



9195 Grant Street, Suite 410  
Thornton, CO 80229  
Phone: 303-280-2229(BABY)  
Fax: 303-280-0765

300 Exempla Circle, Suite 470  
Lafayette, CO 80026  
303-665-6016  
303-665-0121

6363 West 120<sup>th</sup> Avenue, Suite 300  
Broomfield, CO 80020  
303-460-7116  
303-460-8204

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## **INTERSTITIAL CYSTITIS**

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## Interstitial Cystitis: A Bladder Disorder

### Introduction

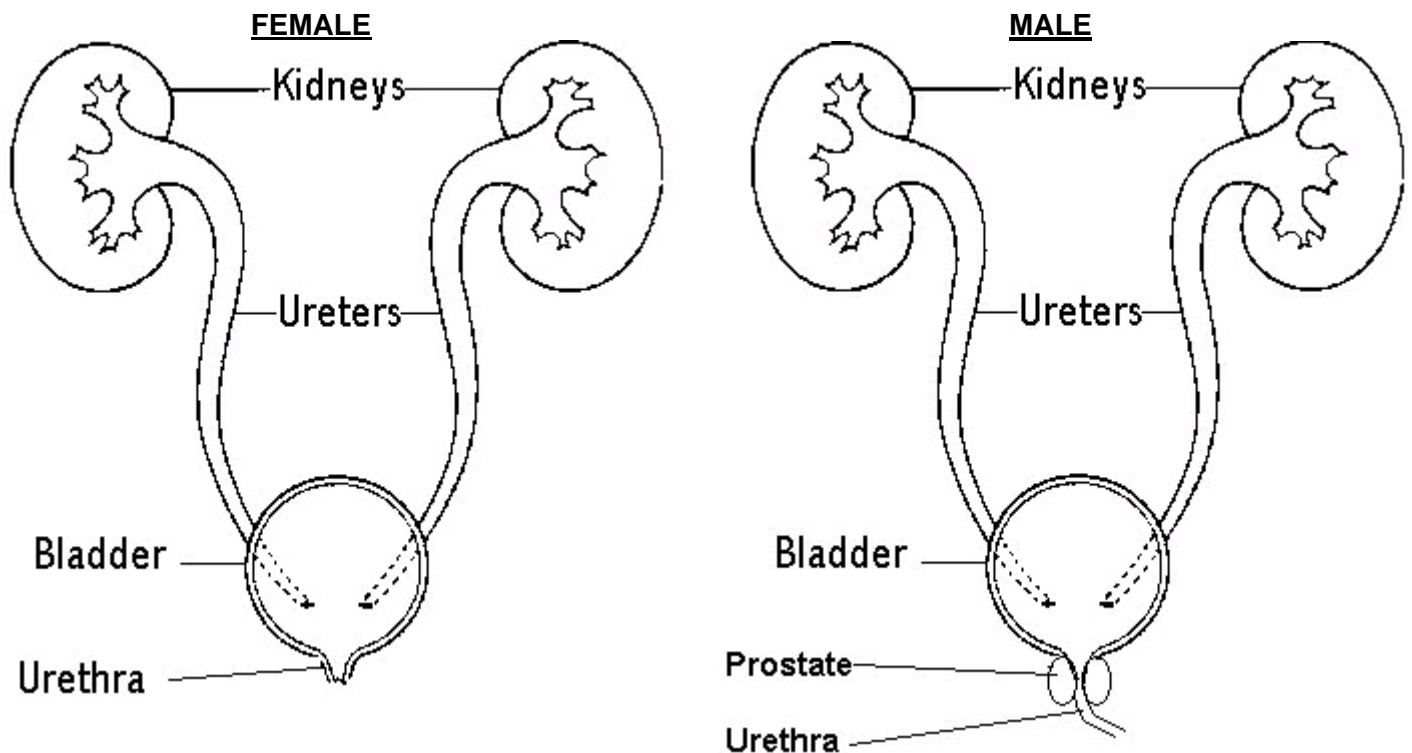
This text is for people who have interstitial cystitis and for their family, friends, and coworkers who want to understand the experiences and challenges associated with the disorder.

It contains information on the causes, diagnosis, and treatment of interstitial cystitis as well as information on current research studies that aim to understand and treat the disorder.

Basic and clinical research is advancing our knowledge of interstitial cystitis, but the disorder still poses many questions that scientists cannot answer. Only further research and the efforts of patients and doctors working together will shed light on improved treatments and, ultimately, a cure for this debilitating disorder.

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### Anatomy of the Urinary Tract



The urinary system consists of the kidneys, ureters, bladder, and urethra. The kidneys, a pair of fist sized organs, are located below the ribs toward the middle of the back. The kidneys remove liquid waste from the blood in the form of urine, keep a stable balance of salts and other substances in the blood. Narrow tubes called ureters carry urine from the kidneys to the bladder in the lower abdomen. Like a balloon, the bladder's elastic walls relax and expand to store urine and contract and flatten when urine is emptied through the urethra. (Note: In the male, the urine goes through the prostatic portion of the urethra before entering the penile urethra.) The typical adult bladder can store about 1 1/2 cups of urine (12 ounces) but with a great deal of variability from patient to patient.

Adults pass about a quart and a half of urine each day. The amount of urine varies, depending on the fluids and foods a person consumes. The volume formed at night is about half that formed in the daytime. (Note: Although as one ages more urine may be created at night even without taking in fluids.



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6363 West 120<sup>th</sup> Avenue, Suite 300  
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**Many older people develop swollen feet or legs during the day. The swelling represents water and salt that it urinated out at night.)**

**Normal urine is sterile. It contains fluids, salts and waste products, but it is free of bacteria, viruses and fungi. The tissues of the bladder are isolated from urine and toxic substances by a coating that discourages bacteria from attaching and growing on the bladder wall.**

**People with interstitial cystitis (IC) have an inflamed, or irritated, bladder wall. This inflammation can lead to scarring and stiffening of the bladder, decreased bladder capacity, glomerulations (pinpoint bleeding) and, in rare cases, ulcers in the bladder lining.**

**IC, also known as painful bladder syndrome and frequency-urgency-dysuria syndrome, is a complex, chronic disorder that has baffled doctors for as long as it has been recognized.**

**Estimates of the number of people who have IC run as high as 500,000, but no one knows for sure how many people have it. About 90 percent of IC patients are women. While people of any age can be affected, about two-thirds of patients are in their twenties, thirties, or forties. IC is rare in children. In a few cases, IC has afflicted both mother and daughter, but there is no evidence that the disorder is hereditary, or genetically passed from parent to child.**

### **Two Types of IC**

**Because IC varies so much in its symptoms and severity, most researchers believe that it is not one but several diseases. Two types of IC are usually described; they are mainly distinguished by whether ulcers have formed on the bladder wall. Most researchers believe that IC does not generally progress from the nonulcerative to the ulcerative form.**

### **Nonulcerative IC**

**This disorder is the most common type of IC. It usually affects young to middle-age women who have a normal, near normal, or increased bladder capacity when measured under general anesthesia. Glomerulations can be seen in the bladder wall.**

### **Ulcerative IC**

**This type of IC tends to be found in middle-age to older women. Bladder capacity is low (less than 1 1/2 cups) when measured under general anesthesia. The decrease is thought to result in part from fibrosis, the formation of threadlike tissue that makes the bladder stiff and small. Cracks, scars, and Hunner's ulcers (star-shaped sores) in the bladder wall may bleed when the bladder is filled to capacity during a cystoscopy.**

### **Cause**

**No one knows what causes IC, but doctors studying the disorder believe it is a real, physical problem-not a result, symptom, or sign of an emotional problem.**

**One area of research on the cause of IC has focused on the lining of the bladder called the glycocalyx, made up primarily of substances called mucins and glycosaminoglycans (GAGs). This layer normally protects the bladder wall from toxic effects of urine and its contents. Researchers at the University of**

California, San Diego, found that this protective layer of the bladder was "leaky" in about 70 percent of IC patients they examined and may allow substances in urine to pass into the bladder wall and trigger IC symptoms. The researchers also found that patients with Hunner's ulcers had "leakier" bladders than patients without the ulcers.

Some people are diagnosed with IC after taking antibiotics for a presumed urinary tract infection. Therefore, it has been suggested that antibiotics may damage the bladder wall and make it "leaky." This idea has been studied carefully, but antibiotics have never been found to harm the bladder wall. Thus, other ideas are more likely to explain why some IC patients are diagnosed after a urinary tract infection. It is possible that the infection started an autoimmune response against the bladder, the patient's original symptoms were from IC all along, or an infecting organism is in bladder cells but is not detectable through routine tests.

### **Symptoms**

The symptoms of IC vary greatly from one person to another but have some similarities to those of a urinary tract infection:

- decreased bladder capacity
- an urgent need to urinate
- frequently day and night
- feelings of pressure, pain, and tenderness around the bladder, pelvis, and perineum (the area between the anus and vagina or anus and scrotum), which may increase as the bladder fills and decrease as it empties
- painful sexual intercourse
- in men, discomfort or pain in the penis and scrotum.

In most women, symptoms usually worsen around the menstrual cycle. As with many other illnesses, stress may also intensify symptoms but does not cause them.

### **Diagnosis**

Because the symptoms of IC are similar to those of other disorders of the urinary system, and because there is no definitive test to identify IC, doctors must rule out other conditions before considering a diagnosis of IC. Among these disorders are urinary tract or vaginal infections, bladder cancer, bladder inflammation or infection caused by radiation to the abdomen, eosinophilic and tuberculous cystitis, kidney stones, endometriosis, neurological disorders, sexually transmitted diseases, low-count bacteriuria, and, in men, chronic bacterial and abacterial prostatitis.

The diagnosis of IC in the general population is based on

- presence of urgency, frequency or pelvic/bladder pain,
- cystoscopic evidence (under anesthesia) of bladder wall inflammation and glomerulations or Hunner's ulcers,
- absence of other diseases that may cause the symptoms.

Medical tests that help identify other conditions include a urinalysis, urine culture, cystoscopy, biopsy of the bladder wall and, in men, laboratory examination of prostate secretions.

### **Urinalysis and Urine Culture**

These tests can detect and identify the most common organisms in the urine that may be causing symptoms. There are, however, organisms such as the bacteria chlamydia that can't be detected with these tests, so a negative culture does not rule out all types of infection. A urine sample is obtained either by catheterization or by the "clean catch" method. For a "clean catch," the patient washes the



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6363 West 120<sup>th</sup> Avenue, Suite 300  
Broomfield, CO 80020  
303-460-7116  
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**genital area before collecting urine "midstream" in a sterile container. White and red blood cells and bacteria in the urine may indicate an infection of the urinary tract, which can be treated with an antibiotic. If urine is sterile for weeks or months while symptoms persist, a doctor may consider a diagnosis of IC.**

#### **Culture of Prostate Secretions**

**In men, the doctor will obtain prostatic fluid from the patient. This fluid will be examined for signs of an infection, which can be treated with antibiotics.**

#### **Cystoscopy Under Anesthesia With Bladder Distension**

**During cystoscopy to diagnose IC, the doctor uses a cystoscope-an instrument made of a hollow tube about the diameter of a drinking straw with several lenses and a light-to see inside the bladder and urethra. The doctor will also distend or stretch the bladder to its capacity by filling it with a liquid or gas. Because bladder distension is painful in IC patients, before the doctor inserts the cystoscope through the urethra into the bladder, the patient must be given either regional or general anesthesia. These tests can detect inflammation; a thick, stiff bladder wall; Hunner's ulcers; and glomerulations (pinpoint bleeding) that may be seen only after the bladder is stretched.**

**The doctor may also test the patient's maximum bladder capacity, the amount of liquid or gas the bladder can hold under anesthesia. Without anesthesia, capacity is limited by either pain or a severe urge to urinate. Many people with IC have normal or large maximum bladder capacities under anesthesia. However, a small bladder capacity under anesthesia helps to support the diagnosis of IC.**

#### **Biopsy**

**A biopsy is a microscopic examination of tissue. Samples of the bladder and urethra may be removed during a cystoscopy and examined with a microscope later. A biopsy helps rule out bladder cancer and confirm bladder wall inflammation.**

#### **Treatment**

**Scientists have not yet found a cure for IC, nor can they predict who will respond best to which treatment. Symptoms may disappear without explanation or coincide with an event such as a change in diet or treatment. Even when symptoms disappear, however, they may return after days, weeks, months, or years. Scientists do not know why.**

**Because doctors do not know what causes IC, treatments are aimed at relieving symptoms. Most people are helped for variable periods of time by one or a combination of treatments, many of which are described briefly in this booklet. However, as researchers learn more about IC, the list of potential treatments may change. Patients should discuss treatment options with a doctor.**

#### **Bladder Distension**

**Because some patients have noted an improvement in symptoms after a bladder distension done to diagnose IC, the procedure is often thought of as one of the first treatment attempts.**

**Researchers are not sure why distension helps, but some believe that the procedure may increase bladder capacity and interfere with pain signals transmitted by nerves in the bladder. Symptoms may**

temporarily worsen 24 to 48 hours after distension, but should then return to predistension levels or improve after 2 to 4 weeks.

### **Bladder Instillation**

This procedure may also be called a bladder wash or bath. During a bladder instillation, the bladder is filled with a solution that is held for varying periods of time, from a few seconds to 15 minutes, before being drained through a narrow tube called a catheter.

The only drug approved by the U.S. Food and Drug Administration (FDA) for bladder instillation is dimethyl sulfoxide (DMSO, RIMSO-50). With DMSO treatments a narrow tube (catheter) is guided up the urethra into the bladder. A measured amount of DMSO is passed through the catheter into the bladder, where it is retained for about 15 minutes before being expelled. Treatments are given every week or two for 6 to 8 weeks, and repeated as needed. Most people with IC who respond to DMSO notice improvement of symptoms 3 or 4 weeks after the first 6- to 8-week cycle of treatments. Highly motivated patients who are willing to catheterize themselves may, after consultation with their doctor, be able to have DMSO treatments at home. Self-administration of DMSO is less expensive and more convenient than going to the doctor's office.

Doctors think DMSO works in several ways. Because it passes into the bladder wall, DMSO may more effectively reach tissue to reduce inflammation and block pain. It may also prevent muscle contractions that may cause pain, frequency, and urgency.

A bothersome but relatively insignificant side effect of DMSO treatments is a garlic-like taste and odor from the breath and skin. This may last up to 72 hours after a treatment. Long-term DMSO treatments have caused cataracts in animal studies, but this side effect has not appeared in humans. Blood tests, including a complete blood count and kidney and liver function tests, should be done about every 6 months.

A variety of other drugs have been used experimentally for bladder washes, including silver nitrate, sodium oxychlorosene (Clorpactin WCS-90), heparin, and pentosanpolysulfate (Elmiron).

Silver nitrate and oxychlorosene sodium are thought to work by first attacking the bladder lining. This triggers the body's immune system to step in and start the healing process. Some patients have been successfully treated with these drugs, but the frequent, painful treatments usually must be done under general anesthesia. Neither drug can be used in people who have urinary reflux, a condition in which urine flows backward up the ureters into the kidneys.

Heparin and pentosanpolysulfate are thought to work by replacing or repairing the "leaky" bladder lining.

### **Oral Drugs**

All drugs--even those sold over-the-counter--have side effects. Patients should always consult a doctor before using any drug for an extended time.

Aspirin and ibuprofen are easy to obtain and may be a first line of defense against mild discomfort. However, they may make symptoms worse in some patients. Over-the-counter forms of phenazopyridine hydrochloride (Azo-Standard, Prodiem, and Uristat) may provide some relief from urinary pain, urgency, frequency, and burning. Higher doses of the drug are available by prescription as Prodiem and Pyridium.

Oxybutynin chloride (Ditropan) and a blend of atropine, hyoscyamine, methenamine, methylene blue, phenyl salicylate and benzoic acid (Urised) may help reduce bladder spasms that can cause frequency,



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6363 West 120<sup>th</sup> Avenue, Suite 300  
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**urgency, and nighttime trips to the bathroom. Urised may also inhibit the growth of organisms in the urine.**

**Amitriptyline (Elavil) and doxepin (Sinequan) act as antidepressants when given in large doses. In smaller doses, they can help IC symptoms by blocking pain, calming bladder spasms, and decreasing inflammation.**

**Some cases of IC may be caused by too much histamine in the bladder. Antihistamine drugs such as hydroxyzine (Vistaril and Atarax) and cimetidine (Tagamet) relieve symptoms in some IC patients. If taken at bedtime, hydroxyzine may also help patients sleep.**

**Nifedipine (Procardia) is a treatment for heart disease and high blood pressure, but it has reduced bladder pain and urgency in some IC patients. Recent studies have suggested that heart disease patients may have more heart or other problems if treated with nifedipine than with other heart medications. It is not known whether these findings would apply to IC patients without heart disease.**

**Pentosan polysulfate sodium (Elmiron) reduces bladder discomfort and pain in some people with IC. Doctors don't know exactly how the drug works, but they believe it may repair leaks in the bladder lining. Elmiron is the first oral drug developed for IC and was approved by FDA in the Fall of 1996.**

#### **TENS (Transcutaneous Electrical Nerve Stimulation)**

**With TENS, mild electric pulses enter the body for minutes to hours two or more times a day either through wires placed on the lower back or the suprapubic region, between the navel and the pubic hair, or through special devices inserted into the vagina in women or into the rectum in men. Although scientists don't know exactly how it works, it has been suggested that the electric pulses may increase blood flow to the bladder, strengthen pelvic muscles that help control the bladder, and trigger the release of hormones that block pain.**

**TENS is relatively inexpensive and allows the patient to take an active part in treatment. Within some guidelines, the patient decides when, how long, and at what intensity TENS will be used. TENS has been most helpful in relieving pain and decreasing frequency in IC patients who have Hunner's ulcers. Smokers do not respond as well as nonsmokers. If TENS is going to help, change usually occurs in 3 to 4 months.**

#### **Diet**

**There is no scientific evidence linking diet to IC, but some doctors and patients believe that alcohol, tomatoes, spices, chocolate, caffeinated and citrus beverages, and high-acid foods may contribute to bladder irritation and inflammation. Some patients also notice a worsening of symptoms after eating or drinking products containing artificial sweeteners. Patients may try eliminating such products from their diet and reintroduce them one at a time to determine which, if any, affect symptoms. It is important, however, to maintain a well-balanced and varied diet.**

#### **Smoking**

**Many IC patients feel that smoking worsens their symptoms. (Because smoking is the major known cause of bladder cancer, one of the best things a smoker can do for the bladder is to quit smoking.)**

## **Exercise**

Many IC patients feel that regular exercise helps relieve symptoms and, in some cases, hastens remission.

## **Bladder Training**

People who have found some relief from pain may be able to reduce frequency using bladder-training techniques. Methods vary, but basically the patient decides to void at designated times and use relaxation techniques and distractions to help keep to the schedule. Gradually, the patient tries to lengthen the time between the scheduled voids. A diary of voids is usually helpful in keeping track of progress.

## **Surgery**

This option is considered only if an IC patient has failed all available treatments and the pain is severe. Most doctors are reluctant to operate because the outcome is unpredictable in individual patients—some people have surgery and still have symptoms.

Anyone considering surgery should discuss the potential risks and benefits, side effects, and long- and short-term complications with a surgeon and family, as well as with people who already have had the procedure. Surgery requires anesthesia, hospitalization, and weeks or months of recovery, and as the complexity of the procedure increases, so do the chances for complications and failure.

To locate a surgeon experienced in performing specific procedures, check with your doctor.

**Transurethral fulguration and resection of ulcers.** Fulguration involves burning Hunner's ulcers using electricity or a laser. When the area heals, the dead tissue and the ulcer fall off, leaving new, healthy tissue behind. Resection involves cutting around and removing the ulcers. Both treatments, done under anesthesia, use special instruments inserted into the bladder through a cystoscope. Laser surgery in the urinary tract should only be done by doctors who have the special training and expertise needed to perform the procedure.

**Denervation** is a complicated procedure done by surgeons who have special training and expertise. Rarely used in the treatment of IC, it involves cutting some of the nerves to the bladder, interfering with pain signals. Many approaches and techniques are used, each of which has its own advantages and complications that should be discussed with the surgeon.

**Augmentation** makes the bladder larger, most often by adding a section of the patient's small intestine, a tube-like structure that absorbs and transports nutrients from food for use by the body. With this treatment, scarred, ulcerated and inflamed sections of the patient's bladder are removed, leaving only healthy tissue and the base of the bladder. A piece of the patient's small intestine is removed, reshaped, and attached to what remains of the bladder. After the incisions heal, the patient may be able to void normally.

Even in carefully selected patients—those with small, contracted bladders—the pain, frequency, and urgency may remain or return after surgery and the patient may have additional problems with infections in the new bladder and difficulty absorbing nutrients from the shortened intestine. Some patients are incontinent while others cannot void at all and must insert a catheter into the urethra to empty urine from the bladder.

**Bladder Removal (Cystectomy).** Different methods can be used to reroute urine once the bladder has been removed. In most cases, the ureters are attached to a piece of bowel that opens onto the skin of the abdomen, called a stoma. Urine empties through the stoma into a bag outside the body. This





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procedure is called a urostomy. Some urologists are using a technique that also requires a stoma but allows urine to be stored in a pouch inside the abdomen. At intervals throughout the day, the patient puts a catheter into the stoma and empties the pouch. Patients with either type of urostomy must use very clean, or sterile, steps to prevent infections in and around the stoma.

With a third method, a new bladder is made from a piece of the patient's bowel (large intestine) and attached to the urethra in place of the removed bladder. After a time of healing, the patient may be able to empty the bladder by voiding at scheduled times or may insert a catheter into the urethra. Few surgeons have the special training and expertise needed to perform this procedure.

Even after total bladder removal, some patients still experience variable symptoms of IC. Therefore, the decision to undergo a cystectomy should only be undertaken after serious deliberation on the potential outcome.

**Electrical Nerve Stimulation.** This surgical treatment is a variation of TENS, described previously, but involves permanent implantation of electrodes and a unit that emits continuous electrical pulses. This relatively new procedure has variable short-term results, unknown long-term effects and, therefore, is not widely used.

## Special Concerns

### Cancer

There is no evidence that IC increases the risk of bladder cancer. However, the long-term effects of IC require further observation and research.

### Pregnancy

Researchers have little information about pregnancy and IC, but believe that the disorder does not affect fertility or the health of the fetus. Some women have a remission from IC during pregnancy, while others have more pain and pressure during the third trimester, possibly due to the weight of the fetus on the bladder.

### Working

Symptom flare-ups that result in frequent absences from work may make it difficult to get or keep a job. The Social Security Administration provides information on Social Security Disability benefits. The National Organization of Social Security Claimants' Representatives can refer you to a lawyer experienced with Social Security claims. (See "Other Resources.")

### Coping

The emotional support of family, friends, and other people with IC is very important in helping patients cope with the disorder. Studies have found that IC patients who learn about the disorder and become involved in their own care do better than patients who do not. The Interstitial Cystitis Association can provide the address and phone number of the nearest support group. (See "Other Resources.")

### Other coping tips:

- Find a health care team that is sympathetic, helpful, and receptive.

- Understand that your health care team does not know all the answers and may be as frustrated as you are.
- Don't become isolated from family and friends.
- Involve your family in treatment decisions.
- Do not allow IC to become the center of your life.
- Try to put IC in perspective -- worse could happen.
- Talk to other people with IC about their experiences and ways of coping.
- Trust yourself.

### **Research**

Although answers may seem slow in coming, researchers are working every day to solve the painful riddle of IC. Some scientists receive funds from the Federal Government to help support their research, and some receive support from other sources such as their employing institution, drug companies, and the Interstitial Cystitis Association. Researchers and doctors around the country, regardless of who funds their work, may competently diagnose and treat IC.

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), a part of the National Institutes of Health (NIH), leads the Federal Government's research efforts on IC. Most studies funded by the NIDDK are a result of unsolicited grant applications sent to NIH by scientists at universities and medical centers throughout the United States. Other NIDDK-funded studies result from solicitations issued to encourage increased research on a certain topic.

### **Suggested Reading**

The materials listed below may be found in medical libraries, many college and university libraries, through interlibrary loan in most public libraries, and at bookstores. Items are listed for information only; inclusion does not imply endorsement by the NIH.

### **Other Resources**

**American Foundation for Urologic Disease  
The Bladder Health Council  
300 West Pratt Street, Suite 401  
Baltimore, MD 21201  
410/727-2908 or 1-800-242-2383**

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**American Pain Society  
5700 Old Orchard Road  
Skokie, IL 60077  
708/966-5595**

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**American Uro-Gynecologic Society  
401 North Michigan Avenue  
Chicago, IL 60611-4267  
312/644-6610**

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**International Pain Foundation  
909 Northeast 43rd Street, Suite 306  
Seattle, WA 98105-6020  
206/547-2157**

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**Interstitial Cystitis Association of America, Inc.  
P.O. Box 1553**

**The Women's  
HEALTH GROUP, P.C.**



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212/979-6057 or 1-800-ICA-1626**

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**National Chronic Pain Outreach Association  
7979 Old Georgetown Road, Suite 100  
Bethesda, MD 20814  
301/652-4948**

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**National Kidney Foundation  
30 East 33rd Street  
New York, NY 10016  
212/889-2210 or 1-800-622-9010**

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**National Kidney and Urologic Diseases  
Information Clearinghouse  
3 Information Way  
Bethesda, MD 20892-3580**

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**National Organization of Social Security  
Claimants' Representatives  
6 Prospect Street  
Midland Park, NJ 07432  
201/444-1415 or 1-800-431-2804**

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**Social Security Administration  
write or call your local office (found in the telephone book under U.S. Government, Department of  
Health and Human Services) or call 1-800-234-5772**

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**United Ostomy Association  
36 Executive Park, Suite 120  
Irvine, CA 92714  
714/660-8624**