

International Painful Bladder Foundation

The IPBF is a voluntary non-profit organization
www.painful-bladder.org

IPBF E-Newsletter, March 2007

Dear PBS/IC patient support groups, country contacts, healthcare professionals and friends around the world,

We once again have pleasure in providing you with an update on international developments and events in the field of **painful bladder syndrome/interstitial cystitis**.

IPBF Survey study

The IPBF is about to start a questionnaire survey study for urologists and (uro)gynaecologists diagnosing and treating PBS/IC patients in the community around the world. The aim of this survey is to obtain a clearer picture about the specific situation relating to diagnosis, treatment and other aspects of PBS/IC in specific countries. For example, what kind of investigations are being used to diagnose PBS/IC and why? What economic or cultural aspects play a role? With your help, we can build up a better global picture. We would be most grateful if you would take the time to do this survey and send us any other information about the situation in your country that you feel is important.

The questionnaire is available on the website: www.painful-bladder.org in MS Word and can be downloaded and filled in, either on your computer or by hand. Download on the IPBF home page or under [Surveys](#) on the menu. It will also be distributed from the **IPBF booth (booth 44 Hall 1.1)** at the annual congress of the European Association of Urology (EAU) in Berlin this month (21-24 March). The deadline for returning your responses is 1 August 2007. Further information on the survey may be obtained from the IPBF at info@painful-bladder.org.

International name and definition debate continues

The past few months have been marked by much international debate, discussion, patient surveys, position statements, controversy and heated emotion on the subject of the change of name for IC announced by the European Society for the Study of IC/PBS (ESSIC), together with their new definition that for the first time omits "urgency" as a characteristic symptom (for further information, see the summary of the ESSIC Consensus: <http://www.essic.eu/pdf/ESSICconsensus2006.pdf>).

The name debate continues unabated. Where the urgency/definition issue is concerned, surveys have indicated that patients feel strongly that urinary urgency is an important element of their bladder disorder. The basic problem here lies with the current ICS definition of urgency ("a sudden compelling desire to pass urine, which is difficult to defer") with its bias towards urgency incontinence patients who do indeed feel a sudden compelling desire to void. It is possible that IC patients are more likely to experience a more gradual build-up of this sensation until it reaches an intolerable level. As we have repeatedly been urging for the past couple of years, a new definition of urgency or a definition of

urgency specifically for PBS/IC patients might help to solve the current urgency impasse, or at least until much-needed research has shed more light on urgency in IC. If urgency is excluded from the definition, there is also a risk of its being forgotten by researchers, whereas finding out why PBS/IC patients have urgency may have important pathophysiological relevance. (See article on urgency by Diggs et al in new scientific literature below)

However, regardless of the medical definitions of PBS/IC and urgency, patient information can nevertheless continue to use the traditional symptom description of: pain (or pressure or discomfort), urgency (an urgent need to find a toilet) and frequency (a frequent need to urinate day and night), or whatever the appropriate terms are in your own language. There is no need for this to change in basic patient information.

Patient involvement a “must”

One aspect that is clearly emerging from all of this debate is that in today's world patients and their representatives cannot be excluded from decision-making processes concerning issues with an important impact on both the patients and the patient support organizations. Patient-Centred Healthcare is the buzzword today worldwide, but this aim cannot be achieved if patients or their representatives are not fully involved in issues and decisions that concern their health and their disease or disorder.

Plea for neutral international consultation

The IPBF would like to make a plea for a neutral, international consultation meeting to be held solely for the purpose of discussing all aspects of nomenclature and definitions for PBS/IC, with medical experts and representatives of all patient organizations wishing to contribute being given the opportunity to do so.

IAPO achieves official relations with WHO

The IPBF is an associate member of the International Alliance of Patients' Organizations (IAPO). This membership gives us a much wider view of patients' interests and healthcare issues than we would normally obtain. IAPO recently announced its admission into official relations with the World Health Organization. According to Albert van der Zeijden, IAPO Chairman, "This is a landmark for patients around the world, which acknowledges the history of collaboration between WHO and IAPO over the past few years, and the contribution patients and their representatives – patients' organizations – can make to align healthcare systems with patients' needs". IAPO works closely with the WHO on health issues including Patient Safety and the WHO International Medical Products Anti-Counterfeiting Taskforce (IMPACT) worldwide.

IAPO will be holding a meeting at the United Nations in New York on 30 March 2007 on **Patient-Centred Healthcare: Aligning Healthcare Systems with Patients' Needs**. This meeting will be attended by the IPBF chairman Jane Meijlink. Feedback concerning this meeting will be given in the next newsletter.

PBS/IC in India

Awareness of PBS/IC is increasing in India, a country with over one billion inhabitants. IPBF board member Nagendra Mishra MD has been doing his utmost to raise awareness for many years now. This year the Urological Society of India

included a special session on PBS/IC in its annual conference USICON 2007 held in Patna, 7-10 February. Chaired by Nagendra Mishra, other speakers in this PBS/IC symposium included Professor Jorgen Nordling from Denmark. Dr Mishra took this opportunity to conduct a questionnaire survey among the urologists to gain an idea of the current situation in India regarding diagnosis and treatment. The questionnaire was also distributed at the Urologica 2007 conference in Goa, 28 February-1 March which also included a PBS/IC presentation by Dr Mishra. The Indian survey results are available on our website at: <http://www.painful-bladder.org/pdf/INDIAN%20SURVEY%20results%202007.pdf> or under "Surveys" on the menu.

ESU Course on CPPS/PBS at EAU congress

Those attending the EAU 2007 congress in Berlin may be interested in participating in ESU Course 5 on Chronic pelvic pain syndromes with special focus on chronic prostatitis and painful bladder syndrome/interstitial cystitis, chaired by Professor J-J Wyndaele from Antwerp. There will also be a poster session on "Urothelium: More than a barrier".

New look EAU website

The European Association of Urology has a redesigned website (www.uroweb.org) which gives easier access to information, including for example the EAU urological guidelines.

New Scientific Literature on IPBF website

A selection of new continually updated scientific literature can be found on our website: <http://www.painful-bladder.org/pubmed.html>. We have chosen a small sample for this newsletter.

Pregnancy and Interstitial Cystitis/Painful Bladder Syndrome

Erickson DR, Probert KJ. Urol Clin N Am 34 (2007)61-69. PMID: 17145362.

At last researchers have turned their attention to a problem that greatly concerns women with IC who are either pregnant or considering pregnancy. This paper by D.R. Erickson and K.J. Probert is both welcome and interesting. It addresses two main issues: how pregnancy affects the symptoms of PBS/IC, although it is clear that little is known about this; and drug safety and the risks that treatments commonly used for IC may carry in pregnancy. The authors also discuss the current state of knowledge on the subject of genetic factors in regard to IC.

Assessing urgency in interstitial cystitis/painful bladder syndrome.

Diggs C, Meyer WA, Langenberg P, Greenberg P, Horne L, Warren JW. Urology. 2007 Feb;69(2):210-4. PMID: 17275075.

Let us hope that this article on urgency in IC stimulates further research into this neglected area too. The authors examined urgency as presented in the Interstitial Cystitis Symptom Index, also known as the O'Leary-Sant Symptom Index. They found that the Index appeared to underestimate the prevalence and degree of urgency because it asked about urgency 'with little or no warning'. The authors conclude by asking that all important question: why do IC/PBS patients have urgency?

Mechanisms of disease: involvement of the urothelium in bladder dysfunction.

Birder LA, de Groat WC. Nat Clin Pract Urol. 2007 Jan;4(1):46-54. PMID: 17211425.

A clearly written review article on the sensory function of the urothelium, ideal for all of those who are finding it difficult to keep up with developments in this complex but very important subject area.

According to the authors, their findings suggest a sensory function for the urothelium which used to be considered a passive barrier. There is evidence that the urothelium responds to both physiological and chemical stimuli and can release a number of signalling molecules.

Full text available via PubMed.

Symptoms of interstitial cystitis, painful bladder syndrome and similar disease in women: a systematic review.

Bogart LM, Berry SH, Clemens JQ. J Urol. 2007 Feb;177(2):450-6. PMID: 17222607

This paper provides a useful overview of the origins and current usage of different terminology for similar symptoms. This study was aimed at developing a case definition of IC for use in epidemiological research. For this purpose, the authors carried out a literature review of IC, PBS, vulvodynia, pelvic floor dysfunction, OAB, chronic urethral syndrome, different urinary infections, endometriosis and types of incontinence. When examining the different symptoms, the authors state "that future research is essential to develop valid assessments of pain that includes the types of words that patients use to describe pain". As a result of their study, they suggest that "IC and PBS can be studied together as the same entity symptomatologically in women, and IC may be considered at this time to be a subgroup of PBS".

Direct access may be obtained to PubMed via:

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?DB=pubmed>

The PMID number is the article number that can be typed into the PubMed search window to find a specific article abstract.

Upcoming events

- **21-24 March 2007, European Association of Urology (EAU) annual congress, Berlin, Germany.**
- **23-25 March 2007: ICICJ PBS/IC symposium, Kyoto, Japan.**
- **30 March 2007, IAPO, Meeting on Patient-Centred Healthcare: aligning Healthcare Systems with Patients' Needs, United Nations New York, USA.**
- **21 April 2007, Interstitial Cystitis United of Texas, Patient Education Day Conference, Hotel Derek, Houston, Texas, USA. For more information, go to: http://www.icutexas.com/conference_2007.html.**
- **3-5 May 2007: ESSIC (European Society for the Study of IC/PBS) annual meeting, Münster, Germany. For programme see: <http://www.essic.eu/pdf/2007ESSICregistration.pdf>**
- **4/5 May 2007: EURORDIS annual membership meeting, Institut Pasteur, Paris, France.**
- **19-22 May 2007: AUA annual conference, Anaheim, California, USA.**
- **22 June 2007, Manejo Diagnostico y Therapeutico del Paciente con Síndrome de Sjogren, Palacio de Congresos de Madrid, with a parallel conference for patients.**
- **20-24 August 2007: ICS annual conference, Rotterdam, the Netherlands.**
- **2-6 September 2007: SIU annual conference, Paris, France.**

- **5-6 October 2007: IACM 4th Conference on Cannabinoids in Medicine, Cologne: 4th European Conference on Rare Diseases, Lisbon, Portugal.**

A more detailed list of conferences with contact addresses and websites can be found on our website under "Calendar".

Donations and sponsoring

The voluntary, non-profit IPBF is entirely dependent on sponsoring and donations to be able to carry out its projects. All donations to our valuable worldwide work will be most gratefully received. The IPBF has fiscal charity status in the Netherlands.

We would like to take this opportunity of thanking our sponsors the Medtronic Foundation, Medtronic Trading Sarl and Bioniche Pharma Group Ltd for their greatly appreciated financial support for our foundation, projects, website and newsletters.

With best wishes

Jane Meijlink

Chairman IPBF

On behalf of the Executive Board

International Painful Bladder Foundation

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The IPBF is an associate member of the International Alliance of Patients' Organizations (IAPO) www.patientsorganizations.org and the European Organization for Rare Diseases (EURORDIS) www.eurordis.org.

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