricula of all the specialties.

Doctors do not have to feel like they have to learn all of these overlapping illnesses inside and out to feel comfortable in managing people's pain. You just have to listen, believe, understand, and educate. The actual techniques can be taught very quickly—not just to doctors, but to anyone who's licensed to do the types of simple office procedures that I have mentioned. It's not rocket science, but it works.

Another important aspect of this type of care is to enlist the help of a significant other as much as possible. This can be a partner, parent, best friend, etc. The less isolated these people are and the more understanding and knowledgeable help they can get from a trusted person in their life, the better they will follow through with their part of the healing process.

What do patients need most?

As far as healing is concerned—which applies to all chronic illnesses and all chronic pain—you need three basic things: love, purpose, and hope. I try to translate that into everyday planning in their treatment regimen. Many of our patients tell us our office is their safe haven. They feel listened to and understood and feel a sense of compassion and love. This is especially true if they do not feel anyone else understands what they are going through. Nonetheless, our goal is to wean them down to fewer visits in order for them to take their own lead in their rehab.

The purpose part is the hardest part. The so-called people who are so difficult that no one knows what to do with them? Their whole lives are spent isolating themselves because no one is helping or believing. If your only purpose in life is just getting rid of your pain, you've lost your life. I had a young man who was housebound and learned to do origami—he found it was the only thing that distracted him. He did it so well, we took pictures of his work and put them on our website. Many others tell us that one of the purposes they begin to feel is to “pass it forward” and start helping others who are beginning their pain journeys.

The last thing is hope. The hopelessness and helplessness that people have needs to be addressed right from the beginning. In the 21st century, no one has to be in constant pain with the technology and medications and techniques we have today. We must do better.

—Mark Toner

Mark Toner is editor of ICA Update.