



Freyja Medical Clinic

570 Price Av., Suite 100, Redwood City, CA

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www.Freyjaclinic.com

WHAT IS INTERSTITIAL CYSTITIS?

WHO IS AFFECTED?

IC can affect people of any age, race or sex. It is, however, most commonly found in women. Recent epidemiological data suggest that there may be greater than 700,000 cases of IC in the US.

SYMPTOMS

Some or all of these symptoms may be present:

FREQUENCY: Day and/or night frequency of urination (up to 60 times a day in severe cases). In early or very mild cases, frequency is sometimes the only symptom.

URGENCY: The sensation of having to urinate immediately, which may also be accompanied by pain, pressure or spasms.

PAIN: Can be in the lower abdominal, urethral or vaginal area. Pain is also frequently associated with sexual intercourse. Men with IC may experience testicular, scrotal and/or perineal pain, and painful ejaculation.

OTHER DISORDERS: Some patients also report muscle and joint pain, migraines, allergic reactions and gastrointestinal problems, as well as the more common symptoms of IC described above. It appears that IC has an as yet unexplained association with certain other chronic diseases and pain syndromes such as vulvar vestibulitis, fibromyalgia and irritable bowel syndrome. Many IC patients, however, have only bladder symptoms.

DIAGNOSIS

Most IC patients have difficulty obtaining a diagnosis. To make a proper diagnosis of IC, a urologist must follow these steps:

- *Take urine cultures* to determine if there is a bacterial infection present.
- *Rule out other diseases and/or conditions* that have symptoms resembling IC. These diseases may include bladder cancer, kidney problems, tuberculosis, vaginal infections, sexually transmitted diseases, endometriosis, radiation cystitis and neurological disorders.
- *Perform a cystoscopy with hydrodistention under general anesthesia* if no infection is present and no other disorder is discovered. If distention under anesthesia is not performed, the diagnosis of IC may be missed. Cystoscopy during a routine office visit may not reveal the characteristic abnormalities of IC and can be painful for those who have IC. It is necessary to distend the bladder under general or regional anesthesia in order to see the pinpoint hemorrhages on the bladder wall that are the hallmark of this disease. A biopsy of the bladder wall may be necessary at this time to rule out other diseases such as bladder cancer and to assist in the diagnosis of IC. IC is not associated with bladder cancer.

TREATMENTS

At this time there is no cure for IC, nor is there an effective treatment which works for everyone. However, a vast majority of IC patients are helped by one or more of the following treatments:



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ORAL MEDICATIONS

ELMIRON® (*pentosan polysulfate sodium*): Elmiron received FDA approval in 1996. It is the only oral medication approved specifically for use in IC. It is believed to work by repairing a thin or damaged bladder lining.

ANTIDEPRESSANTS : Tricyclic antidepressants such as Elavil® (*amitriptyline*) have been shown to help with both the pain and frequency of IC. In IC, these medications are used for their anti-pain properties, not as a treatment for depression.

OTHER ORAL MEDICATIONS : These include anti-inflammatory agents, antispasmodics, bladder analgesics, such as Urimax®, antihistamines, and muscle relaxants.

BLADDER INSTILLATIONS

BLADDER DISTENTION: The bladder is stretched by filling it with water under general anesthesia. This is part of the diagnostic procedure for IC, and may be therapeutic as well.

DMSO (*dimethyl sulfoxide*): This medication is instilled directly into the bladder. It is believed to work as an anti-inflammatory agent and therefore reduces pain. DMSO can be mixed with steroids, heparin, and/or local anesthetics to form a bladder "cocktail."

BCG(*bacillus Calmette-Guerin*): This experimental treatment is currently in the clinical trial phase and is not yet approved for IC by the FDA. It appears to work by boosting the immune system.

CYSTISTAT® (*hyaluronic acid*): This medication is also in clinical trials and is not yet approved for use in IC in the United States. It is thought to work by replacing the defective lining of the bladder. Efficacy is not known at this time.

OTHER BLADDER INSTILLATIONS Clorpactin WCS-90 (*oxychlorosene sodium*), can be very painful and requires general anesthesia, although it has been used in dilute form in an office setting. Silver Nitrate is used infrequently and considered an outdated therapy.

OTHER TREATMENTS

DIET :Eliminating certain foods (acidic, spicy) may decrease the severity of IC symptoms. Also, smoking, drinking coffee or tea, and alcoholic beverages may aggravate IC. Prelief, an over-the-counter dietary supplement, may help IC patients better tolerate acid foods and beverages.

SELF-HELP :Self-help techniques can improve the quality of life and reduce the incidence and severity of flare-ups. These include changes in diet, stress reduction, visualization, biofeedback, bladder retraining and exercise, among others.

ELECTRONIC NERVE STIMULATORS :

Transcutaneous Electrical Nerve Stimulation (TENS): This device, which is worn externally, relieves bladder pain in some people.

Sacral Nerve Stimulation Implants: These surgically implanted devices are approved for use in treating urinary incontinence, urgency and frequency. They are not yet FDA-approved for treating IC pain, but are currently undergoing testing for this purpose.



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SURGERY :For a small minority of patients whose symptoms are severe and who do not respond to other IC treatments, bladder surgery may be considered. However in some cases, IC symptoms may not improve. Several types of surgery have been used to treat IC, including cystectomy and urinary diversion. Laser surgery should be reserved solely for the Hunner's ulcer form of IC.

Brochures and Fact Sheets for many of these treatments are available through the ICA.

THE INTERSTITIAL CYSTITIS ASSOCIATION

The Interstitial Cystitis Association (ICA) is the **only** nationwide non-profit organization working on behalf of all IC patients. Its goals are:

- To provide the most comprehensive and up-to-date information on IC.
- To provide IC patients, their families and friends with a support network.
- To educate the medical community and the public about IC.
- To advocate in the public and private sectors for research funding and patients' rights.
- To promote and provide research funding to find effective treatments and a cure for IC.

PROGRESS AND HOPE

The effect of IC on an individual's life should not be underestimated. IC can be debilitating and may cause the patient to experience feelings of helplessness and despair. Because of the ICA's success in educating the scientific community about the seriousness of this condition, there has been great progress.

Today, more than ever before, there is an improved understanding and awareness of IC by the medical community and the public at large. Privately and publicly sponsored research is underway to help find effective treatments and a cure for IC. Until that happens, the ICA will continue to help IC patients and their families deal with the effects of the disease by providing information, education and support. The ICA will also continue its efforts to educate the medical community and the general public about interstitial cystitis and to fund research on IC.

DR. VICKI RATNER'S STORY

As a medical student, I began to experience severely painful bladder symptoms for which my own physicians could provide little relief. Two years and fourteen doctors later, I went to the medical library myself and found an article on IC. A cystoscopy under general anesthesia was done, and the diagnosis finally determined interstitial cystitis. In 1984 I founded the Interstitial Cystitis Association, dedicated to providing information and support to the hundreds of thousands of Americans who suffer from this debilitating disease, and information and research funding to the medical researchers and clinicians who are our best hope for more effective treatments.

At first the medical community was skeptical or simply uninformed about the very existence of IC. Patients typically had to consult a series of doctors before they could obtain an accurate diagnosis. Today, largely through the efforts of the ICA, treatments are available and research is underway. Patients are diagnosed more quickly, and realize that they are not alone and that there is hope. We hope that you will find the ICA's information helpful and, if you think you may have IC, that you will use this information to inform your physician as well.

ICA ACCOMPLISHMENTS

Since its inception the ICA has made quantum leaps in its effort to provide support for IC patients, educate physicians and the public, and promote IC research. Through our program of national telephone and online support we provide one-on-one assistance to patients in need, and the ICA has assisted in the formation of IC organizations worldwide.



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ICA representatives have testified annually before Congress to seek funding for research through the National Institutes of Health (NIH). As a result of this funding, numerous scientific articles have been published. In addition to the NIH, the ICA itself has funded more than \$1,000,000 in IC research, and has attracted the top physicians in the field to our National Medical Advisory Board. ICA National Meetings and Scientific Symposiums feature top IC researchers from around the world.

Probably the single most effective educational tool in our considerable arsenal of books, newsletters, brochures, fact sheets, reprints, videos, and audiotapes is our Web site, located at www.ichelp.org. People with access to the Internet can and do log on in huge numbers (hundreds of thousands of "hits" every month) to learn the latest research and treatment information, to read the full texts of our brochures, fact sheets and newsletters, to participate in our cyberadvocacy campaign for IC research funding, to support the organization and to order our resource materials and newsletter. The ICA is truly the leader in its field. We hope that you will join forces with us to defeat IC!

(adapted from ICA, 110 North Washington Street, Suite 340, Rockville, MD 20850. at www.ichelp.org.)