

International Painful Bladder Foundation

*The IPBF is a voluntary non-profit organization
for interstitial cystitis and painful bladder syndrome*
www.painful-bladder.org

IPBF E-Newsletter, Issue 10, December 2007

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

**The International Painful Bladder Foundation would like to take this opportunity of sending you
season's greetings and wishing you a healthy, happy and successful New Year 2008!**

IPBF: Successful 2007

The IPBF can look back on a very successful year 2007 in which it has helped provide patients and patient support groups around the world with information on the latest developments in the field and has actively continued its endeavours to raise awareness and increase understanding of PBS/IC among health professionals worldwide so as to ensure that people with PBS/IC obtain the right diagnosis. Without a diagnosis, nobody gets treatment. Without a diagnosis, or with the wrong diagnosis, patients are left in intense physical, social and psychological suffering.

International Symposium on definitions: date for your diary!

The National Institutes of Health /National Institute of Diabetes & Digestive & Kidney Diseases (NIH/NIDDK) have announced that an International Symposium will be held in Bethesda, Maryland, USA, 16-17 June 2008, entitled: **Defining the Urologic Chronic Pelvic Pain Syndromes – A New Beginning**. This will be your chance to participate and have your say on this important issue, so put this date in your diary now!

NIH/NIDDK Workshop on “The Multidisciplinary Approach to Defining the Urologic Chronic Pelvic Pain Syndromes” held in Baltimore, 13/14 December

The over forty participants attending this brainstorming workshop in Baltimore included doctors from the USA, Canada, Europe, Japan, India and Taiwan from various medical disciplines, representatives from industry, as well as a number of representatives from the patient movement including the IPBF.

The overall purpose of the Urologic Chronic Pelvic Pain Working Group is to redefine the two major urologic pelvic pain syndromes (Interstitial Cystitis/Painful Bladder Syndrome and Chronic Prostatitis/Chronic Pelvic Pain Syndrome) in the context of the other major syndromes with which they are commonly associated (Chronic Fatigue Syndrome, Fibromyalgia, Irritable Bowel Syndrome, Vulvodynia and others). The definitions will be finalized at the Symposium in June 2008. These definitions will be utilized for research studies so that published data in all of these relevant areas will be using a common working definition.

The main aims of this workshop were to discuss the disease definitions and diagnostic protocols of the major Chronic Pelvic Pain Co-Morbid Disorders (Interstitial Cystitis, Chronic Prostatitis, Fibromyalgia, Chronic Fatigue Syndrome and Irritable Bowel Syndrome); to discuss interrelationships among these disorders; to identify common symptomatology; to discuss methodology for a comprehensive diagnostic evaluation of persons with these symptoms to ensure a complete evaluation for all relevant co-morbidities.

In other words, this workshop aimed to set in motion a new approach to PBS/IC and CP/CPPS, based on relationships with other pain syndromes, and to look for a common pathway and links between the syndromes. It was specifically not the intention of this workshop to discuss names.

Day one included presentations on evidence for an interrelationship between the chronic pelvic pain disorders covering fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, vulvodynia, chronic abacterial prostatitis/CPPS and IC/PBS and what symptoms all these conditions have in

common and to what extent they overlap. Day two was used to summarise the previous day's intensive discussions. The intention is for two articles to be published: one outlining why the disorders are thought to be related and a second explaining how this changes the way we look at urologic pain syndromes.

Rounding off the workshop, it was concluded that while the perspective has become broader in terms of how the disorder is going to be viewed, IC and CP will not lose their unique identity. Dr Leroy Nyberg from the NIDDK explained that IC and CP have now become part of a large family with many different cousins. Rheumatologist Professor Daniel Clauw (USA) and urologist Professor Jorgen Nordling (Denmark) also reminded us that we should not forget that there may be groups of PBS/IC patients who only have a bladder problem and not a systemic disorder. It is hoped that future studies will identify these groups.

In the meantime a special NIDDK website will be set up on which a summary of this workshop will be placed along with all new developments in the coming period. We will let you know as soon as this website has been launched. It will hopefully be in January 2008.

Be alert to other symptoms and disorders

The NIDDK research project is a reminder to both patients and health professionals treating PBS/IC patients to be on the alert to the possibility of other symptoms which might indicate the presence of other pain syndromes or autoimmune diseases. The IPBF has a useful first screening questionnaire comprising a few questions to assess the possibility of a PBS/IC patient having other disorders. This list drawn up by Dr Joop van de Merwe (Netherlands) at present comprises questions for: allergy, asthma, Crohn's disease and ulcerative colitis, fibromyalgia, irritable bowel syndrome, rheumatoid arthritis, Sjögren's syndrome and systemic lupus erythematosus. This list can be downloaded from: <http://www.painful-bladder.org/pdf/QuestionsAssDisPBS.pdf>.

In reverse, health professionals treating patients with these other disorders should be on the alert for the possibility of bladder symptoms.

IAPO seminar on Public Health and Intellectual Property held in Geneva

IPBF board members Nagendra Mishra and Jane Meijlink attended the IAPO seminar on the complex issues of Public Health and Intellectual Property in Geneva on 6 November 2007 which was held parallel to the 2nd meeting of the World Health Organisation Intergovernmental Working Group (IGWG) on Public Health, Innovation and Intellectual property.

Jo Harkness, Chief Executive of IAPO, took the opportunity to call on the WHO to bring patient groups to the centre of discussions on public health, innovation and intellectual property in an address to WHO member state government delegates and designated experts, among others, at the second session of the intergovernmental working group (IGWG) on public health innovation and intellectual property. Read more: <http://www.patientsorganizations.org/showarticle.pl?id=834>

European Conference on Rare Diseases

Lisbon recently hosted the 4th European Conference on Rare Diseases 27-28 November, 2007. This event was organised by the European Organisation for Rare Diseases (EURORDIS) and nine partners, under the patronage of the Portuguese Ministry of Health in the context of the Portuguese EU Council Presidency and was supported by the Public Health Programme of the European Commission DG SANCO. The conference, attended by the IPBF, was a unique opportunity for patients, healthcare professionals, policymakers and industry representatives to interact with decision-makers from the European Commission and member states and debate on key policies and actions aimed at improving the lives of people affected by rare diseases.

Public Consultation draft document

The European Commission DG SANCO used this rare diseases conference in Lisbon to launch an unprecedented public consultation concerning European action in the field of rare diseases. The draft document will be available online in several languages and the EC would like all interested parties from all parts of the world to read it and send their comments by 14 February 2008 to sanco-rarediseases-consultation@ec.europa.eu

The Consultation document:

http://www.ec.europa.eu/health/ph_threats/non_com/docs/raredis_comm_draft.pdf

Further information can be found on the EURORDIS website:
http://www.eurordis.org/article.php3?id_article=1617

Information on Pain: IASP website

The website of the International Association for the Study of Pain (IASP: www.iasp-pain.org) is a mine of information on pain. The Global Year against Pain in Women 2007-2008 started in October this year and information about this is provided on the website. An excellent selection of pain fact sheets, including chronic pelvic pain, is available on the website in a variety of different languages (English, Spanish, French, Russian, Arabic, and two forms of Chinese). Under "Publications", you will find the Clinical Updates on many different pain topics. A Clinical Update on opioid side effects can also be found here at:

<http://www.iasp-pain.org/AM/AMTemplate.cfm?Section=Home&CONTENTID=3852&TEMPLATE=/CM/ContentDisplay.cfm>
It's well worth browsing around this interesting website for information on pain of all kinds.

PBS/IC Patient Organization News

New patient support group in Argentina

A new IC patient support group has been set up in Rosario, Argentina. Their Spanish language website is: www.araci.org.ar. We wish ARACI President Liliana Bacchi and her committee every success. Further details are on our list of patient organisations and contacts.

New support group association Texas, USA

The former ICU Texas has been replaced by a new patient-led, non-profit organization: PURE HOPE, which is a support group association for chronic pelvic pain conditions based in Texas (President Cindy Sinclair). Their new website can be found at www.pure-hope.org.

Useful source of information on PBS/IC

The University of Maryland Interstitial Cystitis Center: <http://icresearch.umaryland.edu/> has a regular newsletter on IC and information on their trials. The Publications section on this website includes the latest scientific articles from the research centre including "Evidence-based criteria for the pain of interstitial cystitis/painful bladder syndrome in women. Warren JW, Brown J, Tracy JK, Langenberg P, Wesselman U, Greenberg P".

Health-EU

Health-EU <http://health.europa.eu> is the Public Health Portal of the European Union. It is a single point of access to reliable and easy-to-find information on a wide range of health-related issues. Health-EU speaks all the official EU languages.

Education:

ARHP/ICA announce joint education programme

The Association of Reproductive Health Professionals and the Interstitial Cystitis Association in the USA have announced that they have launched a joint education programme entitled Screening, Treatment and Management of Interstitial Cystitis/Painful Bladder Syndrome (IC/PBS). For further information see:

<http://www.arhp.org/healthcareproviders/visitingfacultyprograms/icpbs/index.cfm>

NVA's CME/CE Online Tutorial on Chronic Vulvar Pain

The National Vulvodynia Association (www.nva.org) announced the release of its CME/CE accredited online tutorial for health care professionals entitled, *Vulvodynia: Integrating Current Knowledge into Clinical Practice*. This tutorial, jointly sponsored by the NVA and the Dannemiller Memorial Educational Foundation, is free to all viewers. The programme includes a self-guided presentation on the prevalence, differential diagnosis, treatment and etiology of chronic vulvar pain. To access the tutorial, please visit <http://learn.nva.org>.

If you have any questions about the programme or experience a problem accessing it online, please contact Christin Veasley, NVA Associate Executive Director, by email (chris@nva.org) or phone (401-398-0830).

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>. Most of these have a direct link to the PubMed abstract. In the past year we have seen an increasing number of scientific articles "In Press" being published early online (on the Journal website) as "Epub ahead of print" sometimes long before they are published in the journals. While abstracts are usually available on PubMed, the pre-publication articles can only be read online if you have access to that specific journal.

New scientific articles of interest include:

Re-imagining Interstitial Cystitis.

Hanno PM. Urol Clin North Am. 2008 Feb;35(1):919.

An interesting and useful article on the current definition and nomenclature issues that reviews the historical background, developments and changes from the earliest days of IC and Painful Bladder Syndrome to the present day's apparent impasse and lack of global consensus despite five years of international meetings.

Pharmacologic management of painful bladder syndrome/interstitial cystitis: a systematic review.

Dimitrakov J, Kroenke K, Steer WD, Berde C, Zurakowski D, Freeman MR, Jackson JL. Arch Intern Med. 2007 Oct 8;167(18):1922-9.

Over 180 different therapies have been tried for PBS/IC, yet evidence from trials remains inconclusive. This study concludes that PPS may be modestly beneficial for PBS/IC. There is insufficient evidence for other pharmacologic treatment. A consensus on standardized outcome measures is urgently needed as also emphasized in the Cochrane review below.

Intravesical treatments for painful bladder syndrome/interstitial cystitis.

Dawson T, Jamison J. Cochrane Database Syst Rev. 2007 Oct 17;(4):CD006113.

The aim of this Cochrane review was to assess the effectiveness of intravesical treatment for PBS/IC. It was concluded that overall the evidence base for treating PBS/IC using intravesical preparations is limited and the potential for meta-analysis reduced by variation in the outcome measures used. The quality of trial reports was mixed and in some cases precluded any meaningful data extraction. Randomized controlled trials are still needed and it is suggested that another important consideration in future trials should be the eligibility criteria. NIDDK criteria do not always reflect clinical practice and the authors believe that consideration should be paid to using wider diagnostic criteria based on more clinical grounds

Painful bladder syndrome/interstitial cystitis and vulvodynia: a clinical correlation

Peters K, Girdler B, Carrico D, Ibrahim I, Diokno A

Int Urogynecol J Pelvic Floor Dysfunct. 2007 Nov 24 [Epub ahead of print]

The aim of this study was to clinically evaluate the association of PBS/IC and vulvodynia and possible contributing factors. The authors are of the opinion that the relationship between vulvodynia and PBS/IC may have been underestimated and that further research needs to examine the link between precipitating factors, symptoms and effective treatment options for PBS/IC and vulvodynia.

Voiding urges perceived by patients with interstitial cystitis/painful bladder syndrome

Greenberg P, Brown J, Yates T, Brown V, Langenberg P, Warren JW. NeuroUrol Urodyn. 2007 Oct 11; [Epub ahead of print]

IC/PBS is a symptom-based diagnosis. The authors studied the symptom commonly referred to as "urgency" and its relationship to IC/PBS in a group of women with recent onset of the disease. At least two distinct experiences of urge to urinate are evident in this population. For most, urge is linked with pain relief and is associated with bladder filling/emptying. About 1/5 reported urge to prevent incontinence. A similar portion did not agree with either urge, indicating that they may experience altogether different which needs further study.

Diagnostic Criteria, Classification, and Nomenclature for Painful Bladder Syndrome/Interstitial Cystitis: An Essic Proposal.

Van de Merwe JP, Nordling J, Bouchelouche P, et al. Eur Urol 2008 Jan;53(1):60-7.

The European Society for the Study of IC/PBS (ESSIC) presents its consensus on definitions, classification system and list of confusable diseases and its controversial decision to use

nomenclature based on the urogenital pain taxonomy of the International Association for the Study of Pain (IASP). ESSIC proposes to classify types according to findings at cystoscopy with hydrodistension and morphologic findings in bladder biopsies. For further details including consensus, classification table and list of confusable diseases, see website:
<http://www.essic.eu/pdf/ESSICconsensus2006.pdf>.

Diagnosis of interstitial cystitis/painful bladder syndrome in patients with overactive bladder symptoms.

Macdiarmid SA, Sand PK. Rev Urol. 2007 Winter;9(1):9-16

Overactive bladder and IC/PBS have similar symptoms in some patients, making them difficult to differentiate. According to the authors, both conditions may represent a clinical manifestation of a hypersensitive bladder. It is particularly important that IC be considered in OAB patients who do not respond to treatment. This article is available free online:

<http://www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&pubmedid=17396167>

Neural mechanisms of pelvic organ cross-sensitization.

Malykhina AP. Neuroscience. 2007 Sep 8; [Epub ahead of print]

Recently, increasing attention has been paid to the possibility of pelvic organ cross-sensitization. Clinical observations of viscerovisceral referred pain in patients with gastrointestinal and genitourinary disorders suggest an overlap of neurohumoral mechanism underlying both bowel and urinary bladder dysfunctions. The close proximity of organs in the abdomen complicates identification of the precise source of chronic pelvic pain. This review analyses the complexity of overlapping neural pathways and possible mechanisms underlying crosstalk between pelvic organs.

A prospective, single-blind, randomized crossover trial of sacral vs pudendal nerve stimulation for interstitial cystitis.

Peters KM, Feber KM, Bennett RC. BJU Int. 2007 Oct;100(4):835-9

The aim of this blinded, randomized trial was to compare sacral nerve stimulation (SNS) with pudendal nerve stimulation (PNS) for interstitial cystitis (IC) in 22 patients with well-documented, refractory IC. A tined lead was placed at S3 and a second electrode implanted at the pudendal nerve via a posterior approach. A pudendal lead was implanted successfully in all patients, and most chose PNS as giving a better result than SNS.

Diagnostic criteria for Pudendal Neuralgia by Pudendal Nerve Entrapment (Nantes Criteria).

Labat JJ, Riant T, Robert R, Amarenco G, Lefaucheur JP, Rigaud J. Neurorol Urodyn. 2007 Sep 7; [Epub ahead of print]

The diagnosis of pudendal neuralgia by pudendal nerve entrapment syndrome is essentially clinical. There are no specific clinical signs or complementary test results of this disease, but various clinical features can be suggestive of the diagnosis. The authors' aim was to define criteria to aid diagnosis. A working party validated a set of simple diagnostic criteria (Nantes criteria) and exclusion criteria. They concluded that while the pudendal neuralgia by pudendal nerve entrapment syndrome is essentially clinical, a combination of criteria can be suggestive of the diagnosis.

Book review:

NORD Compendium of Rare diseases and Disorders

This fully revised and expanded NORD Compendium of Rare Diseases and Disorders from the National Organization for Rare Disorders (NORD) in the USA is the most comprehensive and authoritative resource of its kind, providing information on the diagnosis and management of over 1,100 rare diseases and disorders. For further information and to order, visit: www.liebertpub.com.

Upcoming events 2008:

International Alliance of Patients' Organizations (IAPO)

The IAPO 3rd Global Patients Congress will be held 20-22 February 2008 in Budapest, Hungary. IAPO's vision of patient-centred healthcare will be the over-arching theme of this event with a special focus on how patient involvement in all levels of decision-making can help to align healthcare systems with patients' needs. How patient-centred healthcare can improve access to health, patient information and patient safety will also be central to the programme.

IAPO's Global Patients Congress provides a unique opportunity for patient representatives to meet and work together towards a common vision of patient-centred healthcare worldwide. Representatives

from patient organizations will also have the opportunity to interact with health professionals, healthcare policy-makers and industry representatives from all over the world. For more information please see IAPO's website: www.patientsorganizations.org/congress2008

Fundacion Geiser

The Fundacion Geiser (Geiser Foundation) – a group providing linkage, research and support for rare diseases in Latin America – is organizing the first Latin American Congress of Rare Diseases and Orphan Drugs, 27-29 March 2008 in Buenos Aires, Argentina. Further information about this organization and the congress can be found on their website: <http://www.fundaciongeiser.org>.

4th International Consultation on Incontinence (ICI) including PBS

The 4th ICI will be held 5-8 July, Paris, France. It will include presentations by 23 Committees on many aspects of incontinence and pelvic dysfunction. The presentation by Committee 19, chaired by Philip Hanno MD, on Painful Bladder Syndrome will take place on Sunday 6 July.

This workshop is designed to help transform data into knowledge and knowledge into action following the principles of Evidence Based Medicine. It will:

1. Review the current state of knowledge on Incontinence.
2. Propose a widely accepted strategy for the practical diagnostic and therapeutic management of Incontinence following the Evidence Based Medicine principles.
3. Propose validated standard international instruments (i.e. Symptom Scores) to evaluate incontinence in collaboration with the major associations involved in the field of Incontinence
4. Help standardize response criteria and recommendations for clinical research on Incontinence.

The consultation's methodology follows the Evidence Based Medicine Principles defined in collaboration with the Oxford and the Cochrane groups.

The recommendations of the committees will be published in book form and will include discussions that take place during the 4th ICI.

World Pain Congress with satellite symposium on urogenital pain

The 12th World Congress on Pain (17-22 August 2008, Glasgow) will include an official satellite symposium entitled: "Update on Urogenital Pain: Current Issues and Controversies" on 15-16 August 2008 at the Glasgow Marriott Hotel. Topics will include Past, Present and Future of Urogenital Pain, Current Practice and Published Outcomes, Future models for the management of urogenital pain, Assessment algorithms, Treatment algorithms. Further information is obtainable from the IASP website: www.iasp-pain.org.

Dates for your diary in brief:

- **International Alliance of Patients Organizations (IAPO)**, Global Patients' Congress 2008: Patient-Centred Healthcare, 20-22 February 2008, Hilton Budapest, Hungary.
- **Geiser Foundation: Congreso Latino Americano de Enfermedades Raras** (Latin American Congress on Rare Diseases), 27-29 March 2008, Buenos Aires, Argentina.
- **European Association of Urology annual congress**, 26-29 March 2008, Milan Italy
- **International Pelvic Floor Dysfunction Society**, International Congress, 9-11 April 2008, Moscow, Russia.
- **American Urological Association annual meeting**, 17-22 May 2008, Orlando, Florida, USA.
- **ICORD 2008: The 4th International Conference on Rare Diseases and Orphan Drugs:** Global Approaches for Rare Diseases Research and Orphan Products Development, 20-22 May 2008, Washington D.C., USA
- **European Society for the Study of IC/PBS (ESSIC) annual meeting**, 5-7 June, Rome, Italy (members only).
- **NIH/NIDDK International Symposium: Defining the Urologic Chronic Pelvic Pain Syndromes.** 16-17 June 2008, Doubletree Hotel Bethesda, Maryland, USA.
- **4th International Consultation on Incontinence (ICI)**, 5-8 July 2008, Palais des Congres, Paris, France.
- **12th World Congress on Pain**, 17-22 August 2008, Glasgow, Scotland, UK. Preceded by a satellite symposium organised by the IASP special interest group on Pain of Urogenital Origin (PUGO) 15-16 August, 2008, Glasgow Marriott Hotel, Scotland: "Update on Urogenital Pain – Current Issues and Controversies."
- **International Urogynaecological Association (IUGA) annual conference**, 11-14 September 2008, Taipei International Convention Center, Taipei, Taiwan.

- **International Continence Society (ICS) annual conference**, 20-24 October 2008, Cairo, Egypt, including a Public forum.

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

Donations and sponsoring – the IPBF needs your help!

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 charitable status in the Netherlands.

We would like to take this opportunity of thanking our sponsors: the Medtronic Foundation, Medtronic Trading Sarl, Bioniche Pharma Group Ltd and private donors 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 of the
International Painful Bladder Foundation
email: info@painful-bladder.org
www.painful-bladder.org

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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