



# ICA Research Digest

*Translating Science, Empowering Patients*

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No. 1



## Greetings from the inaugural ICA Research Digest!

I'm Dr. Laura Santurri, the Chief Operations Officer at the ICA, and I'm thrilled to introduce our very first Research Digest. This newsletter aims to translate timely and relevant scientific literature to equip our community with the knowledge needed to make the best possible decisions regarding their care.

As a public health professional, I am passionate about ensuring that the research literature is accessible to everyone. In addition, I also believe in the importance of ensuring that research results are not overgeneralized or used in ways that may take advantage of others (e.g., turned into oversimplified headlines that become "clickbait"). Research is complex, but that doesn't mean it can't be made understandable.

Each of the Research Digests will have summaries of recent studies that apply to those living with interstitial cystitis/bladder pain syndrome (IC/BPS), which includes research on common co-morbid conditions (i.e., other conditions that are common in IC/BPS patients). As always, I welcome feedback, questions, and ideas for studies you might like to see summarized here; you are welcome to reach out to me at [laura.santurri@ichelp.org](mailto:laura.santurri@ichelp.org).

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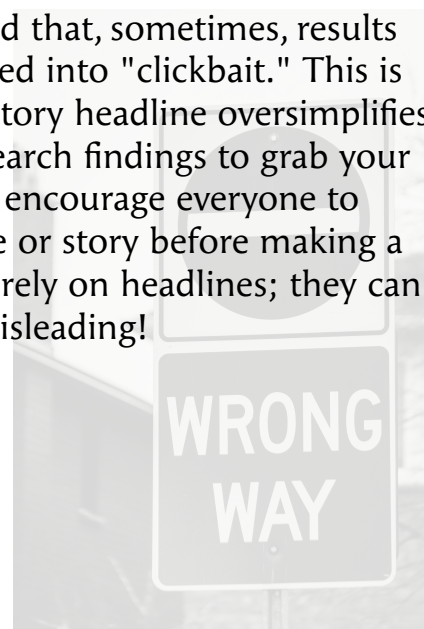
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## Quick Tip!

Above, I mentioned that, sometimes, results of studies are turned into "clickbait." This is when a media or story headline oversimplifies or exaggerates research findings to grab your attention. I always encourage everyone to read the full article or story before making a conclusion. Don't rely on headlines; they can be intentionally misleading!





## Definition Spotlight

### What are chronic overlapping pain conditions?



The National Institutes of Health (NIH), a government agency in the U.S. that has primary responsibility over our nation's medical research, recognizes IC/BPS as part of a group of conditions called "chronic overlapping pain conditions" or COPCs. COPCs are a group of conditions that commonly occur together and also include endometriosis, vulvodynia, migraine headache, and chronic lower back pain. These conditions tend to be more common in women than men.

#### References

Chronic Pain Research Alliance. (2023). *About COPCs*. [https://chronicpainresearch.org/about\\_copcs/](https://chronicpainresearch.org/about_copcs/)

Maixner, W., Fillingim, R. B., Williams, D. A., Smith, S. B., & Slade, G. D. (2016). Overlapping chronic pain conditions: Implications for diagnosis and classification. *The Journal of Pain*, 17(9 Suppl), T93–T107. <https://doi.org/10.1016/j.jpain.2016.06.002>

## Patient Question



### Should I stop taking my Elmiron?

Elmiron, or pentosan polysulfate sodium, is currently the only oral medication approved by the Food and Drug Administration to treat IC/BPS. However, recent studies, including the one noted below, have produced emerging evidence of potential side effects, including maculopathy and gastrointestinal symptoms.

However, all medications come with potential risks and side effects. As with all treatment strategies, the ICA recommends consulting with your healthcare team (don't forget your pharmacist!) to evaluate the risks and benefits of taking Elmiron as part of your IC/BPS care.

#### References

Santina, A., Feo, A., Bousquet, E., et al. (2024). Pentosan polysulfate sodium maculopathy: Final analysis of a prospective cohort, updated review, and association with inflammatory bowel disease. *Survey of Ophthalmology*. Advance online publication. <https://doi.org/10.1016/j.survophthal.2024.12.002>

## An Update on Pentosan Polysulfate Sodium (aka Elmiron) & Maculopathy

A 2025 meta-analysis reviewed six large-scale cohort studies to explore the link between pentosan polysulfate sodium (PPS), a drug used to treat IC/BPS, and the risk of maculopathy, an eye disease. The analysis, which included over 411,000 patients, found that PPS significantly increases the risk of maculopathy, especially with long-term use. Patients treated with PPS for both less than and more than five years showed higher risks compared to those not treated with PPS. While the study faced challenges, such as variability in data and study design, it confirmed earlier findings about PPS-related maculopathy. It highlights the importance of balancing the benefits of PPS with its potential eye-related risks and calls for better screening and larger future studies to further understand this connection.

#### References

Lee, J., Kim, Y. J., Lee, K., Kim, Y. K., Rhee, T. G., Shim, S. R., & Kim, J. H. (2025). Pentosan polysulfate sodium and maculopathy in patients with interstitial cystitis: A systematic review and meta-analysis. *World Journal of Men's Health*. <https://doi.org/10.5534/wjmh.240295>



## Recent Studies on Vulvodynia & IC/BPS

Vulvodynia and IC/BPS commonly occur together and are both known as chronic overlapping pain conditions (COPCs). Below are summaries of two recent studies about these related conditions.

### The association between urological conditions across the life course and provoked vulvodynia

This study examined the link between vulvodynia, vaginismus, and various urological conditions using Swedish National Registry data. Vulvodynia, a chronic pain condition in the vulvar area, is often associated with IC/BPS, but this research found it is also tied to a broader range of urological issues. Comparing 7,101 women with vulvodynia or vaginismus to 15,332 without vulvar pain, the study found women with vulvar pain had a higher risk of conditions like cystitis, urethral disorders, and general urinary symptoms, even after adjusting for factors like age and education. The risk was especially high for women with multiple urological issues. Possible causes include pelvic floor muscle problems and chronic inflammation. The study highlights the need for doctors to consider both vulvar and urological symptoms when treating vulvodynia, as it is linked to a wide range of urinary problems, not just IC/BPS.

#### References

Harlow, B. L., Muhlrads, H., Yan, J., Lu, D., & Bohm-Starke, N. (2025). The association between urological conditions across the life course and provoked vulvodynia. *Journal of Women's Health*. Advance online publication. <https://doi.org/10.1089/jwh.2024.0933>

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### Comorbid bladder pain syndrome and vulvodynia - a cross-sectional analysis of the UNICORN-4 study

This study explored the differences among women with IC/BPS and vulvodynia, focusing on symptoms, mental health, and sexual function. Researchers analyzed 134 patients and 82 healthy controls, identifying three groups: one with moderate symptoms, another with severe bladder and overactive bladder symptoms, and a third with severe vulvodynia, high psychological distress, and mild bladder symptoms. Sexual dysfunction was common in all groups but was worst in the vulvodynia-predominant group, which also showed high emotional distress and sexual aversion. The study found that standard tools for assessing sexual function often miss issues like sexual avoidance or trauma, highlighting the need for better evaluation methods. These results show the importance of customized treatment that addresses physical, emotional, and sexual health challenges in IC/BPS and vulvodynia patients.

#### References

Okui, N. (2025). Comorbid bladder pain syndrome and vulvodynia: A cross-sectional analysis of the UNICORN-4 study. *BMC Women's Health*, 25(72). <https://doi.org/10.1186/s12905-025-03602-9>

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