

# “IC - THE GYNECOLOGISTS PERSPECTIVE”

## *DIAGNOSIS & THE RELATIONSHIP OF IC TO ENDOMETRIOSIS, VULVODYNIA, VULVAR VESTIBULITIS & IBS*

FEATURING: DR. BRUCE KAHN, MD, FACOG  
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Dr. Kahn is a member of the Department of Obstetrics and Gynecology at Scripps Clinic & Research Institute in La Jolla, CA. He completed his undergraduate studies in Biological Sciences at the University of California, Irvine. He received both his master’s degree in physiology and his medical degree at Georgetown University. He completed a medical internship at St. Joseph Hospital and Healthcare Center in Chicago, Illinois and then began a residency in the Division of Radiation Medicine at George Washington University Medical Center in Washington DC. He then switched career paths to Obstetrics & Gynecology and completed residency training at Cedars-Sinai Medical Center in Los Angeles, CA and at Abington Memorial Hospital, near Philadelphia, PA.

Following residency training, Dr. Kahn was commissioned as a Lieutenant Commander in the United States Naval Reserve. He served on active duty as a staff physician in the Department of Obstetrics & Gynecology at the Naval Medical Center, San Diego. His duties there included patient care as well as teaching resident physicians and medical students. During his “tour of duty”, he was appointed as Director of the *Chronic Pelvic Pain Clinic*. He also received an initial appointment as a Clinical Instructor for the Department of Reproductive Medicine at the University of California, San Diego (UCSD).

Following his active-duty assignment, Dr. Kahn was recruited to the full-time faculty in the Department of Reproductive Medicine at UCSD, where he was appointed as an Assistant Clinical Professor of Reproductive Medicine and Director of Ambulatory Gynecologic Services in Hillcrest. A major focus of his work at UCSD was strengthening the residency-training program in primary healthcare for women.

Dr. Kahn joined the Department of Obstetrics & Gynecology at Scripps Clinic in 1999. Soon after his arrival, he pioneered work in the department and the region on the technique of laparoscopic supra-cervical hysterectomy. Over one hundred patients have successfully undergone this procedure at Scripps Clinic. Those patients have benefited in a much shorter recovery from surgery compared with those who require traditional abdominal hysterectomy. Dr. Kahn continues to work on the latest advances in medical and minimally invasive surgical techniques for his patients.

Dr Kahn’s commitment to teaching also continues. At Scripps Clinic, he developed a clinical teaching program for advanced gynecologic surgery for senior residents in obstetrics & gynecology. As part of this work, he was appointed Assistant Adjunct Professor of Obstetrics & Gynecology at the Uniformed Services University of the Health Sciences. He is currently Director of Graduate Medical Education in Obstetrics & Gynecology at Scripps Clinic. He also lectures nationally and internationally about his research on chronic pain as well as other topics.

Dr. Kahn is a Fellow of the American College of Obstetrics & Gynecology. He is a diplomate of both the National Board of Medical Examiners and the American Board of Obstetrics & Gynecology. He is a reviewer for the journal *Obstetrics & Gynecology*. His clinical and research interests include the diagnosis and treatment of pelvic and vulvar pain disorders, as well as the evaluation and management of menstrual disorders, adnexal masses, pelvic relaxation, vaginitis, sexually transmitted diseases, infertility, cervical dysplasias/HPV, premenstrual syndrome, and menopause. He has several clinical research trials currently underway.

[icnmgrjill] Tonight.... he joins us to discuss IC from the gynecologist's perspective and also to discuss the potassium sensitivity test and the relationship of IC to endometriosis, vulvar vestibulitis, vulvodynia... etc. Welcome Dr. Kahn!!!

[DrBruceKahn] Thank you very much for having me. It's really a pleasure and honor to be invited to take part in this discussion group.

**[icnmgrjill] How did you first become interested in IC?**

[DrBruceKahn] Following my residency, I received a commission in the Naval Medical Corps and was stationed at Naval Medical Center in San Diego (NMCS D). This was one of the first medical centers in the country that described using a multi-disciplinary approach to treating chronic pelvic pain (CPP) in women back in the early 1980s. I started working there in the mid 90s and that's really where I began my journey learning to diagnose and treat chronic pain in women. From there, I moved to UCSD and continued to learn about treating pain in a multi-disciplinary fashion. It was at UCSD that I met Lowell Parsons and he suggested that the bladder might be involved in the chronic pain in many of my patients. This was almost five years ago. Since then, I've been participating in clinical trials exploring this association. The results we have uncovered have been truly fascinating. My patients seem to be enjoying the results as well...

**[icnmgrjill] What was your first reaction to Dr. Parson's theory. It is fair to say that some obgyns don't believe in IC??**

[DrBruceKahn] I was interested and curious, but skeptical. Gynecologists generally don't know about IC. They traditionally have not been trained to consider the bladder when diagnosing and treating patients with chronic pain. Most gynecologists don't focus on the bladder symptoms when they see patients with chronic pain. As our research progressed, I learned that the symptoms of IC very often overlap with other syndromes such as endometriosis, vulvodynia, irritable bowel syndrome and fibromyalgia. Further, treatment for one of these syndromes often helps symptoms in other body systems. For instance, Elmiron has a common side effect of loose stools. This is often a nice side effect for the patient with symptoms of IBS...

**[icnmgrjill] You worked with Dr. Parsons in conducting some ground breaking studies using the potassium sensitivity test to diagnose IC in women with pelvic pain. Can you tell us more about these studies?**

[DrBruceKahn] Our first study was on a large group of women at four different gynecology centers across the country. Women with complaints of chronic pelvic pain were first assigned a "clinical diagnosis". That is, we assigned a diagnosis after talking with and examining patients, before any diagnostic procedures were performed. The diagnoses assigned included common gynecologic problems such as endometriosis, vulvar vestibulitis, recurrent yeast infections as well as IC and other conditions. We then administered a questionnaire to screen for IC – the "PUF Questionnaire". The PUF questionnaire was developed by Dr. Parsons and can be filled out by patients in less than a minute. It asks about frequency, urgency and pain as well as other symptoms. It then rates their response numerically. A low PUF score suggests that the bladder is not involved. A high PUF score indicates that the bladder may be involved. We've found that this small survey helps us quickly identify patients that may have IC. It's not a perfect screening test, but it is a very helpful tool to quickly identify those patients that may have IC. ([link here to PUF questionnaire](#))

Following this, we administered a potassium sensitivity test (PST) to better identify bladder involvement in chronic pelvic pain. The PST can help diagnose patients who may have IC and/or a damaged bladder lining. Two solutions are instilled into the bladder (H2O and KCL) to check for sensitivity to either of these solutions. Water usually does not cause any reaction (though sometimes it does). If a patient reacts to the KCL solution, that suggests that their bladder wall is damaged and that they may be an IC patient. ([link here to KCL info](#)) If patients have any reaction

to the potassium, then a third "rescue" solution containing heparin and an anesthetic (lidocaine) is quickly instilled into the bladder to relieve any symptoms the potassium may have caused. Some feel that the test might be unduly painful or uncomfortable. At Scripps Clinic, we take care to recognize any reaction to potassium quickly and stop that part of the test immediately if a reaction occurs. We have found that the test really only causes minimal discomfort, especially when compared with the classic diagnostic test for IC – cystoscopy with hydrodistention.

In our study, we found that over 75% of women had significant urinary symptoms (nocturia, frequency and urgency) and that over 85% reacted to the KCL test. Surprisingly, we found that our original clinical diagnosis didn't matter. The rate of positive testing on the KCL was fairly constant through all the clinical diagnoses we had given to the patients. This suggested that the bladder may be involved in other pelvic pain conditions or that these patients may actually have IC rather than these other conditions.

Our second study involved a larger group of patients evaluated in the same way. Their symptoms and findings were compared with a control group of women. The control group included volunteers with very low "PUF" scores (2 or less). That is, these women had no urinary symptoms or pain. None of the 47 women in the control group reacted to the potassium. I personally did ten of these in my clinic. Before completing this study, I honestly wasn't convinced on the relationship of the bladder to chronic pelvic pain... These findings however, changed my understanding of the connection between the bladder and chronic pelvic pain.

Currently, I don't *need* to use the KCL test to diagnose IC. However, the notion that the bladder is part of the problem is often a very "new" concept for patients in my office. (Remember, I am a gynecologist.) I have found the PST is often helpful for women to better understand the connection between their bladder and their pain. Moving forward with treatment for IC then makes more sense to these patients.

**[icnmgrjill] Are there women who don't believe that their bladder is causing some of these symptoms??**

[DrBruceKahn] Yes, I see a lot of women coming to see me with chronic pain problems who think they have "ovarian" pain or recurrent yeast infections or have intense pain with intercourse. These same women usually get up several times at night to urinate or urinate 15 times a day (which is high). They have had urinary symptoms for years and just never made the association between these two things. They think their voiding habits are normal. So, if I can reproduce the symptoms for which they came to see me by simply instilling a potassium solution into their bladder, it helps to make the connection more clear.

**[icnmgrjill] It sounds like this has become a wonderful new clinical tool. Are other gynecologists using it as well???**

[DrBruceKahn] I believe that the more gynecologists learn about the diagnosis and treatment of IC, the more comfortable they will become helping women with this problem. I have been giving lectures nationally to gynecologists across the country and have been amazed at the interest doctors have shown. Unfortunately, this is new territory for a lot of gynecologists, so it will take some time before this becomes a routine part of patient care and again, I don't truly think it is necessary prior to treatment.

**[icnmgrjill] Let's walk a patient through a first visit in your clinic...**

[DrBruceKahn] Ninety percent of a patient's first visit in my office is spent discussing her medical history and the history of her pain. It's important to check for symptoms in all the different organs in the pelvis, and to screen for things such as endometriosis, IC, IBS, fibromyalgia, trigger points as well as for symptoms of depression or anxiety. If I find that a patient has symptoms from two or more organ systems, I begin to suspect that IC may be involved, especially if their PUF score is higher than about 10.

After our discussion, I start with a gentle abdominal exam. I explore for the presence of trigger points or generalized hypersensitivity in the muscles of the abdominal wall. If a trigger point is present, I often will anaesthetize this small area (like a dentist anesthetizes a tooth) before doing a pelvic exam. I probably perform 12 of these a month and 9 or 10 of the injections will result in significant and immediate pain relief. This indicates that muscles are commonly involved in chronic pelvic pain. A few trigger point injections given over a several weeks can often result in long-lasting pain relief in that small area. (This is an example of multi-modal therapy for chronic pain.)

I seldom find that the whole problem is in one organ system. More often, I find evidence of multi-organ dysfunction.

Then, I perform a traditional pelvic exam but I also check for things such as pelvic muscle and bladder tenderness. Finally, if the history and physical exam indicate that IC may be involved, I finish up by discussing this possibility. I then direct the patient to places such as the ICN and ICA to learn more about IC. I point them there first before diagnostic testing because I think it's important that they learn about the problem first. I strongly feel that one of the best ways to treat IC is to put women in charge of managing the problem. Knowledge is power. I see myself as a facilitator of that process.

**[icnmgrjill] One of the "dark secrets" of IC is that some patients experience this very odd sensation of arousal that can come and go. It can be very uncomfortable and painful. Because it's embarrassing, patients often don't tell their doctors about it. Have you seen anything similar to this??**

[DrBruceKahn] I must admit that I don't ask specifically about this, though I do always ask about pain women have during and/or after intercourse and have seen a lot of women with this problem. Pain associated with sexual activity can range from arousal pain to flares of pain that last several days after intercourse. I think that this is probably part of IC, but sometimes there are discrete trigger points in the vulvar area that can be treated...

The PUF questionnaire is a good tool for exploring pain associated with sexual function. It contains questions specifically related to this. Often it is difficult for women to openly talk about this problem. The PUF questionnaire however is just a piece of paper. Some women find answering a question on a piece of paper much easier than discussing the problem verbally.

**[icnmgrjill] Dr. Kahn, one of things that patients ask about all the time is if there is a relationship between IC and endometriosis. Could you please give us your thoughts on this?? Let me qualify that by saying that some patients feel that their endometriosis may have contributed to the onset of their IC, while others have been mistakenly diagnosed with endometriosis only to discover that they had IC instead. Talk about confusing. Your thoughts?**

[DrBruceKahn] I think the relationship between endometriosis and IC is pain. I further believe these syndromes are different manifestations of the same problem – visceral pain.

Endometriosis is a painful syndrome diagnosed mostly by gynecologists that includes symptoms of cyclic pelvic pain related to the menstrual cycle, pain with intercourse, and the presence of endometrial tissue outside of the uterus - on the lining of the pelvis, on the ovaries or fallopian tubes. Endometrial tissue is usually found only on the inside lining of the uterus. The presence of this tissue type outside the uterine lining is what "defines" endometriosis.

Many gynecologists currently think the only way to correctly diagnose endometriosis is through laparoscopic surgery. The problem with this model is that many women with severe endometriosis have NO pain whereas women with very little endometriosis can have severe pain. Yes, the treatments for endometriosis do work. But perhaps they work in ways we do not yet understand... I personally *doubt* that the endometrial implants in the pelvis are the cause of pain.

I think pain is the problem. Pain can be manipulated with hormones or with surgical treatments. I usually favor medical therapy over a surgical approach to chronic pain.

IC is "defined" as the presence of abnormalities in the bladder wall that can be seen during cystoscopy. Many urologists feel that the only way to diagnose IC is through cystoscopy with hydro-distension. However if the diagnosis of IC is restricted to women with surgical evidence of disease, then a lot of women with IC will be missed. I think that this model of IC has the same problems as the model for endometriosis described above.

Personally, I believe that the findings that gynecologists observe in the pelvis at surgery (endometrial implants) are about as significant as the findings of urologists at cystoscopy (petechial hemorrhages) for IC. In other words, I don't think that they really matter. What matters is the PAIN. These women feel pain. The pain is visceral pain – pain that is mediated through the nerves of the visceral (abdominal) organs.

**[icnmgrjill] We did a year long survey of patients asking them what they felt triggered their symptoms. The results were very interesting. The #1 correlation that we saw was with a UTI. Some patients developed IC after having a UTI that was treated with antibiotics but their symptoms remained. Other patients reported that their symptoms began after some type of abdominal surgery or after having a baby. Does that correlate at all with what you've seen?**

I think that endometriosis, IC IBS and sometimes fibromyalgia are all different manifestations of visceral pain. The nerve fibers that transmit pain signals in the pelvis run through visceral nerve pathways. These are the nerves that run next to the motor nerves for the viscera – the bowel and bladder and the gynecologic organs - and that's why you see the overlapping conditions of constipation, diarrhea, frequency, urgency or pain related to sexual intercourse.

There are several possible causes of visceral pain. I think that most pelvic pain begins with an injury or a trigger of some sort. The nerves in the pelvis that transmit pain then become hypersensitive. That is, they become and remain more sensitive than normal. What results is that a sensation that should feel like "soft-touch" is then perceived as pain.

The triggers of chronic pain in the pelvis can be from any physical injury or psychologic trauma. The triggers you mentioned or others such as an ovarian cyst, a tubal infection or even a history of sexual abuse or rape are just a few examples of triggers for chronic pelvic pain.

There is a large body of data indicating that women with a history of sexual abuse or rape have an increased incidence of chronic pelvic pain. This does NOT mean that most women with chronic pelvic pain (or IC) have been a victim of sexual assault. But I do believe that the trauma of sexual abuse can cause nerves in the pelvis to become hypersensitive every bit as much as can a physical trauma like a urine infection or an ovarian cyst. Sexual assault is a physically painful event associated with terrible psychologic trauma. Compare this with childbirth: This is a physically painful event that is usually associated with an emotionally wonderful experience. This is why childbirth is not usually associated with chronic pelvic pain. Most importantly, it is not "all in her head". It is real physical pain.

**[icnmgrjill] Let's move on to vulvodynia. Many IC patients struggle with vulvar sensitivities and pain. In fact, for many years, we've called vulvodynia "IC on the outside." Do you see vulvodynia as more of referred pain from the bladder ... or just a totally separate visceral pain event??**

[DrBruceKahn] I also believe that most vulvar pain has a bladder association. My partner, Dr. John Willems, is a national expert on vulvodynia. He started his work with Dr. Friedrich, the person who first described vulvodynia in the literature. Working with Dr. Willems, I've seen a lot of patients with vulvar pain.

There are two main categories of patients that I see with vulvar pain.

- Patients in whom the entire vulvar region hurts – (e.g., vulvodynia)
- Patients with pain in very small discreet areas of the vulva – (e.g., vulvar vestibulitis)

Some have pain constantly and other have it only when the area is touched or stimulated. There is also a large group of women I see that have symptoms of recurrent "yeast" infections. They have the burning and itching of a yeast infection but they don't have the characteristic thick white discharge.

In our studies, we've observed women with all these types of vulvar pain and we found that most of them also have IC. So, the answer to your question is that I think that a lot of women with vulvodynia have IC. I have a manuscript in preparation focusing on these findings. My hope is that other gynecologists will start to consider IC in women who have these symptoms. Vulvar pain is a truly difficult area for many gynecologists. Uncovering this relationship will potentially help thousands of women receive more successful treatment for their vulvar pain.

**[icnmgrjill] Do patients with vulvodynia flare??**

[DrBruceKahn] Absolutely. Common causes of flares can be related to a variety of stressors such as menstruation, intercourse, diet, chemical sensitivities, travel, clothing, just to name a few.

**[icnmgrjill] How do you normally treat vulvodynia???**

[DrBruceKahn] From a pure gynecologic perspective, calcium supplementation (calcium citrate) is thought to be helpful. Some believe that oxalates in the urine can trigger vulvar sensitivity. Calcium is believed to bind with the oxalates and reduces the potential for irritation. Estrogen creams also can be very helpful for treating vulvar pain. We also utilize biofeedback, physical therapy, and even acupuncture. While there is data supporting the use of surgery for vulvodynia, I have not utilized this mode of therapy for patients with vulvar pain.

**[icnmgrjill] Do you find that women with vulvodynia have pelvic floor muscle issues??**

[DrBruceKahn] Yes, sometimes. Many women have what is called "pelvic floor dysfunction" which is a chronic contraction of the pelvic floor muscles. There are theories that this is related to potassium leak from the bladder, but no direct evidence of this connection exists. Many women find relief through biofeedback and physical therapy for these particular symptoms, though I think that treatment for IC often helps as well.

----- Audience Questions Begin -----

**[icnmgrjill] Morgan asks "Do you think that some women have had hysterectomies for their IC that they really didn't need? (i.e. that they had the same pain symptoms before and after the surgery)"**

[DrBruceKahn] Yes, but I don't think that the doctors have necessarily done something "wrong". The practice of medicine changes as new information becomes available from studies. Hysterectomy has been a standard treatment for pelvic pain for many years. There also is a fair body of published research data supporting the effectiveness of hysterectomy in the treatment of chronic pain. This doesn't mean that it works all the time or nor that it is the best way to treat the pain. As we learn more about pelvic pain, we are learning that non-surgical treatment sometimes works better. This is however, relatively new territory in gynecology. Most doctors honestly do the best they can for their patients. As our knowledge advances, our treatments change.



**[icnmgrjill] Jesser says... Fibro and endo are autoimmune. Do you think that IC is also an autoimmune disorder??**

[DrBruceKahn] Yes. There is a fair body of evidence that the immune system is involved in IC. Mast cells are immune system cells that have been found in increased concentrations in the bladder walls of IC patients. Other immune system cells have been found in increased concentration in the pelvises of women with endometriosis. These cells release substances like histamine that generate an inflammatory reaction. Inflammation causes pain. Hopefully, over the next several years, we will gain a better understanding of the connection of the immune system with chronic pain. I hope to be involved in this research. I am optimistic that new treatments that modulate the immune system response and decrease pain will emerge from this research.

**[icnmgrjill] What would be best way that a patient can work with their gynecologist to get the best treatment possible?**

[DrBruceKahn] Being in charge of the problem is the best thing that you can do. Physicians will have varying levels of knowledge about IC. If you have a physician who is open to the idea and interested, there are resources available where he or she can learn more about IC. I'm happy to speak with any other doctors and would be happy to facilitate any practitioners who are just learning about it.

**[bonus question] My doctor has suggested that I have a hysterectomy to reduce my pelvic pain. But, I'm confused... because my urologist says it's in my bladder. Do hysterectomies reduce pelvic pain and/or bladder pain?**

[DrBruceKahn] Yes, hysterectomy can help reduce pain. But it is more complicated than that. I do not usually recommend hysterectomy as a treatment solely for pain. My patients having hysterectomy most often have another reason for the procedure such as recurrent cysts, large fibroids, or bleeding that cannot be treated adequately with hormones. Removing these sources of pain often relieve or reduce pain. But I seldom resort to hysterectomy for endometriosis alone. Remember what I said about the relationship of pain to ALL of the organs in the pelvis. What I have found is that the more organ systems involved in the pain, the higher the likelihood that treatment without surgery will be successful. This is why 90% of patient's first visit in my office is spent reviewing the history of their pain and their symptoms in all their body systems.

**[bonus question] How can we, the patient, help in the education of gynecologists for IC?? What can we do to help??**

Be in charge of your care. Understand that different doctors will have different levels of expertise in dealing with chronic pain. Visiting a local or regional clinic that specializes in helping patients with chronic pain can often be helpful. These clinics often will be able to offer a multi-disciplinary approach to treatment. If you are in an area where this is not feasible, and you have symptoms in multiple body systems consider consulting with different specialists in your area and ask them individually to help you integrate the treatments they offer. Finally, understand that there are no one-size-fits-all treatments for chronic pain. Patience and perseverance are often necessary to find the combination of treatments that will work best to relieve pain. Further, treatments will often vary with time (due to flares and remissions). But know that there are lots of different treatments available to treat chronic pain and most people CAN find long-term pain relief.

----- Audience Question & Answer Session Ends -----

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