ISSUE #6

ICA Research Digest: Translating Science, Empowering Patients

August 2025

A Note From Laura

As summer comes to a close, I've been thinking quite a bit about the complexity of IC/BPS, especially as I continue to spend time reviewing the scientific literature. In some ways, this complexity is daunting, but I am also finding comfort that, in all the potential variations (or phenotypes) of this condition, there are still so many shared experiences that should, hopefully, make us feel less alone. Whether you have a Hunner lesion or not, whether pelvic floor therapy has helped you or not, whether your main symptom is pain or something else, we all know what it's like to live with IC/BPS. We can also all look collectively to the research for hope. And I hope this research digest can play some small role in that.

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.

Sincerely,

Laura Santurri, Ph.D., MPH - Executive Director, ICA

Quick Tip!

When evaluating health information, look for whether the claims are supported by references to credible scientific studies or official sources (like peer-reviewed journals, government health agencies, or reputable health organizations). Reliable information usually cites where the data comes from, so you can verify it yourself. If sources aren't provided or are vague ("studies say…"), be cautious about accepting the claims at face value.

Patient Question - Where can I find the most up-to-date guidelines for IC/BPS treatment?

The American Urological Association maintains guidelines for both the diagnosis and treatment of IC/BPS. These guidelines are based on current scientific consensus. You'll note that treatment approaches are categorized into "behavioral or non-pharmacological treatments," "oral medications," "intravesical instillations," and "procedures." Importantly, there are also some treatments that are NOT recommended for IC/BPS. When seeking healthcare for your IC/BPS, it's a good idea to ask your healthcare provider if they are familiar with these guidelines. These guidelines can help you determine the direction of your treatment approach.

Definition Spotlight - "Multidisciplinary"

In the three articles highlighted in this research digest, all emphasize the need for collaboration among various healthcare professionals (urologists, gynecologists, physical therapists, psychologists, etc.) to effectively diagnose, manage, and treat IC/BPS and its associated conditions.

Definition: *Multidisciplinary refers to involving multiple medical and healthcare specialties working together to address complex conditions comprehensively.*

The remainder of this research digest is devoted to additional published articles from the Global Consensus on IC/BPS meeting in April 2025. Please reach out to me (laura.santurri@ichelp.org) if you'd like a full text copy of any of these articles.

Interstitial Cystitis/Bladder Pain Syndrome in Men

The article *"Interstitial Cystitis/Bladder Pain Syndrome in Men"* reviews the challenges and gaps in understanding, diagnosing, and treating IC/BPS in men. Long thought to primarily affect women, IC/BPS is now increasingly recognized in men, although diagnosis is difficult due to overlapping symptoms with conditions like chronic prostatitis and bladder outlet obstruction. Common symptoms include pain during bladder filling, frequent urination, nocturia, and pain in the lower back, scrotum, or perineum.

Diagnostic tools like bladder diaries, urinalysis, ultrasound, and cystoscopy are used, but no specific tests or biomarkers exist for men. Treatments often combine lifestyle changes, medications, physical therapy, and invasive procedures, though data specific to men is limited.

The article highlights the need for more research focused on men, including studies on hormonal and anatomical factors, as well as differences in treatment responses. Emerging therapies, such as stem cell treatments and neuromodulation, show promise but lack robust evidence for male patients. Mental health conditions like anxiety and depression are also common in men with IC/BPS, emphasizing the importance of psychological support and multidisciplinary care. To improve outcomes, the article calls for uniform scoring systems, better phenotyping, and more male-specific studies.

Reference:

Snipes M, Whitman W, Pontari M, Anger J, Samarinas M, Taneja R. Interstitial cystitis/bladder pain syndrome in men. *Neurourology and Urodynamics*. 2025;1-6. doi:10.1002/nau.70103. https://onlinelibrary.wiley.com/doi/10.1002/nau.70103

Role of Gynecologic Findings in Interstitial Cystitis/ Bladder Pain Syndrome: A Consensus

The review *"Role of Gynecologic Findings in Interstitial Cystitis/Bladder Pain Syndrome: A Consensus"* highlights how gynecologic conditions often overlap with IC/BPS, a chronic pelvic pain condition with urinary symptoms. Five key comorbidities were identified: endometriosis/adenomyosis, vulvodynia, sexual dysfunction (Genito-Pelvic Pain/Penetration Disorder), overactive pelvic floor muscles, and hormone-related changes.

These conditions share similar pain mechanisms, including inflammation, neuropathic pain, and muscle tension, which complicate diagnosis and treatment. For instance, endometriosis overlaps in 65% of IC/BPS patients, and up to 85% also have vulvodynia or pelvic floor dysfunction. Hormonal fluctuations, like during the menstrual cycle, can worsen symptoms.

The authors emphasize the need for thorough history-taking, trauma-informed pelvic exams, and multidisciplinary care involving urologists, gynecologists, and physical therapists. Addressing these overlapping conditions is critical for effective management of IC/BPS. The review calls for personalized treatment plans and further research into the connections between IC/BPS and gynecologic comorbidities to improve patient care.

Reference:

Sullivan ME, El Haraki A, Padoa A, Vincent K, Whitmore KE, Cervigni M. Role of gynecologic findings in interstitial cystitis/bladder pain syndrome: A consensus. *Neurourology and Urodynamics*. 2025;1-7. doi:10.1002/nau.70099. https://onlinelibrary.wiley.com/doi/10.1002/nau.70099

Patient Related Outcomes for Interstitial Cystitis/Bladder Pain Syndrome Recommendations for Clinical Trials and General Urology Practice

The article *"Patient Related Outcomes for Interstitial Cystitis/Bladder Pain Syndrome"* highlights the importance of patient-reported outcomes (PROs) and measures (PROMs) in managing IC/BPS, a condition causing bladder pain and urinary symptoms. Due to the variability in symptoms and associated conditions like pelvic floor dysfunction and anxiety, the article emphasizes the need for reliable tools to track patient progress and treatment outcomes.

The group recommends using the Numerical Rating Scale (NRS)/Visual Analogue Scale (VAS) for pain and voiding diaries as primary endpoints in clinical trials. For secondary outcomes, tools like the Genitourinary Pain Index (GUPI) and Interstitial Cystitis Symptom Index (ICSI/PI) are preferred, while quality-of-life surveys like SF-12, SF-36, and EQ-5D are also suggested.

For general practice, the NIH-GUPI or Pain Urgency Frequency (PUF) questionnaire is recommended for tracking symptoms and treatment effects. However, the authors stress the need for a new IC/BPS-specific PRO that better reflects patient experiences. Until then, the existing tools provide reasonable options for both clinical trials and routine care.

Reference:

Hayes B, Namugosa M, Evans RJ, Hajebrahimi S, Janssen D, King C, Pandey S, Nickel JC. Patient related outcomes for interstitial cystitis/bladder pain syndrome: Recommendations for clinical trials and general urology practice. *Neurourology and Urodynamics*. 2025;1-11. doi:10.1002/nau.70107. https://onlinelibrary.wiley.com/doi/10.1002/nau.70107

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

The ICA provides advocacy, education, and connection throughout the IC/BPS community. If you find the free resources we provide to be helpful, please consider donating today!

Donate Today!

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