



ISSUE #8

ICA Research Digest: Translating Science, Empowering Patients

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A Note From Laura



As mentioned in the last edition of the ICA Research Digest, the ICA was pleased to host the IC Connection: Science, Strategies, & Support virtual conference on Saturday, September 27th. Dr. Robert Moldwin, renowned IC expert and physician, was our keynote speaker, providing an update on the current state of the science around IC/BPS. Additional session topics included the IC diet and food fear, advocating for our physical and emotional needs, the role of occupational therapy in IC care, and what we know about men and IC.

Missed the [conference](#)? No worries! You can still access all the recordings for \$25; they are available for purchase [here](#) (click on "Purchase Conference Sessions" at the top right).

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!

If you're at the doctor's office and a member of your healthcare team recommends a treatment strategy, remember that it's okay to ask about other options. Every treatment usually has more than one path—ask what alternatives exist and what would happen with no treatment. If something sounds confusing, ask your clinician to explain it in simpler terms.



Patient Question - If I've had a cystoscopy, and my doctor has told me the inside of my bladder looks normal but I'm having symptoms, is it still possible that I have IC/BPS?

The short answer is yes! In the past, small spots of bleeding (called petechial hemorrhages or glomerulations) on the bladder lining were thought to mean someone had IC/BPS. Today, most doctors and researchers agree that you can still have IC/BPS even if your bladder looks normal during a cystoscopy (a test where a small camera looks inside the bladder).

Some people who *don't* have IC/BPS also have these small bleeding spots, which is why they're no longer used to confirm the diagnosis. Only about 1 in 10 people with IC/BPS have something called a Hunner lesion—an ulcer on the bladder lining.

Definition Spotlight - "Hunner Lesion"

Some people with IC/BPS develop a specific type of sore in the bladder lining called a Hunner lesion. These lesions are found in around 10% of people diagnosed with IC/BPS.

To look for Hunner lesions, doctors use a test called a cystoscopy, which lets them see inside the bladder with a tiny camera. A basic cystoscopy may not be enough to diagnose IC, but it helps rule out other conditions. The standard way to check for a Hunner lesion is by doing a cystoscopy while the bladder is gently stretched and then restretched (this is called hydrodistention).



A Hunner lesion appears as a red, irritated area in the bladder lining, often with tiny blood vessels spreading out from a small central scar. When the bladder is stretched, the area may split and bleed slightly, sometimes looking like a "waterfall" of blood.

If a doctor takes a small tissue sample (a biopsy) from the lesion, it typically shows signs of inflammation and healing, such as immune cells, new tissue formation, and small clumps of protein (called fibrin deposits).

The remainder of this research digest is devoted to recently published articles on IC/BPS. Please reach out to me (laura.santurri@ichelp.org) if you'd like a full text copy of any of these articles.

Transurethral Fulguration of Hunner Lesion Was Effective for Primary Management of Pelvic Pain in Patients With Interstitial Cystitis: A Long-Term Follow-Up Study

This study examined the long-term effectiveness of transurethral fulguration (TUF) of Hunner lesions to treat pelvic pain in patients with IC/BPS. Among 275 patients treated between 2005 and 2019, 240 underwent initial cystoscopic surgery, including TUF.



Of these, 70% managed their pain through conservative or surgical treatment, while 26.7% required a second TUF due to recurrence, with a median recurrence interval of 12 months. Only 7.5% of patients needed cystectomy for severe, persistent pain.

The results showed that TUF effectively reduced pelvic pain in most patients, although some required additional procedures over time. Complications were rare, but bladder capacity decreased slightly with repeated surgeries. The study concluded that TUF is a safe and effective treatment for IC/BPS with Hunner lesions, though long-term follow-up is essential due to the chronic nature of the condition. This study had limitations, including its retrospective design, single-center data, and the lack of standardized pain measurement tools.

Reference:

Jeong HJ, Kang YJ, Choo MS, Jeong SJ, Oh S-J. Transurethral fulguration of Hunner lesion was effective for primary management of pelvic pain in patients with interstitial cystitis: a long-term follow-up study. *Neurourol Urodyn*. 2025;44(5):1047-1053. doi:10.1002/nau.70051. <https://onlinelibrary.wiley.com/doi/full/10.1002/nau.70051>

Short and Long-term Clinical Results of a Minimally Invasive Syringe Adapter for Catheter Free Instillation of Intravesical Treatments



This study evaluated the effectiveness and safety of a syringe adapter (Ialuadapter®) for catheter-free intravesical therapy in patients with IC/BPS, recurrent urinary tract infections (rUTIs), and overactive bladder (OAB).

Among 61 mostly female patients (average age 55.4), 75% successfully used the device, with 69% succeeding within two attempts. Patients reported less pain (41%), fewer urinary tract infections (10% during follow-up), and greater ease of use (23%) compared to traditional catheters. Long-term adherence after three years was 40%.

The device showed benefits, such as reduced discomfort and infection risk, especially for patients with pelvic pain. However, some challenges included leakage during use, often due to anatomical issues or pelvic floor overactivity. Limitations included the retrospective design, single-center data, and lack of direct comparison with catheterization. Overall, the study concluded that the syringe adapter is a safe and effective alternative to conventional catheters, improving patient comfort and adherence to treatment.

Reference:

Pothoven R, Derks JAM, Arendsen E, Janssen DAW. Short and long-term clinical results of a minimally invasive syringe adapter for catheter-free instillation of intravesical treatments. *Continence*. 2025;13:101723. doi:10.1016/j.cont.2024.101723. <https://www.sciencedirect.com/science/article/pii/S2772973724009986>

Safety and Efficacy of Intravesical Instillation of Botulinum Toxin-A in the Treatment of Interstitial Cystitis/Bladder Pain Syndrome and Overactive Bladder: A Systematic Review and Meta-Analysis



This systematic review and meta-analysis examined the safety and effectiveness of intravesical botulinum toxin-A (BTX-A) instillation for treating overactive bladder (OAB) and IC/BPS. The analysis included 11 trials from 5 studies with 500 patients.

While no statistically significant differences were found between BTX-A and placebo, BTX-A showed potential benefits, such as reducing urgency urinary incontinence (UUI) and increasing void volume (VV), particularly at lower doses (≤ 200 units) and at shorter follow-up times (4 weeks). Safety results showed fewer urinary tract infections (UTIs) and lower post-void residual (PVR) compared to placebo.

Challenges remain due to BTX-A's difficulty penetrating the bladder lining, leading to the use of carriers like liposomes and hydrogels. While some studies showed symptom improvements, results were inconsistent, especially with hydrogel-assisted BTX-A. The study calls for further research to confirm the effectiveness of BTX-A and to improve delivery methods, as current evidence shows promise but lacks consistent outcomes.

Reference:

Zhou Y, He Z, Xiang T, Cao X, Cong H, Liu Q, Sun H, Liao L. Safety and efficacy of intravesical instillation of botulinum toxin-A in the treatment of interstitial cystitis/bladder pain syndrome and overactive bladder: a systematic review and meta-analysis. *Front Pharmacol*. 2025;16:1586845. doi:10.3389/fphar.2025.1586845. <https://www.frontiersin.org/journals/pharmacology/articles/10.3389/fphar.2025.1586845/full>

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.

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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