

International Painful Bladder Foundation

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

IPBF E-Newsletter, Issue 8, June 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**. The past few months have been a very busy time for us at the IPBF and for the PBS/IC world as a whole. Debate continues at all levels on the controversial issue of the name/renaming of the disease and the difficult and very complex issue of finding an adequate definition.

IPBF Questionnaire Survey study - reminder

The IPBF is currently conducting 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. The questionnaire is available on the IPBF website home page (www.painful-bladder.org) in MS Word and can be downloaded and filled in, either on your computer or by hand. It will also be distributed from the IPBF booth at the ICS 2007 conference in Rotterdam and the SIU conference in Paris. The IPBF would be grateful for your cooperation.

COB Foundation DVD “Living with Interstitial Cystitis”

The Cystitis & Overactive Bladder Foundation (COB Foundation) in the United Kingdom has produced a new and very moving DVD, comprising individual interviews with five IC patients about their pain and the impact of their bladder condition on their life, relationship and employment. This video really opens your eyes to the awful reality of this disease. Highly recommended for patients, families of patients and all health professionals working with IC patients. Price of the DVD is £3. Please contact the COB Foundation for details: info@cobfoundation.org. (Website www.cobfoundation.org)

EAU Annual Congress, 21-24 March 2007, Berlin, Germany

Although there have been IC information booths at the EAU congress since 2000, there are nevertheless many doctors and nurses every year still seeking practical

and up-to-date information for themselves or for their patients that they are apparently not receiving adequately elsewhere in their professional training, update courses or local conferences. However, today we see very clearly that doctors, nurses and other health professionals who have even just one IC patient are today seeking the best possible solutions for that patient.

As expected, many people – doctors and pharmaceutical representatives – stopped by the booth to discuss the problem of terminology and definitions. While there was no enthusiasm for a change of name, the right definition was considered to be very important. But what the doctors wanted most of all was detailed information on treatment options. There is a lack of information for doctors on all treatment that could be used, the most likely reason for this being that much of the treatment used for IC patients consists of non-evidence-based, off-label use of drugs. There is continued frustration about the unavailability and/or unaffordability of treatments and about what they should do with patients who fail to respond to any of the available treatments. There is also increasing interest in and awareness of associated disorders, particularly IC and irritable bowel syndrome symptoms.

A need was expressed by the health professionals for support groups and/or websites for patients with information in their own language. The IPBF has been asked to lend a hand in several different countries.

Our report on the EAU congress including reviews of relevant abstracts presented in Berlin can be found on:

http://www.painful-bladder.org/pdf/2007_EAU_Berlin.pdf.

2nd ICICJ, 23-25 March 2007, Kyoto, Japan

Overlapping with the EAU congress, the 2nd ICICJ symposium on interstitial cystitis was held in Japan that included discussions by invited international guests on the issue of nomenclature and definitions for IC. Nagendra Mishra MD, who represented India and the IPBF at this meeting, has provided an overview which can be found on:

http://www.painful-bladder.org/pdf/2007_ICICJ_Kyoto_NM.pdf.

The official full report of the meeting will be published in due course.

What are the issues that were being debated in Kyoto?

An important issue is on the one hand how to reach international consensus on **definitions and criteria** for research purposes that will ensure a scientifically homogeneous group of patients who have been diagnosed on a standard basis for studies, and on the other hand to provide doctors with clear guidelines for diagnosis in a clinical setting that will ensure that no patients slip through the net and are left in a limbo with no diagnosis at all and consequently no treatment, no access to social benefits and in many instances no reimbursement of medical expenses.

The **name issue** is no simple matter either, since while it is realized that interstitial cystitis is not the most accurate name medically speaking, the name painful bladder syndrome or bladder pain syndrome is not perfect either since some patients diagnosed with IC have no pain, only pressure. This is naturally an issue which requires careful consideration in joint consultation with ALL parties

involved and with ALL aspects and consequences of a name change being taken into account and is not an issue on which instant decisions can be made. Bearing in mind continuity and the many practical aspects related to a disease name, it is considered desirable by patient organizations - who are particularly affected by any name change - that the name IC should not be completely dropped. Patient organizations also expressed the opinion that the name should only be changed when and if research into IC comes up with an important medical breakthrough that truly necessitates a name change.

The current situation is as follows: the name *Interstitial Cystitis* is known, used and recognized worldwide, the more recent name *painful bladder syndrome*^{1,2} is now also used quite extensively, often in the combinations IC/PBS or PBS/IC. The currently controversial name *bladder pain syndrome* was very recently put forward by the International Association for the Study of Pain (IASP) and supported by the European Society for the Study of IC/PBS (ESSIC) in 2006. Another new (umbrella) name was proposed at ICICJ in Kyoto by Yukio Homma MD on behalf of the Japanese IC doctors: *hypersensitive bladder syndrome* (HBS).

Leroy Nyberg MD, speaking in Kyoto on behalf of the NIDDK, announced that the NIDDK had decided to take an entirely new approach to the study of IC since research so far has not led to any breakthrough in finding adequate treatment for the disease. According to Dr Nyberg, there is a need to change gear and the NIDDK will therefore hold a meeting in the autumn of 2007 to re-define the research definition. They plan to make the research definition less "bladder-centric" and make it more patient-centric and more holistic, focusing on IC as a systemic disease, with manifestations in the bladder, but also elsewhere in the body and will involve doctors from various disciplines, including international experts.

No international consensus was reached at this meeting which ended on a dramatic note with the building shaking from an earthquake. The Japanese doctors remained unperturbed by this and the Question & Answer session continued as though nothing was happening!

¹Abrams P *et al.* The standardisation of terminology of lower urinary tract function: report from the Standardisation Sub-committee of the International Continence Society. *Neurourol Urodyn* 2002, 21: 167-178

²Incontinence, 3rd International Consultation on Incontinence June 26-29, 2004, edited by P. Abrams, L. Cardozo, S. Khoury, A. Wein. Chapter 21 Painful Bladder Syndrome (including interstitial cystitis). Published 2005. Available online via www.icsoffice.org

IAPO top conference at United Nations, New York, 30 March 2007

The International Alliance of Patients' Organization is a unique global alliance representing patients of all nationalities and from all disease areas and promoting patient-centred healthcare around the world. Representatives of IAPO member organizations from around the world including the IPBF, United Nations NGO Health Committee members, healthcare professionals, academics, pharma representatives and other stakeholders converged on the United Nations in New York on 30 March 2007 for a day-long landmark meeting. The meeting successfully raised awareness of Patient-Centred Healthcare (PCH) at an international level, generated considerable support for the patient-led IAPO

Declaration on Patient-Centred Healthcare and produced a number of recommendations for future action. A full report on this unique conference can be found on: http://www.painful-bladder.org/pdf/2007_IAPO_NewYork.pdf
Detailed information on Patient-Centred Healthcare can be found on the IAPO website. The declaration can be downloaded at: www.patientsorganizations.org/declaration.

AUA annual meeting 19-24 May, 2007, Anaheim

Throughout the AUA conference in Anaheim, a main topic of conversation and behind-the-scenes discussions between IC experts, including the patient representatives attending the conference, was (as one might expect) the issue of nomenclature ("what are we supposed to call this disease?" "Is it essential to change the name right at this moment?") and the complex problem of finding a usable definition for both research and clinical diagnosis. The new holistic approach proposed by the NIDDK may cast light on the direction to be followed for research purposes.

During the conference, 27 abstracts were presented on studies that directly or indirectly concerned PBS/IC with many of these presented in a dedicated moderated poster session on *Infections/Inflammation of the Genitourinary Tract: Interstitial Cystitis* (abstracts 111-136).

A report on this conference including a review of all IC-related abstracts can be found on: http://www.painful-bladder.org/pdf/2007_AUA_Anaheim.pdf.

Webcasts from the AUA conference are available to browse through on: <http://webcasts.prous.com/aua2007/>

Annual membership meeting of EURORDIS, 4-5 May 2007, Paris

The European Organisation for Rare Diseases (EURORDIS) is a patient-driven alliance of patient organizations and individuals active in the field of rare diseases. The IPBF, an associate member of EURORDIS, attended the special 10th anniversary annual conference in Paris organized by Eurordis and Alliance Maladies Rares with the main theme of 'Gaining access to rare disease research resources'. It included a gala reception at which European MEP Françoise Grossetete spoke on rare disease legislation and the European Parliament. See: http://www.eurordis.org/article.php3?id_article=1248 for a full report with pdf files of presentations made at the workshop. It was announced that a European Union Conference on Research on Rare Diseases will be held in Brussels on 13 September 2007, further information will follow.

Vulvodynia in The Times

The National Vulvodynia Association in the US drew our attention to the fact that the British newspaper *The Times* published a very moving personal story of a patient's personal struggle with vulvodynia on 2 June 2007. You can read the article online by clicking on this link:

http://women.timesonline.co.uk/tol/life_and_style/women/body_and_soul/article1870117.ece

New Scientific Literature on IPBF website

A continually updated selection of new scientific literature can be found on our website: <http://www.painful-bladder.org/pubmed.html>.

A Supplement to Urology dedicated to interstitial cystitis was published in April: **Interstitial Cystitis as a disease: a new paradigm emerges**. Volume 69, number 4A. This supplement contains a large number of useful articles covering all aspects of IC.

In recent months we have seen a number of articles focusing on sexuality and IC including the following excellent study:

Sexual function is a determinant of poor quality of life for women with treatment refractory interstitial cystitis. Nickel JC, Tripp D, Teal V, Probert KJ, Burks D, Foster HE, Hanno P, Mayer R, Payne CK, Peters KM, Kusek JW, Nyberg LM; Interstitial Cystitis Collaborative Trials Group. J Urol. 2007 May; 177(5): 1832-6.

This study finds that sexual functioning plays a primary role in determining mental quality of life in women and suggests that multimodal therapy should include treatment aimed at improving this aspect of the IC patient's life.

Currently published online ahead of print but expected to be published in July: **Effect of comestibles on symptoms of interstitial cystitis**. Shorter B, Lesser M, Moldwin RM, Kushner L. J. Urol. 2007 May 10 [Epub ahead of print]. 92% of patients with PBS/IC in a validated questionnaire study indicated that consumptions of certain foods or beverages exacerbated their symptoms. The authors found no correlation between allergies and the effect of food and drink on symptoms. The most frequently reported and bothersome food items were coffee, tea, soda, alcoholic beverages, citrus fruits and juices, artificial sweeteners and hot pepper.

Upcoming events:

- 22 June 2007, Manejo Diagnostico y Therapeutico del Paciente con Sindrome de Sjogren, Palacio de Congresos de Madrid, Spain 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.
- 13 September 2007: European Union Conference on Research on Rare Diseases, Brussels, Belgium
- 5-6 October 2007: IACM 4th Conference on Cannabinoids in Medicine, Cologne, Germany
- 27-28 November 2007: 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 Board

International Painful Bladder Foundation

email: info@painful-bladder.org

www.painful-bladder.org

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