

# International Painful Bladder Foundation

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

## **IPBF E-Newsletter,**

Issue 11, March 2008

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

### **23<sup>rd</sup> ANNUAL EAU CONGRESS, 26-29 March, MILAN**

The IPBF will once again have a booth at the EAU congress (booth number 24a) and will be providing health professionals with the most up-to-date information on PBS/IC. If any IC support groups would like their leaflets to be included on our table, please post them by 20 March to the address at the bottom of this newsletter.

#### **Course to be held on CPPS, CP and PBS/IC**

As usual, the EAU annual congress scientific programme will include educational courses. ESU Course 7, chaired by Professor J.J. Wyndaele, will deal with chronic pelvic pain syndromes, with special emphasis on chronic prostatitis (CP) and painful bladder syndrome/interstitial cystitis (PBS/IC). This will be held on Thursday 27<sup>th</sup> March, 12.15 - 15.15 hours.

#### **Poster Session on PBS/IC**

Poster session 53 starting at 14.00 hours on Friday 28<sup>th</sup> March will include PBS/IC.

### **UPDATED IPBF BROCHURE**

The IPBF brochure has once again been updated and a new short 4 page overview has also been compiled which can be used for a variety of purposes. Both can be downloaded from the IPBF website. Go to the home page [www.painful-bladder.org](http://www.painful-bladder.org) and click on the top right-hand corner "Quick Find".

All suggestions for amendments or additions are welcome. Our publications are continually updated and evolving and our aim is to provide information that you really need. In order to achieve this, we need your feedback.

### **NIH/NIDDK INTERNATIONAL SYMPOSIUM 16-17 June 2008**

#### **"DEFINING THE UROLOGIC CHRONIC PELVIC PAIN SYNDROMES – A NEW BEGINNING"**

A reminder that the NIH/NIDDK international symposium, "Defining the Urologic Chronic Pelvic Pain Syndromes - A new beginning", will be held 16-17 June 2008, Doubletree Hotel, Bethesda, USA. The purpose of the symposium is to enlist expert opinion related to the multiplicity of factors involved in defining the urologic pelvic pain syndromes. The meeting will include updates on such topics as: classifying

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. This symposium will explore the pros and cons of unifying a definition, as well as the need for phenotyping persons with the disorders. It will be an interactive meeting between speakers, participants and the panel of consultants. The meeting will be informative for clinicians, basic scientists, patients, advocacy groups, pharmaceutical representatives and the public interested in developing a further understanding of the urologic chronic pelvic pain syndromes and the 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 (MAPP). The meeting is open to all, however pre-registration is essential because of seating limitations.

Information: Maria Smith – [MSmith@scgcorp.com](mailto:MSmith@scgcorp.com). Registration will be possible online in approximately 2 weeks' time. We will keep you updated.

### **IC & RELATED DISORDERS – BE ON THE ALERT**

With the holistic NIDDK MAPP project about to get off the ground in mid-2008, we would like to repeat our reminder to health professionals to be on the alert for other symptoms in IC patients and to IC patients to be aware of the possibility of related or associated disorders. For example pain (syndromes) elsewhere in the body, joint/muscle pain, allergies (including medicine intolerance), chronic fatigue, fibromyalgia, irritable bowel syndrome or inflammatory bowel disease, vulvodynia, systemic autoimmune diseases such as Sjogren's syndrome, SLE and RA, and thyroid disorders. The right diagnosis can lead to the right treatment and a better quality of life for the patient.

### **IASP: REAL WOMEN, REAL PAIN**

Within the framework of the Global Year Against Pain in Women of the International Association for the Study of Pain (IASP), useful information on pain and pain syndromes can be found at: [www.iasp-pain.org/RealWomenRealPain](http://www.iasp-pain.org/RealWomenRealPain).

The 18 IASP Global Year Fact Sheets on pain are now also available in Hindi and Gujarati in addition to English, Arabic, Chinese, French, Russian and Spanish.

### **IAPO PATIENT CONFERENCE BUDAPEST: WE HAVE TO MAKE PATIENT-CENTRED HEALTHCARE A REALITY FOR PATIENTS WORLDWIDE**

Over 180 delegates from more than 30 countries attended the third Global Patients Congress of the International Alliance of Patients' Organizations (IAPO), held in Budapest, Hungary from 20-22 February 2008. The participants represented patient organizations – including the International Painful Bladder Foundation - as well as other stakeholders such as the European Commission, the World Health Organization (WHO) and global health professionals' associations. Keynote presentations highlighted the central role that patients are increasingly playing in healthcare today.

## **Collaboration essential between patients and all other stakeholders**

Sir Liam Donaldson, Chief Medical Officer, England and Chair of the WHO World Alliance for Patients Safety, Ms Katalin Rapi, Secretary of State for Health Policy at the Ministry of Health, Hungary and Mr. Andrzej Ryś, Director, Public Health & Risk Assessment at the European Commission, DG SANCO, all highlighted the importance of developing collaboration between patients and all other healthcare stakeholders.

IAPO calls on all stakeholders in healthcare to include patients in a meaningful and sustainable way in all levels of their work and at all points of decision-making, and to build on existing models of involvement in collaboration with patients around the world. "To meet patients' needs, decisions that affect a patient's healthcare should not be taken without the full involvement of the patient at all levels of care, whether that be in the choosing of treatment options, developing healthcare policy or designing healthcare systems." Myrl Weinberg, IAPO Chair and President of the National Health Council (USA).

IAPO is the only global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare worldwide. Its full members are patients' organizations through which IAPO represents at least 365 million patients worldwide. IAPO's vision is that patients throughout the world are at the centre of healthcare.

For more information about IAPO and how your patient organization can join, see [www.patientsorganizations.org](http://www.patientsorganizations.org)

A review of the congress in Budapest can be found on the IPBF website at: [http://www.painful-bladder.org/pdf/2008\\_IAPO\\_Budapest.pdf](http://www.painful-bladder.org/pdf/2008_IAPO_Budapest.pdf)

## **PROCAIM internet-based survey**

PROCAIM is the People Reported Outcomes from Complementary, Alternative & Integrative Medicine network. People with fibromyalgia, IBS, interstitial cystitis, chronic pain and other chronic and recurring conditions are being invited to sign up and participate in a year-long internet-based survey called PROCAIM. There is no geographical limit to this survey.

This is a web-based study composed of surveys that will recur at intervals over 1 year. For further information, visit the website [www.procaim.org](http://www.procaim.org) or contact Deborah Ackerman (Department of Epidemiology, UCLA School of Public Health) at [Deborah.Ackerman@ucla.edu](mailto:Deborah.Ackerman@ucla.edu).

## **SECOND MEETING OF PBS/IC PATIENTS IN INDIA**

A second meeting of PBS/IC patients in India was held in Ahmedabad on 6 January 2008, organized by urologist Dr Nagendra Mishra. Fifteen patients attended the three hour meeting which gave the patients an opportunity to exchange ideas with each other. The main topic of discussion was the availability (or lack of it) of various treatment modalities in India and the difficulty in getting the disease diagnosed. The patients in India face many difficulties, not least because drugs such as PPS are not available and there is an acute lack of physicians interested in treating PBS/IC patients.

## **PROBLEMS WITH OFFICIAL RECOGNITION OF IC BY AUTHORITIES IN DIFFERENT COUNTRIES**

If new patient groups are experiencing problems in getting the name of their bladder disease officially recognised in their country, particularly for the purpose of social security benefits, health insurance and reimbursement of treatment, try contacting your country's World Health Organization representative. The WHO has an official list of recognized diseases and interstitial cystitis is one of these.

## **ARTICLE ON CYCLOSPORINE IN UROLOGY TIMES**

A useful and informative article by medical journalist Penny Allen in Urology Times 1 December 2007 with an in-depth review of cyclosporine treatment for interstitial cystitis can be found at:

<http://www.urologytimes.com/urologytimes/Inflammation%20and%20Infection/Cyclosporine-shows-dramatic-results-in-severe-inte/ArticleStandard/Article/detail/475196>.

## **NIDDK TERMINATES IICRN MYCOPHENOLATE MOFETIL (CellCept) Study**

It was recently announced by the Interstitial Cystitis Association (ICA) that the NIDDK has terminated its Interstitial Cystitis Clinical Research Network (IICRN) mycophenolate mofetil (CellCept) clinical trial due to lack of efficacy and potential side-effects. Mycophenolate mofetil is an immunosuppressive drug frequently used for organ transplants, and was being studied for the treatment of severe PBS/IC unresponsive to other therapies.

## **SOCIETY FOR URODYNAMICS & FEMALE UROLOGY (SUFU) 2008 WINTER MEETING, 28 February – 2 March, MIAMI**

Interesting and informative presentations at the SUFU winter meeting related to PBS/IC included:

- SUFU Basic Science Research Meeting with a panel discussion on Urothelium – Translational Research on Interstitial Cystitis. Moderator Deborah Erickson MD with Lori Birder PhD speaking on Urothelial Nociceptive Functions, Tony Buffington DVM, PhD on a Feline Model of IC and Susan Keay MD, PhD on an Antiproliferative Factor Update.

- The basic science poster session included:

Poster BS5: GENE EXPRESSION DURING DIFFERENTIATION OF CULTURED UROTHELIAL CELLS FROM INTERSTITIAL CYSTITIS AND CONTROL

BLADDERS. D.R. Erickson, J.K. Dixon, C.J. Clark, M.A. Hersh, S.R. Schwarze.

Significant alterations in gene expression occurred after changing cultured urothelial cells to a differentiation-inducing medium. Some of these were expected, confirming the ability of IC cells to undergo differentiation in vitro. New findings were also seen, which may lead to better understanding of the urothelial differentiation process.

- A presentation was given by Michael Pezzone MD on: PELVIC ORGAN NEUROPHYSIOLOGY: IMPLICATIONS FOR CHRONIC PELVIC PAIN AND THE OVERLAP OF CHRONIC PELVIC PAIN DISORDERS.

Pelvic neural “cross-talk”, necessary for normal regulation of sexual, bladder and bowel function, may be mediated by convergence of sensory pathways in the spinal cord both peripherally and centrally. It was suggested that there may be a genetic component and there may be a predisposition to cross-talk. It is hypothesized that any kind of assault, disease or chronic irritation can ultimately lead to changes in the end organ, sensitization of the pain nerves and cause chronic pelvic pain. Certain people may possibly be more susceptible to the development of long-term effects from initial assaults. This concept forms a basis for the multidisciplinary approach of the coming NIH MAPP study project.

- Posters presented on PBS/IC:

Poster 27: CORRELATIONS BETWEEN SUBJECTIVE AND OBJECTIVE DATA IN IDENTIFYING PATIENTS WITH INTERSTITIAL CYSTITIS. D. N. Sastry, K.E. Whitmore.

The aim of this study was to evaluate correlations between symptoms of IC/PBS and physical findings on cystoscopy, bladder overdistension and bladder biopsy based on the hypothesis that the severity of symptoms reported in questionnaires such as visual analog scales, O’Leary-Sant scales and the short form Urinary Distress Inventory correlate with the severity of IC revealed by reduced bladder capacity, glomerulations, presence of Hunner’s ulcers, and/or mast cell counts. A significant correlation was found.

Poster 28: PRIMARY CARE PHYSICIAN PRACTICE PATTERNS IN THE MANAGEMENT OF INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME. J.Q. Clemens, E.A. Calhoun, M.S. Litwin, M. McNaughton Collins.

This study concluded that while most primary care physicians (PCPs) are familiar with IC/PBS, they manage it infrequently. They also appear to have a significant lack of knowledge concerning the clinical features of IC/PBS. There is a variation in the way the condition is diagnosed and treated. Educational efforts should be directed at PCPs so as to improve the care of these patients.

Poster 29: PILOT STUDY OF ACUPUNCTURE FOR TREATMENT OF INTERSTITIAL CYSTITIS. C. Twiss, V. Arboleda, V. Triaca, A. Smith, J.H. Kim. S. Raz, S. Tan, L. Rodriguez.

This was a small pilot study of IC patients. It was found that three months of acupuncture led to a modest improvement in overall urinary and painful bladder symptoms, but did not lead to an improvement in sexual functioning. The majority of patients reported a small degree of improvement in their overall condition. The long-term impact of this therapy on IC patients is unknown. A large randomized study to evaluate the potential role of acupuncture in therapy for IC is warranted.

Poster 30: LONG TERM OUTCOMES OF CYSTECTOMY WITH BLADDER SUBSTITUTION IN THE TREATMENT OF WOMEN WITH REFRACTORY INTERSTITIAL CYSTITIS. N. Dhar, C. Moore, A. Bhatt, A.V. Hernandez, C. Zippe, S. Vasavada, R.R. Rackley.

This is the first study to assess long-term outcomes of patients with refractory IC who underwent cystectomy and bladder substitution. In this group of patients, cystectomy with bladder substitution resulted in durable improvement in sexual function, pain

relief (without recurrence of pain in the diversion), voiding symptoms, sleep and overall quality of life.

## 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.

New scientific articles include:

### **THE USE OF BOTULINUM NEUROTOXIN TYPE A (BoNTA) IN UROLOGY.**

Apostolides A, Fowler CJ. *J Neural Transm.* 2008 March 6 [Epub ahead of print]. PMID: 18322639

A review article on the use of Botulinum neurotoxin type A (BoNTA) in the lower urinary tract. It summarizes data on the clinical efficacy and safety of the growing use of botulinum neurotoxins in urology while exploring the scientific background to its use. Although the focus of the article is on lower urinary tract symptoms associated with detrusor overactivity, as in e.g. overactive bladder, it also pays some attention to the use of this therapy in PBS/IC. The authors note that conflicting results have been seen with PBS/IC patients regarding the effect on pain, as well as variable improvements in frequency, nocturia, bladder capacity and cystometric volume at first desire to void. The main side effects in this group of patients were voiding dysfunction and increased post-void residuals.

### **INSIGHT INTO UROGYNECOLOGIC FEATURES OF WOMEN WITH INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME.**

Gardella B, Porru D, Ferdeghini F *et al.* *Eur Urol* 2008 Feb 6 [Epub ahead of print]. PMID: 18276064. In this study from the urogynaecologic world, vulvodynia was found in 85.1% of IC/PBS patients and in 6.4% of control patients. It was concluded that patients with a definite diagnosis of IC/PBS appear to have a high risk of vulvodynia with the implication of negative sexual functioning. The investigators believe that a multidisciplinary approach involving the gynaecologist would be the logical way to provide these patients with optimum treatment.

### **PATIENT PERCEIVED OUTCOMES OF TREATMENTS USED FOR INTERSTITIAL CYSTITIS.**

Hill JR, Isom-Batz G, Panagopoulos G, Zakariasen K, Kavalier E. *Urology*, 2008 Jan;71(1):62-6. PMID: 18242366. 750 patients with a diagnosis of IC took part in a computerized survey that questioned each patient about their demographics, symptoms, concomitant diagnoses, treatments and their perceived treatment outcomes. The patients were asked about therapies used to treat IC and whether they felt their condition to be improved after 6 months. Both invasive and medical therapies were surveyed. It was concluded that medical treatment is perceived to be superior to invasive therapy in treating IC. Medication should be considered the first line therapy for IC. Several medications showed a large percentage of patients with an improvement in

symptoms. These medications were: calcium glycerophosphate, phenazopyridine and pentosan polysulfate sodium.

**LONGIDAZE IN THERAPY OF PATIENTS WITH INTERSTITIAL CYSTITIS [Article in Russian].** Zaitcev AV, Pushkar DU. *Urologiia*, 2007 Sept-Oct;(5):35-7. PMID: 18254223.

This interesting Russian pilot study used the injected enzyme agent longidaze (conjugate of hyaluronidase with activated derivate of N-oxide poly-1,4-ethylenpiperazine) in a study group of 30 patients (including 7 Hunner's ulcer patients): 3000 IU, 10 injections, every 5 days. The authors are of the opinion that the algorithm for the Hunner's ulcer patients should include Holmium laser coagulation as a first step, followed by longidaze treatment. In non-ulcerative patients the longidaze is added to multimodal treatment. The aim of the therapy is to correct inflammatory disorders, prevent progressive fibrosis, and restore detrusor elasticity. The results of this pilot study were positive with a significant decrease in pain and a reduction in urgency/frequency. There are plans to continue the study in Russia. This agent can be used in the form of intramuscular or subcutaneous bladder injections, but is now also available as a rectal suppository.

**GUIDED IMAGERY FOR WOMEN WITH INTERSTITIAL CYSTITIS: RESULTS OF A PROSPECTIVE, RANDOMIZED CONTROLLED PILOT STUDY.** Carrico DJ, Peters KM, Diokno AC. *J Altern Complement Med*. 2008 Jan 16 (Epub ahead of print). PMID: 18199015.

This study with 30 patients with diagnosed IC is the first study on the effect of guided imagery in patients with IC, using a 25 minute guided imagery CD created specifically for women with pelvic pain and IC. This CD focuses on healing the bladder, relaxing the pelvic floor muscles and calming the nerves specifically involved in IC. It was concluded that guided imagery may be a useful tool to offer women with IC for pain and IC symptom management. It is an intervention without negative side-effects and the CD is readily available.

**DYSPAREUNIA RESPONSE IN PATIENTS WITH INTERSTITIAL CYSTITIS TREATED WITH INTRAVESICAL LIDOCAINE, BICARBONATE AND HEPARIN.** Welk BK, Teichman JM. *Urology*. 2008 Jan;71(1):67-70. PMID: 18242367.

In this study, 23 sexually active patients with IC were treated intravesically with a therapeutic solution of lidocaine, heparin and sodium bicarbonate to assess the response in relation to dyspareunia. The patients were treated three times weekly for three weeks. They returned three weeks later for follow-up. The results of this study indicate that this intravesical therapeutic solution can provide relief for voiding symptoms, pain and dyspareunia in IC/PBS patients. A randomized, prospective trial is now warranted.

**HYALURONAN TREATMENT OF INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME.** Riedl CR, Engelhardt PF, Daha KL, *et al*. *Int Urogynecol J Pelvic Floor Dysfunct* 2007 Dec 21 [Epub ahead of print]. PMID: 18097627.

This study evaluated the efficacy of intravesical hyaluronan [sodium hyaluronate] therapy in 126 patients with IC/PBS and mean disease duration of 6.1 years. To be eligible for hyaluronan treatment, a positive modified potassium test was required as a sign of a urine-tissue barrier disorder. Patients were treated with weekly instillations of a 50 ml phosphate-buffered saline solution containing 40 mg sodium hyaluronate.

Data were obtained by a visual analogue scale (VAS) questionnaire rating from 0 to 10 that asked for global bladder symptoms before and after therapy. Additional questions evaluated the therapeutic impact on quality of life. 85% of the patients reported symptom improvement. Following therapy, 55% had minimal or no bladder symptoms; 84% reported significant improvement of their quality of life. Intravesical therapy had to be initiated again in 43 patients (34.5%) as symptoms recurred after discontinuation of treatment, while the rest stayed symptom-free for up to 5 years. In general, hyaluronan therapy was well tolerated and, with the exception of mild irritative symptoms, no adverse reactions were reported for a total of 1,521 instillations. The authors conclude that timely hyaluronan instillation therapy may lead to complete symptom remission or even cure in part of the IC/PBS patients, while some responders need continuous intravesical therapy. The results of this study suggest that selection of patients for hyaluronan therapy by potassium testing may improve the outcome of intravesical therapy with a response rate of >80%

**BOTULINUM A TOXIN INTRAVESICAL INJECTION IN PATIENTS WITH PAINFUL BLADDER SYNDROME: 1-YEAR FOLLOW-UP.** Giannantoni A, Porena M, Costantini E, Zucchi A, Mearini L, Mearini E. J Urol. 2008 Jan 17 [Epub ahead of print]. PMID: 18206941.

In this small study to evaluate the efficacy and tolerability of intravesically injected botulinum toxin A in refractory PBS/IC patients, the therapy appeared to be effective for short-term treatment of PBS/IC that has failed to respond to other treatment. However, this form of treatment needs to be repeated after a few months.

**FOLLOWUP OF PATIENTS WITH INTERSTITIAL CYSTITIS RESPONSIVE TO TREATMENT WITH INTRAVESICAL BACILLUS CALMETTE –GUERIN OR PLACEBO.** Probert KJ, Mayer R, Nickel JC, Payne CK, Peters KM, Teal V, Burks D, Kusek JW, Nyberg LM, Foster HE; Interstitial Cystitis Trials Group. J Urol. 2008 Feb;179(2):552-5. PMID: 18082224.

The results of this study into the longer term response of IC patients who initially responded to intravesical bacillus Calmette-Guerin (BCG) or placebo in a randomized clinical trial argue against the routine use of BCG in this patient group since, although most patients who respond to treatment with BCG or placebo maintain symptom improvement for up to 68 weeks after the start of the treatment, initial response rates are low. Moreover, placebo responders showed basically the same response durability as BCG responders.

**TIME TO INITIATION OF PENTOSAN POLYSULFATE SODIUM TREATMENT AFTER INTERSTITIAL CYSTITIS DIAGNOSIS: EFFECT ON SYMPTOM IMPROVEMENT.** Nickel JC, Kaufman DM, Zhang HF, Wan GJ, Sand PK. Urology. 2008 Jan;71(1):57-61. PMID: 18242365

In a retrospective analysis of 128 IC patients treated with PPS 30 mg/day for 32 weeks in a multicentre trial, it was concluded that starting PPS treatment within 6 months of diagnosis may result in greater improvement in symptoms and symptom bother.

#### **UROSOURCE WEBSITE: ESU COURSES 2007 WITH SLIDES**

To find the information and slides used in Course 5 on CPPS, CP and PBS/IC, either go to this page:

[http://www.urosource.com/content/educational-courses/view/browse/2/article/berlin-2007-esu-course-5/?tx\\_ttnews%5BbackPid%5D=53&cHash=d01d4cd571](http://www.urosource.com/content/educational-courses/view/browse/2/article/berlin-2007-esu-course-5/?tx_ttnews%5BbackPid%5D=53&cHash=d01d4cd571)

or go to the Urosource home page [www.urosource.com](http://www.urosource.com) and click on the right on: ESU Course Berlin 2007. Go to ESU Course 5: Chronic pelvic pain syndromes (CPPS) with special focus on chronic prostatitis (CP) and painful bladder syndrome/interstitial cystitis (PBS/IC). Click at the bottom on "View course material/slides and you will find the slides and other information per speaker.

## UPCOMING EVENTS 2008:

### 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>.

### 4<sup>th</sup> International Consultation on Incontinence (ICI) including PBS/IC

The 4<sup>th</sup> 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 on Painful Bladder Syndrome/Interstitial Cystitis will take place on Sunday 6 July. The recommendations of the committees will be published in book form and will include discussions that take place during the 4<sup>th</sup> ICI.

### World Pain Congress with satellite symposium on urogenital pain

The 12<sup>th</sup> 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 on the IASP website: [www.iasp-pain.org](http://www.iasp-pain.org).

### Dates for your diary in brief:

- **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.
- **Eurordis Membership Meeting, "Acting Together for Patient-Centred Care for Rare Diseases"**, 16-17 May 2008, Copenhagen, Denmark, [www.eurordis.org](http://www.eurordis.org)
- **American Urological Association annual meeting**, 17-22 May 2008, Orlando, Florida, USA.
- **ICORD 2008: The 4<sup>th</sup> 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 (see website [www.essic.eu](http://www.essic.eu)).
- **NIH/NIDDK International Symposium: Defining the Urologic Chronic Pelvic Pain Syndromes**. 16-17 June 2008, Doubletree Hotel Bethesda, Maryland, USA.

- **4<sup>th</sup> 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 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, Bioniche Pharma Group Ltd and private donors for their greatly appreciated financial support for our foundation, projects, website and newsletters.

The Board of the International Painful Bladder Foundation  
 email: [info@painful-bladder.org](mailto:info@painful-bladder.org)  
[www.painful-bladder.org](http://www.painful-bladder.org)

*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).*

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*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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