Interstitial Cystitis/Bladder Pain Syndrome, Hunner Lesion, Hypersensitive Bladder, Chronic Pelvic Pain

Interstitial cystitis/bladder pain syndrome, also known as painful bladder syndrome and hypersensitive bladder, is a debilitating, chronic bladder disorder of unknown cause(s), with symptoms of pain, pressure or discomfort related to the bladder, with or without Hunner lesions, 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, discomfort or other unpleasant sensation that usually increases as the bladder fills; urinating often 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 and/or stabbing pain in the bladder, in the form of spasms in or around the bladder, or stabbing vaginal pain, or as irritation, or patient may simply feel a feeling of pressure or fullness, irritation or discomfort 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/BPS is found in all races and all parts of the world. While a higher percentage of IC/BPS patients are women, a smaller 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/BPS 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 gynecological 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, carbonated drinks and even medicines 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/BPS 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/BPS 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/BPS 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/BPS, 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 yet been found.

Since there are still no specific diagnostic tests available for IC/BPS, diagnosis is based on symptoms and exclusion of all other possible causes of these symptoms supported by findings from cystoscopy with/without hydrodistension and the option of biopsy.

There are currently two known types: Classic IC with Hunner lesions (known in the past as Hunner’s ulcer), diagnosed by cystoscopy, and IC/BPS with no lesions in the bladder and sometimes with a normal looking bladder despite symptoms. These two types are thought to be most likely two separate diseases.

While there is at present no cure for IC/BPS, treatment is aimed at alleviating the symptoms. Treatment is highly individual and needs to be tailored to the specific symptoms and needs of each individual patient and the type of IC/BPS. At the present time, there is no single medication that is equally effective in all IC/BPS patients.

Treatment options consist of diet and lifestyle modification, stress reduction, 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 lesion may be treated with laser, electrocoagulation, resection, triamcinolone injections or bladder instillations.

Physical therapy, myofascial pain therapy, acupuncture and relaxation exercises such as yoga or guided imagery may also help some IC/BPS patients.

Some IC/BPS patients suffer from one or multiple other disorders such as allergy/hypersensitivity, medicine intolerance, irritable bowel syndrome, migraine, chronic fatigue, joint/muscle pain and other chronic pain syndromes. IC/BPS appears to occur 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:
Mahlerlaan 4
1411 HW Naarden
The Netherlands
+31-(0)35-8879516

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 2019

www.painful-bladder.org