

# Interstitial Cystitis

## Painful Bladder Syndrome, Bladder Pain Syndrome, Hypersensitive Bladder Syndrome

Interstitial cystitis (IC) is a debilitating, chronic bladder disorder of unknown cause, with symptoms of pain, pressure or discomfort related to the bladder and usually associated with a frequent and urgent need to urinate day and night. While the symptoms may resemble bacterial cystitis, there is no infection to be seen in the urine and no other identifiable disorder that could account for the symptoms. The characteristic symptoms are:

### **Pain (or discomfort), urgency and frequency.**

- Pain, pressure or discomfort that may increase as the bladder fills; urinating usually alleviates the pain and gives a temporary sense of relief;
- Suprapubic pain, lower abdominal (pelvic) pain, sometimes in the lower part of the back, groin and thighs;
- In women there may be pain in the vagina;
- In men, pain in the penis, testicles, scrotum and perineum;
- Both may have pain in the urethra;
- Pain with sexual intercourse (men + women);
- A frequent need to urinate, including at night;
- An often urgent or compelling need to urinate.

The pain may be experienced as a burning sensation in the bladder, in the form of spasms in or around the bladder, or stabbing vaginal pain, or a feeling of pressure or fullness in the bladder. It may be constant or intermittent. Pain may also be felt throughout the pelvic floor and lower back. Sexual intercourse may be painful for both male and female patients and for some even impossible.

IC is found in all races and all parts of the world. While the majority of IC patients are women, a small

percentage are men who may in the past have been incorrectly diagnosed as having chronic non-bacterial prostatitis (inflammation of the prostate gland) or prostatodynia (pain in the prostate gland). IC also occurs in children.

The symptoms may begin spontaneously for no apparent reason, or sometimes following a pelvic operation, particularly in the case of women after hysterectomy or other gynaecological surgery, after childbirth or following bacterial infection of the bladder.

Spontaneous flares and remission of symptoms are a characteristic feature of interstitial cystitis. Women may find that their symptoms worsen just before or during menstruation and during the menopause. Many patients also find that food and drink containing caffeine, acid (e.g. citrus fruit, tomatoes, vinegar etc), hot spices (especially containing hot pepper), artificial sweeteners, alcohol and carbonated drinks can exacerbate symptoms. However, this is highly individual and varies from patient to patient.

While physical or emotional stress may exacerbate symptoms, it is important to emphasize that IC is not a psychosomatic illness. The pain, frequency and consequent lack of proper sleep may be a significant cause of not only exhaustion, but also stress, anxiety and depression. IC has a huge impact on the patient's quality of life. The constant need to urinate can form a major obstacle to work, travel, visiting friends, or simply going shopping. When outside the confines of the home, the IC patient's life is dominated by the question 'where am I going to find the next toilet?'

Despite considerable research into many different aspects of IC, the cause is still unknown. There have been many different theories such as autoimmunity,

allergy, occult infection, a defect in the bladder lining, vascular, neurological and even environmental factors, but no answers have as yet been found.

Since there is as yet no specific diagnostic tests available for IC, diagnosis is based on symptoms and exclusion of all other possible causes of these symptoms supported by findings from cystoscopy, hydrodistension and the option of biopsy. There are currently two known subtypes: Classic IC with Hunner's lesions (known in the past as Hunner's ulcer) and IC with no lesions in the bladder.

Since there is as yet no cure for IC, treatment is aimed at alleviating the symptoms. Treatment is highly individual and has to be tailored to the specific symptoms and needs of each individual patient and the type of IC. At the present time, there is no single medication that is equally effective in all IC patients. Treatment options consist of diet and behavioural modification, oral drugs, bladder instillations or injections, bladder distension, neuro/electro-stimulation and various forms of surgery, with bladder removal (cystectomy) only as a very last resort. Hunner's lesion may be treated with laser, electro-coagulation or resection. Physical therapy, myofascial pain therapy, acupuncture and relaxation exercises such as yoga or guided imagery may also help some IC patients.

Some IC patients suffer from one or multiple other disorders such as allergies, medicine intolerance, irritable bowel syndrome, migraine, chronic fatigue, joint/muscle pain and other chronic pain syndromes. IC occurs more frequently than normal in association with fibromyalgia, vulvodynia, rheumatoid arthritis, systemic lupus erythematosus (SLE), Sjögren's syndrome and thyroid disorders.

## Board of the IPBF:

Jane Meijlink (Chairman)  
Florentina Ferreyra (Treasurer)  
Toby Meijlink (Secretary)  
Dot Milne RN  
Nagendra Mishra MD

## Contact:

info@painful-bladder.org  
www.painful-bladder.org

## Address:

Burgemeester L. F. de Montigny laan 73,  
3055 NA Rotterdam  
The Netherlands  
Tel/fax: +31-10-4613330

The International Painful Bladder Foundation is a non-profit voluntary foundation registered at the Chamber of Commerce Rotterdam, the Netherlands under number: 24382693

The International Painful Bladder Foundation does not engage in the practice of medicine. It is not a medical authority nor does it claim to have medical knowledge. The IPBF advises patients to consult their own physician before undergoing any course of treatment or medication.

© International Painful Bladder Foundation 2009

# International Painful Bladder Foundation

## Interstitial Cystitis

Painful Bladder Syndrome,  
Bladder Pain Syndrome,  
Hypersensitive Bladder Syndrome

The logo for the International Painful Bladder Foundation (IPBF) consists of the letters "IPBF" in a white, bold, sans-serif font, centered within a dark blue rectangular background.

[www.painful-bladder.org](http://www.painful-bladder.org)