

# International Painful Bladder Foundation

*The IPBF is a voluntary non-profit organization  
for interstitial cystitis/ painful bladder syndrome  
[www.painful-bladder.org](http://www.painful-bladder.org)*

## **IPBF E-Newsletter, Issue 14, November 2008**

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

### **ICS ANNUAL MEETING IN CAIRO WAS A PERFECT OPPORTUNITY TO RAISE AWARENESS OF IC IN NORTH AFRICA**

The International Continence Society held its annual meeting 20-24 October 2008 in Cairo against a décor of the ancient pyramids of Giza on the one hand and the bustling city of Cairo with its dense traffic day and night on the other. Where the International Painful Bladder Foundation was concerned, this formed a truly unmissable opportunity to organize a first IPBF information stand in Africa to raise awareness of interstitial cystitis/painful bladder syndrome and distribute up-to-date information on the latest developments and insights in this field. The CDs, brochures and leaflets were disappearing at top speed, indicating a huge need for information. The IPBF stand also included leaflets from many IC support groups from around the world. "Nobody has ever done anything like this before for IC patients here in Egypt", said conference chairman Professor Sherif Mourad. IPBF chairman Jane Meijlink also gave a presentation on IC and the painful bladder at the ICS Public Forum in Cairo. Our review of this meeting with an overview of selected abstracts in the field of IC/PBS can be found on the website at:

[http://www.painful-bladder.org/pdf/2008\\_ICS\\_Cairo.pdf](http://www.painful-bladder.org/pdf/2008_ICS_Cairo.pdf)

### **Announcement of the first World Continence Week**

It was announced at this ICS meeting that the first **World Continence Week** will be held 22-28 June 2009.

### **NIH LAUNCHES UNIQUE EFFORT TO ADVANCE STUDY OF UROLOGIC CHRONIC PELVIC PAIN DISORDERS**

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), part of the National Institutes of Health (NIH), recently announced awards to eight academic research centres to conduct collaborative studies of urologic chronic pelvic pain disorders by looking for clues outside the bladder and prostate. The total research investment for the five-year project is estimated to be up to \$37.5 million. The Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network includes six Discovery Sites that will conduct the studies and two Core Sites that will coordinate data collection, analyse tissue samples, and provide technical support. The Discovery Sites are at: Northwestern University, Chicago; the University of California, Los Angeles; the University of Iowa, Iowa City; the University of

Michigan, Ann Arbor; the University of Washington, Seattle; and Washington University, St. Louis. Core Sites are at the University of Colorado, Denver and the University of Pennsylvania, Philadelphia.

The MAPP initiative is unusual in requiring investigators to conduct highly collaborative research of the most common urologic chronic pelvic pain syndromes from a broadened systemic perspective. This is a major shift from earlier organ-specific research on the two most prominent urologic chronic pelvic pain disorders, interstitial cystitis/painful bladder syndrome, and chronic prostatitis/chronic pelvic pain syndrome.

"The MAPP Network's expanded scientific approach will address many persistent questions about urologic chronic pelvic pain," said NIDDK Director Griffin P. Rodgers, M.D. "Knowing whether there are risk factors common to all the disorders and whether clinical profiles can be identified for each will provide invaluable, fundamental information for developing treatment strategies."

For more information on the MAPP Research Network, visit <http://www2.nidk.nih.gov/Research/ScientificAreas/Urology/MAPP>.

### **UROLOGICAL PELVIC PAIN COLLABORATIVE RESEARCH NETWORK (UPPCRN).**

The UPPCRN represents the overarching organization for collaborative research in chronic prostatitis, chronic pelvic pain syndrome, and interstitial cystitis. It serves as the official NIDDK Working Group on chronic pelvic pain of urological origin, to facilitate interaction of study groups and investigators, both nationally and internationally, to advance understanding, diagnosis, and treatment of these diseases. Full details can be found on the website:

[http://porter.cceb.upenn.edu:7778/servlet/page?\\_pageid=389,391,400&\\_dad=portal30&\\_schema=PORTAL30](http://porter.cceb.upenn.edu:7778/servlet/page?_pageid=389,391,400&_dad=portal30&_schema=PORTAL30)

### **NEW AND UPDATED IC/PBS INFORMATION ON THE IPBF WEBSITE**

In the past few months we have updated our IPBF 37 page brochure:

([http://www.painful-bladder.org/pdf/Diagnosis&Treatment\\_IPBF.pdf](http://www.painful-bladder.org/pdf/Diagnosis&Treatment_IPBF.pdf))

and the smaller 4 page booklet:

(<http://www.painful-bladder.org/pdf/IPBF%20Publ%2005%20UK%20booklet.pdf>) .

We also have a new 2-page fact sheet for primary care:

(<http://www.painful-bladder.org/pdf/IPBF%20Publ%2006.pdf>)

and a flyer on IC/PBS in Arabic:

([http://www.painful-bladder.org/pdf/leaflet\\_arabic.pdf](http://www.painful-bladder.org/pdf/leaflet_arabic.pdf)).

### **IASP PAIN CLINICAL UPDATES: CHRONIC PELVIC AND UROGENITAL PAIN SYNDROMES**

A very useful and interesting Pain Clinical Update (Volume XVI, Issue 6, September 2008) on Chronic Pelvic and Urogenital Pain Syndromes by Ursula Wesselmann, MD is available on the website of the International Association for the Study of Pain (IASP, website [www.iasp-pain.org](http://www.iasp-pain.org)) and can be found either via the home page of the IASP website or through this link:<http://www.iasp-pain.org/AM/Template.cfm?Section=Home&Template=/CM/ContentDisplay.cfm&ContentID=6831>

## **P.U.R.E. H.O.P.E. FORCED TO POSTPONE PATIENT MEETING DUE TO HURRICANE IKE! NOW RESCHEDULED FOR 24 JANUARY 2009!**

Just imagine you have been planning and preparing a patient conference for many months and a hurricane hits the area exactly on the weekend of your conference and everything has to be cancelled. This nightmare scenario actually happened to the P.U.R.E. H.O.P.E. Pelvic & Urological Resources & Education organization in Texas. The planned conference had to be cancelled at the very last meeting with Hurricane Ike slamming into Texas. President Cindy Sinclair is now happy to announce that the 4<sup>th</sup> Annual Pelvic Health Conference has been rescheduled to Saturday 24 January 2009 in Houston Texas. We will keep our fingers crossed this time. Further information from: <http://www.pure-hope.org/conference.htm>

## **VULVODYNIA IN POLISH**

For speakers of Polish, there is a wonderful new website on vulvodynia available: [www.vulvodynia.pl](http://www.vulvodynia.pl). This website is aimed at women suffering from vulvodynia and related disorders as well as medical professionals. There is also a forum in Polish for patients: <http://forum.vulvodynia.pl/>.

## **LOOK UP ONGOING CLINICAL TRIALS**

The WHO portal at <http://www.who.int/ictrp/en/> is the place to search for ongoing trials. This website was set up specifically to allow people to search simultaneously all the licensed registries of clinical trials on one website.

## **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.

### **Antecedent nonbladder syndromes in case-control study of interstitial cystitis/painful bladder syndrome.**

Warren JW, Howard FM, Cross RK, Good JL, Weissman MM, Wesselmann U, Langenberg P, Greenberg P, Clauw DJ.

Urology. 2008 November 7. [Epub ahead of print]. (PMID: 18995888).

Seeking clues to the pathogenesis of IC/PBS, these researchers sought antecedent nonbladder syndromes that distinguish incident IC/PBS from matched controls. Eleven antecedent syndromes were more often diagnosed in those with IC/PBS, and most syndromes appeared in clusters.

Among the hypotheses generated was that some patients with IC/PBS have a systemic syndrome and not one confined to the bladder.

A full version of this article can be found on the University of Maryland IC Research Center website: <http://icresearch.umaryland.edu/publications.asp>

*The following two articles come from France and are only available in French but have an English abstract on PubMed.*

### **Diététique et cystite interstitielle.**

Saussine C, Mouracade P. *Pelv Perineol* (2008) 3:50-52

Article in French. English abstract.

The authors discuss the fact that the role of diet as an aggravating factor of interstitial cystitis (IC) symptoms is increasingly being acknowledged. Many IC patients note that some foods worsen their symptoms and that diet modification may relieve symptoms. However, the same foods do not aggravate symptoms in all patients. Furthermore, some patients have found that diet has no effect.

### **Utilisation des nouveaux critères diagnostiques de la cystite interstitielle dan la pratique quotidienne” à propos de 156 cas. [Using the interstitial cystitis new diagnostic criteria in daily practice: about 156 patients].**

Mouracade P, Lang H, Jacqmin D, Saussine C. *Progrès en Urologie*. 2008

Nov;18(10):674-7. Epub 2008 Jul 1.

Article in French, abstract in English. (PMID: 18971112).

P. Mouracade and colleagues from France found that 26% (41 patients) of 156 patients (all diagnosed with IC with pain) were excluded by the ESSIC 2005 definition (which - like the ICS 2002 definition - specified "suprapubic pain"). However, when applying the most recent ESSIC definition ("Chronic pelvic pain, pressure or discomfort perceived to be related to the urinary bladder..."), 15% (23) of these 41 patients were re-integrated. However this still left 11% excluded.

Comment: this article once again underlines the fact that we still have no international consensus on a definition and no definition that has as yet been shown to cover all patients.

### **Depression, abuse and its relationship to interstitial cystitis.**

Goldstein HB, Safaeian P, Garrod K, Finamore PS, Kellogg-Spadt S, Whitmore

KE. *Int Urogynecol J Pelvic Floor Dysfunct*. 2008 Sep 3. [Epub ahead of print].

(PMID: 18766291)

In this study, the authors found that the prevalence of childhood sexual abuse in the sample was not significantly different than the US average. They also found that the prevalence of physical abuse in the sample was not statistically different than the US average.

### **A real-life multicentre clinical practice study to evaluate the efficacy and safety of intravesical chondroitin sulphate for the treatment of interstitial cystitis.**

Nickel JC, Egerdie B, Downey J, Singh R, Skehan A, Carr L, Irvine-Bird K. *BJU Int*.

2008 Sep 3. [Epub ahead of print]. (PMID: 18778342)

This multi-centre, community-based open-label study of 53 patients suggests that intravesical chondroitin sulphate may have an important role in the treatment of IC and validates the rationale for a randomized placebo-controlled trial.

### **Chronic Pelvic Pain Syndrome and the Overactive bladder: the inflammatory link.**

Saini R, Gonzalez RR, Te AE. *Curr Urol Rep*. 2008 Jul;9(4):314-9. (PMID: 18765131)

This paper reviews the role of cytokines in the pathophysiology of CP/CPPS, OAB and PBS/IC. The authors suggest that cytokines may play a role by recruiting inflammatory cells and ultimately in inducing symptoms.

#### **Summation model of pelvic pain in interstitial cystitis.**

Klumpp DJ, Rudick CN. *Nat Clin Pract Urol*. 2008 Sep;5(9):494-500. (PMID: 18769376).

In this paper, the authors suggest that pelvic organ crosstalk might modulate symptoms of pelvic pain by spatial and temporal summation, suggesting a mechanism for the benefits of dietary modification in patients with IC, as well as therapeutic opportunities.

#### **Intravesical glycosaminoglycan replenishment with chondroitin sulphate in chronic forms of cystitis. A multi-national, multi-centre, prospective observational clinical trial.** Nordling J, van Ophoven A. *Arzneimittelforschung*. 2008;58(7):328-35. (PMID: 18751498)

In this study the effectiveness, safety and tolerability of instillation therapy with chondroitin sulphate was investigated in 286 patients with chronic forms of cystitis including radiation cystitis, overactive bladder, chronically recurring cystitis and IC. The instillation was found to be effective and well tolerated in the treatment of chronic forms of cystitis associated with a possible GAG layer deficit, but the results need to be confirmed in a controlled study.

#### **A systematic review on the effectiveness of treatment with antidepressants in fibromyalgia syndrome.**

Uçeyler N, Häuser W, Sommer C. *Arthritis Rheum* 2008;59:1279-98

In this systematic review it is concluded that amitriptyline (25-50 mg/day) reduced pain, fatigue, and depressiveness in patients with fibromyalgia and improved sleep and quality of life. Most SSRIs and the SNRIs duloxetine and milnacipran are probably also effective. The authors recommend short-term treatment of patients with fibromyalgia using amitriptyline or another of the antidepressants that were effective in randomized-controlled trials but warn that data on long-term efficacy are lacking.

#### **Differences in the clinical presentation of interstitial cystitis/painful bladder syndrome in patients with or without sexual abuse history.**

Seth A, Teichman JM. *J Urol*. 2008 Sep 17 [Epub ahead of print]. (PMID: 18804240)

The author found that patients with IC/PBS with a history of sexual abuse have a different clinical presentation compared to those without an abuse history.

Furthermore, patients with a history of sexual abuse have more pain and fewer voiding problems. They may have increased central sensitization.

#### **Recommendations on the use of botulinum toxin in the treatment of lower urinary tract disorders and pelvic floor dysfunctions: a European Consensus Report.**

Apostolidis A, Dasgupta P, Denys P, Elneil S, Fowler CJ, Giannantoni A, Karsenty G, Schulte-Baukloh H, Schurch B, Wyndaele JJ. *Eur Urol*. 2008 Sep 17. [Epub ahead of print]

The authors write that the increasing body of evidence and number of potential indications for the use of botulinum neurotoxins (BoNTs) in the lower urinary tract (LUT) underlines the pressing need for evidence-based guidelines. A European expert panel consensus conference was therefore convened with the main aim of

evaluating the evidence and clinical considerations for the use of BoNTs in the treatment of urologic and pelvic-floor disorders and to propose relevant recommendations. The consensus committee recommends larger placebo-controlled and comparative trials to evaluate the efficacy of single and repeat injections, the duration of effect, the optimal dosage and injection technique, the timing for repeat injection, and the short- and long-term safety of the treatment in LUT and pelvic-floor disorders.

#### **UPCOMING EVENTS 2009:**

##### **P.U.R.E. H.O.P.E.**

##### **4<sup>th</sup> Annual Pelvic Health Conference**

Saturday 24 January 2009, Houston, Texas, USA

##### **WIP2009**

##### **5th World Congress World Institute of Pain**

13-16 March 2009,

New York, NY, USA

##### **24<sup>th</sup> European Association of Urology (EAU) Congress**

17-21 March 2009. Stockholm, Sweden

##### **American Urological Association (AUA) annual conference**

25-30 April 2009, Chicago USA

##### **ESSIC Annual Meeting**

4-6 June 2009, Göteborg, Sweden

##### **World Continence Week**

22-28 June 2009

##### **10th International Symposium on Sjogren's Syndrome**

1-3 October, 2009, Brest, France.

##### **30<sup>th</sup> Congress of the Societe Internationale d'Urologie (SIU)**

1-5 November 2009, Shanghai, China

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 TO CONTINUE ITS INTERNATIONAL PATIENT ADVOCACY AND AWARENESS CAMPAIGN AROUND THE GLOBE IN 2009.**

The voluntary, non-profit IPBF is entirely dependent on sponsoring and donations to be able to continue to carry out its projects and international advocacy and activities. 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 bv, Bioniche Pharma Group Ltd and private donors for their greatly appreciated financial support for our foundation, projects, patient advocacy, website and newsletters during the year 2008.

#### **The Board of the International Painful Bladder Foundation (IPBF)**

*The IPBF is an associate member of the International Alliance of Patients' Organizations (IAPO) [www.patientsorganizations.org](http://www.patientsorganizations.org) and the European Organization for Rare Diseases (EURORDIS) [www.eurordis.org](http://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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