What's interesting about the IC movement today??

The progress of IC research! Many studies that we were hopeful would work for IC simply have not worked and now we have an idea why. It's all about phenotyping. Many patients sent to our clinic with a diagnosis of IC hurt somewhere between the belly button and their knees but, in many cases, it’s not really their bladder that’s the problem. It's often their muscles, nerves or perhaps bowel issues. To me, what’s really important about a clinical trial is to understand what type of patients should be enrolled in the trial.

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—Dr. Ken Peters

Patients with classic “Interstitial cystitis” (i.e. Hunner’s lesions) are a good target for a clinical trial and you can measure the results, such as the size and the appearance of the ulcer. So, if you’re studying a bladder specific treatment, Hunner’s patients are a good way to measure its effectiveness. In the LiRIS study for Hunner’s lesions, we clearly see improvement and I’m excited about the new clinical trial going forward this year. That's the easy IC. No one can dispute that this is a bladder disease.

Unfortunately, that’s the minority of patients. We have this other, much larger, group of patients with pain, urgency and frequency caused by something outside the bladder, such as the pelvic floor muscles. If I put a pelvic floor patient in a “bladder treatment” trial, the chance of me being successful is zero.

My sense is that we’ve become smarter in the last ten years and that the companies trying to develop new treatments and do clinical trials are trying to target them more effectively. When you look at the old NIH trials that we did, we were putting patients in the study who if you made their bladder perfect, they’d still have pain. It’s hard to win in that situation. The LiRIS® and the Lipella studies are working hard to enroll the bladder centric patient rather than pelvic floor or a systemic hypersensitivity disorder patients.

How common is pelvic floor dysfunction in your clinic?

Eighty percent of the patients we see who have been on traditional bladder treatments jump off the table if you put your finger on their pelvic floor muscles. We’ll use pelvic floor physical therapy, vaginal valium, trigger point injections and, if necessary, nerve blocks to reduce that muscle tension. If at the end of the treatment their pelvic floor has improved, but they are still having bladder problems, then we’ll treat them with bladder specific therapies.

Most of these patients have never had a pelvic floor exam. They’ve been given Elmiron® and other therapies and labeled with “interstitial cystitis.” I don’t think that does patients any good. When a patient visits our clinic, we evaluate them using a multidisciplinary approach, identify their triggers and treat each one to improve their overall symptoms.

Why do so many patients not believe that their muscles can be part of the problem?

Patients are often resistant to the idea. They’ve been invested in the label of “interstitial cystitis,” often for years and have gone to multiple clinicians who has reinforced this diagnosis. They simply don’t understand that the pelvic floor muscles can trigger many of the symptoms that they think of as IC. Once you convince them to be treated, it is gratifying to see how much they improve.

Why are so many doctors not diagnosing pelvic floor dysfunction?

Doctors don’t know about it. Our medical training did not include the role of the pelvic floor and how it influences the other organs in the pelvis. When we give talks about pelvic pain to clinicians and we explain how to do an appropriate pelvic floor exam, you can see the lightbulbs go off. When you see them in the future they’ll say, “You’ve