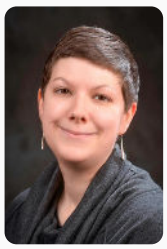
ICA Research Digest

Translating Science, Empowering Patients

April 2025 No. 2

A Note from Laura: The Role of Advocacy in Research



Last week, members of the ICA staff and board were on Capitol Hill to advocate for federal resources for IC/BPS research, education, and awareness. Specifically, we advocated for increased funding for the Centers for Disease Control and Prevention IC Education & Awareness Program, the continued inclusion of IC as an eligible condition for the Department of Defense's Peer-Reviewed Medical Research Program, and, in general, robust funding for the National Institutes of Health. Being on the Hill was a good reminder for me of how important it is to ensure that patient voices are heard. Without this advocacy, we cannot ensure that these vital sources of research funding are established, maintained, and, hopefully, enhanced. I am grateful to be a part of the ICA, the only nonprofit organization in the U.S. that engages in this type of national advocacy on behalf of the IC/BPS community.

As always, I welcome feedback, questions, and ideas for 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.

Quick Tip!

Anything that seems too good to be true...is often too good to be true. Be careful with messages that make big claims, like a "proven cure" or a treatment that works unusually well. In science, claims like these are often improbable and require an entire body of literature to support them (i.e., NOT just one study). People making these claims generally do not have the right evidence to support them (and you should be especially skeptical if someone is trying to sell you something!).

In this edition:

What is evidence?

Definition Spotlight

In my Quick Tip above, I mentioned that big claims (like a "proven cure") often don't have the right or enough evidence to support them. So, what is evidence? In the context of the research literature, evidence is literally facts or data produced or resulting from research studies. Not all evidence is equal, however, as some research studies produce results that are more applicable than others. If you're interested in learning more about the different levels of evidence and how to critically appraise a research study's results, we encourage you to view the ICA's webinar, Using Research to Make Informed Health Decisions.

Patient Question

What are your thoughts on home UTI test strips and a trusted outcome?

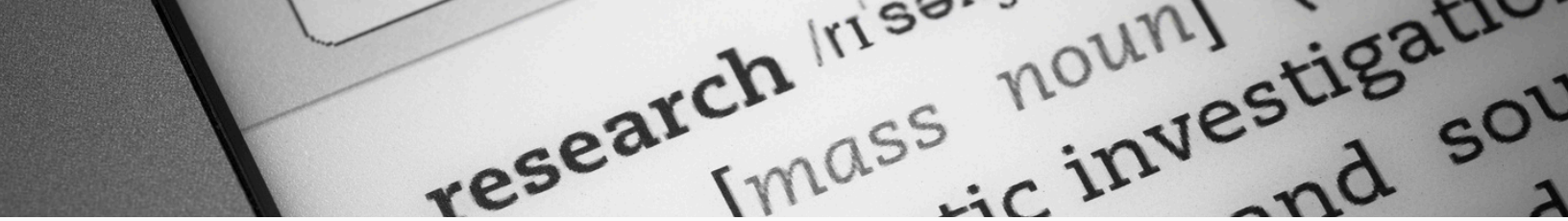
When living with IC/BPS, there may be times when it's hard to distinguish between an IC/BPS flare and a urinary tract infection (UTI). While at-home UTI tests can be helpful, you have a higher likelihood of getting a false negative (i.e., missing a positive test result) vs. when you get a test from a healthcare provider. In addition, sometimes, you need to have a urine culture completed in order to assess which medication will be effective in treating any identified infection. It can be helpful to establish a trusted relationship with a healthcare provider who understands your situation and is willing to accommodate you coming in for a urinalysis if your symptoms flare and you want to confirm whether it's your IC/BPS or an actual infection.

Recent Study Highlight: Assessment of the role of pelvic floor physical therapy in male patients with pelvic and urogenital pain following urological assessment

This study examined outcomes for male patients with chronic urogenital and pelvic pain referred to pelvic floor physical therapy (PFPT) from a urology clinic. A review of 107 patients (2019–2024) assessed pain levels and treatment results. At baseline, median pain scores were 4/10, with the highest and lowest levels at 8/10 and 2/10. Pain was located in the genitals (50%), pelvis/abdomen (24%), or both (26%), with 51% reporting bladder issues and 42% reporting bowel issues. Among 38 patients who attended follow-up therapy, 68% reported pain improvement, 29% had a >50% reduction in pain, and 18% achieved complete pain resolution. The findings suggest PFPT may help reduce pain for this difficult-to-treat condition, highlighting the need for further research.

Reference

Schrup, S., Dumbrava, M., Ziegelmann, M., & Adams, K. (1 May 2025). Assessment of the role of pelvic floor physical therapy in male patients with pelvic and urogenital pain following urological assessment. *Journal of Urology*, https://doi.org/10.1097/01.JU.0001109900.23127.a9.37.



Additional Recent Research Studies of Note:

A standardized protocol for modified platelet-rich plasma collection for the treatment of interstitial cystitis/bladder pain syndrome

This study evaluates a new, standardized protocol for collecting and using platelet-rich plasma (PRP) to treat interstitial cystitis/bladder pain syndrome (IC/BPS). PRP, rich in growth factors, promotes tissue repair and reduces inflammation, but conventional preparation methods are inefficient and risky. This study used a modified protocol with a COBE Spectra blood cell separator, which reduces contamination, preserves other blood components, and optimizes platelet concentration.

Seventeen patients with non-Hunner's IC/BPS, previously unresponsive to other treatments, were included. Each patient was scheduled for six PRP injections, with PRP collected in a sterile, closed system and stored for future use. PRP was injected into multiple bladder sites under anesthesia. After treatment, 70.59% of patients reported symptom improvement, with significant reductions in pain scores. One patient experienced gross hematuria, which resolved quickly, and no other adverse events occurred. Deep vein catheterization was needed for 11 patients due to challenges with superficial veins.

The study concludes that the new PRP protocol is relatively safe and shows promise in efficacy and reducing patient discomfort compared to traditional methods. However, it should be noted that broad conclusions should not be made based on this pilot study; additional research with more patients and more rigorous study designs is needed.

Reference

Zheng, Q., Zhang, P., Guo, W., Zhang, J., Zhang, F., Ma, C., Yang, Y., Cui, L., Wu, Y., & Zhang, L. (2025). A standardized protocol for modified platelet-rich plasma collection for the treatment of interstitial cystitis/bladder pain syndrome. *Bladder, 12*(1), e21200034. https://web-api.polscientific.com/uploads/file/asp/20250314151652699260830.pdf

Use of clinical characteristics, cystoscopic findings, and urine biomarkers in predicting satisfactory treatment outcome in women with interstitial cystitis/bladder pain syndrome

This study looked at ways to predict treatment success for IC/BPS, focusing on non-Hunner IC (NHIC) and Hunner IC (HIC). Researchers analyzed 315 patients who underwent bladder therapies like hyaluronic acid installations, botulinum toxin-A injections, platelet-rich plasma injections, and low-energy shock wave therapy. Results showed that NHIC patients with larger bladder capacity, better bladder sensation, and lower levels of urinary inflammation markers had better outcomes. Patients with less bladder inflammation responded best to treatments. HIC patients, who had more severe symptoms and higher inflammation, were less likely to improve. This study highlights the importance of using bladder capacity and inflammation markers to guide treatment, though more research is needed to improve predictions and treatment strategies.

Reference

Liu, M.-C., Jhang, J.-F., Jiang, Y.-H., & Kuo, H.-C. (2025). Use of clinical characteristics, cystoscopic findings, and urine biomarkers in predicting satisfactory treatment outcome in women with interstitial cystitis/bladder pain syndrome. Urological Science. https://doi.org/10.1097/us9.0000000000000065

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