

International Painful Bladder Foundation

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

IPBF E-Newsletter, January 2007

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

We would like to take this opportunity of wishing everyone around the world a very Happy and Healthy New Year 2007!

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**.

NIDDK Symposium Summary Report

The **2006 NIDDK Symposium: Frontiers in Painful Bladder Syndrome and Interstitial Cystitis Summary Report** has now been posted by the NIDDK with a link on the symposium website and is available to download at:

<http://www.niddk.nih.gov/fund/other/niddkfrontiers/>.

It can also be reached via our website home page www.painful-bladder.org. This is important reading for all those who were unable to attend the symposium and a valuable work of reference for all those who were in Bethesda. Much important research and new developments and insights were presented in Bethesda. Many thanks are due to the NIDDK.

Annual conference of the International Continence Society

The annual conference of the International Continence Society (ICS) was held 27 November to 1 December 2006 in Christchurch, New Zealand against a backdrop of snowcapped mountains even though it was summer in the southern hemisphere. The New Zealand IC Support Group took full advantage of this event in Christchurch to organise a 2-day patient meeting immediately prior to the ICS conference, with Dr Anna Rosamilia over from Australia for the ICS as one of the speakers. Congratulations to Dot Milne NZ ICSG coordinator and her committee for this excellent weekend meeting.

The ICS conference included two workshops relating to PBS/IC. It was clear from these workshops that there are considerable regional differences in the approach to PBS/IC. A large number of abstracts on PBS/IC were submitted for this conference.

The IPBF and the New Zealand support group shared a complimentary and ideally located IC info booth. The large number of visitors to the booth included many nurses and physiotherapists who – certainly in this part of the world – are showing a great deal of interest in PBS/IC. The many doctors who came to the booth made it clear that life would be a lot easier if only there could be international consensus on terminology, definitions, criteria and diagnostic procedures and less confusion caused by the current proliferation of different terms. Let us hope that the international consultations on PBS/IC being held at the 2nd ICICJ in Kyoto, Japan in March will come up with positive results in this respect.

We were delighted at long last to have the opportunity of meeting in person clinical nurse consultant Christine Murray from the Mercy Hospital in Heidelberg, Australia. Christine Murray has been running an IC patient support there for some years and told us that they hold regular patient meetings.

For our full report on all the PBS/IC activities surrounding the ICS conference including the patient meeting, ICS scientific programme and abstracts of interest to the PBS/IC world, see:

<http://www.painful-bladder.org/pdf/2006ICSreport.pdf>.

ICS 2006 webcasts and the abstract database can be found on the ICS website: www.icsoffice.org.

Australians take their toilets seriously

Take a look sometime at the Australian National Public Toilet Map website: www.toiletmap.gov.au. This is a project of the National Continence Management Strategy of Australia. If every national and local authority around the world took its public toilet responsibilities as seriously, life would be a lot easier for PBS/IC patients. Serious global campaigns are needed a) to get public toilets provided in the very many places where they don't exist and b) to get the existing toilets cleaned up!

Education through comic strips

In order to combat the problem of taboos surrounding incontinence, the Australian Commonwealth Government has produced an ingenious cartoon comic strip brochure on incontinence for indigenous Australians (Aboriginals and Torres Strait Islanders) entitled **The Continence Gang – Stories of gaining control over bladder and bowels**, by Esther Quintal and superbly illustrated by Simon Kneebone. This excellent initiative could be a great idea for other bladder conditions including IC in countries with similar problems.

Catalan patient support group

There is now a Catalan support group for IC patients in Barcelona, Spain. President of this group is Monica Hernandez. Their website and contact details can be found at <http://cistintersticial.webcindario.com/> or <http://www.acaci.tk>.

Course in Spanish on Sjögren's syndrome for professionals

We recently heard from Jenny Inga Diaz, chairman of the Spanish support group for Sjögren's patients, that a course for professionals on the diagnosis and treatment of Sjögren's syndrome (Manejo Diagnóstico y Terapéutico del Paciente con SS), organized by Dr D. Ramos-Casals, is to be held on 22 June 2007 at the Palacio de Congresos de Madrid. Further information may be obtained from Jenny (aessjogren@hotmail.com).

A parallel patient conference will be held for Sjögren's patients and may be of interest to Spanish-speaking IC patients who want to know more about this autoimmune disease or who have the combination IC/SS. This group has an excellent magazine **Gota a Gota** and a website at www.aesjogren.org.

New Scientific Literature on IPBF website

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

Sensory bladder disorders.

Nordling J. Int J Clin Pract Suppl. 2006 Dec; (151):38-42

A very useful up-to-date overview of diagnosis and evaluation of patients with an update on treatment.

Management of recurrent vulvovaginal candidiasis: unresolved issues.

Sobel JD. Curr Infect Dis Rep. 2006 Nov; 8(6):481-6

This review looks at the limitations of treatment with fluconazole and a discussion of the possible reasons for these limitations and a failure to cure.

This article is of interest in relation to IC patients since this group of patients can suffer very painful exacerbation of their IC bladder symptoms if they also have vulvovaginal candidiasis.

Discovery of morphological subgroups that correlate with severity of symptoms in interstitial cystitis: a proposed biopsy classification system.

Leiby BE, Landis JR, Propert KJ, Tomaszekewski JE; Interstitial Cystitis Data Base Study Group. J Urol. 2007 Jan; 177(1):142-8.

In this study, the researchers identified morphologically distinct subgroups in IC using cluster analysis and investigated the associations between cluster membership and urinary symptoms. Their data indicate the presence of subgroups within the clinical diagnosis of IC. The researchers are of the opinion that these subgroups may represent a severity index relating primary symptoms to biopsy features. They propose a new working system for the classification of bladder biopsies in patients fulfilling clinical criteria for IC. Their results suggest an important role for histopathological features in the predictive modelling of IC symptoms and subgroup identification.

IPBF website – Scientific literature on selected topics

This new section of our website (to be found via the menu) now provides scientific literature references for anyone wishing to know more on specific topics. Many of the references are linked through to the PubMed abstract or have a PMID code which can be typed into the PubMed search window.

Book review

While written for health professionals, **A Practical Guide to Female Pelvic Medicine**, edited by Gamal Ghoniem & G Willy Davila is so clearly written and well laid out that it is a valuable basic read for anyone wanting an overview of female pelvic floor disorders distilled into one easily readable volume. Written in plain and uncomplicated English, it could therefore also provide those with responsibility for running support groups for IC patients with useful background medical information and allow them to see PBS/IC in the wider context of the pelvic floor. A chapter on the assessment of the chronic pelvic pain patient and a separate chapter on interstitial cystitis are a clear indication of the increasing attention being paid to pelvic pain syndromes and IC.

Published by Informa Healthcare. ISBN: 1841843989.

Upcoming events in 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 Consultation on PBS/IC, Kyoto, Japan.
- **3-5 May 2007: ESSIC (European Society for the Study of IC/PBS)** annual meeting, Münster, Germany.
- **4/5 May 2007: EURORDIS** annual membership meeting, Institut Pasteur, Paris, France.
- **19-22 May 2007: AUA** annual conference, Anaheim, California, USA
- **20-24 August: ICS** annual conference, Rotterdam, the Netherlands

- **2-6 September: SIU** annual conference, Paris, France.
- **27-28 November: 4th European Conference on Rare Diseases**, Lisbon, Portugal.
- **5-6 October: IACM 4th Conference on Cannabinoids in Medicine**, Cologne, Germany.

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 support of our foundation, projects, website and newsletters.

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 and the European Organization for Rare Diseases (EURORDIS) www.eurordis.org.

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