

IC Awareness Month - September 2020 - [icawareness.org](http://icawareness.org)

## **Saving The Eyesight of Patients With IC/BPS Elmiron® Use Linked To Progressive Eye Disease**

FOR IMMEDIATE RELEASE  
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(Santa Rosa, CA) A tragedy is happening in ophthalmology clinics around the nation as patients learn that they have sustained potentially permanent and progressive eye damage from a medication they have used to treat bladder symptoms.

*“Researchers at the Emory Eye Institute were the first to make the connection between Elmiron® use and retinal damage in 2018”* offered Jill Osborne, National IC Support Group Leader & Founder of the Interstitial Cystitis Network. She continued *“More than a dozen studies have now confirmed the presence of pigmentary maculopathy in patients who have used Elmiron® in clinics across the country. Multiple lawsuits against the manufacturers are under way.”*

The FDA issued an extensive warning for Elmiron® in June of 2020 suggesting that patients report any changes in their vision, including difficulty reading, slow adjustment to low light and blurred vision. Pigmentary changes have been observed in patients who have used the medication for three years or longer, however cases have been seen with a shorter duration of use. Patients are strongly encouraged to have a baseline retinal examination in their first six months of use so that their eyes can be monitored over time. If pigmentary changes in the retina develop, most researchers suggest stopping the medication.

*“Of great concern is the progressive nature of the damage. A new study has found that the retinal damage progressed even after the medication was stopped,”* said Ms. Osborne. *“Despite the FDA warning, some urologists are still telling patients not to worry*

*about their eyesight, including those who have used the medication for many years. We believe that this is a grave mistake. Patients should be educated about the potential risks vs. benefits of this medication.”*

September 1st launches the annual IC Awareness Month campaign. This year, we are asking patients who have used Elmiron® to have their eyes examined. If damage is found, they should have a discussion with their urologist about other possible therapies and, if they continued to have symptoms even while using Elmiron®, to revisit their diagnosis. Since Elmiron® was approved in 1996, we’ve learned that pelvic floor injury or trauma can trigger bladder symptoms (urinary frequency, urgency, pressure and/or pain). Fibroid tumors, endometriosis, pelvic congestion syndrome and tarlov cysts can also mimic the symptoms of IC demonstrating that the bladder can be a victim of another dysfunction in the pelvis. Many of these patients may benefit from other treatment modalities rather than bladder therapy.

Learn more about IC Awareness Month at: [www.icawareness.org](http://www.icawareness.org)

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References:

1. Pearce WA et al. Pigmentary Maculopathy Associated with Chronic Exposure to Pentosan Polysulfate Sodium. Ophthalmology. 2018 May 22.
2. Jain N, et al. Association of macular disease with long-term use of pentosan polysulfate sodium: findings from a US cohort. Br J Ophthalmol. 2019 Nov 6.
3. Shah R, et al. Pentosan Polysulfate Maculopathy: Disease Course after Drug Cessation. ARVO Annual Meeting Abstract | June 2020
4. Osborne J. Elmiron Label in USA Now Includes New Warning About Eye Disease. Interstitial Cystitis Network. June 17, 2020.

For Additional Information:

- Elmiron Eye Disease Information Center - <https://www.pentosaneyedisease.org>
- Downloadable Fact Sheet For Care Providers - <https://www.ic-network.com/wp-content/uploads/2020/08/ElmironFactSheet.pdf>