



CAIRIBU CONNECTIONS DISCUSSION

INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME GLOBAL CONSENSUS MEETING

SUMMARY 9/17/2025 CAIRIBU CONNECTIONS

Goal: Summarize the proceedings and outcomes of the April 2025 <u>Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS) Global Consensus meeting</u>	CAIRIBU CONNECTIONS	
	Stephen Walker, PhD - Wake Forest University	
	INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME GLOBAL CONSENSUS MEETING	
	09/17/25 [1PM ET]	



Introduction to the Global Consensus Meeting on Interstitial Cystitis Bladder Pain Syndrome (IC/BPS)

- Dr. Walker discussed the complexity of IC/BPS and challenges in defining and understanding the condition.
- In response to these challenges, Gopal Badlani, MD (Wake Forest University) organized a global consensus meeting in Winston-Salem to bring experts together to discuss IC/BPS.
- Goals of the meeting were to advance current knowledge, build on past efforts, and develop a common language for research teams globally.
- Stakeholders included the NIH/NIDDK, the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP Network), the ESSIC Consortium, the Global Interstitial Cystitis, Bladder Pain Society (GIBS), Asian organizations, and various patient groups.

Reviewing the Progress on IC/BPS Research and Clinical Approaches

Urologic Chronic Pelvic Pain Syndrome (UCPPS): Patient Phenotypes

- The MAPP consortium's work on urologic chronic pelvic pain syndrome (UCPPS) highlighted the systemic contributions to IC/BPS, suggesting that IC/BPS is a whole-body disorder, not just a bladder disease as suggested by previous research that overemphasized the bladder and prostate as source of disorders.
- Dr. Walker describes the two main phenotypes of IC/BPS: bladder-centric and systemic pain disorders.
 - The bladder-centric subset is characterized by unique findings and is more likely to lead to cystectomy.
 - The systemic pain disorder subset experiences urologic characterizes and co-occurring pain conditions and non-urologic symptoms.
- Dr. Walker stressed the importance of interactions between clinical and basic research, expertise beyond traditional urology, and a focus on patient-centered approaches.

MAPP Consortium and Deep Phenotyping

- The MAPP consortium's initial phase (2008-2014) involved deep phenotyping of IC patients across the U.S.
- The study included 12-month cohort studies with healthy controls and positive controls (patients with one of several conditions that commonly occur in IC such as IBS, chronic fatigue syndrome, or fibromyalgia).
- The second phase of the MAPP consortium (2014-2016) was a 36-month cohort study.
- The MAPP consortium's work provided insights into the characteristics and co-occurring conditions in IC patients.

Ancillary Studies and Molecular Differences

- An ancillary study on bladder hydro-distention and its duration of benefit in IC patients used validated questionnaires and additional phenotyping methods to explore molecular differences in IC patients, with a focus on bladder capacity and its relationship to phenotypes.
- The study identified low bladder capacity while under anesthesia as a measure of bladder-centric phenotyping.

Diagnosis, Etiology, and Pathology

- The diagnostic criteria for IC/BPS were discussed, with a focus on developing a pragmatic and streamlined definition.
- The role of gynecologic findings in women with IC/BPS was highlighted, including endometriosis, sexual dysfunction, and pelvic floor issues.

- The histopathologic and molecular findings in IC/BPS were reviewed, with a focus on the Hunner lesion disease.
- The main takeaway is that it is important to understand the etiology and pathology of different IC/BPS phenotypes.

Therapeutic Approaches and Patient-Reported Outcomes

- Managing IC/BPS requires a multi-disciplinary approach and multiple therapeutic attempts, especially when addressing patients with Hunner lesion disease versus without.
- Listening to patients and understanding their primary concerns and outcomes is crucial – underscoring the need for better IC specific patient-reported outcomes (PROs).

Global Registry and Consensus Document

- Although a comprehensive international IC/BPS registry would be helpful for future IC/BPS research and clinical care, feasibility and funding challenges remain barriers to implementation.
- Dr. Badlani authored an editorial summarizing the consensus meeting, including the post-meeting survey results, which indicated a strong preference to retain the name IC/BPS, with 90% of participants agreeing. This is important as having experts agree on standard nomenclature and terminology in IC/BPS establishes a common framework for researchers to build on.

Stephen Walker, PhD, is a Professor at Wake Forest University Institute for Regenerative Medicine (Winston-Salem, NC). His research focuses broadly on understanding the molecular and functional genomic features that underlie complex disease, specifically: (1) autism spectrum disorder (ASD) and an associated inflammatory bowel condition (ASD associated ileocolitis) in children and, (2) interstitial cystitis/bladder pain syndrome (IC/BPS), a complex urologic disorder in men and women aged 18-80 years old. Through his work with clinicians, he has amassed tissue banks that allow him to draw biomaterials (e.g. biopsy tissue, whole blood, serum) for molecular profiling. His goals are (a) to understand the biology of the disease, (b) to identify clinically relevant subgroups with these complex disorders and, (c) using actual patient specimens, to identify biomarkers that will aid in diagnosis and treatment of patients presenting with these very heterogeneous conditions. To date, his research has resulted in: (1) the first ever molecular description of gastrointestinal inflammation in GI-symptomatic children with autism, (2) a putative blood-based biomarker for GI inflammation in children with ASD, and (3) clinical sub-phenotyping in interstitial cystitis/bladder pain syndrome that distinguishes a bladder-centric disease phenotype from a systemic pain syndrome phenotype.
