

Your IC Awareness Month Kit

MILLIONS SUFFER, FEW UNDERSTAND

Interstitial Cystitis / Bladder Pain Syndrome

It's time to talk about IC/BPS

Join us and share your story!



SEPTEMBER 2013 IS IC AWARENESS MONTH!

Six Ways You Can Help

September is IC Awareness Month and this year's theme is "Millions Suffer, Few Understand: It's time to talk about IC/BPS" Why? Despite the millions of dollars invested in research and some fabulous new breakthroughs in treatment, we are still shackled by the perception that IC isn't that serious and bladder diseases are inconsequential. Every week, we receive stories from patients who are told that IC is "all in their heads." Yes, hundreds of physicians are now treating patients compassionately but there are thousands more who simply don't have a clue. Even Dr. Drew Pinski minimized IC as a "grab bag diagnosis" on his national TV show last year.

You are the eyes and ears of your community and, more importantly, what you do today will influence how IC patients the future are treated. Do you want any more patients to be told that IC is all in their heads? Do you want more women to undergo completely inappropriate hysterect-

omies only to discover that their pain is coming from their bladders?? Do you want children with IC to be punished by their teachers for asking to use the restroom?? If not, then let's do something about it TOGETHER!

1. Spread the Word with Social Networking

- Share our campaign website (<http://www.icawareness.org>) with all of your friends and colleagues on Facebook, Twitter, Pinterest, Instagram and LinkedIn.
- Add the IC Awareness Month timeline and profile pictures to your Facebook page.
- Write a few sentences or even a story about the campaign for your blog or "what's on your mind statement"
- Every day in September, add our IC Daily Fact to your Facebook page or blog. You can find a new fact for each day on the campaign website.

2. Ask for Proclamations

- Encourage your City Council, County Board of Supervisors, State

Assembly or Senators and US Senate or Congressmen to pass a proclamation to honor IC Awareness Month. To make this easy for you, please photocopy the letter we've included at the end of this article.

- Send your US Senator or Representative a personal letter asking them to support increased funding for urologic and pain research through the National Institutes of Health.

3. Send Out Our Press Release

- Send our press release to your local and regional paper, asking if they would do a story about IC and IC Awareness Month. The press love personal, local stories. Share a few paragraphs about your life with IC in your community, as well as any obstacles you have faced with finding doctors, getting pain care and/or the public perception of bladder diseases.
- Donate some IC books to your local library. You can purchase any books in the ICN Shop and designate a library that you would like us to send it to.

- Ask about health conferences in your community and see if you can provide a booth on IC and pelvic pain.

4. Educate Your Doctors

- Bring IC Awareness materials and a poster to each of your physicians and nursing staff to place in their offices and waiting rooms.

- Share the latest IC articles with your physicians. The new handouts on the AUA Guidelines would be an excellent resource to share.

- If the doctors in your community are not knowledgeable about IC, ask your local hospital or medical association if they can include “*interstitial cystitis / bladder pain syndrome*” as a training topic in their resident “grand rounds” or “cme programs.” Contact the hospital education department and ask who coordinates educational programs! If they are interested and would like to have a speaker, the IC Network will help. Please send us an email at: info@icawareness.org

5. Make a Donation

- Is there a nearby support group that could use an extra \$25 to help underwrite their costs? Often support

group leaders pay for support group activities out of their own pockets. They may not ask, but they can undoubtedly use some help! Give them a call and ask if there is anything that you can do to help in their efforts. It may be funding, it may be helping to find a meeting location or perhaps assembling newsletters. The more hands available, the better!



- We think money raised in YOUR area should benefit the patients in YOUR area. From support groups to research centers, low income organizations to health advocacy programs, these are the groups that make the biggest difference. Please carefully consider the needs of your region and then support those organizations that are making a difference in your daily lives, whether it be food banks, senior centers, health organizations and more! We commend IC patients Delia & Victoria Hernandez for setting up an Interstitial Cystitis Endowed Fund at KU Med Hospital during the 2010 IC Awareness campaign which benefits patients in the Kansas City area.

- We encourage you to donate directly to IC research centers whenever possible! You can find a list on our website.

6. Mobilize Your Support Group

- If there is no support group in your area, consider starting a new group to provide support and build friendships among patients who often feel very isolated and alone. Yes, it takes time and effort but it can change lives for the better.

- If you're in a support group, ask them to participate in IC Awareness

Month. They should have a meeting in September and, if possible, send a press release out to the local paper promoting your group and the meeting date.

- As a group, reach out to an IC patient who is housebound. Call them and ask if they need any help. Bring support to their home, along with some IC friendly foods and companionship.

- Spread the word about drug assistance programs to friends who are having trouble paying for medications. Learn more at: <http://www.ic-network.com/drugassistance/>

- If you have children with IC in your community, write a letter to your local Board of Education asking for compassionate restroom use policies.

7. Keep us Informed

Please share your activities with us! We'd love to hear what you're doing. Send press clippings or links to: info@icawareness.org

Design a Poster!

We're giving \$10 ICN Gift Certificates to everyone who designs and donates a poster for use for IC Awareness Month with your own interpretation of the theme "Millions Suffer, Few Understand." All posters will be added to our website and the winner will receive a \$75 gift certificate from the ICN Shop! The winning design may be featured on IC Awareness Month T-shirts and clothing, the proceeds of which will be dedicated to IC research.

Requirements – It must include three things:

#1 - It must say IC Awareness Month and include the URL: icawareness.org

#2 - It must fit on an 8.5 by 11" piece of paper

Email entries by September 15, 2013 to info@icawareness.org

Facebook Timeline Image Contest

We would love to offer a selection of Timeline images that patients can pick from for the month of September! Like the poster contest on this page, please create an image that shares your story and/or life with IC. All languages welcome and needed so that we can expand our international outreach effort.

Requirements:

#1 - It must say IC Awareness Month and include the URL: icawareness.org

#2 - It should be 850 px wide by 315 px high

#3 - It should be a .jpg, .gif or .png file

#4 - Please share it on the Interstitial Cystitis Network & IC Awareness Month Facebook pages

Email the file to: info@icawareness.org

IC Awareness Month - September 2013 - icawareness.org

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



Dear

My life and/or the life of a family member or friend has been severely disrupted by interstitial cystitis, a devastating pelvic pain condition. I hope that you will consider issuing a proclamation on behalf of IC Awareness Month to help educate our community about the needs of the 12 million men and women (in the USA) struggling with this often agonizing condition.

IC Awareness Month Proclamation

Whereas, 3 to 8 million women in the USA and 1 to 4 million men of all ages suffer the devastating effects of this chronic pelvic pain disorder; and

Whereas, many physicians are unaware of the symptoms and effects of interstitial cystitis/bladder pain syndrome, causing patients to suffer for years before they obtain a correct diagnosis and medical treatment; and

Whereas, medical research efforts into interstitial cystitis/bladder pain syndrome have yet to discover the cause nor cure for this disabling medical condition and federal research money has been severely reduced; and

Whereas, there is a critical need to educate and support individuals and families affected by interstitial cystitis;

Now, Therefore, Be It Resolved that September 2013 is hereby designed as Interstitial Cystitis Awareness Month during which patients, support groups and organizations call for increases in public and private sector funding for medical research, targeted educational programs for health professionals, patients and the public and recognition of urological disorders as a significant public health issue.

Proclaimed This Day, 1 September 2013

I thank you for your consideration.

Sincerely,

IC Awareness Month is a project of Interstitial Cystitis Network, a social advocacy and health education company founded by IC patients for IC patients. Learn more about IC by visiting: <http://www.ic-network.com>

IC Network, PO Box 2159, Healdsburg, CA 95448 - 707.538.9442 (v) 707.538.9444 (f) icnetwork@mac.com (e)

IC Awareness Month - September 2013 - icawareness.org

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



FOR IMMEDIATE RELEASE
Sept 1, 2013

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.

PRESS RELEASE (continued)

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.

Contact: Jill Osborne, President
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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.

IC Awareness Month - September 2013 - icawareness.org

“Millions Suffer, Few Understand”

It's time to talk about IC/BPS

Fact Sheet

What is it: Interstitial cystitis is a chronic pelvic pain condition with an unknown etiology. Patients typically experience *"an unpleasant sensation (pain, pressure, discomfort) perceived to be related to the urinary bladder"* that lasts longer than six weeks in the absence of infection or other identifiable causes. Some patients have large, bleeding ulcers in their bladders, known as "Hunner's Ulcers." Others may have more modest bladder wall irritation and inflammation. Some have no bladder wall damage yet still have severe bladder symptoms. IC patients often struggle with coexisting medical conditions such as pelvic floor dysfunction, vulvodynia, prostatodynia, irritable bowel syndrome, anxiety disorder and others.

Names: This syndrome is called by a variety of names, including:

- interstitial cystitis (IC) - *commonly used throughout the world*
- bladder pain syndrome (BPS) - *primarily in Europe*
- hypersensitive bladder syndrome (HBS) - *primarily in Japan*
- urologic chronic pelvic pain syndrome (UCPPS) - *in research studies*
- chronic pelvic pain syndrome (CPPS)
- complex abdominal and pelvic pain syndrome (CAPPS)



Symptoms: The symptoms can vary greatly between individuals and even for the same person throughout the month, including:

- urinary frequency - as often as every 10 minutes or a total of 60 times a day
- urgency - sudden, unpredictable moments when they desperately need to empty their bladder
- pressure - an uncomfortable feeling of heaviness or fullness in the bladder
- pelvic or bladder pain - mild tenderness to intense, agonizing pain. Pain typically worsens as the bladder fills with urine and is then relieved after urination. Pain may also radiate to the lower back, upper legs, vulva and penis.

Epidemiology: In 2009, the RAND Interstitial Cystitis Epidemiology (RICE) study provided astonishing new data on the prevalence of IC in the USA. This National Institutes of Health funded study estimated that 3.4 to 7.8 million women in the USA have symptoms of interstitial cystitis, much higher than was previously thought. Approximately 1 to 4 million men struggle with symptoms though the true rate has yet to be determined because men are often diagnosed chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS) instead. IC can occur in children, teens, young adults and the elderly.

Causes: The cause of IC remains a mystery though compelling research suggests that IC may be part of a regional chronic pelvic pain disorder, involving neurosensitization and pelvic floor tension. IC patients also have a protein in their urine, the antiproliferative factor (APF), which appears to block the normal growth of the cells that line the inside wall of the bladder. Thus, it may take longer for an IC patient to heal when their bladder is injured or irritated. Researchers are also exploring the role of heredity in IC. In some cases, IC has affected a mother and a daughter or two sisters, but it does not commonly run in families.

FACT SHEET (continued)

Diagnosis: It's not unusual for patients to have seen five or more physicians as they seek medical treatment. A diagnosis of IC/BPS is based on clinical symptoms, including the presence of pain (usually occurring as the bladder fills with urine), frequency and/or urgency. The diagnosis of IC can be made confusing because of the wide variety of names that are often used to describe the symptoms above. It's not unusual for IC patients to have been misdiagnosed with *cystitis*, *bacterial cystitis*, *overactive bladder*, *urethral syndrome*, *trigonitis*, *urethritis* or a "sensitive" bladder before they receive a correct diagnosis. Men are often mislabelled as *prostatitis* patients.

Treatments: In 2011, the [American Urological Association](#) released guidelines for the diagnosis and treatment of IC, including a six step treatment protocol. Patients generally begin with the least invasive therapies and, if needed, progress through the various steps to more invasive therapy.

- Step 1 - adequate water intake, diet modification, heat or cold packs, OTC supplements, meditation and guided imagery, pelvic floor relaxation, bladder training, the treatment of other related conditions and the reduction of stress.
- Step 2 - Physical therapy for pelvic floor dysfunction, pain management, various oral medications (Amitryptiline, cimetidine, hydroxyzine, pentosan polysulfate), bladder instillations (lidocaine, heparin, dms0).
- Step 3 - low pressure, short duration hydrodistention, hunner's ulcer treatment with fulguration, electrocautery, triamcinolone
- Step 4 - neuromodulation
- Step 5 - cyclosporine A, botulinum toxin A
- Step 6 - surgical interventions

The [UPOINT System for Clinical Phenotyping for Chronic Pelvic Pain](#) can also help physicians create a customized treatment plan, particularly for complex and difficult to treat patients who have multiple medical conditions.


Diet: Diet modification is usually the first suggestion offered by physicians and is critical for patients struggling with bladder irritation and inflammation. Foods high in caffeine, acid and alcohol irritate the wounds in the bladder triggering IC flares, pain and discomfort. The foods most patients must avoid include decaf and regular coffees, black teas, green teas, sodas, all cranberry products, most fruit juices, energy drinks, tomato based foods, chocolate and some vitamins (Vitamin C and B6). On the otherhand, some foods can be soothing to an irritated bladder. A comprehensive diet list can be found at: <http://www.ic-network.com/diet/>

Flares: Interstitial cystitis patients often struggle with a sudden and dramatic worsening of their bladder symptoms, known as an IC flare. Lasting from hours to weeks, flares can be unpredictable, disruptive, frustrating and difficult to manage for both newly diagnosed and veteran IC patients. The most frequent types of flares occur when the bladder wall is irritated, when the pelvic floor muscles become tight or spasm and, for women, when hormone levels change.

September 2013

Millions Suffer, Few Understand!

icawareness.org



It's time to
talk about
IC/BPS!

Patients around
the world
ask for respect,
compassionate care &
a cure!

**Interstitial Cystitis
Bladder Pain Syndrome
Awareness Month**

Flare
Bladder Pain Syndrome

Frequency
Urgency
Pressure

PAIN

Nocturia
Dyspareunia

Pelvic Floor
Dysfunction

IBS

Vulvodynia
Prostatitis
Endometriosis