

# International Painful Bladder Foundation

*The **IPBF** is a voluntary non-profit organization*  
[www.painful-bladder.org](http://www.painful-bladder.org)

## IPBF E-Newsletter – August 2006

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

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

### **ESSIC Consensus Report 2006 with new classification method for PBS/IC**

The European Society for the Study of IC/PBS (ESSIC) held its 4<sup>th</sup> meeting in London in June this year. ESSIC recently posted a summary of its 2006 meeting consensus report on its website ([www.essicoffice.org](http://www.essicoffice.org) which can now also be accessed via [www.essic.eu](http://www.essic.eu)). This summary includes a revolutionary new classification method for PBS/IC patients presented in a table. If you take a look at the 2 page summary on the ESSIC website, you will see on page 1 the classification table and explanation of the symbols. ESSIC has endeavoured to classify PBS/IC patients on the basis of findings during cystoscopy with hydrodistension and morphological findings from biopsy. As you will see in the table, classification goes from **X** (not done) to **3** (most severe findings). This classification will be of great value in comparing patients. The ESSIC classification system will be presented during the NIDDK symposium in October. The fact that ESSIC has elected to use the name Bladder Pain Syndrome (BPS) instead of the recently adopted Painful Bladder Syndrome (PBS) will doubtless give rise to a lively debate in the coming period. Page 2 of the ESSIC summary gives an updated list of confusable diseases and how to exclude or diagnose them.

### **2006 NIDDK International Symposium**

A reminder to readers that the NIDDK International Scientific Symposium: Frontiers in Painful Bladder Syndrome and Interstitial Cystitis will be held at the Bethesda Marriott, Bethesda, MD, USA 26-27 October 2006. A very exciting scientific programme has been organized for this symposium with top researchers speaking on every aspect of PBS/IC. Excellent networking is guaranteed! This symposium is the ideal opportunity for doctors and researchers to exchange information and ideas on PBS/IC. The meeting website is <http://www.nidDK.nih.gov/fund/other/nidDKfrontiers>. Registration is possible online from this website. Please note that the deadline for submitting abstracts is 1 September.

### **ICA Bethesda Regional Conference**

The NIDDK Symposium will be immediately followed by the Interstitial Cystitis Association Bethesda regional conference to be held on 28 October at the Hyatt Regency Hotel Bethesda. Speakers will include top doctors and researchers attending the NIDDK Symposium. Further details will be published on the ICA website [www.ichelp.org](http://www.ichelp.org), in the July/August issue of ICA Update or may be requested from [icamail@ichelp.org](mailto:icamail@ichelp.org).

### **New Airline Security measures mean medication documentation is essential**

New airline security measures have led to restrictions on cabin baggage including medication. Patients travelling by air are now facing new restrictions regarding what they may take on board the aircraft in their hand baggage. Stringent restrictions are in place in the United Kingdom for all outgoing flights. The same applies to flights to and from many other countries, including the USA. If patients need to travel with prescription or nonprescription medication or medical devices (e.g. catheters), they are advised to contact their airline, travel

agent or government transport department for the latest news on restrictions. It is better to know in advance rather than to have your vital medication or equipment confiscated at the airport security check.

Medication may only be taken in hand baggage if verified as authentic. Patients are recommended to request an official letter from their doctor stating that they need to take specific medication or devices in the cabin, including non-prescription medication. Furthermore, the name on pharmacy labels on this medication will need to match the name on the passenger's ticket.

Urostomy appliances: We asked the Urostomy Association in the United Kingdom what advice should be given to patients wearing a urostomy appliance. They say that they are advising their members to carry a certificate, signed by their doctor, stating that they wear an appliance. They are also recommended to contact their airline to find out if they can carry all their appliances as hand luggage (which is usually recommended by the association) or whether they will need to put them in the hold.

See also: [http://www.painful-bladder.org/airlines\\_security.html](http://www.painful-bladder.org/airlines_security.html). We will endeavour to keep the website updated with the latest information.

### **Problems faced by patient organizations – how to keep pace?**

In recent years there have been so many developments in the field of IC that it has been difficult for patient organizations to keep pace. This is rapidly becoming a major problem for the patient organizations around the world which are the source of so much of the information available on PBS/IC. The patient organizations provide websites, leaflets, brochures, books, CDs, videos etc to patients, the general public, hospitals, government institutions and a variety of health professionals including family doctors. Education of the patient representatives responsible for this work is a big problem. New treatments, new insights, new approaches, new terminology mean that the patient organizations are soon left behind, while a national patient support group should really be the source of the most up-to-date information. It would be ideal if professional urology societies could organize an education programme for patient representatives from time to time. This could perhaps be linked to national or international urology conferences in different parts of the world. In this way, those responsible for writing and updating information for patients and the general public could stay abreast of developments and provide uniform medical information while retaining the different cultural approaches necessary for individual countries and regions.

### **Surfing the web... Useful websites**

#### **Health-EU Portal**

The Health-EU Portal is the new official public health portal of the European Union and presents a wide range of information and data on health-related issues at both European and international. The main objective of this Portal is to provide European citizens with easy access to comprehensive information on public health initiatives and programmes at EU level.

This will be a very useful reference site, particularly if you are seeking EU Legislation links, EU policies, events, publications and the latest health headlines. This website will hopefully facilitate life for everyone working in health fields in the EU.

[http://ec.europa.eu/health-eu/index\\_en.htm](http://ec.europa.eu/health-eu/index_en.htm)

#### **NIH Stem Cell information**

If you wish to learn more about stem cells, go to the official USA National Institutes of Health resource for stem cell research, with information ranging from the basics to research topics:

<http://stemcells.nih.gov/>

#### **Tissue Engineering**

Tissue engineering is also a hot topic these days. More information can be found on the Tissue Engineering Pages:

<http://www.tissue-engineering.net/>

### **Urological Pelvic Pain Collaborative Research Network (UPPCRN)**

The UPPCRN represents the overarching organization for collaborative research in chronic prostatitis, chronic pelvic pain syndrome, and interstitial cystitis; it serves as the official NIDDK Working Group on chronic pelvic pain of urological origin, to facilitate interaction of study groups and investigators, both nationally and internationally, to advance the understanding, diagnosis, and treatment of these diseases.

[http://porter.cceb.upenn.edu:7778/servlet/page?\\_pageid=389,391,400&\\_dad=portal30&\\_schema=PORTAL30](http://porter.cceb.upenn.edu:7778/servlet/page?_pageid=389,391,400&_dad=portal30&_schema=PORTAL30)

From here you can access the Chronic Prostatitis Collaborative Research Network and the Interstitial Cystitis Collaborative Research Network.

### **Google Scholar Beta**

<http://scholar.google.com>

Even though Google is right there inside my pc, I wouldn't have known about Google Scholar Beta if I hadn't read about it in the July/August issue of Urology News from the UK.

Its aims are:

- a) to search diverse sources from one place,
- b) help the user to find paper, abstracts and citations,
- c) to locate complete papers through your own library on the web,
- d) to help you learn about key papers in any area of research.

Not as specialized as PubMed, but nevertheless looks as though it may be a useful aid to searching for literature, especially once it has been further refined.

### **Scientific literature**

A selection of new scientific literature can be found on our website:

<http://www.painful-bladder.org/pubmed.html>. We would like to draw your attention to a small sample of these in this newsletter.

#### **♦ Recent developments of intravesical therapy of painful bladder syndrome/interstitial cystitis: a review**

Toft BR, Nordling J. Curr Opin Urol 2006;16:268-72

- A very useful up-to-date review of intravesical treatment.

#### **♦ Differential effects of the antimuscarinic agents darifenacin and oxybutynin ER on memory in older subjects.**

Kay G, Crook T, Rekedal L, et al. Eur Urol 2006;50:317-26

- An interesting article because oxybutynin is used not only by overactive bladder patients, but also by many PBS/IC patients. This study concludes that oxybutynin ER causes significant memory deterioration and that memory decline may be wrongly attributed to aging. Patients who may be susceptible can better avoid this medication.

#### **♦ Biology and therapy of fibromyalgia. New therapies in fibromyalgia.**

Arnold LM. Arthritis Res Ther 2006;8:212

- A review of new therapies in fibromyalgia. Useful for patients who have PBS/IC in association with fibromyalgia.

### **Upcoming events**

#### **LVII Congreso Nacional de Urología, Mexico**

The Mexican national urology conference, to be held 16-20 November 2006 in Puerto Vallarta, will include a pre-conference course on Painful Bladder Syndrome/Interstitial Cystitis on 16 November.

The Mexican IC support group ACI will be participating in the conference with a booth providing information on both PBS/IC and stress urinary incontinence.

ACI President Florentina Ferreyra continues with her regular appearances on radio and television on behalf of IC and incontinence patients. She and Mexican urologist Dr J.L. Campos were recently interviewed by a top radio station. These amazing PR activities are having a high impact with a spin-off throughout Latin America.

### **ICS 2006 Christchurch, New Zealand**

The annual conference of the International Continence Society which will be held in Christchurch, New Zealand from 27 November to 1 December 2006 will provide a unique opportunity for the IC support groups in New Zealand (Chairman Dot Milne) and Australia (Alice Terry) to profile themselves both at home and abroad. Dot Milne is taking every opportunity to maximise the impact with a pre-conference patient meeting. The New Zealand and Australian support groups say they normally feel so far away from all the action. In November they will at last have a slice of the action on their own doorstep. Further details about these support groups are available on the IPBF website [www.painful-bladder.org](http://www.painful-bladder.org).

In addition, the scientific programme of the ICS conference will feature three workshops of special interest to us:

*Painful Bladder Syndrome/Interstitial Cystitis and associated disorders: diagnosis & treatment*, chaired by Jørgen Nordling MD;

*Pelvic floor muscle and bladder pain syndromes: conservative management*, chaired by physiotherapist Helena Frawley;

*More than just a barrier: urothelium as a drug target for urinary bladder pain*, chaired by Lori Bird MD and Ricardo Saban MD.

All in all, this should greatly increase awareness and knowledge of many aspects of PBS/IC in this part of the world and internationally.

ICS conference website: [www.ics2006.co.nz](http://www.ics2006.co.nz).

### **Other upcoming events**

#### **2006**

- **13-16 September 2006: Pain in Europe V**  
*Istanbul. Turkey.*

#### **2007**

- **7-10 February 2007: Urological Society of India** annual conference, Patna, India  
(with PBS symposium)
- **21-24 March 2007, European Association of Urology (EAU)** annual congress,  
Berlin, Germany.
- **23-25 March 2007: ICICJ** International Consultations on PBS/IC, Kyoto, Japan.

*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.

With best wishes

**Jane Meijlink**

Chairman IPBF

On behalf of the Executive Board  
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The IPBF is an associate member of the International Alliance of Patients' Organizations (IAPO) [www.patientsorganizations.org](http://www.patientsorganizations.org) and the European Organization for Rare Diseases (EURORDIS) [www.eurordis.org](http://www.eurordis.org).

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