

IC Awareness Month - September 2013 - icawareness.org

Millions Suffer, Few Understand: It's time to talk about IC/BPS



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September is IC Awareness Month

Diagnostic and treatment guidelines offer hope

(Santa Rosa, CA) This September, patients around the world will unite to share their personal stories and struggles with interstitial cystitis / bladder pain syndrome (IC/BPS). The 2013 theme, “Millions Suffer, Few Understand” encourages patients and providers to talk openly about this common yet often misunderstood pelvic pain condition.

“I see patients every day who have been exposed to a medical system that has often been poorly responsive to their needs. Frequently, the condition is not diagnosed or the clinician feels uncomfortable with available, effective management strategies. Furthermore, there appears to be a general lack of knowledge in the lay community that the condition even exists.” offered Robert Moldwin MD (Smith Institute of Urology, NY). *He continued “My greatest hope is that IC Awareness month will have a positive impact for both clinicians AND patients.”*

Interstitial cystitis can be disabling. Hunner’s ulcers and/or pinpoint hemorrhages are found on the bladder wall, allowing urine to penetrate deeply into the tissue. Inflammation then triggers symptoms of urinary frequency, urgency, pressure and/or pain, disrupting sleep, work and normal daily life. Simple tasks such as driving, sitting and intimacy can be painful.

Researchers are trying to determine why IC/BPS patients often struggle with other conditions such as: pelvic floor dysfunction, irritable bowel syndrome, endometriosis, fibromyalgia, chronic headache and TMJ. An abnormal pain processing or nerve hypersensitivity disorder may be part of the problem.

Jill Osborne MA, President of the IC Network, offered *“During IC Awareness Month, patients are encouraged to be health activists. They can distribute educational materials to physicians and community clinics, design posters, start local or virtual support groups, encourage their political representatives to issue proclamations, share their stories with local media outlets and donate to IC research centers.”*

One key goal is to encourage patients to talk with their doctors if they are continuing to struggle with symptoms. New guidelines were released by the American Urological Association (2011) which provide updated diagnostic and treatment strategies. Patients who are low income and/or lack health insurance are given a variety of behavioral and OTC strategies that may help.

Learn more about IC and the campaign by visiting our website, <http://www.icawareness.org>.

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Additional media materials, backgrounders, expert interview opportunities, and IC fact sheets are also available.

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Founded in 1995, the Interstitial Cystitis Network (<http://www.ic-network.com>) is a woman owned, "social advocacy" health education company dedicated to interstitial cystitis and other pelvic pain disorders. Using the internet, we create innovative solutions to the pressing problems facing patients diagnosed with urologic conditions, medical care providers who care for them and the research community seeking new treatments and cures. For the past 18 years, we have provided critical 24/7 support to patients in need, developed new educational materials, conducted vital research, provided webinars/lectures and created IC awareness campaigns, all at NO COST to the patients who visit our website.