

# VISION

**THE INTERNATIONAL PELVIC PAIN SOCIETY**

*Professionals engaged in pain management for men and women.*



## **A Tribute to Dr. C. Paul Perry: One Clinician's Experience with a Successful Model for Chronic Pelvic Pain Management**

By Robert J. Echenberg, MD

I was encouraged to write this article for IPPS Vision following the recent untimely and tragic passing of Dr. C. Paul Perry. Though we never met in person, he and I corresponded via email and were looking forward to speaking with each other at the IPPS 2008 Annual Meeting.

I have been a member of the IPPS for five years, following my growing interest in, and development of, a chronic pelvic pain (CPP) program.

My ob-gyn career began in 1970. By the new millennium, I was no longer practicing obstetrics. In 2001, the chief of our department asked me to establish a CPP program that would focus primarily on a *non-surgical* approach to assessment and management. This new modality was based on our findings that a significant percentage of diagnostic laparoscopies and other invasive and costly diagnostic studies traditionally resulted in either negative or minimally positive findings that didn't truly "explain" the pathophysiology of non-cyclic chronic female pelvic pain.

Having spent over 30 years as a gynecologist, I believed that at least 70-80% of CPP was due to pelvic endometriosis, and that ovarian cysts, pelvic adhesions, and pelvic inflammatory disease rounded off the remaining 20-30%. However, I became increasingly frustrated over the years performing surgeries and exhaustive testing on so many otherwise "healthy appearing" young women, and still coming away too frequently unable to adequately diagnose and treat their pain and suffering. Thus began my journey toward specializing in CPP.

I saw my first severe CPP patients in a small extra examining room in the hospital's general pain management center. Working closely with a pain specialist (an anesthesiologist with a pain management fellowship) was especially good for me in those early months.

He gave me a number of pointers regarding the medical management of chronic pain, and was extremely pleased with my intense interest in treating pelvic pain, which was most uncommon at that time. He reminded me that his training and specialization did not include CPP. I have since discovered that this holds true for most pain management specialists.

Pain generated from the visceral triggers of urinary bladder, lower bowel, and gynecologic dysfunctions, as well as sexual pain disorders remain distinctly out of the realm of interest or schooling of most pelvic specialists, including urologists, gynecologists, gastroenterologists, general internists, and orthopedists. There may be upwards of 30 million reproductive-aged women with CPP in America, and many of them seek help from these "specialists," often going from one to another in search of a diagnosis and proper treatment, many treated for single symptoms/conditions when multiple triggers are present.

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I soon read through Dr. Steege's and Dr. Fred Howard's textbooks on pelvic pain as well as everything I could find from authors and researchers both in the U.S. and abroad, many of whom remain prominent members of the IPPS. I also attended meetings related to chronic pain in general, such as those held by the American Pain Society, and joined the International Association for the Study of Pain (the group who, incidentally, designated 2008 as the *Year Against Pain in Women*).

I corresponded with, and personally met many members of the pain research community and began to understand and appreciate CPP as a chronic regional pain syndrome.

It became apparent that I knew almost nothing of the differences between "acute" and "chronic" pain. In medical school, we were taught the acute pain "model," which all too often continues to be used as our only "tool" in dealing with chronic pain in women. Therefore, if evidence of acute tissue damage was not visually documented either through surgical or radiological means, and the patient's subjective account of her pain far exceeded the "findings," then the symptoms were either disregarded, discounted, minimized, and worse, looked upon as "hysterical," psychological, or purely emotional.

How wrong we all have been. Through my research and experience, I learned that, in fact, the bladder and lower bowel were the major triggers of pelvic pain 80% of the time and that purely gynecologic reasons were much less common. Nonetheless, our gynecologic literature still promotes searching harder for the often "invisible" lesions that surely must be there if only we look deeper, and continues to focus on invasive assessment and therapies for CPP.

I was still working for the hospital when my referral base began to grow. I gave more grand rounds in regional facilities about CPP, particularly focusing on painful bladder syndrome/interstitial cystitis (PBS/IC). As one might suspect, many of the referrals were "train wrecks," having been "through the mill" of multiple testing, specialists, and surgical interventions.

In some cases, I saw young women under the age of 25 who had been through seven or eight previous laparoscopies and even hysterectomies. Even more tragic was the fact that when they came to me, their pain was worse than ever.

My patients' relationships at home, work, school, etc., were suffering. Depression, anxiety, frustration, and anger were common. Their distrust of the "system" was already significant, which meant that a great deal of time was required with each of them to begin the healing process.

I needed to spend at least one to two hours with new patients, in order to establish trust before even beginning treatment. These women needed to be heard, validated, given hope for relief, and most importantly, not rushed out of the office.

Our nurse named the comfortable lounge chair next to my desk the "crying and memory chair." Tears and memories of past issues commonly pour out during that first visit. In addition, a process of reeducation was a necessary component.

"Visceral triggers, central sensitization, up-regulation, hyperalgesia, allodynia, and neurogenic inflammation" all became part of my conceptualization of CPP. I also learned a great deal about medical management of neuropathic pain and became more comfortable with the effective use of opioids.

Myofascial pelvic floor dysfunction, sexual pain disorders, including vulvodinia, and vulvar vestibulitis, also became an integral part of our assessment and management. Among other medical specialists, we also began working with several well-trained pelvic floor physical therapists, psychological counselors interested in pelvic pain, an acupuncturist, a yoga instructor who previously suffered from CPP herself, and recommended books and websites for techniques of meditation and relaxation.

My CPP patients were the most grateful patients for whom I had ever cared. For decades, obstetric care was my passion, and I believed that I would never love any aspect of my work more than that. I was wrong.

Working with CPP patients, I was not "curing" but "caring," and significantly improving the quality of life of most of these women. So many of these pain patients told me that finally being heard, believed, and validated in their pain contributed to the fact that they felt better

for the first time in months, years, and even decades.

The program was a great success and we provided hospital administration with a business plan indicating that the center was already modestly profitable, and with a limited budget and cost center, this unique program could grow and flourish. I spent nearly two years attempting to obtain budgetary support from hospital administration.

Regrettably, I was never able to obtain that help. My disappointment soon turned to frustration and acceptance that if I were to continue building the CPP program, I would have to leave the hospital setting and open my own office. I proceeded to do so and now know that I could not have made a better decision.

Over the past two years, our CPP practice has more than exceeded all expectations. I could not ask for a more dedicated and talented staff and we have associated ourselves with an exceptional multidisciplinary team. I continue to spend up to two hours with each new patient (seeing four new patients a week). Our success demonstrates how an independent private office can maintain significant financial viability without doing hospital-based procedures.

We are performing an increasing number of office procedures, including bladder instillations, pudendal blocks, ilioinguinal blocks, and abdominal and vaginal wall trigger point injections. *These procedures are fully reimbursable by insurance carriers, which allows for a far more profitable venture than previously projected.*

Though I have no time available for clinical research, we have collected a wealth of data, which I hope to share in collaboration with larger institutional studies. We can provide documented demographic and epidemiological information that could provide much assistance in the overall understanding of CPP. For instance, as others in the field, in our practice we have recognized a strong linkage between CPP and many other chronic regional pain syndromes, such as migraine, fibromyalgia, TMJ as well as a connection with chronic allergic and auto-immune disorders.

Another extremely important finding in our patient base is that the younger, sometimes most severe patients, have commonly had long-term histories of sports and physical activities, such as gymnastics, dance, cheerleading, track and field, volleyball, soccer, etc. There appears to us to be a growing "epidemic" of CPP and pelvic trauma associated with these physically demanding activities. Well-designed studies in these areas are greatly needed.

I believe strongly that CPP should be a multidisciplinary subspecialty of its own. Every reasonably sized community could support a CPP center. Until younger professionals are trained, older and more experienced pelvic specialists such as gynecologists and urologists could establish these very effective and profitable office-based practices. Such CPP centers would require relatively low overhead, low malpractice rates, and in the process, cut down drastically on innumerable and often unnecessary, expensive, and anxiety-provoking invasive diagnostic and surgical procedures.

As my own experience over these past few years has demonstrated, this is an eminently doable proposition. Because of the success of my venture and protocol, my first goal is to formalize the strategies and tools to educate and aid a variety of health care professionals (i.e., the gynecologist as well as the network of specialists) so they can develop their own centers to put these principles and skills into action.

Education is essential to train women's health care providers to understand how visceral and somatic pain commonly converge, in order to accurately diagnose and treat the many common conditions that cause CPP sooner and more effectively using a multi-organ system and a multi-disciplinary, multi-modal approach.

The second goal of the educational aspect of my program, and what propelled me into initially contacting Dr. Perry earlier this year, was to discuss my plans to inform as many women as possible about CPP. Today, most women (and men) do not recognize that the functions of their pelvic organs – lower bowel, urinary bladder, reproductive and sexual functions – are all intimately linked neurologically. Once we show them how dysfunctions and pain of any one of these organs can adversely affect all the others, they are more likely to seek appropriate care sooner.

To this end, over the past year, I have been collaborating with Susan Bilheimer, a writer and sufferer of CPP. We are under contract to write a book called, "Secret Suffering." Our website, [www.secretssuffering.com](http://www.secretssuffering.com), and the book (in progress), relate the personal stories of women, their partners, and those of a number of professional leaders in the field. Our goal is to expose how common these conditions are, how they affect relationships, how sexual pain is such a common thread in all of CPP, and why it is so difficult for women to find help in our current health care system. It is also our intention to provide hope and direction for those who suffer to find information and appropriate treatment for this devastating condition.

When I put out a request through the IPPS list-serve for members to be interviewed for the book, we had a very significant response. Dr. Perry was among those who answered us almost immediately. He graciously consented to an interview with Susan and expressed his pleasure that someone was writing such a book. He admitted that ten years ago, he, himself, had planned to write a book for the general public, but just never could get to it. Needless to say, it was tremendously gratifying and validating for us to hear this from such an expert and strong advocate in the field.

We were honored by his thoughts, his contributions to the project, and his good wishes. Aside from my personal regret that I did not have the opportunity to meet and talk with him at the annual meeting, I know that he will be sadly missed, but never forgotten, for his pioneering efforts to change the field of CPP treatment.

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