INTERSTITIAL CYSTITIS (IC) PAINFUL BLADDER SYNDROME (PBS):

THE BASIC FACTS

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IC/PBS is a chronic, debilitating, often painful, and surprisingly common condition that is often misdiagnosed or even undiagnosed. IC/PBS is typically characterized by urinary ***urgency***, ***frequency***, and/or ***pelvic pain.*** This condition predominantly affects women. Left unrecognized and untreated, IC/PBS can worsen resulting in a significant decrease in bladder capacity (often to just a few ounces instead of the normal capacity of about 12 ounces) and thus a major impairment in daily functioning and quality of life.

What is the cause of IC/PBS?

No one knows for sure, but a growing consensus is that IC/PBS us due to a ***bladder epithelial dysfunction.*** This is an abnormality of the cells that line the inside of the bladder, resulting in abnormal permeability (absorption) of toxins and irritants present in the urine. When toxins such as potassium penetrate the inner lining and enter the wall of the bladder, they can cause inflammation and nerve irritation (neural hyperactivity), giving rise to urgency, frequency, and pelvic pain. The inner surface lining of the bladder is normally protected by a special layer called the ***glycosaminoglycan*** layer (GAG layer), that prevents the urinary toxins from doing damage, much as the stomach has a special lining that prevents the stomach acids from damaging its lining and causing an ulcer.

What are the symptoms of IC/PBS?

The classic three symptoms of IC/PBS are urgency, frequency, and pelvic pain. However, 15% of patients with IC/PBS have pelvic pain in the absence of urinary symptoms. Initially, many patients present with only one symptom, and it may take as long as five years for all three symptoms to become apparent. As previously stated, many patients with IC/PBS are not diagnosed immediately or are misdiagnosed, and thus may see a number of physicians before the correct condition is recognized. ***Nocturia*** (night time urinary frequency), ***dysuria*** (burning or painful urination), and ***dyspareunia*** (painful intercourse) are other symptoms that may be part of the IC/PBS syndrome, further complicating the correct diagnosis.

IC/PBS can vary between mild to severe symptoms, and is often characterized by flare-ups, with periods of remission between such flare-ups. Flare-ups may be triggered by sexual activity or may occur prior to menstruation, complicating the process of distinguishing IC/PBS from gynecological problems. Other triggers are allergies, emotional and physical stress, and high potassium-content foods.

What other medical problems may be confused with IC/PBS?

- Recurrent urinary tract infections
- Bladder cancer
- Endometriosis
- Overactive bladder
- Vulvodynia (a condition in which there is intense pain of the external female genitals)
- Irritable bowel syndrome
- Abdomino-pelvic adhesions (a condition in which there is scar tissue within the abdomen, often due to prior surgery)

How is IC/PBS properly evaluated?

Medical history is the starting point for evaluation. The history will establish the answers to the following questions:

- Do you have obstructive voiding symptoms? hesitancy, decrease in force of the stream, decrease in caliber of the stream, intermittency, the need to strain to void, the feeling that you are not emptying completely, the need to double void?
- Do you have irritative voiding symptoms? urgency, precipitancy, frequency, nocturia?
- Do you have an introital (vaginal) bulge?
- Do you have urinary tract infections?
- Do you have pelvic pain? Do you have pain associated with urinating or when your bladder is full? Are you sexually active, and if so, do you have painful intercourse?
- Are your symptoms related to sexual activity, menstruation, or the intake of certain foods?
- What medical problems do you have?
- What medications do you take?
- What allergies do you have to medications?
- What surgery have you had?

Pelvic examination is important to elicit tenderness of the anterior vaginal wall and bladder base. A thorough pelvic examination involves visual observation, a single blade speculum exam, passage of a small female catheter into the bladder, and a bi-manual pelvic exam. Initial inspection will determine the presence of uro-genital atrophy (loss of tissue integrity of the genital area, including thinning of the skin, redness, irritation, etc.), commonly seen after menopause. A small caliber catheter is passed after voiding in order to determine the residual urinary volume and to submit a urine culture in the event that the urinalysis suggests a urinary infection. Finally, a bi-manual examination is performed to check for pelvic masses. This is a combined internal and external exam in which the pelvic organs are felt between an internal examining finger within the vagina and an external examining finger on the lower abdomen.

Urinalysis is a dipstick and microscopic examination of the urine that will test for the presence of sugar in the urine (possibly indicating the presence of diabetes), protein in the urine (possibly indicating kidney disease), and pus cells and bacteria in the urine (often indicative of a urinary tract infection), as well as the presence of blood in the urine (which may indicate an abnormality in the urinary tract).

Urine Culture is a test to see if bacteria are present in the urine, and if so, what particular type of bacteria.

Urinary Cytology is a "PAP smear" of voided urine. A specimen is sent to a laboratory where a pathologist will examine it microscopically. This test can detect early cancers of the bladder and urinary tract.

Voiding Diary is a 24-hour record of urination in which the time of urination and the precise volume of urination is recorded by the patient. This is a simple and objective means of documenting the frequency of urination as well as the bladder's capacity for storing urine.

The PUF (Pelvic Pain and Urgency/Frequency) questionnaire offers a rapid, self–administered means of screening and diagnosing patients with IC/PBS.

The PST (Potassium Stimulation Test) is an optional test that involves instilling a potassium chloride solution into the bladder and if urgency and/or pain are experienced, the presence of abnormal epithelial permeability is inferred.

Cystoscopy is a test in which a tiny, lighted, flexible instrument attached to a camera is inserted to visually inspect the urethra and bladder. This is a very helpful test to assess ***cracking*** or ***scarring*** of the bladder wall, the presence of ***glomerulations*** (classic appearance of capillaries of the bladder in patients with IC/PBS), ***Hunner's ulcers*** **(**classic inflammatory lesions of the bladder wall in patients with IC/PBS), and the detection of

terminal hematuria after ***hydrodistension*** (the presence of blood-tinged urine after over-stretching the bladder with irrigation fluid), all of which may be characteristic of IC/PBS. Bladder biopsy may be required to rule out other disorders.

Urodynamic Testing is a very sophisticated study of lower urinary tract storage and emptying. Simultaneous measurements of bladder and abdominal pressures, urinary flow rates, pelvic floor muscle activity, and at times, fluoroscopy (dynamic X-ray imaging) of the bladder are obtained and recorded on a computer.

What are treatment options for IC/PBS?

Changes in diet and lifestyle

As stated, for many patients with IC/PBS, symptom flares may be provoked by a number of factors. Some patients suffer flares during allergy season or after eating specific foods. It is important to identify those dietary items that provoke the IC/PBS flare, and try to eliminate or moderate their intake. The following may provoke IC/PBS flares:

- Coffee
- Alcohol
- Carbonated beverages
- Citrus fruits
- Tomatoes
- Chocolate
- Stress
- Sexual activity
- Pre-menstruation

Oral medication

- Pentosan Polysulfate (Elmiron)—This medication is the only FDA approved oral therapy for the treatment of IC/PBS. It aids in the restoration of the lining of the bladder, enhancing its impermeability to agents that irritate or damage the bladder lining. This medication is safe, well tolerated, and effective,

particularly the longer you use it. Symptomatic improvement may take from 3-6 months, perhaps longer, at the recommended dose of 100 mg three times daily.

- Tricyclic anti-depressants—Medications such as amitriptyline (25 mg prior to sleep) may be used to treat pain due to IC/PBS-associated neural hyperactivity.
- Anti-histamines—Hydroxyzine (25-100 mg/ daily) is useful for IC/PBS triggered by allergies.
- Anti-cholinergics—Patients with IC/PBS who have severe urgency and frequency can be treated with Detrol LA or Ditropan XL, bladder relaxant medications that can improve these irritative symptoms.
- Narcotics—In extreme cases, a prescription pain medication may be necessary to control the pain of IC/PBS.

Bladder instillation

Combinations of medications such as heparin, Elmiron, local anesthetics, sodium bicarbonate, and steroids are often instilled in the bladder in order to improve the symptoms of IC/PBS. This is a simple office procedure in which a small catheter is placed in the bladder, the urine drained, and a "cocktail" of the medication instilled for 10-20 minutes. Instillations generally provide much more rapid symptomatic relief than oral therapy.

Cystoscopy and hydrodistension is used for the diagnosis of IC/PBS as well as for symptomatic relief. Hydrodistension involves over-distending the bladder with irrigation fluid in order to blunt the sensory nerves that are responsible for the pain sensation. If classic inflammatory lesions of the bladder wall (Hunner's ulcers) are seen on cystoscopy, they may require cauterization.

Where can I get more information about interstitial cystitis?

- The Interstitial Cystitis Network: WWW.IC-NETWORK.COM
- The Interstitial Cystitis Association: WWW.ICHELP.COM

Appendix 1 VOIDING DIARY

For a 24 hour period, every time that you urinate record the *time of day* and the *volume voided* by using a measuring cup calibrated in ounces. Please bring this completed diary with you at the time of your next visit.

	Time of Day	Volume voided
void #1		
void #2		
void #3		
void #4		
void #5		
void #6		
void #7		
void #8		
void #9		
void #10		
void #11		
void #12		
void #13		
void #14		
void #15		
void #16		
void #17		
void #18		
void #19		
void #20		

Appendix 2

Patient Assessment Questionnaire

For each question below, please circle the answer that best describes how you feel.

The last 2 columns on the right are for your doctor to assess your score. Please do not mark anything in these columns. Be sure to bring this questionnaire with you into the examination room so that you can review your answers with your doctor.

Patient's name: _____ Today's date: _____

		0	1	2	3	4	Symptom Score	Bother Score
1	How many times do you go to the bathroom during the day?	3-6	7-10	11-14	15-19	20+		
2	a. How many times do you do the bathroom at night?	0	1	2	3	4+		
	b. If you get up at night to go to the bathroom, does it bother you?	Never	Mildly	Moderate	Severe	Never		
3	Are you currently sexually active? **Yes**_____ **No** _____							
4	a. **If you are sexually active**, do you now or have you ever had pain or symptoms during or after sexual intercourse?	Never	Occasionally	Usually	Always	Never		
	b. If you have pain, does it make you avoid sexual intercourse?	Never	Occasionally	Usually	Always	Never		
5	Do you have pain associated with your bladder or in your pelvis (vagina, lower abdomen, urethra, perineum, testes, or scrotum)?	Never	Occasionally	Usually	Always	Never		
6	Do you have urgency after going to the bathroom?	Never	Occasionally	Usually	Always	Never		
7	a. If you have pain, is it usually...		Mild	Moderate	Severe			
	b. Does your pain bother you?	Never	Occasionally	Usually	Always	Never		
8	a. If you have urgency, is it usually...		Mild	Moderate	Severe			
	b. Does your urgency bother you?	Never	Occasionally	Usually	Always	Never		
						Symptom Score (1,2a,4a,5,6,7a,8a) - SUBTOTAL		
						Bother Score (2b, 4b, 7b, 8b) - SUBTOTAL		
						TOTAL SCORE (Symptom Score + Bother Score) =		

About the Author

Dr. Andrew L. Siegel is a urological surgeon at Hackensack University Medical Center, an Assistant Clinical Professor of Urology at the University of Medicine of New Jersey, and is the Director of The Center for Continence Care. Dr. Siegel is uniquely qualified to hold this directorial position given his post-medical school fellowship in incontinence, urodynamics, reconstructive and female urology. During his specialized training at the University of California School of Medicine, Los Angeles, California, Dr. Siegel studied under the direction of Dr. Shlomo Raz, the world-renowned expert in incontinence and female urology.

Dr. Siegel's other educational experience includes earning a bachelor of science degree magna cum laude from Syracuse University, Syracuse, New York, in 1977, and a medical degree from the Chicago Medical School, Chicago, Illinois, in 1981, where he was elected to the Alpha Omega Alpha Honor Medical Society.

He completed a two-year residency in general surgery at the North Shore University Hospital, Manhasset, New York, an affiliate of Cornell University School of Medicine. Dr. Siegel then went on to undertake residency training in urology at the University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania, from 1983 to 1987. In 1988, following his fellowship training, Dr. Siegel joined Bergen Urological Associates.

Dr. Siegel is a diplomate of the American Board of Urology and the National Board of Medical Examiners. He is a member of the American Urological Association, the New York section of the American Urological Association, the American Medical Association, the Society for Urodynamics and Female Urology and the American Uro-Gynecological Society.

Dr. Siegel has authored chapters in urology textbooks including *Current Operative Urology* and *Interstitial Cystitis,* and has published articles in numerous professional journals including *Urology, Journal of Urology, Urologic Clinics of North America, Postgraduate Medicine*, *Neuro-Urology and Urodynamics, International Urogynecology Journal, Radiotherapy and Oncology,* and the *Journal of Brachytherapy International.* He has presented papers at professional meetings for many medical societies including the Philadelphia Urological Society, the American Academy of Pediatrics, and the American Urological Association, both nationally and internationally. He is the author of the book *Finding Your Own Fountain of Youth - The Essential Guide to Maximizing Health, Wellness, Fitness & Longevity*. For more information: **www.findingyourownfountainofyouth.com**

July 2009 Printing