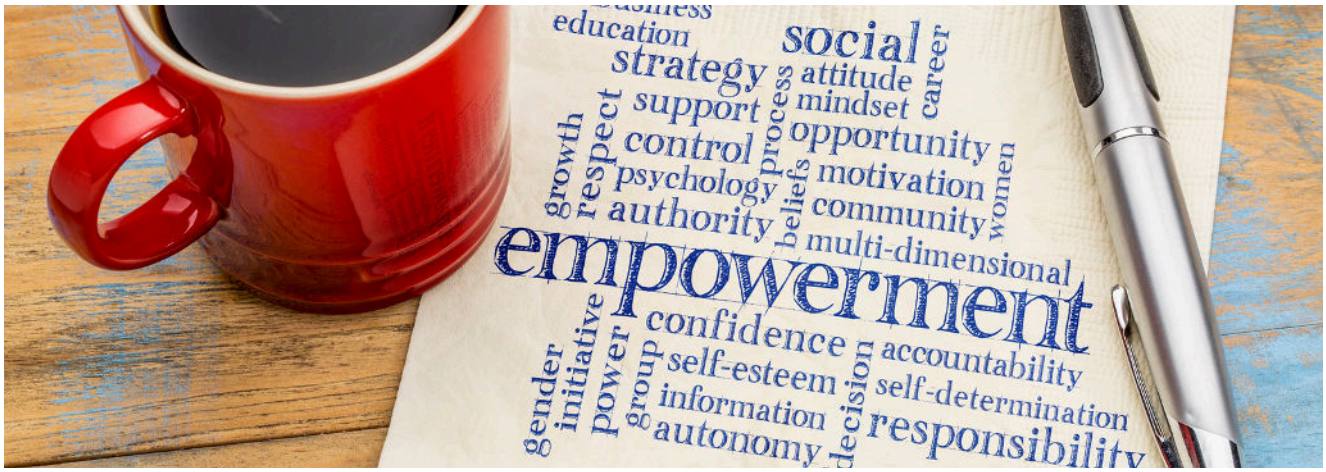
ISSUE #4

ICA Research Digest: Translating Science, Empowering Patients

June 2025



A Note from Laura: A Call to Action

As is always the case, there are no shortage of issues around which advocacy efforts are needed. Today, I'd like to draw your attention to a few that are specific to research funding for interstitial cystitis/bladder pain syndrome (IC/BPS). As you may be aware, the ICA team is regularly engaged in advocating for robust funding that supports desperately-needed research around understanding the cause of IC/BPS and how to diagnose and treat it effectively. This research funding comes from the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Department of Defense Peer-Reviewed Medical Research Program (DoD PRMRP).

As Congress makes progress on a budget for fiscal year 2026, the ICA needs your engagement with your representatives to ensure that this important research funding remains. To that end, we'd like to ask you to consider reaching out to your congressional representatives to share your stories and make the following asks:

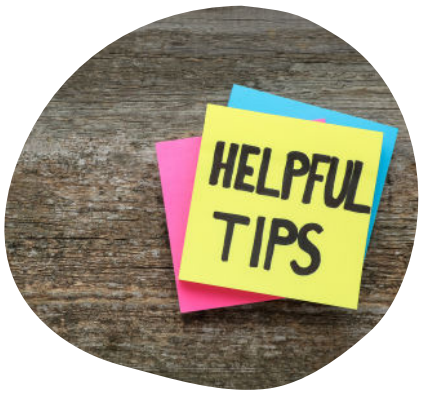
- Provide the NIH with at least $51.3 billion, a $4.1 billion increase over fiscal year 2025 (FY25).
- Provide the CDC with $11.6 billion, a $2.4 billion increase over FY25. Specifically, fund the CDC IC Education & Awareness Program at $1.5 million.
- Include IC as an eligible condition for study in the DoD PRMRP. Restore full funding to the DoD PRMRP.

Advocacy can feel overwhelming, but when we each do our part, it's amazing what we can accomplish. Should you need help identifying your congressional representatives or would like templates/language to use, please reach out to Kaitlyn Dries at dries@hmcw.org.

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.

Laura Santurri, Ph.D., MPH

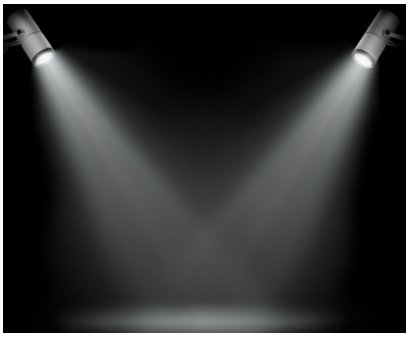
In this newsletter you can expect:



Quick Tip!

Be cautious of health information that uses fear to push a message or product. Fear-mongering often exaggerates risks or promotes unproven solutions—always seek evidence-based information from reputable sources and consult your healthcare provider to separate fact from hype.

Definition Spotlight - " Biomarker"



According to the FDA-NIH Biomarker Working Group, a biomarker is defined as, "*A defined characteristic that is measured as an indicator of normal biological processes, pathogenic processes or responses to an exposure or intervention.*"

While we often talk about biomarkers in the context of diagnosis (e.g., something unique in the urine of IC/BPS patients that could be detected and used as a likely indicator of the condition), there are many different types of biomarkers, including those that are used in monitoring a condition, predicting effects from medications, or determining disease progression. If you'd like to learn more, I recommend reading Biomarker Definitions and Their Applications.

References

Califf RM. Biomarker definitions and their applications. Exp Biol Med (Maywood). 2018;243(3):213-221. https://pmc.ncbi.nlm.nih.gov/articles/PMC5813875/#bibr3-1535370217750088

FDA-NIH Biomarker Working Group. BEST (Biomarkers, EndpointS, and other Tools) Resource. Silver Spring (MD): Food and Drug Administration (US); Bethesda (MD): National Institutes of Health (US), www.ncbi.nlm.nih.gov/books/NBK326791/ (2016, accessed 22 September 2017)

Recent Article Highlight: The Role of Netrin-1 in the Diagnosis and Prognosis of Bladder Pain Syndrome /Interstitial Cystitis: A Comparative Study

This study, published in the World Journal of Urology, explores the role of Netrin-1, a protein found in the human body, as a biomarker for diagnosing and monitoring IC/BPS. Researchers compared 40 IC/BPS patients with 20 overactive bladder (OAB) patients and 20 healthy individuals. They found that Netrin-1 levels were significantly higher in IC/BPS patients than in the OAB and healthy groups. A diagnostic analysis showed Netrin-1 had high accuracy. Levels of Netrin-1 also correlated with symptom severity, including urination frequency and pain scores. After two months of treatment, which included bladder hydrodistension and weekly instillations, Netrin-1 levels dropped significantly, aligning with symptom improvement. The study concludes that Netrin-1 *could* be a valuable tool for diagnosing and tracking IC/BPS, though further research is needed to understand its role in the disease.

Reference

Ang XJ, Xia KG, Qian YM, et al. The role of netrin-1 in the diagnosis and prognosis of bladder pain syndrome/interstitial cystitis: a comparative study. World J Urol. 2025;43(3):351. https://link.springer.com/article/10.1007/s00345-025-05659-5

Patient Question - What is the FDA Adverse Event Reporting (FAERS) Public Dashboard?

The FAERS is an online tool intended by the Food & Drug Administration (FDA) to provide transparent access to information. Included in it are adverse events that have been reported in humans as a result of taking a medication or biologic product. While this can be an informative tool for the public, its contents should never be used to scare anyone.

This is because the information in this dashboard has limitations. For example, there may be duplicative reports (i.e., someone submitted the same report multiple times), the information in the system has not been verified by anyone (e.g., it does not mean a doctor has confirmed that it happened), and it is not possible to determine whether the adverse event was caused by the medication or biologic (as there are many factors that may cause something to happen). It's not to say that this isn't a useful tool in making healthcare decisions, but it should be used with caution (and in conjunction with other tools).

References

Food and Drug Administration. FDA Adverse Event Reporting System (FAERS) Public Dashboard. Published online. Accessed June 11, 2025. https://www.fda.gov/drugs/questions-and-answers-fdas-adverse-event-reporting-system-faers/fda-adverse-event-reporting-system-faers-public-dashboard

Additional Studies of Note

Here, I'd like to highlight a couple of articles published in the last year that discuss how we think and talk about IC/BPS. While each of these articles may seem at first to advocate for something very different, both are proposing a new umbrella term and recognizing subtypes of the overall condition.

Joint Terminology Report: Terminology Standardization for Female Bladder Pain Syndrome

The Joint Terminology Report: Terminology Standardization for Female Bladder Pain Syndrome (FBPS), created by the International Urogynecological Association (IUGA) and the American Urogynecologic Society (AUGS), aims to clarify and standardize terminology for FBPS, a chronic condition affecting women. FBPS is defined as at least three months of bladder pain or discomfort, often linked to bladder filling, without other known causes. The report proposes replacing "older" terms like interstitial cystitis (IC) and bladder pain syndrome (BPS) to reduce confusion and improve diagnosis. Symptoms may include bladder pain, pressure, urgency, or frequency, and some cases involve Hunner lesions, a distinct inflammatory subtype visible on cystoscopy.

The report emphasizes the need to exclude other conditions, such as urinary tract infections, overactive bladder, or endometriosis, through patient history, physical examination, and tests. Diagnostic tools such as voiding diaries and validated symptom questionnaires are recommended. Treatments range from conservative options like pelvic floor therapy and dietary changes to medications, bladder instillations, and advanced interventions like botulinum toxin injections or surgery. The report emphasizes the importance of conducting further research into biomarkers, phenotypes, and targeted therapies to enhance care for FBPS patients, while providing a standardized framework for clinicians and researchers.

Reference

Khullar V, Jain A, Chrysostomou A, et al. Joint Terminology Report: Terminology Standardization for Female Bladder Pain Syndrome. Int Urogynecol J. 2025; https://link.springer.com/article/10.1007/s00192-024-05923-z

Definition Change and Update of Clinical Guidelines for Interstitial Cystitis and Bladder Pain Syndrome

The updated guidelines for interstitial cystitis (IC) and bladder pain syndrome (BPS) distinguish them as separate conditions under the umbrella of hypersensitive bladder (HSB) symptoms, which include pelvic pain, pressure, urgency, and frequency. IC is defined as a bladder disease characterized by Hunner lesions and significant inflammation, whereas BPS exhibits similar symptoms but lacks Hunner lesions and notable inflammation. Diagnosis relies on cystoscopy to identify Hunner lesions, along with symptom assessment, physical exams, and tests to rule out other conditions. Histopathology confirms IC through chronic inflammation and epithelial damage, while BPS tissues usually appear normal.

Treatment approaches differ: IC focuses on anti-inflammatory therapies, intravesical instillations, and lesion fulguration, while BPS emphasizes pain management, physiotherapy, and stress reduction. Advanced options, such as botulinum toxin injections, stem cell therapy, or surgery, are available for severe cases. The guidelines aim to improve diagnosis and care by tailoring treatments to the unique characteristics of each condition and encourage further research into biomarkers and targeted therapies. An algorithm is provided to guide individualized patient management.

Reference

Homma Y, Akiyama Y, Kim JH, et al. Definition change and update of clinical guidelines for interstitial cystitis and bladder pain syndrome. LUTS: Lower Urinary Tract Symptoms. 2024;16:e12532. https://pubmed.ncbi.nlm.nih.gov/39267358/

Thank you for reading!

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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.