

International Painful Bladder Foundation

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

IPBF E-Newsletter, Issue 12, June 2008

An IPBF update for IC/PBS patient support groups, country contacts, healthcare professionals and friends around the world.

IC/PBS SCIENTIFIC HIGHLIGHTS AT THE AUA 2008, ORLANDO

With the innovative NIH/NIDDK Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) research programme about to be launched, an unprecedented amount of attention was paid to IC/PBS and chronic pelvic pain syndromes at the annual meeting of the American Urological Association in Orlando. Research varied from the most complex basic science to clinical studies of every description presented in several different sessions, along with no fewer than three educational courses on IC/PBS/ CPP and a state-of-the-art plenary lecture by Dr Philippe Zimmern on the urologist's approach to pelvic pain syndrome in women.

The main take-home messages and highlights were:

- Locate the source of the pain. Is it in the bladder or elsewhere? Identify other possible pain generators.
- Exclude other possible causes of the symptoms. Don't automatically assume that all patients with pain, urgency and frequency have IC/PBS. They may have some other curable condition.
- Get the patient treated at the earliest possible stage.
- In the field of treatment, the spotlight was on intravesical alkalized lidocaine, with or without heparin.
- A new method of cystoscopy from Japan using narrow band imaging attracted considerable attention.
- A study on urgency focused on differentiating between urgency in IC/PBS and urgency in OAB.

Read our Detailed Review of the IC/PBS scientific highlights per presentation, abstract or course on our website:

http://www.painful-bladder.org/pdf/2008_AUA_Orlando.pdf

EAU 2008 CONGRESS IN MILAN

The 23rd congress of the EAU was a great success with over 14,000 participants, surpassing the record set in Berlin 2007. Delegates came from over 84 countries worldwide. As EAU Secretary-General Professor Per-Anders Abrahamsson told delegates, the EAU may be based in Europe, but it is now fast becoming a urological society with global influence. There was relatively little research presented this year on IC/PBS. However, the IPBF once again had a very successful booth at the EAU

congress with all kinds of information in a variety of languages and leaflets from many different patient support groups. Huge amounts of information were distributed on every aspect of IC and related disorders. This is a clear indication that there is still a great need worldwide for even the most basic information. Our booth at the EAU congress is also an important opportunity to gain feedback from clinicians working at the grass roots in countries around the world. The biggest problem is treatment and the fact that IC patients respond so differently. There is no such thing as the “standard” IC patient. Input received on the IPBF booth underlines the huge social, cultural, ethnic and economic differences around the globe. Western approaches are not always in tune with cultures in other corners of the earth. Many doctors came to our booth to ask how to set up a patient support group. It is clear to physicians that patients learn to cope better if they have contact with each other and can help each other.

Our review of the EAU congress can be found at:

http://www.painful-bladder.org/pdf/2008_EAU_Milan.pdf

NIDDK SYMPOSIUM: DEFINING THE UROLOGIC CHRONIC PAIN SYNDROMES: A NEW BEGINNING

We would like to remind you that an international symposium will be held 16-17 June 2008 at DoubleTree Hotel and Executive Meeting Center Bethesda, Bethesda, USA. The purpose of this symposium is to enlist expert opinion concerning the numerous factors involved in defining the urologic pelvic pain syndromes. Updates will be given on such topics as: classifying urologic chronic pain syndromes, advanced diagnostic studies for characterizing the pain syndromes, epidemiological data for overlap of chronic pelvic pain syndromes, developing biomarkers for the chronic pain syndromes, and many other topics. The meeting will explore the pros and cons of developing a unifying definition, as well as the need for phenotyping persons with these disorders. Interactive discussions will be strongly encouraged among speakers, participants, and the panel of consultants. The meeting will be informative for clinicians, basic scientists, patients, patient advocacy groups, pharmaceutical representatives, and the public interested in developing a further understanding of the urologic chronic pelvic pain syndromes and associated disorders. A major outcome will be development of a definition of these diseases and their phenotypes, which will be used in future NIDDK-funded research studies and the upcoming network for a Multidisciplinary Approach to the Study of Pelvic Pain.

Registration is free of charge and the meeting is open to all interested parties. The symposium website with all details of registration and the programme can be found at:

<http://www3.nidk.nih.gov/fund/other/UrologicPainSynd/index.htm>

INTERSTITIAL CYSTITIS RESEARCH PROGRAMME GRANT APPLICATIONS INVITED FROM UK-BASED RESEARCHERS

Following a legacy from a member of the Cystitis and Overactive Bladder Foundation (COB), the COB Foundation is pleased to invite grant applications for research in one or more of the following areas:

- Aetiology of interstitial cystitis
- Epidemiology of the disease
- Neurophysiology
- Serum or urine markers

- Potential IC treatment modalities
- Alternative treatments for IC
- Dietary requirements and IC

Suitable applicants will be specialists in urology, or urogynaecology, with a special interest in Interstitial Cystitis. The COB research programme is for one or more projects from £2,000 up to £20,000. Research must be completed within one year.

Deadline for application(s): 21st July 2008. For further information and a grant application form, please contact: The COB Research Panel, The Cystitis and Overactive Bladder Foundation (COB), 76 High Street, Stony Stratford, Bucks, MK11 1AH, United Kingdom. Tel: 01908 569 169. Email: info@cobfoundation.org

NATIONAL VULVODYNIA ASSOCIATION INVITES RESEARCH PROPOSALS

The National Vulvodynia Association (USA) invites research proposals focusing on the classification, etiology, diagnosis and/or treatment of generalized vulvodynia or vulvar vestibulitis syndrome.

Grants typically range from \$15,000 to \$25,000. NVA requires confirmation that all funds will be applied to direct research costs, not institutional costs.

If you are interested in applying, please submit a 1-page letter of intent to Christin Veasley (chris@nva.org) by **June 30, 2008** outlining the following:

- Name and professional background of the primary investigator
- Study objective and time frame
- Budget summary (US dollars)

NVA will email you application guidelines following receipt of your letter of intent.

Completed applications are due August 8, 2008.

If you have previously submitted a proposal to NVA, you are invited to re-apply.

Applicants do not have to be US residents.

Summaries of studies previously funded by the NVA can be viewed on NVA's web site: http://www.nva.org/for_medical_professionals/research_fund.html.

NVA welcomes correspondence about potential projects. Contact Christin Veasley via email (chris@nva.org) or phone (401-398-0830).

NEW IPBF CONTACT PERSON IN SAO PAULO, BRAZIL

We are very happy to have a second contact person for IC patients in Brazil: Dr Fernando Almeida, chief of the Female Urology & Voiding Dysfunction division at the Federal University of Sao Paulo. Contact details are on our website under Brazil: http://www.painful-bladder.org/globalgroups_etc.html.

NEW PATIENT LITERATURE

IC/PBS handbook from the UK

A new updated handbook for patients and their families on Interstitial Cystitis/Painful Bladder Syndrome is now available from the Cystitis and Overactive Bladder Foundation (COB). This clearly written handbook provides practical information about all aspects of diagnosis, treatment and living with IC/PBS. Please contact info@cobfoundation.org for ordering details.

NIDDK Easy-to-Read patient information

The NIDDK's online easy-to-read publications now also include: "What I need to know about Interstitial Cystitis/Painful Bladder Syndrome".

http://kidney.niddk.nih.gov/kudiseases/pubs/interstitialcystitis_ez/index.htm

This easy-to-read text is in addition to its well-known, more detailed online patient brochure:

<http://kidney.niddk.nih.gov/kudiseases/pubs/interstitialcystitis/index.htm>.

For a complete list of all NIDDK patient information in the field of kidney & urologic diseases, please go to:

<http://kidney.niddk.nih.gov/kudiseases/pubs/interstitialcystitis/index.htm>. Some of this patient information is available in Spanish as well as English.

TAIWANESE IC GROUP HAS A CHINESE LANGUAGE WEBSITE

The Taiwan Interstitial Cystitis Association (TICA), initiated by Dr Lee Ming-Huei, has a Chinese language website for IC patients at: www.twica.org.tw. An English-language video about IC and the many activities of TICA can be seen at <http://www.youtube.com/watch?v=rb94yL06cTU>. TICA also publishes a quarterly newsletter and organizes patient meetings with talks by health professionals. Urologists in Taiwan are very active in the field of PBS/IC, not only nationally but also in the international arena with Dr Alex Tong-Long Lin playing a leading role.

Please contact TICA if you would like information about IC in Chinese (icatw@mail.taic.doh.gov.tw).

ARACI SUPPORT GROUP (ARGENTINA) GETS INTERNATIONAL PUBLICITY AT LATIN AMERICAN RARE DISEASES CONFERENCE

Asociación Rosarina Afectados Cistitis Intersticial (ARACI), a recently founded support group for IC in Argentina, was represented at Congreso Geiser (Latin American Congress on Rare Diseases) 27-29 March by ARACI chairman Liliana Bacchi and Alejandra Reviglione who have both worked very hard to get this new support group off the ground. They produced a poster on IC and distributed information material on IC. This was a perfect way to raise awareness of what is still a little known disease in Latin America and a fantastic initiative which will help to ensure that IC becomes better known in this part of the world. Congratulations!

UroToday

UroToday regularly produces many different kinds of review on IC. Go to www.urotoday.com, take a look down the menu on the left and click on IC/PBS/BPS to stay updated. You can register for free access and sign up for email UroAlerts, an ideal way to keep up with your armchair research.

UroToday International Journal® (UIJ)

As stated by Karl-Erik Andersson MD, editor-in-chief, in his introduction to this new online journal, UIJ is a “peer-reviewed, fast-tracked urology and urologic oncology publication. UIJ focuses specifically on the professional global urology and urologic oncology community. It will elevate the access to relevant urology and oncology science to professionals around the world. UIJ will make the scientific information available to a much wider audience than that reached by other journals, including potential readers who do not have access to a research library that can afford to pay

for journal subscriptions. There is no charge to register, submit or publish an article in the UIJ.” Read more about this unique venture at:

http://journal.urotoday.com/urotoday_international_journal/

PRE-SUFU 2008 INTERNATIONAL MEETING IN MIAMI DISCUSSED AREAS OF AGREEMENT AND CONSENSUS IN IC/PBS/BPS

An international meeting was organized by the Society for Urodynamics and Female Urology on 27 February prior to their Winter Meeting in Miami. It was attended by IC experts from around the world, including Libby Mullin speaking on behalf of the ICA and Jane Meijlink for the International Painful Bladder Foundation.

Philip Hanno MD, who also co-chaired the meeting with Roger Dmochowski MD, has written a review of all presentations that can be found on UroToday at:

http://www.urotoday.com/99999999/browse_categories/prostatitis/sufu_2008_winter_meeting_society_for_urodynamics_and_female_urology_holds_international_meeting_to_assess_areas_of_consensus_and_disagreement_regarding_interstitial_cystitis_bladder_pain_syndrome.html.

IASP CLINICAL UPDATE: GENDER, PAIN AND THE BRAIN

The International Association for the Study of Pain (IASP, www.iasp-pain.org) has clinical updates on its website that are freely available to all website visitors. Go to the IASP website, click on “Publications” and then click on “Clinical Updates”. Their latest very interesting clinical update is: “Gender, Pain and the Brain”. It makes a fascinating read. You may also find it interesting to look at the clinical update from February: “Opioid-induced hyperalgesia”.

Keep your eye on this website. It is a mine of useful information on pain.

EAU EUROPEAN UROLOGY WEEK

The European Association of Urology will organise Urology Week from 15-19 September 2008. The aim is to create more awareness among European men and women over 50 years with regard to urological conditions and the work of the urologist. The EAU has defined 3 key subjects for this year: prostate conditions, erectile dysfunction and incontinence. It plans to officially launch a new website in September, www.urologyweek.org. The site will be a patient-oriented site which should help patients find information about their complaints and how to solve them. Although there is no IC/PBS this year, at least the chronic prostatitis patient groups in Europe should be able to join in. For further information, please contact Lindy Brouwer: l.brouwer@uroweb.org.

PHASE II INTRAVESICAL TREATMENT POSITIVE RESULTS

Urogen Pharmaceuticals Inc. recently closed a Phase II study of URG101 due to positive, statistically significant results at interim analysis with 50 percent patient enrolment. URG101, an investigational bladder instillation for the treatment of IC/PBS, is a proprietary pharmaceutical treatment comprised of lidocaine and heparin. This Phase II study was a multi-centre, double-blind, randomized, placebo-controlled, cross-over study comparing URG101 to placebo. Further information can be found at: <http://www.rogen.com/>.

INTERNATIONAL MEETING ON UROGENITAL PAIN Update on Urogenital Pain: Current Issues and Controversies

A 2-day meeting will be held 15-16 August 2008 at the Glasgow Marriott Hotel, Scotland. This meeting is being organised by the PUGO (Pain of Urological Origin, a special interest group of the International Association for the Study of Pain, PUGO website: <http://www.indoorcat.org/pugo/>). The international faculty will comprise experts in the field of urogenital pain at both clinical and research levels. There will be time for discussion and the development of consensus opinions. This meeting precedes the World Congress on Pain in Glasgow, allowing delegates to remain in the city for both events if they so wish. The PUGO satellite meeting is an important meeting for all those interested in the IASP pain taxonomy.

4TH INTERNATIONAL CONSULTATION ON INCONTINENCE (ICI) 5-8 July 2008, Paris, France

The 4th International Consultation on Incontinence is organized by the International Consultation on Urological Diseases (ICUD) and the International Society of Urology (SIU) in collaboration with the major associations of urology gynaecology and urodynamics. The objectives of the consultation are to help transform data into knowledge and knowledge into action following the principles of evidence-based medicine. 23 topics will be under discussion. Committee 19 chaired by Philip Hanno MD will discuss painful bladder syndrome. Following the presentation of the committee's findings, delegates attending will have the opportunity to comment and these comments will be taken into account in the preparation of the ICI report in book form. Details are available at:

<http://www.congress-urology.org/congres2008/accueil.html>.

SELECTED NEW SCIENTIFIC LITERATURE

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.

Please note that our review of the latest IC/PBS research presented at the AUA 2008 meeting can be found at:

http://www.painful-bladder.org/pdf/2008_AUA_Orlando.pdf

Recent scientific articles include:

On the origin of bladder sensing: Tr(i)ps in urology.

Everaerts W, Gevaert T, Nilius B, De Ridder D. *Neurourol Urodyn.* 2008;27(4):264-73. PMID: 17489480

A review article from Belgium. The mammalian TRP family consists of 28 channels that can be subdivided into 6 different classes. In this review, the authors endeavour to summarize existing knowledge about TRP channels in the urogenital tract.

Although only TRPV1 (the vanilloid receptor) has been extensively studied so far, more evidence is steadily accumulating about the role of other TRP channels in the (patho)physiology of the urogenital tract, according to the authors.

Results of endovesical hyaluronic acid/chondroitin sulphate in the treatment of interstitial cystitis/painful bladder syndrome.

Porru D, Cervigni M, Nasta L, *et al.* Rev Recent Clin Trials 2008;3:126-9. PMID: 18474023.

The purpose of the study was to find a more viscous (thicker) substance than hyaluronic acid (hyaluronan) alone for intravesical treatment of IC/PBS patients and to see if this would improve quality of life for the patient. The theory behind this is that both of these substances help to restore the glycosaminoglycan protective layer of the IC/PBS bladder and that a more viscous substance would adhere better to the bladder wall and therefore protect it better. This was a preliminary study with just 23 female patients but led to a significant improvement. The authors concluded that this combination appears to be a safe and efficacious form of treating IC/PBS and that a follow-up study is warranted. It may hopefully prove to be a useful addition to the treatment arsenal.

Mast cell-derived histamine mediates cystitis pain.

Rudick CN, Bryce PJ, Guichelaar LA, *et al.* PLoS ONE 2008 May 7;3(5):e2096 PMID: 18461160

In this study, the authors were looking for what causes the pelvic pain in their mouse model. They found that mast cells were required for the pain. They demonstrated this by showing that mice which lacked mast cells had no pelvic pain, but that pain was restored when bladder mast cells were restored. They found that mice that lacked either histamine receptor 1 (H1R) or histamine receptor 2 (H2R) had much less pelvic pain. After trying antihistamines to selectively block histamine receptors, they concluded that mast cell histamine was causing pelvic pain in their IC/PBS model by activating H1R and H2R and that only H1R and H2R are treatment targets (in the mouse model). They also showed that these drugs were not functioning by reducing bladder damage. Instead histamine causes pelvic pain strictly at the level of pain, not pathology. These data are also consistent with previous clinical findings that the antihistamines cimetidine and hydroxyzine show at least partial efficacy in IC patients. The authors believe that it would be interesting to see if newer generation antihistamines are even more effective against pelvic pain and IC.

The full article is available free at:

[PLoS ONE: Mast Cell-Derived Histamine Mediates Cystitis Pain](#)

Quantifying mast cells in bladder pain syndrome by immunohistochemical analysis.

Larsen MS, Mortensen S, Nordling J, Horn T. BJU Int. 2008 Apr 2 [Epub ahead of print]. PMID: 18384636.

The traditional method of counting mast cells is considered to be rather cumbersome. This study evaluated an alternative, simpler method of counting mast cells in bladder biopsy samples from IC patients using a less complicated method with tryptase staining and smaller slices of bladder muscle. Both methods showed similar results.

Psychological profile of Taiwanese interstitial cystitis patients.

Fan YH, Lin AT, Wu HM, Hong CJ, Chen KK. Int J Urol. 2008 May;15(5):416-8

PMID: 18452458.

These researchers found that most of their Taiwanese patients had significant depression and anxiety and that the extent of the symptoms appeared to correlate with the severity of the IC symptoms.

Treatment of Bladder Pain Syndrome/Interstitial Cystitis 2008: Can we make evidence-based decisions?

Fall M, Oberpenning F, Peeker R. Eur Urol 2008 Apr 3 [Epub ahead of print]. PMID: 18403099.

A review of treatment for IC/PBS/BPS for which, according to Magnus Fall and colleagues, there are so many hypotheses that it is difficult to identify the most relevant. "This mirrors lack of knowledge; our understanding of basic mechanisms causing bladder pain is fragmentary and insufficient." Controlled studies are few and far between. A significant problem is the issue of inclusion and exclusion criteria for studies. Definitions have become loose and vary markedly between centres and in different parts of the world. Studies give conflicting results: sometimes a pilot study looks positive while a follow-up study is negative. Everyone has their own different perceptions as to what interstitial cystitis and painful bladder syndrome are and how they should be treated. According to the authors, this disease is in fact "a heterogeneous spectrum of disorders, still poorly defined, and different experts have varying perceptions as to what IC is about."

Evidence-based criteria for pain of interstitial cystitis/painful bladder syndrome in women.

Warren JW, Brown J, Tracy JK, *et al.* Urology 2008;71:444-8. PMID: 18342184.

In this Events Preceding Interstitial Cystitis study, pain that worsened with a certain food or drink and/or worsened with bladder filling and/or improved with urination was reported by 151(97%) of 156 patients; these were the only three criteria that applied directly to the bladder. The same three criteria described the pain of 262 (97%) of 270 women in the Interstitial Cystitis Database who "definitely" had IC/PBS. The authors concluded that this triad might describe the pain of IC/PBS and contribute to a sensitive case definition. They warn, however, that pain has only recently been considered to be an essential component of IC/PBS and that previous studies reported only 63%-92% of IC patients with pain. There may indeed be IC patients who do not perceive pain.

This article is available free at:

<http://www.pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&pubmedid=18342184>

PhD DISSERTATION ON CYCLOSPORINE A IN THE TREATMENT OF IC

We would like to congratulate Jukka Sairanen MD from the Department of Urology, Helsinki University Central Hospital, Finland on his PhD dissertation on cyclosporine in the treatment of IC presented at the University of Helsinki this year. This dissertation makes a valuable contribution to our understanding of cyclosporine and its experimental use in intractable IC/PBS patients. The dissertation can be accessed at: <https://oa.doria.fi/bitstream/handle/10024/33607/cyclospo.pdf?sequence=1>

PAIN MANAGEMENT FOR OLDER ADULTS: A SELF-HELP GUIDE

This book is IASP's first self-help book for patients. It focuses specifically on the pain management needs of older adults. It contains self-assessment checklists, progress charts, photos and illustrations as well as easy instructions for the management of pain.

Pain Management for Older Adults: a Self-Help Guide. Editors: Thomas Hadjistavropoulos, Heather D. Hadjistavropoulos. 201 pages. Cost: US\$ 29.95.

For more information or to order the book, go to: www.iasp-pain.org/olderadults.

UPCOMING EVENTS 2008:

- **European Society for the Study of IC/PBS (ESSIC) annual meeting and course**, 5-7 June, Rome, Italy.
- **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.
- **Contemporary Management of Chronic Pelvic Pain: A multidisciplinary approach**. 11-12 July 2008, Hyatt Regency Vancouver, Vancouver, British Columbia, Canada.
- **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 for patients.

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 global 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, Oxyor, Bioniche Pharma Group Ltd and private donors for their greatly appreciated financial support for our foundation, projects, patient advocacy, website and newsletters.

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.

The International Painful Bladder Foundation does not engage in the practice of medicine. It is not a medical authority nor does it claim to have medical knowledge. Information provided

in IPBF emails, newsletters, patient information and website is not medical advice. The IPBF recommends patients to consult their own physician before undergoing any course of treatment or medication.

The IPBF endeavours to ensure that all information it provides is correct and accurate, but does not accept any liability for errors or inaccuracies.

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