ISSUE #5

ICA Research Digest: Translating Science, Empowering Patients

July 2025

A Note From Laura

In the May edition of the ICA Research Digest, I mentioned that the ICA had recently attended the Global Consensus on IC/BPS Meeting in Winston-Salem, NC. At that 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. I am excited to report that the consensus papers from that meeting are now being published and are openly accessible. In this edition of the ICA Research Digest, I highlight three of these papers on IC/BPS etiology (i.e., potential causes of the condition), diagnosis, and phenotyping. Stay tuned for more!

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 reviewing information for the first time, approach it with curiosity and skepticism. Ask yourself who created the content, what their goal might be, and whether evidence supports their claims. Cross-check facts with reliable, unbiased sources to ensure accuracy before forming conclusions.

Patient Question - Where can I find a healthcare provider who is familiar with IC/BPS research?

The ICA maintains a healthcare provider registry, which includes health professionals who have either requested to be on the registry or who are recommended by fellow IC/BPS patients. The providers on this registry represent various health disciplines (urology, physical therapy, and mental health, among others) and are in the U.S. or Canada. While the ICA does not recommend any particular providers, we hope that this registry includes health professionals who are more likely to understand IC/BPS and treat IC/BPS patients with compassion and care.

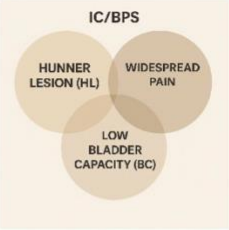
Definition Spotlight - "Consensus"

Given that we're highlighting "consensus" papers in this edition of the ICA Research Digest, I thought I'd take a moment to define consensus (and how it differs from "guidelines").

Consensus refers to a general agreement among experts or stakeholders based on the current evidence, clinical experience, and shared understanding of a chronic condition. It reflects collective opinions but may not always be backed by rigorous, standardized protocols.

Guidelines, on the other hand, are systematically developed, evidence-based recommendations designed to help clinicians and patients make informed decisions about managing the condition. While consensus can inform guidelines, guidelines are typically more structured, rooted in high-quality research, and regularly updated.

A Review of the Etiopathology of Phenotypes in Interstitial Cystitis/Bladder Pain Syndrome



The article reviews the causes and characteristics of three main phenotypes of interstitial cystitis/bladder pain syndrome (IC/BPS): Hunner lesion (HL), low bladder capacity (BC), and widespread pain. The HL phenotype is marked by visible inflammatory bladder lesions, immune cell activity, and high levels of inflammatory biomarkers. These patients typically experience bladder-focused symptoms and respond well to treatments like lesion fulguration or triamcinolone injections. The low BC phenotype involves reduced bladder capacity during hydrodistension and severe bladder-centered symptoms, often linked to inflammation and fibrosis.

The widespread pain phenotype is different, involving systemic pain and conditions like fibromyalgia and irritable bowel syndrome. This type is caused by central nervous system changes, leading to amplified pain throughout the body. Brain imaging shows altered brain structure and activity in these patients, who often benefit more from systemic treatments rather than bladder-specific therapies. By understanding these distinct phenotypes, clinicians can better diagnose IC/BPS and provide targeted treatments for each group.

Reference:

Sandberg ML, Santurri L, Klumpp D, Rodriguez LV, Clauw D, Lai H. A review of the etiopathology of phenotypes in interstitial cystitis/bladder pain syndrome. *Neurourology and Urodynamics*. 2025;1-8. https://onlinelibrary.wiley.com/doi/10.1002/nau.70097

Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS) Diagnosis: Current Limitations and a Pragmatic Clinical Diagnostic Definition

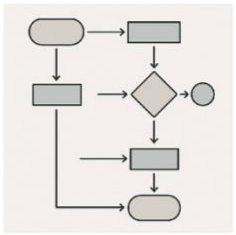
The article focuses on improving the diagnosis of IC/BPS, a chronic condition causing bladder pain, discomfort, or pressure, along with symptoms like urgency, frequent urination, and nocturia. The authors criticize the outdated 1988 NIDDK criteria, which exclude many patients due to their strict and research-focused requirements, and instead propose practical diagnostic criteria. The new approach is based on patient history, physical exams, and urinalysis, requiring symptoms lasting at least three months that worsen with bladder filling and improve with emptying, without the presence of other conditions like infections or cancer.

The article highlights that IC/BPS often overlaps with other conditions, such as pelvic floor dysfunction or endometriosis, which require separate treatments but don't rule out an IC/BPS diagnosis. Diagnostic tools like cystoscopy are recommended to identify Hunner lesions, a specific IC/BPS subtype, while tests like potassium sensitivity or hydrodistension are less useful. The proposed criteria aim to simplify diagnosis, avoid unnecessary tests, and focus on identifying IC/BPS through basic clinical assessments, improving care for patients with this complex condition.

Reference:

Werneburg GT, Moldwin R, Parsons CL, Priyadarshi MS, Sinha S, Clemens JQ. Interstitial cystitis/bladder pain syndrome (IC/BPS) diagnosis: Current limitations and a pragmatic clinical diagnostic definition. *Neurourology and Urodynamics*. 2025;1-7. https://onlinelibrary.wiley.com/doi/10.1002/nau.70112?af=R

Interstitial Cystitis/Bladder Pain Syndrome Patient Phenotyping



The article reviews how classifying IC/BPS patients into specific groups can improve diagnosis and treatment. IC/BPS is a chronic pain condition with varied symptoms and treatment responses. The authors identify three main phenotypes: (1) Bladder-Centric, including patients with Hunner lesions (HL) or low anesthetic bladder capacity (aBC), which involve bladder inflammation and respond well to targeted treatments like lesion fulguration and cyclosporine A; (2) Systemic, characterized by widespread pain, comorbid conditions like fibromyalgia and anxiety, and central nervous system involvement, where systemic treatments like amitriptyline are more effective; and (3) Variable Phenotypes, such as myofascial pelvic pain (MPP), recurrent urinary tract infections (rUTIs), and bladder-filling pain, which may overlap with the other groups or represent separate conditions.

The study highlights that IC/BPS is a complex condition involving both bladder and systemic symptoms, and a one-size-fits-all approach doesn't work. Tools like the UPOINT system can help tailor treatments based on patients' specific phenotypes. The authors call for more research to refine these classifications and better understand how different factors, such as bladder capacity, inflammation, and widespread pain, affect treatment outcomes. A multidisciplinary and empathetic approach is recommended to provide more effective and personalized care for IC/BPS patients.

Reference:

Wolff DT, Tranchina S, Schrepf A, Doiron RC, Chai TC, Walker SJ. Interstitial cystitis/bladder pain syndrome patient phenotyping. *Neurourology and Urodynamics*. 2025;1-7. https://onlinelibrary.wiley.com/doi/10.1002/nau.70098?af=R

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!

Our Contact Information

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