

International Painful Bladder Foundation

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

IPBF E-Newsletter, November 2006

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**.

NIDDK Symposium on PBS/IC

The highlight in recent months was undoubtedly the NIDDK scientific symposium: "Frontiers in Painful Bladder Syndrome and Interstitial Cystitis", October 26-27 at the Bethesda Marriott on the outskirts of Washington. Our full report can be found on our website at: http://www.painful-bladder.org/2006_NIDDK_Bethesda.html

Pain focus

This year there was a bigger focus than ever seen before at an NIDDK symposium on both research into pain and treatment of pain. Hopefully, insights from the research will ultimately lead to new therapeutic possibilities. It was repeatedly stressed that many patients suffer from multiple pain syndromes. A question put to the participants was: why do some IC patients suffer from multiple pain syndromes and others only from painful bladder syndrome/IC? Some patients have several concomitant disorders with IC, why some patients but not all? If only we knew the answers! It was clear to everyone that IC patients are all different and respond differently to treatment. IC is still an enigma.

Sexual dysfunction

Dr J. Curtis Nickel from Canada gave a very welcome presentation on the impact of IC on the sexual life of patients, displaying great empathy and understanding for the patients. "Are we not essentially sexual beings?" he asked. "This is a fact that most urologists and other physicians managing patients diagnosed with IC/PBS appear to have forgotten or ignored".

European ESSIC consensus

A session devoted to European opinion on PBS/IC led to a great deal of debate. Professor Jørgen Nordling from Denmark presented the consensus reached by members of ESSIC (European Society for the Study of IC/PBS www.essic.eu) on a new definition for PBS/IC, with a new classification system based on typing and a new name which would replace the name IC completely. The classification system is fully described in our report on our website. The new name is Bladder Pain Syndrome (BPS) and comes from the Task Force on Taxonomy (taxonomy = classification) of the International Association for the Study of Pain (IASP). This name, we were informed, is in line with the IASP terminology for other pelvic pain syndromes. However logical this name change may seem to the scientists, the patient organizations not surprisingly expressed the deepest concern during the symposium regarding the huge potential impact on the patient movement and the patients themselves. It has taken them many

years of hard work to get the name IC and the disease IC accepted in the healthcare world for the benefit of patients.

However, we will have to await developments in the coming year to see whether this proposed name is accepted by the IC world as a whole or not. It is to be hoped that further discussions will be held between all parties worldwide. More will follow on this subject in our following newsletter.

Exclude confusable diseases

Also from ESSIC, Dr Joop P. van de Merwe emphasized that every effort needs to be made to exclude other relevant causes (so-called “confusable diseases”) of the symptoms, but that it should be remembered that some patients may have one (or more) of these confusable diseases and IC together. Excluding confusable diseases means excluding them as the sole cause of the symptoms.

“Urgency” in IC

A further point of discussion was the fact that the term ‘urgency’ has been removed from the ESSIC definition. It was pointed out by the IPBF that urgency is an important element of IC in the eyes of the patient. Research into urgency and IC should now be given priority before any further refinement of the term ‘urgency’ and exclusion of IC patients from use of this term takes place. It was therefore gratifying to see a poster at the symposium by Dr Jack Warren and colleagues on “Assessing urgency in interstitial cystitis/painful bladder syndrome”.

With the annual conference of the International Continence Society starting next week in Christchurch, we can expect to see further discussions on nomenclature, definitions and the issue of urgency and IC during the conference in New Zealand. Abstracts can be found on the ICS website (www.icsoffice.org) and include a number on PBS/IC, including one from Australia on urgency. We will report back on this in our next newsletter

Patient survey poster

We were delighted and very honoured that our abstract on the “Patient survey on nomenclature and definition of painful bladder syndrome/interstitial cystitis and the nature of urgency in PBS/IC patients” was accepted for the poster session at the NIDDK symposium. The abstract, poster and a full report on the patient survey can be found on the home page of the IPBF website (www.painful-bladder.org). I would like to thank all the patients who so kindly took the time to respond to the survey and thereby made this possible.

ICA regional meeting

The NIDDK symposium was followed the next day by a regional conference of the Interstitial Cystitis Association (ICA) at the Hyatt Regency Hotel nearby in Bethesda. A packed audience listened spellbound to two excellent speakers, both of whom have very evident compassion and commitment for IC patients. Dr Robert Moldwin, author of the Interstitial Cystitis Survival Guide and always an exciting and energetic speaker, spoke on Interstitial cystitis: where are we now, where are we going? He reviewed all aspects of IC and answered questions from patients. This presentation was followed by the well-known pain consultant Dr Daniel Brookoff who emphasized that the treatment you want is the treatment that gets you better! Like many speakers at the NIDDK symposium, he also underlined that all patients are different and all respond differently to treatment. Drugs for IC work on some people and not on others. This makes treatment so frustrating for both doctors and patients.

Airline security and medication

If you are traveling by air, please check out the latest security information regarding hand baggage. At the moment passengers are permitted to take medication with authentication from your doctor or pharmacy, but all liquid medication has to be placed in resealable plastic bags and handed separately for security screening at the airport security point. New security measures came into effect on 6 November 2006 for all flights departing from the UK and arriving or in transit in the UK. The latest information can be obtained from the website of the British Department for Transport: http://www.dft.gov.uk/stellent/groups/dft_transsec/documents/page/dft_transsec_613514.hcsp

Whatever country you are travelling to or from, please check with your airline and own country regarding liquid medication.

Cure-IC (Center of Urologic Research Excellence – Interstitial Cystitis)

website: <http://mediasite.cidde.pitt.edu>

To access this website, go to the Pittsburgh mediasite, look on the menu on the left and click on “Awareness and Hope for Interstitial Cystitis” where you can enjoy five lectures by five different speakers,

The mission of “Hope for IC – Fishbein Family Foundation - Cure-IC” as explained by Dr Michael Chancellor is “to bring exciting research from the lab to the bench top to help patients today”. There are excellent presentations on Research Directions in IC, Pain Management, Physical Therapy and Symptom Management in IC.

If you click on lecture 4 with Dr Vicki Ratner, president of the ICA, you will be able to follow a very clear overview of all aspects of the disease and its impact on the patient, including her personal experience as a patient.

Highly recommended for both patients and professionals, these presentations also provide very useful information for patient support groups with the added bonus that you can keep playing them over and over again. This is particularly useful for those whose native language is not English.

NVA revised website www.nva.org

The National Vulvodynia Association in the USA, an excellent source of the latest information on vulvodynia for both patients and professionals, has a revised website. Particularly interesting is the booklist: there are plenty of books here that an IC patient would also find useful. Healthcare professionals can benefit from the teaching program on chronic vulvar pain available on this website and from the section specifically for professionals.

Guided Imagery CD – For relaxation in women with pelvic pain or interstitial cystitis.

This CD comes from the William Beaumont hospital WISH program (Women’s Initiative for Pelvic Pain and Sexual Health) Guided Imagery uses words to direct one’s thoughts and attention to imagined sensations that one seems to see, hear, touch or smell in order to feel more relaxed. The imagery on this CD is specific for the pain, frequency and urgency symptoms that the women with IC and Pelvic Pain feel. It is intended to decrease these symptoms and promote healing. Please note: it is not a substitute for healthcare.

For further information and ordering, please contact: LLampkins@beaumont.edu or phone: 1-248-551-3565.

3rd ICI publication now online

The 3rd International Consultation on Incontinence (ICI) set of 2 volumes is now available online on the ICS website. Go to www.icsoffice.org. Click on [documents](#). Scroll down the page until you reach “The following publications are available online”.

Here you will find the link to the two volumes of this publication. Published in 2005, this is a very useful work of reference.

IASP website

The website of the International Association for the Study of Pain (IASP): www.iasp-pain.org.

UroToday

The UroToday website provides an update on scientific information in all fields of urology, including IC. Go to www.urotoday.com and look down the menu for interstitial cystitis.

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.

Dysfunction of bladder urothelium and bladder urothelial cells in interstitial cystitis.

Graham E, Chai TC. Curr Urol Rep 2006;7:440-6

A very useful review for those who can't yet quite follow the scientific technicalities of the urothelium. Contains a clear description of the structure of the urothelium.

Cross-organ interactions between reproductive, gastrointestinal and urinary tracts: modulation by estrous stage and involvement of the hypogastric nerve.

Winnard KP, Dmitrieva N, Berkley KJ. Am J Physiol Regul Integr Comp Physiol 2006;291:R1592-601

The authors tell us that central nervous system neurons process information converging from the uterus, colon and bladder, partly via the hypogastric nerve. This study with rats tested the hypothesis that acute inflammation of one pelvic organ (including the bladder) might produce signs of inflammation in other pelvic organs, suggesting that the cross-organ effects involve the hypogastric nerve and are at least partly centrally mediated. The authors suggest that effects of this kind could contribute to co-occurrence and cyclicity of distressing pelvic disorders in women

There is low incidence of recurrent bacteriuria in painful bladder syndrome/interstitial cystitis patients followed longitudinally.

Stanford E, McMurphy C. Int Urogynecol J Pelvic Floor Dysfunct 2006 Oct 12

The purpose of this study was to establish whether patients with diagnosed PBS/IC presenting with UTI symptoms actually have a bacterial infection or a flare of the PBS/IC symptoms. The results of the study suggest that the symptom flares of IC are not usually associated with recurrent urinary tract infections and, therefore, are likely due to a triggering of the other painful mechanisms in IC patients with a negative culture.

Vulvodynia: a state-of-the-art consensus on definitions, diagnosis and management.

Bachmann GA, Rosen R, Pinn VW, Utian WH, Ayers C, Basson R, Binik YM, Brown C, Foster DC, Gibbons JM Jr, Goldstein I, Graziottin A, Haefner HK, Harlow BL, Spadt SK, Leiblum SR, Masheb RM, Reed BD, Sobel JD, Veasley C, Wesselmann U, Witkin SS. J Reprod Med. 2006 Jun;51(6):447-56.

A consensus document published in June 2006 with recommendations from a panel of experts on definitions, diagnostic procedures and treatment of the different types of vulvar pain (vulvodynia)

This article was reviewed in detail in [NVA News](#), volume XI, issue III, Summer 2006.

Cranberry and urinary tract infections: slightly fewer episodes in young women, but watch out for interactions. *Prescrire Int.* 2006 Aug;15(84):145-6.

This article is in the English language version of the French journal *Prescrire* (www.prescrire.org). It originally appeared in *Prescrire* in May 2006 (no. 272). It states that while daily use of cranberries in the form of juice or tablets was shown to be of slight help in reducing infections, it warns that several case reports of interactions with [warfarin](#) have been published, including one involving severe bleeding. Patients on vitamin K antagonists should be warned about this risk of interaction so that avoid consuming cranberry-based products without medical supervision.

Upcoming Events

ICS 2006 Christchurch, New Zealand

The annual conference of the International Continence Society will be held in Christchurch, New Zealand from 27 November to 1 December 2006. The International Painful Bladder Foundation, shared with the IC Support Group of New Zealand.

PBS/IC is well represented among the abstracts on the conference website www.ics2006.co.nz. There will also be three workshops in this field:

- 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.

Other upcoming events:

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**

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

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