

International Painful Bladder Foundation

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

IPBF Newsletter – March 2006

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

Special news this month includes the publication in the March 2006 issue of European Urology Today (the news magazine of the European Association of Urology - EAU) of **“Interstitial Cystitis: definitions and confusable diseases. ESSIC Meeting 2005 Baden”**. You can find a direct link to this report on our home page: www.painful-bladder.org under “new literature”.

ESSIC is the **European Society for the Study of IC/PBS**, their new website can be found at www.essicoffice.org. Here too on the home page there is a direct link to the EUT article and also a link to the report in its original format. This report is the summary of the consensus reached on definitions and confusable diseases for painful bladder syndrome/interstitial cystitis at the meeting of ESSIC in Baden, 16-18 June 2005. The report comprises six sections: definitions, confusable diseases, procedures/tests that are necessary to detect the confusable diseases, proposed sequence of action in patients with IC-like symptoms, summary of the Report of the ESSIC Meeting Copenhagen 2003 with modifications, comments. A particularly interesting point is the new name put forward for Hunner's ulcer: Hunner's lesion. There is also for the first time a clear description of a Hunner's lesion. The comprehensive list of confusable diseases will help remind everyone of the fact that patients with symptoms of pain, urgency and frequency do not automatically have PBS/IC. There is a whole range of other possible causes of these symptoms which should be excluded. The precise detailing of the recommended procedures for diagnosis and evaluation will hopefully go a long way towards achieving standardisation and providing a sounder basis for future studies.

We would like to congratulate ESSIC members - and particularly Dr Joop P van de Merwe and Professor Jørgen Nordling who authored the report - for forging ahead despite the many obstacles. This consensus report is a new milestone in the history of PBS/IC for doctors and patients worldwide and forms a strong basis for further international scientific consultations. ESSIC will be organising its 4th annual meeting and course 8-10 June in London.

Hilarious but very apt cartoon

Professor J.J. Wyndaele recently described I.C. as being an abbreviation for **International Confusion**. If you take a look at www.essicoffice.org, click on the menu on **ESSIC: diagnostic criteria** (<http://www.essicoffice.org/criteria.html>), you will find a very amusing and extremely apt cartoon. However, the ESSIC report has shown that **International Confusion** does not necessarily have to be the case and that, despite coming from different countries and cultures, ESSIC members have been able to reach consensus.

Other new scientific literature

As always, a selection of new scientific literature can be found on our website: <http://www.painful-bladder.org/pubmed.html>. We have made just a small selection for this newsletter.

Dyspareunia and urinary sensory symptoms in India: population-based study.
Padmadas SS, Stones RW, Matthews Z. J Sez Med. 2006 Jan;3(1):114-20.

Bearing in mind next year's PBS symposium in India (see below), this study from Southampton, United Kingdom is particularly interesting. Although Dr Sabu Padmadas explained to us that there are limitations in this study since they did not conduct a clinical study to investigate dyspareunia, but instead used national level survey data, it is nevertheless the first of its kind and will be very useful for the Indian PBS symposium referred to above. The aim of the study was to determine the prevalence of dyspareunia and identify associated symptoms and sociocultural factors. The authors concluded that the prevalence of dyspareunia and the associated symptoms reported in this analysis could be underestimated due to possible underreporting and that there is a substantial hidden burden of sexual health problems, especially affecting young women.

Interstitielle Zystitis: Eine Wichtige Differentialdiagnose [Interstitial Cystitis: An important differential diagnosis]. *Van Ophoven A, Oberpenning F. Urologe A. 2006 Mar 14;*

This is a review in German in which the authors underline that neither the etiology nor the pathogenesis of the condition are as yet fully understood, that although distinct histopathological findings in the bladder wall are frequently found, they are not pathognomonic, and that any dogmatic utilization of the NIDDK diagnostic criteria will lead to an underdiagnosis of IC in 60% of the patients.

Cool and menthol receptor TRPM8 in human urinary bladder disorders and clinical correlations. *Mukerij G, Yiangou Y, Corcoran SL, et al. BMC Urol 2006 Mar 6;6(1):6*

According to the authors, this study demonstrates increased cold-menthol sensory receptors (TRPM8) in nerve fibres of overactive and painful bladder syndromes, and its relationship with clinical symptoms. They suggest that TRPM8 may play a role in the symptomatology and pathophysiology of these disorders and may provide an additional target for future overactive and painful bladder pharmacotherapy.

Keratin expression profiling of transitional epithelium in the painful bladder syndrome/interstitial cystitis. *Laguna p, Smedts F, Nordling J, Horn T, Bouchelouche K, Hopman A, De la Rosette J. Am J Clin Pathol. 2006 Jan;125(1):105-10.*

Bladder urothelium in PBS/IC showed distinct differences in the profiles of keratins 7,8,14,17,18 and 20 compared with literature reports for normal bladder urothelium. The severity of these changes varied between biopsy specimens. Whether these changes are primary or secondary to another underlying condition remains to be determined, according to the authors. NB: Keratins, of which 20 types are known, are the most important parts of the skeleton of the cell.

IFPMA Clinical Trials Search Portal

The non-profit, non-governmental organisation International Federation of Pharmaceutical Manufacturers & Associations (IFPMA) has a website with a Clinical Trials Search Portal which provides access to both ongoing and completed clinical trials:

<http://www.ifpma.org/clinicaltrials.html>

You can search here for clinical trials that are currently active and possibly recruiting patients in your country and you can also search for the results of completed clinical trials.

Instructions are given on how to search and how to refine your search. It is very simple to use. For example: type in interstitial cystitis and you will find trials worldwide, you can then refine this by adding the name of a country etc. Or you can search using the name of a drug.

Taipei Interstitial Cystitis Forum 22 April 2006

Professor Alex Lin of Taipei, Taiwan and the Taiwanese Continence Society have put together an excellent programme to cover all aspects of PBS/IC for the Taipei Interstitial Cystitis Forum 2006. Speakers include Professor Philip Hanno from the USA, Professor Yukio Homma and Dr Tomohiro Ueda from Japan with others from Taiwan, Malaysia, Korea and Hong Kong. The symposium will be held on 22 April at the Grand Formosa Regent Taipei. Professor Lin has expressed the hope that this meeting will generate useful information that will lead to better care for PBS/IC patients in Asia.

Painful Bladder Syndrome symposium, USICON 2007, India

The annual conference of the Indian Urological Society to be held in Patna, India, 7-10 February 2007, will include a symposium on Painful Bladder Syndrome. Dr Nagendra Mishra hopes that this will increase knowledge and awareness in India and help to ensure that more patients receive the right diagnosis and treatment. As symposium chairman, he will be inviting international speakers and patient organisations to attract the attention of the Indian urologists.

EAU congress – IPBF booth and course on CPPS, CP and PBS/IC

The annual congress of the European Association of Urology, 5-8 April in Paris, is now close at hand. The International Painful Bladder Foundation, booth B18, looks forward to seeing congress delegates at its booth during the congress.

The EAU congress always includes a range of excellent ESU courses. Course number 8 on 6th April will be on Chronic pelvic pain syndromes (CPPS) with special focus on chronic prostatitis (CP) and painful bladder syndrome/interstitial cystitis. Chaired by Professor Jørgen Nordling, other speakers are Professor JJ Wyndaele and Professor M. Fall. I think we can safely say that it promises to be an excellent course that will bring everyone fully up to date with the latest developments and insights.

9th Campbell's Urology – new chapter on PBS/IC

The 9th edition of this well-known urology reference work will be published in December 2006 under the new name of Campbell-Walsh. Philip Hanno MD has updated the chapter on IC, now featuring as Painful Bladder Syndrome/Interstitial Cystitis and Related Disorders and appearing as chapter 10. If you take a look at the website www.campbellsurology.com, you will find a sample chapter on the site for publicity purposes. I can assure you, you are in for a pleasant surprise! The sample chapter is chapter 10!!

Patient News

Belgium – ICPB patient conference 18 February 2006, Vilvoorde, Belgium

Although this was the second patient conference to be held in Belgium for PBS/IC patients, it was the first official conference and annual general meeting of the new patient support group Interstitiële Cystitis Patiëntenvereniging België. On 18 February in Vilvoorde, the acting chairman, Josee De Raa, and her committee were formally confirmed by the members. Since part of Belgium speaks Dutch and part speaks French, the ICPB - which is currently a Dutch-language organisation for Flemish patients - is now hoping to set up a French section for the French-speakers in Belgium. This means of course that everything will have to be translated into French. All patient organisations in Belgium have to deal with this language

problem. The ICPB is also planning to organise informal regional meetings for small groups of patients. They believe that this will give patients the opportunity to talk about their specific problems, exchange experiences and thereby help each other. The ICPB already has a twice yearly magazine for PBS/IC patients: Atlantis. The main problem faced by the ICPB at the moment is the usual one of “funding”!

An excellent presentation was given by Professor JJ Wyndaele on painful bladder syndrome/interstitial cystitis, followed by the opportunity for the patients to put their questions to the panel of Professor Wyndaele and IPBF chairman Jane Meijlink.

A detailed report of the meeting and Professor's Wyndaele's presentation can be found at: http://www.painful-bladder.org/2006_ICPB_Belgium.html

2nd Global Patients Congress of the International Alliance of Patients Organizations (IAPO), Barcelona, Spain

“Together we can...” promote patient-centred healthcare worldwide

Over 150 participants from IAPO member organizations worldwide, including the International Painful Bladder Foundation which was also on the organising committee, descended on Barcelona, 22-24 February, for the 2nd Global Patients Congress organized by IAPO in association with the Spanish Coalition of Citizens with Chronic Illness and the Catalan Rheumatology League.

The Congress in Barcelona brought together patient leaders from around the world, alongside healthcare representatives, including the global health professionals associations and the World Health Organization (WHO), to work together to develop strategies to bring patients to the centre of healthcare systems. The delegates from disease-specific and cross-disease organizations represented millions of patients with conditions including Alzheimer's disease, arthritis and rheumatism, asthma, autoimmune related diseases, Crohn's disease, cancers, diabetes, epilepsy, haemophilia, heart conditions, HIV/AIDS, incontinence, infertility, migraine and headache conditions, multiple sclerosis, osteoporosis, painful bladder syndrome/interstitial cystitis, polio, rare diseases and ulcerative colitis. The congress was the perfect opportunity for networking and making new contacts and delegates took full advantage of this throughout the congress.

The theme of the congress was fully supported by participants, reflecting their commitment to effect change through working in partnership to address the main issues considered during the Congress: **Patient-Centred Healthcare and Patient Safety.**

One of the key events of the week was the launch of **IAPO's Declaration on Patient-Centred Healthcare** on Wednesday 22 February. It is the first globally accepted definition of patient-centred healthcare developed by and representing the global patients' movement.

A second policy focus, on Thursday 23 February, lay on **patient safety** responding to the global problem of patient safety and counterfeit medicines.

Training and workshop sessions were conducted throughout the Congress focusing on:

- advocacy and communications;
- fundraising and maximising resources;
- effective networking.

A full report on this interesting global patient conference can be read on the IPBF website: http://www.painful-bladder.org/2006_IAPO_Barcelona.html

Coming up - Eurordis Annual Conference, Berlin

Eurordis, the European Organisation for Rare Diseases, will be holding its annual membership meeting 5-6 May 2006 in Berlin, Germany, consisting of the Annual General Assembly, Rare Diseases Awareness Conference and three Workshops. The three strategic issues of centres of reference, rare disease databases and patient registries and patient-driven research will be discussed. The conference is also an opportunity to network and meet members of Eurordis as well as many other people concerned with rare diseases.

The International Painful Bladder Foundation is an associate member of Eurordis.

Calendar for the coming months:

5-8 April 2006: European Association of Urology (EAU) annual congress, Paris, France.

22 April 2006: Taipei Interstitial Cystitis Forum 2006, Taiwan

27-29 April 2006: 9th International Symposium on Sjögren's Syndrome, Washington DC, USA.

10-13 May 2006 World Meeting on Gynecological Pelvic Pain and Endometriosis, Milan, Italy.

20-25 May 2006: American Urological Association (AUA) annual conference, Atlanta, Georgia, USA.

8-10 June 2006: 4th ESSIC Meeting, London, United Kingdom

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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