

ICA Research Digest: Translating Science, Empowering Patients

May 2025



A Note from Laura: Coming to a Global Consensus on IC/BPS

On April 23-24, 2025, members of the ICA team had the privilege of attending the [Global Consensus on IC/BPS meeting](#), in Winston-Salem, North Carolina. At this meeting, researchers, clinicians, and patient advocates from around the world came together to discuss the current state of the science on IC/BPS, ranging from the current understanding of what may cause this condition to how it is diagnosed and treated. All attendees were grouped into committees and responsible for reviewing the literature on their assigned topic and presenting their findings at the meeting. Some excellent discussions were had during this meeting, and final papers representing a global consensus are forthcoming.

What struck me the most about these consensus conversations, especially comparing the science I was aware of when I was first diagnosed over 25 years ago, was the organization of thought around the different phenotypes of

IC/BPS (i.e., that there are categories of IC/BPS patients, including those with bladder-centric disease and those with widespread pain). While there is still much more work to be done, it seems the consensus around these phenotypes is leading to new ideas around what causes this condition and how it can be diagnosed and treated. I left feeling optimistic about the future!

As always, I welcome feedback, questions, and ideas for topics or studies you might like to see summarized in the ICA Research Digest; you are welcome to reach out to me at laura.santurri@ichelp.org.

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Quick Tip!

We receive information every day from many different sources. When receiving health information, it's important to ask, "Who is sharing this message and why?" Is there a potential for a conflict of interest? For example, is the person or organization benefiting financially or otherwise from the advice they're giving? Are they promoting products or services they sell? Being a little skeptical can help you make informed decisions and avoid falling for misinformation!

Definition Spotlight - "Phenotype"

According to the National Human Research Genome Institute, a phenotype is defined as, "*an individual's observable traits, such as height, eye color and blood type. A person's phenotype is determined by both their genomic makeup (genotype) and environmental factors.*"



The National Institutes of Health-funded Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network has described three broad IC/BPS phenotypes—patients with widespread pain beyond the bladder and pelvis, patients with bladder-centric symptoms (with or without Hunner lesions), and patients with pelvic floor dysfunction. Importantly, the discussion about these phenotypes, or the different ways in which IC/BPS patients present, is still ongoing. In addition, individual patients may fall under multiple phenotypes at once.

References

Lai HH, Pickersgill NA, Vetter JM. Hunner Lesion phenotype in interstitial cystitis/bladder pain syndrome: a systematic review and meta-analysis. *J Urol.* 2020;204:518-23. <https://www.auajournals.org/doi/10.1097/JU.0000000000001031>

Gupta P, Gallop R, Spitznagle T, et al. Is pelvic floor muscle tenderness a distinct urologic chronic pelvic pain syndrome phenotype? findings from the multidisciplinary approach to the study of chronic pelvic pain research network symptom pattern study. *J Urol.* 2022;208:341-9. <https://www.auajournals.org/doi/10.1097/JU.0000000000002679>

Lai HH, Jemielita T, Sutcliffe S, et al. Characterization of whole body pain in urological chronic pelvic pain syndrome at baseline: a mapp research network study. *J Urol.* 2017;198:622-31. <https://pmc.ncbi.nlm.nih.gov/articles/PMC5562525/>

Recent Article Highlight: Interstitial Cystitis/Bladder Pain Syndrome: Matching Therapies to the Patient

This review highlights the importance of phenotyping to improve treatment for IC/BPS, a condition with varied symptoms that often fails to respond to generalized therapies. IC/BPS has been grouped into four main types: bladder-centric with Hunner lesion disease (HLD), bladder-centric without HLD, widespread/centralized pain, and myofascial pelvic floor dysfunction. Matching treatments to these types can lead to better results. For example, patients with HLD respond well to localized treatments like hydrodistention and fulguration, while non-HLD bladder-centric patients may benefit from dietary changes, intravesical therapy, or pain relievers. Myofascial dysfunction is treated with pelvic floor physical therapy and muscle relaxants, while widespread pain, often linked to chronic pain conditions, requires systemic treatments like antidepressants and neuromodulation. Psychological support is crucial for all patients, as many experience anxiety, depression, and poor coping skills. Although phenotyping is still evolving, it offers a more personalized, effective approach to care, shifting from rigid guidelines to tailored, multidisciplinary treatments. Future research should focus on identifying biomarkers to further refine these approaches.

Reference

Moldwin JF, Moldwin RM. Interstitial cystitis/bladder pain syndrome: Matching therapies to the patient. *Curr Bladder Dysfunct Rep.* 2025;20:4. <https://link.springer.com/article/10.1007/s11884-025-00772-y>

Patient Question - Is it possible that IC/BPS is caused by an embedded UTI?



There is some scientific literature to support that, for *some* IC/BPS patients, a hypersensitivity to bacteria could play a causative role in the condition. However, there is no confirmatory evidence that IC/BPS is caused by embedded urinary tract infections (UTIs). Importantly, there is also no scientific evidence demonstrating that long-term antibiotic therapy improves patient outcomes. Clinicians and researchers have also expressed concern about prescribing long-term antibiotics as a treatment for IC/BPS due to side effects and the risk of creating antibiotic resistance.

To answer the question in short—it is possible, but there is no current evidence to support it. Long-term antibiotic treatment also has risks.

We also want to clearly state that this answer is not meant to invalidate any particular patient's experience. In all cases, we recommend talking about potential diagnostic and treatment approaches with trusted members of your healthcare team.

References

Nickel JC, Cotechini T, Doiron RC. Secondary Analysis of Interstitial Cystitis/Bladder Pain Syndrome Patients Enrolled in a Recurrent Urinary Tract Infection Prevention Study Provides a Novel Paradigm for Etiopathogenesis and Practical Management of This Infection Phenotype. *Pathogens*. 2024; 13(5):396. <https://www.mdpi.com/2076-0817/13/5/396>

Szlachta-McGinn A, Douglass KM, Chung UYR, Jackson NJ, Nickel JC, Ackerman AL. Molecular Diagnostic Methods Versus Conventional Urine Culture for Diagnosis and Treatment of Urinary Tract Infection: A Systematic Review and Meta-analysis. *Eur Urol Open Sci*. 2022;44:113-124. Published 2022 Sep 2. <https://www.sciencedirect.com/science/article/pii/S2666168322008801?via%3Dihub>

Zering J, Stohs EJ. Urine polymerase chain reaction tests: stewardship helper or hinderance?. *Antimicrob Steward Healthc Epidemiol*. 2024;4(1):e77. Published 2024 Mar 6. <https://pmc.ncbi.nlm.nih.gov/articles/PMC11077600/#ref6>

Additional Studies of Note

Here, I'd like to highlight one article relevant to PCR testing, which some advocate using for detecting recurrent/embedded UTIs, and another article on the microbiota of IC/BPS patients.

Urine Polymerase Chain Reaction Tests: Stewardship Helper or Hinderance?

This commentary examines the use of urine polymerase chain reaction (PCR) testing for diagnosing urinary tract infections (UTIs) in long-term care facilities (LTCFs) and its impact on antibiotic stewardship (AS) programs. Urine PCR is a non-FDA-approved test that detects bacteria and some resistance genes. While it is faster and more sensitive than standard urine culture (SUC), it has significant drawbacks. Its high sensitivity can lead to false positives by identifying non-infectious bacteria, causing overdiagnosis, overtreatment, and unnecessary antibiotic use. Many studies on urine PCR fail to follow proper UTI diagnosis practices or ensure correct urine sample collection, with some methods, like swabbing briefs, being inappropriate. PCR also cannot provide antibiotic susceptibility data, and there is no strong evidence that it improves patient outcomes. SUC remains reliable for detecting common UTI pathogens like *E. coli*, with PCR offering limited benefits. The authors advise caution when using urine PCR and recommend working with AS teams to ensure proper diagnostic practices, use antibiograms, and educate staff on appropriate testing. More research is needed to determine if urine PCR has a meaningful role in UTI care.

Reference

Zering J, Stohs EJ. Urine polymerase chain reaction tests: stewardship helper or hinderance?. *Antimicrob Steward Healthc Epidemiol*. 2024;4(1):e77. Published 2024 Mar 6. <https://pmc.ncbi.nlm.nih.gov/articles/PMC11077600/#ref6>

The Microbiota in Patients with Interstitial Cystitis/Bladder Pain Syndrome: A Systematic Review

The systematic review examined differences in microbiota between patients with IC/BPS and healthy individuals, focusing on urinary, gut, and vaginal microbiota. The review included 12 studies, most of which analyzed urine microbiota, finding significant differences in bacterial diversity and composition. Results regarding *Lactobacillus* were mixed, with some studies linking it to protective effects and others to possible overgrowth. Specific metabolites, like sphingosine 1-phosphate and theophylline, may also play a role in the disease. The studies used different methods for sample collection and analysis, making it hard to draw clear conclusions. Most focused on women, reflecting the higher prevalence of IC/BPS in females, but the role of hormones like estrogen in microbiota changes and symptom severity needs more research. Limited studies on gut microbiota found lower levels of anti-inflammatory bacteria in IC/BPS patients, while vaginal microbiota studies showed no major differences but noted stronger connections between vaginal and urinary bacteria in these patients. Other microbiota, such as blood and skin, are largely unexplored.

The review highlights the need for standardized research methods, including better sampling and analysis techniques, to improve reliability. Future research should look at how microbiota, hormones, and different IC/BPS subtypes interact, while also expanding to study fungi, viruses, and other microorganisms. These findings suggest that changes in the urinary microbiota may play a key role in the development and treatment of IC/BPS.

Reference

Fu C, Zhang Y, Liang L, et al. The microbiota in patients with interstitial cystitis/bladder pain syndrome: a systematic review. *BJU Int*. 2024;134(6):869-880. <https://bjui-journals.onlinelibrary.wiley.com/doi/10.1111/bju.16439>

Thank you for reading!

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I acknowledge the use of GPT 4o to generate information for background research and in the drafting of language for this newsletter.

The ICA does not provide medical advice or consulting, nor do we recommend particular healthcare providers. In all cases, we recommend that patients communicate with their healthcare team before trying new treatment/management strategies. If you are currently in distress, please consider contacting the Suicide & Crisis Lifeline by dialing 988. If you are having a medical emergency, please dial 911.