



GLOBAL INTERSTITIAL CYSTITIS  
BLADDER PAIN SOCIETY

# GIBS Clinical Guidelines for IC/BPS

Version 3.0 (2024)



*Dedicated to our patients who have  
helped us understand IC/BPS more than  
textbooks and teachers*

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# Message from Patron



*Dear Clinicians,*

*It's a dream come true for Swati Spentose Pvt Ltd, with the vision of "Innovation made in India" - for the WORLD. We have successfully established the pillars and foundation for an exciting future, in our global journey of IC/BPS with a successful GIBS 2016, historic ESSIC - 2016 - bring the European society, for the first time to Asia & super successful GIBS 2017. With the second edition of GIBS 2017, we intended to take the subject to the next level.*

*Progressing our approval for a generic Elmiron (Pentosan) at the US-FDA, something what no pharmaceutical company was able to do for last 7 years since the patent expired in Jan 2010, is indeed exciting.*

*To bring relief to the suffering patients in USA who are unable to afford the only drug in the world for IC / BPS, of which prices have gone up from USD 1/cap to USD 10/cap. And with 40,000 registered patients & more than 4 million people suffering as per RAND study, it's an extremely soul satisfying feeling and more so to make available the same drug to our country first in the world at USD 1/cap, with the same quality from an US FDA approved site. With the US statistics above, imagine the unserved and underserved patient's pool suffering without a solution across the world and in India, who need to be urgently attended to. Imagine the untapped opportunity for all of us as stake holders, including the doctors to speak at global forums and treat patients worldwide (also keeping in mind the medical tourism being big in India). The next logical move of course remains to involve gynaecs and uro-gynaecs across the country, for which we are now extending collaboration to associations across the country and all over the world. We invite clinicians across specialties (like neurologists, anesthetics) who meet bladder patients, to come forward and bring their colleagues and associations to collaborate with us. And take the subject forward and be part of this exciting journey of 'Innovation Made in India for the World' & serving the huge unserved and underserved pool of suffering patients.*

*Don't miss the opportunity to be a founding partner with one of the most scientific privately held company in India. A behemoth in the making.*

*Vishal Jajodia  
CMD, Swati Spentose Pvt Ltd*

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## Introduction

Interstitial Cystitis/Bladder Pain Syndrome is a heterogenous disease. This is evident by the many names that have been attributed to this disease like interstitial cystitis, painful bladder syndrome, urethral syndrome, trigonitis, and bladder pain syndrome. Definition of IC has been hampered by the lack of specific diagnostic criteria, lack of specific histopathologic changes, unpredictable fluctuation in symptoms and the extreme variability among patients in terms of symptoms, objective findings, and treatment responses. Classically diagnosis is described as “Aunt Minnie”— I can’t define it but I know it when I see it.

Different societies have defined this condition but there are some limitations in each. The GIBS committee members discussed the various definitions provided by various scientific societies and tried to propose a consensus based on literature and personal experience.

## Problems in nomenclature

Most of these definitions and terms come close to define IC/BPS but the search for an ideal definition still continues. The term IC is reserved for PBS with typical cystoscopic and histologic features because the term IC is not descriptive of the clinical syndrome or the pathologic findings in many cases. It is often misleading because it directs attention only to the urinary bladder and inflammation. It excludes patients with typical IC symptoms but normal cystoscopic and histologic findings. IC should include some form of inflammation in the deeper layers of the bladder wall which is not necessarily present in all patients of IC/BPS. PBS should include pain in the region of the bladder and diagnosis of BPS made on basis of exclusion of confusable diseases and confirmation by recognition of presence of specific combination of symptoms and signs of BPS.

We can however not banish the term IC because Interstitial Cystitis is widely prevalent term at present and problems can arise in different health systems by affecting reimbursement and possibility for patients to gain disability benefits. Hence the GIBS Society endorses the term IC/BPS as representative of the clinical syndrome.

## GIBS perspective

The ideal definition should allow treatment to begin after a relatively short symptomatic period and avoid unnecessary exclusions. The definition should provide flexibility and cover a wide spectrum of cases while maintaining good sensitivity and specificity.

The current challenges in definition are standardization of medical history, physical examination, laboratory tests, symptoms evaluation, urodynamics, and the technique and classification of cystoscopic and histologic findings. The definition should be able to select patients who need further evaluation for the presence of BPS.

Pain is important in IC/BPS definition. Pain is: “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. Pain or equivalent pressure, discomfort perceived to be related to bladder is considered prerequisite for BPS. Many patients report a sensation of pressure or discomfort in the bladder/pelvic area not as pain but urgency which needs to be probed into.

# GIBS Definition of IC/BPS

## **Pain or discomfort in lower abdomen and / or urogenital area**

- Of more than 3 months duration
- Which is usually worst on full bladder
- Along with one or more lower urinary tract irritative symptoms like frequency, urgency, nocturia,
- With or without standard stigmata on cystoscopy
- Provided another discernable pathology likely to cause these symptoms has been excluded

Clinical evaluation of the patients should start with standard steps of History and Physical examination. High clinical index of suspicion is the key to diagnosis. It is equally important not to over diagnose this condition.

## 1) History

### A) The description of Pain / Discomfort

The following characteristics are essential for the clinical diagnosis of IC/BPS

1. Pain or discomfort in lower abdomen and / or urogenital area
2. Of more than 3 months duration,
3. Which is worst on full bladder
4. Along with one or more lower urinary tract irritative symptoms like frequency, urgency, nocturia,

- Pain may occur in other areas in addition to these. These may include rectum, lower back, and inner thighs.
- It is important to make the patient understand the micturition cycle as the clinician does. Extracting correct information regarding relationship of pain with different phases of urination from the patient might be a difficult task but is the sheet anchor of diagnosis.
- A leading question can be: " If you have a sudden desire to go to washroom, what is your fear? Is it that you would be afraid of leaking urine which will be embarrassing or you would get immensely uncomfortable due to increasing pain while holding on? The answer will help to quickly exclude OAB ( Overactive Bladder) from IC/ BPS
- When the patient wakes up from sleep to pass urine, is it because of a sensation of full bladder ( desire to pass urine) or due to pain. The patients often learn to evacuate their bladder to get rid of pain in cases of IC/ BPS.
- Pain relieved of passing stools or flatus should point towards the Intestinal tract as cause of the symptoms
- Pain intensity changing with the menstrual cycle should be viewed as originating from uterus and adenexa
- Deep Dyspareunia in women is suggestive of IC/BPS while superficial Dyspareunia is indicative of Vulvovaginitis.

### B) History of confusable diseases

One must exclude the following in History

- Prior pelvic surgery
- Urinary stone disease
- Pelvic inflammatory disease ( History of Vaginal discharge )
- History of pelvic radiation
- Infertility
- Diagnosis of endometriosis
- History of neurological disease ( suggestive of Neurogenic bladder)

# Clinical Approach

## C) History suggestive of aetiology

- History of allergies/ bronchial asthma /Seasonal hay fever / drug allergies / urticaria
- History of obstructive symptoms , in women due to pelvic floor spasm , in men due to prostatic pathology or stricture urethra
- History 'Burning character' of pain suggestive of neuropathic pain
- Recent change in diet , like health drinks, excessive tea/ green tea/ coffee/ dark chocolates or something else which the patient wasn't used to earlier. Change of diet due to geographical translocation.
- Recent drug treatment for unrelated disease

## D) History of associated diseases

It is important to record the associated medical co morbidities like

- Fibromyalgia
- Migraine
- Mental stress
- Irritable Bowel syndrome

## II Examination

General examination starts as soon as the patient and caretaker enter the consulting room. This includes the amount of medical records they are carrying, the dismal look on the patient and her/his attendant.

### A) General Examination

- Gait of the patient
- Mental state of the patient
- Somatic signs of anxiety like pallor, sweating etc.

### B) Abdominal examination

- Scars of previous surgeries
- Any abdominal masses
- Tenderness in abdomen, mainly suprapubic. Any other area of tenderness may be noted.

### C) Local examination

- Pelvic examination in a female starting from standard inspection , per speculum, and digital pelvic examination.
- Digital rectal examination should be done in men
- Any area of tenderness in perineum
- Tone of the pelvic floor muscle
- Trigger points need to be noted
- Any Myofascial bands must be looked for

### D) Focused neurological examination if indicated



# Investigations

Considering Indian Scenario, the GIBS council has proposed the following guidelines for investigating a suspected case of IC/BPS .

Table 1 Diagnostic tests for of IC/BPS (Proposed by GIBS Council)

<b>Mandatory (Essential)</b>	<b>Recommended (In selected cases)</b>	<b>Optional</b>
Clinical history Physical Examinations Frequency Volume chart Urinalysis Ultrasonography* Cystoscopy ± Biopsy**	Urine culture*** Urine cytology**** Symptom scores# QOL scores Frequency-volume chart	Urodynamic study

One day frequency Volume Chart is also an important preliminary investigation that can give a fair about the function of the urinary bladder. Considering the non invasive nature and economics involved this test is also a recommended test in evaluation of such patients. Frequency volume chart involves measurement of voided urine and fluid intake with respect to time accompanied by remarks such as pain, leak etc. A record of 24 hours starting from the second void of the day to the first void of the next day is sufficient and practical.

\*We propose inclusion of Ultrasonography as mandatory test for diagnosis of IC/BPS. This will avoid over diagnosis of IC/BPS as well as chances of missing many pelvic pathologies requiring immediate attention eg. one can also rule out high residual urine (occult retention). This eventually will be cost effective as inappropriate treatments can be avoided, especially when regular follow up is missing in periphery.

\*\*Most of entities in differential diagnosis such as bladder cancer, vesical stones, urethral diverticula, and intravesical foreign bodies may be ruled out, just on basis of symptoms and few non-invasive diagnostic modalities including urine microscopy and radiology. Till date, we don't have any diagnostic criteria like symptom score or biomarker, to even suspect the presence of HLs. Though many studies have been done to allocate HLs as distinct phenotype with different course and response to treatment. In addition, cystoscopy could pick up missed serious diagnoses as transitional cell carcinoma, proliferative cystitis and Uretero Vesical junction Calculi

\*\*\*We agree Urinalysis to be as essential test in all patients but recommend Urine culture only in presence of high suspicion eg. positive nitrates, Leukocyte Esterase and/ or significant pus cells due to high sensitivity and specificity of these values for diagnosing Urinary Tract Infection (UTI). Although AUA (American Urological Association) dictates that Urine culture may be indicated even in patients with a negative urinalysis in order to detect lower levels of bacteria that are clinically significant but not readily identifiable with a dipstick or on microscopic exam.

\*\*\*\*We recommend Urine cytology not only in presence of history of chronic smoking and/ or unevaluated microhematuria, but also in case of persistent irritative lower urinary tract symptoms with no response to initial treatment (Provided all essential tests were negative)

# Investigations

# The aim is to obtain baseline symptoms & then to measure subsequent treatment effects. There is no gold standard or optimal method. The examples are

- Aggregated or composite symptom scores
- Individual symptom scores
- Variables of voiding recording (i.e. voiding frequency and single voided volume)
- QoL scores
- Global response assessment by patients' subjective impressions
- Apollo clinical scoring system

## Despite controversy on diagnostic or follow-up value of Cystoscopy, the council believes objective findings are important for diagnosis, prognosis and ruling out other treatable conditions. But hydrodistension is not mandatory for the diagnosis, as glomerulations can be seen on overdistension of any bladder with small functional capacity. Therefore, its role is only for therapeutic purpose after establishing the diagnosis.

### Biopsies should be reserved only to exclude important differential diagnoses by histological examination like carcinoma in situ and tuberculous cystitis, when there is clinical suspicion.

Rest of the tests like X – ray, Prostate-specific antigen and Potassium tests, have already being aborted by most of the latest guidelines because of questionable value in diagnosis and lack of evidence in the literature.

All Pathologies which mimic the above-mentioned symptoms must be carefully excluded

## **Bladder diseases**

Overactive bladder, neurogenic bladder, benign or malignant bladder tumor, bladder calculus, radiation cystitis, chemotherapy induced cystitis (Cyclophosphamide, ketamine, tiaprophenic acid etc.)

## **Prostate and urethral diseases**

Prostatic hypertrophy, urethral diverticulum, urethral stricture

## **Genitourinary infections**

Bacterial cystitis, tubercular cystitis, urethritis, prostatitis (within 3 months period), chronic pelvic inflammatory diseases, active genital herpes, vaginal candidiasis

## **Gynecologic diseases**

Endometriosis, uterine myoma, vaginitis, climacteric disturbance, uterine/ cervical/vaginal cancer

## **Other conditions**

Polyuria, pelvic floor muscle spasm, vulvodynia, vestibulodynia, pelvic congestion syndrome

# Treatment Guidelines

## **Patient education:**

Normal bladder function, What is BPS/IC?, benefits and risks of available treatment options .

## **Counseling:**

Natural history of waxing and waning, no curable single treatment available, reasonable expectations about treatment outcome

## **Behavioral therapy**

Timed voiding, controlled fluid intake, pelvic floor muscles relaxation exercises, stretching exercises, hyperbaric oxygen, stress reduction techniques, managing working hours, patient support groups,

## **Diet manipulation**

Avoiding dietary triggers, acidic beverages, tea ,coffee, soda, spicy food, artificial sweetener and alcohol.

## **Management of chronic pain:**

Alleviating anxiety, psychotherapy, antidepressants, hypnosis, bio feedback, relaxation techniques, meditation, acupuncture, analgesics

## **Avoiding painful bladder flares**

Treating bladder infections and gastrointestinal problems. Reducing or modifying painful activities like sex and prolonged sitting

## **Oral medications**

- Amitriptyline 10-75 mg / day, Nortriptyline, Doxepin, S.E.:constipation, palpitation, drowsiness, dry mouth, weight gain
- Hydroxyzine 25-75 mg /day useful in patients with allergies S.E.:drowsiness, confusion in elderly
- Pentosan polysulfate 300mg/day, takes 3-6 months for optimum response  
Side effects: nausea,diarrhea, hair loss, headache, rectal bleeding
- Urinary alkalisers
- Skeletal muscle relaxants ( for overactive pelvic floor) Cyclobenzaprine, diazepam suppositories, clonazepam

## **Cystoscopy:**

Low pressure short duration hydrodistention, fulguration of Hunner's lesion, intravesical triamcinolone injection

## **Intravesical treatment**

Intravesical drugs are administered due to poor oral bioavailability establishing high drug concentrations at the target, with few systemic side-effects. Disadvantages include the need for intermittent catheterisation, which can be painful in BPS patients, cost, and risk of infection.Following agents have been recommended by various guidelines:

## **DMSO** (recommended by AUA and RCOG guidelines Gr C, Asian guidelines Gr B).

Instillation dwell time should be limited to 15-20 minutes; as it is rapidly absorbed into the bladder wall and longer periods of holding are associated with significant pain. Most patients recognized a garlic-like odor, and a few patients felt bladder spasm possibly due to mast cell degranulation.If used in "cocktail" preparation, then one should be aware that DMSO potentially enhances absorption of other substances, creating the possibility for toxicity from drugs such as lidocaine.other substances, creating the possibility for toxicity from drugs such as lidocaine.

# Treatment Guidelines

Heparin (recommended by AUA and Asian guidelines Gr C, RCOG guideline Gr D)

Intravesical dose ranges from 10,000 IU to 40,000 IU.

AEs were infrequent and appear minor.

Lidocaine (recommended by AUA, RCOG and Asian guidelines Gr B)

Alkalinization increases urothelial penetration of lidocaine and therefore is expected to improve efficacy but it also can increase systemic absorption and potential toxicity. No published studies have directly compared lidocaine with and without alkalinization. No studies have directly compared different lidocaine concentrations.

AEs are typically not serious but include dysuria, urethral irritation, and bladder pain and also the relief is short-term (i.e., less than two weeks)

Hyaluronic acid (recommended by RCOG Gr B and Asian guidelines Gr c), Chondroitin sulfate (recommended by Asian guidelines Gr c and RCOG Guidelines Gr D) and Pentosan polysulfate intravesical preparation (recommended by Asian guidelines Gr c) are commercially not available in India.

Intravesical resiniferatoxin and Intravesical Bacillus Calmette–Guérin are therapies that are not recommended for BPS.

In Pregnancy

Intravesical heparin is considered safe option in pregnancy .Although one course of DMSO may be used prior to pregnancy for symptom remission with good pregnancy outcomes (delivery at term, normal birth weight and postnatal symptom control), DMSO is known to be teratogenic in animal studies. (RCOG Gr D)

Cocktail Therapy

International Painful Bladder Foundation has recommended following regimes (September 2008) and the rationale is that combination might potentiate the effect resulting in better outcome.

1. Anaesthetic cocktail – Robert Moldwin, MD

1:1 mixture of 0.5% Marcaine and 2% Lidocaine jelly – about 40 cc total.

To this solution are added:

Heparin sulphate 10,000 IU

Triamcinolone 40 mg

Gentamycin 80 mg or a post-procedural prophylactic antibiotic.

2. Hydrocortisone and Heparin cocktail –Rajesh Taneja MD ( Scandanavian Journal)

Hydrocortisone 200 mg

Heparin 25,000 IU

In physiological saline to 40 ml volume

3. DMSO cocktail – Philip Hanno, MD

DMSO (Rimso 50) 50 cc

Sodium bicarbonate 44 meq (one ampule)

Kenalog 10 mg

Heparin sulphate 20,000 IU

4. Heparin cocktail – Kristene Whitmore, MD

Heparin 10,000 units/ml-2ml's

Solu cortef 125 mg

Gentamicin 80mg/2ml-2ml's

Sodium Bicarbonate 8.4% -50ml's

Marcaine 0.5% -50 ml's

# Treatment Guidelines

5. Pentosan polysulfate cocktail - Jurjen J. Bade, MD  
Pentosan polysulfate sodium 300mg (=3 ampules each 100mg)  
Lidocaine 2% 10cc  
Sodium bicarbonate 4.2% (but can also be 4.8%) - 10cc

6. Heparin cocktail with alkalinized lidocaine – C. Lowell Parsons, MD  
Heparin sulphate 40,000 IU  
Lidocaine 2% 8 mL  
Sodium bicarbonate 8.4% 3 mL  
To reach a total fluid volume of 15 mL

7. Marcaine with steroid cocktail – Nagendra Mishra, MD  
Marcaine 40 ml  
Heparin sulphate 10,000 IU  
Dexamethasone 2 cc  
Sodium bicarbonate 20 ml

- No clinical studies have addressed the safety or increased efficacy of these preparations alone or of various cocktails in comparison to one another.
- Due to placebo controlled trials, it is difficult know the balance between benefits and risks/burdens of any intravesical therapies.
- Mostly interval between instillation therapies is kept at 1- 2 weeks but patients are using it as and when required basis also. Currently no guidelines has clear recommendations in this regard.

## **OTHERS:**

Intra vesical Botulinum toxin injections , electrical nerve stimulation, sacral neuromodulator

## **SURGERY:**

Subtotal cystectomy urinary diversion, augmentation cystoplasty

## **SUMMARY OF TREATMENT**

- Multiple treatment options- most of them lacking high level evidence. Spectrum of treatment varies from conservative therapy e.g. patient education, counseling, behavioural therapy to the most invasive option i.e. cystectomy and urinary diversion in a end stage small fibrotic bladder.
- Treatment would depend upon the severity, stage and the possible aetiopathogenesis of the disease along with clinical judgement and patient preference.
- Often a multi modal treatment approach is advised.
- Phenotyping the treatment plan for a particular patient is probably the best way to achieve maximum response.
- Ineffective therapy should be stopped after a reasonable time and diagnosis should be reconsidered if there is no benefit even after multi modal therapy,
- AVOID long term antibiotics, oral steroids, use of long duration high pressure hydrodistention, intravesical BCG.

# Pain Management

Managing pain in BPS is a challenge and is a multidisciplinary and multimodal approach. It is an integral part at every tier of management.

A good history and physical examination are a must for the management. These patients almost always have a history of mental trauma and stress which needs to be dealt with. The character, intensity, duration, radiation and pain score is important in determining the treatment strategy. On examining, one can find "Myofascial Bands" which are palpable nodules, in the perineum, suprapubic region, thigh and even back.

Assurance is very important at each step and the patient should be educated about the disease and also goals of management discussed and also counseled that it takes time for the pain to be controlled and it is stepwise approach.

To begin the treatment, WHO step ladder analgesic pattern is followed which states to use non opioids, Paracetamol or non steroidal anti-inflammatory drugs like Diclofenac 50 mg twice to thrice a day or Etoricoxib twice a day. But these medications cannot be given for long period of time, because of its side effects. If patient doesn't respond, go to next step of weak opioid like Tramadol / Tapentadol 50 mg twice a day in beginning and can go as high as four times a day. Also an adjuvant can be added as by the time patient comes, her/his pain becomes chronic and neuropathic due to central sensitization. Adjuvants can be Gabapentine starting from 100 mg once to three times a day and can be given upto 900 mg in divided doses. Pregablin can be used instead of gabapentine in starting doses of 75mg and upto 300mg in divided doses. Amitryptiline can be given along with all these to start as 10 mg at night time and gradually increase to 75 mg in divided doses.

Physical therapy is to be started along with pharmacological management in the form of TENS, release of myofascial bands and relaxation exercises for pelvic floor.

Pelvic floor strengthening is CONTRAINDICATED in BPS.

Along with physical therapy, underlying stress is dealt with by involving psychological counsellor for starting cognitive behavioural therapy.

If pharmacological management doesn't work, minimally invasive interventions can be done. Trigger point injections can be given at myofascial bands which relieves pain significantly. Followed by continuation of physical therapy and CBT.

There is some role of Pudendal nerve block in patients whose pain area is in perineum and anal region. It can be given as guided block by ultrasound.

If pain is widespread in pubic, suprapubic and more of neuropathic character, superior hypogastric plexus block can be considered as an option for managing pain.

Assessment and reassessment is the key for managing pain.

# Pain Management Protocol in IC/BPS

## Step I Assesment, Assurance, Education

- History and Physical examination, dietary history, stress history, map area of pain look for myofascial bands
- Reassurance and patient education

## Step II Reassurance Education

- Start NSAIDs or Paracetamol or weak opiods like tramadol/tapentadol/buprenorhine according to pain score
- Add Gabapantine / Pregablin and Amitryptiline
- Physical Therapy
- Cognitive Behavioural Therapy

## Step III Reassessment Reassurance Education

- Strong Opiods like morphine/fentanyl
- Myofascial Block
- Gbapantine/pregablin + Amitryptiline
- Physical Therapy
- Congnitive Behavioural Therapy

## Step IV Reassessment Reassurance Education

- Pudendal Nerve Block
- Increase dose of Weak or strong opiods
- Increase doses of gabapantine / pregablin + Amitryptiline
- Physical Therapy
- Congnitive Behavioural Therapy

## Step V Reassessment Reassurance Education

- Superior Hypogastric Plexus Block
- Increase dose of Weak or strong opiods
- Increase doses of gabapantine / pregablin + Amitryptiline
- Physical Therapy
- Congnitive Behavioural Theraph

## Appendix 1

Name: \_\_\_\_\_ Registration No: \_\_\_\_\_

Date of 1st visit.

Date of admission if any:

Date of discharge:

Date of surgery:

Address:

State:

Telephone no:

Age \_\_\_\_\_ Sex: M / F

Race: Asian Indian / Non Indian Asian / Non Asian

Religion:

Education: nil / primary / secondary/ graduate

Profession: farmer / labourer/ housewife/ self employed / professional

### II. History of presenting complaints: ( baseline variables)

#### 1. Pain.

a) location: suprapubic / lower back / external genitalia/ scrotal / perineal / perianal

b) duration: months / weeks

c) worsening factor :           bladder filling                           yes / no  
  dietary products                   yes / no | if yes please specify

d) relieving factor :           after voiding                           yes / no

e) intensity :                   VAS Score                               / 10

f) remission / excecration:           yes / no | if yes symptom free duration :

2. urgency :                   yes / no                           Score: /10

3. Urge Incontinence :           yes / no                           if yes proportion ( incontinence/ urgency episode):

4. Frequency:                   yes / no  
                                  a) total                           / 24 hours  
                                  b) day time  
                                  c) night time

### III. Presence of non bladder syndromes:

1. chronic fatigue syndrome (CFS)           yes / no

2. fibromyalgia (FM):                           yes / no

3. Irritable Bowel Syndrome (IBS):           yes / no

4. Sicca Syndrome:                           yes / No

5. Migraine :                                   yes / no

6. Chronic Pelvic Pain (CPP):                   yes / no

7. Panic Disorder:                           yes / no

8. Vulvodynia:                               yes / no

9. Allergy:                                   yes / no

10. Asthma:                                 yes / no

11. Depression:                           yes/ no



## IV. Clinical Symptom Scales:

- A. University of Wisconsin Symptom Instrument ( not validated)
- B. O'Leary-Sant (ICSI) Score : /20
- C. Interstitial Cystitis Problem Index ( ICPI): /16.
- D. Pelvic pain and urgency/frequency Patient symptom scale (PUF) : / 35.
- E. Male genito urinary pain index( GUPI):
- F. Female genito urinary pain index (GUPI):

## V. Voiding Diary:

- a) day time frequency
- b) night time frequency
- c) urgency episode
- d) urgency incontinence episode
- e) functional bladder capacity:

## VI. Reproductive History

- 1. Menstrual history: Menorrhagia / Dysmenorrhoea / Amenorrhoea  
LMP
- 2. Gravida Para  
Normal deliveries Caesarean sections
- 3. Contraception None/ Condom/ Oral pills/ IUCD
- 4. Deep Dyspareunia / Pelvic pain
- 5. Female hormone replacement therapy: yes /no
- 6. Use of douche: yes/no
- 7. Painful ejaculation: yes/ no.

## VII. Medication history: Cyclophosphamide, aspirin, NSAIDs, Allopurinol: yes / no

## VIII. Physical Examination:

- A. General: Weight Height Body Mass Index (BMI) Pallor Generalized lymphadenopathy
- B. Chest & CVS
- C. Abdomen  
Suprapubic tenderness: yes / no
- D. Per Rectal examination: (Any abnormal findings)
- E. Digital/ Speculum vaginal examination  
Tenderness of anterior vaginal wall: yes / no  
Evidence of infection: yes / no

## IX. Investigations:

- A) Haematological:  
Haemoglobin:  
Total Leucocyte Count:  
Differential Leucocyte Count:  
Neutrophils- Lymphocytes- Eosinophils- Monocytes-  
ESR  
Blood Urea:  
Serum Creatinine:  
Random Blood Sugar:

# IC/BPS Patient Performa

- B) Urine ( RE & Microscopy)
  - Sugar | Albumin | RBC | Pus cell | Bacteria
- C) Urine culture & sensitivity:
- D) Urine Cytology: Negative / positive / suspicious
- E. USG findings if any:
  - 1. kidneys
  - 2. bladder
  - 3. post void residual urine volume:
  - 4. uterus
  - 5. Ovaries
- F. Urodynamic study if any:
  - a) filling phase:
    - 1. First Sensation of Filling (FSF)
    - 2. First Desire to Void (FD)
    - 3. Strong Desire to Void (SD)
    - 4. Cystometric Bladder Capacity (CBC)
    - 5. Compliance
  - b) voiding phase
    - 1. pdet Qmax
    - 2. Volume Voided
    - 3. PVR
- G. Cystoscopy & biopsy if any:
  - 1. Maximum Bladder Capacity (MBC)
  - 2. Hunners Ulceration      yes / no
  - 3. Glomerulations: Grade :    0 / 1/ 2/ 3/ 4
  - 4. Hydrodistension done :    yes / no
  - 5. Biopsy done                yes / no
  - 6. Fulguration done        yes / no
  - 7. Biopsy Findings: -
- H. Urinary Markers: Anti Proliferative Factor ( APF):
- X. Treatment given:
  - a) **First Line Treatment:**      YES /NO                      Duration
  - Stress Managemen
  - Pain Management
  - Patient Education
  - Behavioural Modification

**b) Second Line Treatment:** YES /NO                      Duration

Physical Therapy Oral:

Amitriptyline

Cimetidine

Hydroxyzine

PPS

Intravesical Therapy:

DMSO

Heparin

Lidocaine

Pain management

**c) Third Line Treatment:** YES /NO                      Duration

Cystoscopy & Hydrodistension

Treatment of Hunner Ulcer

Pain Management

**d) Fourth Line Treatment:** YES /NO                      Duration

Intradetrusol Botox

Neuromodulation

Pain Management

**e) Fifth Line Treatment:** YES /NO                      Duration

Cyclosporin A

Pain Management

**f) Sixth Line Treatment:** YES /NO                      Duration

Diversion with or without cystectomy

Substitution Cystoplasty

Pain Management

XI. Outcome Assessment

Voiding Diary                      At 3 months                      At 6 months At 12 months

VAS Score

ICSI Score

ICPI Score

UDS if any

GRA

GRA ((Global Response Assessment Score 1-7): Markedly Worse, Moderately Worse, Slightly Worse, No Change, Slightly Improved, Moderately Improved, Markedly Improved

Name of Consultant

Dated:

## Appendix 2

### Apollo clinical Scoring System for Interstitial Cystitis / Bladder Pain syndrome

#### 1. Urgency (0-5)

How often have you felt the strong need to urinate with little or no warning?

- 0. Not at all
- 1. Less than 1 in 5 times
- 2. Less than half the time
- 3. About half the time
- 4. More than half the time
- 5. Almost always

#### 2. Frequency (0-5)

How often have you had to urinate less than 2 hours after you finished urinating?

- 0. Not at all
- 1. Less than 1 time in 5
- 2. Less than half the time
- 3. About half the time
- 4. More than half the time
- 5. Almost always

#### 3. Nocturia (0-10)

How often did you most typically get up at night to urinate?

- 0. Never
- 2. Once
- 4. 2 times
- 6. 3 times
- 8. 4 times
- 10. 5 times or more

#### 4. Pain (0-20)

Have you felt Burning, pain, discomfort, or pressure in your bladder?

- 0. Not at all
- 4. Once a day
- 8. A few times a day
- 12. Fairly often
- 16. Almost always
- 20. Persistent pain that is not reduced after emptying bladder

#### 5. Sexual dysfunction (0-5)

##### A) Female

- 0. No problem in sexual activity
- 1. Can engage in sexual activity with minimal discomfort.
- 2. Non penetrative genital contact can be tolerated.
- 3. No genital contact can be tolerated.
- 4. Vulvodynia
- 5. Aversion to sexual thoughts

##### B) Male

- 0. No problem in sexual activity
- 1. Post ejaculatory discomfort.
- 2. Moderate to severe pain post ejaculation
- 3. Pain at the time of erection
- 4. Complete loss of erection
- 5. Loss of libido with ED

#### 6. Psychological impact (0-5)

How much have the symptoms bothered you mentally (score 0-5):

- 0.No problem
- 1.Very small problem
- 2. Small problem
- 3. Medium problem
- 4. Big problem
- 5.Suicidal tendency

**Total Score..... / 50**

## Appendix 3

GiBS methodology of cystoscopy

Diagnostic and therapeutic cystoscopy in bladder pain syndrome Interstitial cystitis: systemic review of literature and consensus on methodology. International urogynecology journal, Jan 2023  
[doi.org/10.1007/s00192-023-05449-w](https://doi.org/10.1007/s00192-023-05449-w)

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