

# 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 17, July 2009**

*An IPBF update for patient support groups, country contacts, healthcare professionals and friends around the world in the field of interstitial cystitis (painful bladder syndrome, bladder pain syndrome, hypersensitive bladder syndrome, chronic pelvic pain syndrome).*

### **NIH/NIDDK SYMPOSIUM PLANNED FOR EARLY 2010.**

The NIH/NIDDK is planning a symposium in early 2010 which will focus on Neuroimaging and the Urological Chronic Pelvic Pain Syndromes. We will provide you with further information and a date when available, but please bear this in mind when making your plans for 2010.

### **INDIAN IC/PBS SOCIETY: INDIAN CLINICAL GUIDELINES**

A meeting of leading IC/PBS experts in India was held in Goa, India on 20<sup>th</sup> and 21<sup>st</sup> June 2009. Dr Nagendra Mishra informs us that an Indian IC/PBS Society has now been set up and that they are currently working on an Indian Clinical Guideline. The members of this new society have undertaken to carry out time bound research for a period of one year to consolidate and validate the new guideline.

The following main points were decided.

**Name:** The nomenclature to be used is IC/PBS

**Definition:** Recurrent pelvic pain or discomfort (pressure, burning, throbbing, etc.) of at least 4-6 weeks' duration, which increases with bladder filling and/or decreases with micturition in the absence of definable pathology associated with urinary frequency and/or urgency.

**Investigations:**

- Frequency volume chart for 24 hours
- Urine routine and culture
- Ultrasonography of kidney, ureter and bladder with post void residue
- Cystoscopy under anaesthesia. Biopsy to be done if any other lesion is suspected.

**Management:**

- Therapeutic hydrodistension
- Oral drug therapy in second stage if hydrodistension is not effective.
- Intravesical therapy if oral therapy fails or patient develops flare-up.

The following decisions were also taken by the Society members: Multi-centre research will be undertaken during the coming year to consolidate the expert views in the guidelines. Research work has been delegated to various members to study the sensitivity and specificity of the definition, the role of biopsy, the role of urodynamics,

the role of testing for genitourinary tuberculosis and the role of urinary cytology. It is expected that preliminary results will be available in one year. The guidelines will be reviewed after one year and if necessary changes will be incorporated. All the centres taking part in research will maintain a net-based database and share patient data after the legal requirements of participating centres are met. Furthermore, every endeavour will be made to establish a World IC/PBS Society and convene an international meeting.

## **EAST ASIAN - JAPAN, KOREA, TAIWAN - CLINICAL GUIDELINE PUBLISHED ONLINE (EARLY VIEW IJU)**

The much awaited paper on Clinical Guidelines for Interstitial Cystitis and Hypersensitive Bladder Syndrome from the East Asian Committee on Interstitial Cystitis (Japan, Korea, Taiwan) has now been published online (under Early View) on the website of the *International Journal of Urology*.

### **Definitions**

The committee has decided on the following definitions for their guideline:

*We define interstitial cystitis (IC) as a disease of the urinary bladder diagnosed by three conditions:*

- 1) lower urinary tract symptoms,*
- 2) bladder pathology and*
- 3) exclusion of confusable diseases.*

*The characteristic symptom complex is termed as hypersensitive bladder syndrome (HBS), which is defined as bladder hypersensitivity, usually associated with urinary frequency, with or without bladder pain.*

*Explanatory note:*

- 1) lower urinary tract symptoms such as bladder hypersensitivity, urinary frequency, bladder discomfort and bladder pain;*
- 2) bladder pathology such as Hunner's ulcer and mucosal bleeding after over-distension;*
- 3) exclusion of confusable diseases such as infection, malignancy and calculi of the urinary tract.*

This East Asian Committee is therefore proposing a new symptom syndrome: Hypersensitive Bladder Syndrome (HBS). This would be a clinical entity that is more inclusive than pain syndromes alone since it incorporates patients with and without pain. The authors explain that HBS can be used as a descriptive term for the symptom complex, or as a diagnostic name for the condition in a patient suspected of having IC but who has not fulfilled all the requirements for the diagnosis of IC as given above.

Cystoscopy is considered essential for the diagnosis of Interstitial Cystitis. Without it, the diagnosis remains the symptom syndrome HBS. The authors also state that because of the importance of the cystoscopic findings, they should be recorded before and after distension in a standardized way.

In this guideline, bladder biopsy is not considered to be an essential part of diagnosis. When performed, however, it is advisable to do it after hydrodistension to avoid the risk of bladder rupture, even though histological findings may be affected by this procedure.

The authors are of the opinion that it would be unrealistic in a clinical setting to consider discomfort and pressure to be a type of pain. Patients do not consider discomfort and pressure to be the same as pain. If pain is considered to embrace discomfort and pressure, many patients not complaining of pain would remain undiagnosed.

The authors interestingly draw a distinction between two types of Hunner's ulcer: the Hunner's ulcer and the Atypical Hunner's ulcer.

The committee also calls for standardisation of inclusion and efficacy criteria for clinical trials to improve research.

A useful clinical algorithm is included in this very detailed guideline aimed at guiding care providers in the diagnosis and treatment of patients with hypersensitive bladder syndrome.

This practical and realistic guideline is targeted at all healthcare professionals involved in the diagnosis and treatment of IC and IC-related conditions. Further information and article reference can be found in this e-newsletter under Selected New Scientific Literature.

#### **REVIEW OF ESSIC ANNUAL MEETING, GÖTEGORG, SWEDEN 4-6 JUNE 2009**

The 2009 ESSIC annual meeting, held in the Swedish city of Göteborg, was attended by 52 participants including over 20 from the pharmaceutical industry, indicating a very welcome, continuing interest in research into this disease area by industry. While the Thursday sessions were reserved for members, sessions on Friday and Saturday morning were open to non-members. The IPBF was represented by its chairman Jane Meijlink who also gave a presentation on historical aspects of IC as a background to the Hunner's Symposium at this meeting.

Andrey Zaitcev MD, urologist from Moscow, presented research on endovesical Ho:YAG laser coagulation in the complex treatment of IC patients with Hunner's lesions. This study in Moscow evaluated the effectiveness of endovesical Ho:YAG laser in patients with Hunner's lesion who had been unresponsive to other treatments. They found that Ho:YAG laser treatment achieved a decrease in pain, urgency and frequency in all cases. Severe symptoms recurred within periods varying from 6 months to 3 years and could be retreated. Cystoscopy revealed either Hunner's lesion recurrence or new lesion formation. They concluded that endovesical coagulation with Ho:YAG laser of areas of the bladder with Hunner's lesions resulted in significant immediate reduction in symptoms and considerable improvement in the patient's quality of life. Professor Zaitcev also handed meeting attendees a useful DVD from the Department of Urology at Moscow State Medical Stomatological University showing 7 photos of Hunner's lesions and a variety of cystoscopic findings (plus some wonderful photographs of Moscow!).

Monica Baptiste, clinical nurse specialising in urogynaecology, presented a study on behalf of colleagues from Birmingham (UK) on the evaluation of Patient Reported Outcome Measures for treatment with intravesical chondroitin sulphate in 18 IC/PBS patients, using EQ-5D, a standardised measure of health status developed by the

EuroQol Group. In this study, EQ-5D indicated that intravesical administration of chondroitin sulphate is effective. A larger study is required to confirm the findings.

The study group of Jørgen Nordling, MD from Denmark discussed its study to characterize and evaluate a Danish population with IC/PBS, concluding that nocturia, detrusor mastocytosis and infrafascicular fibrosis are associated with multiple treatments and presumed failure of standard urologic therapy in IC/PBS patients, while bladder capacity and glomerulations are not, although valid conclusions could not be drawn due to numerous study limitations.

The team of Mauro Cervigni MD from Italy presented a study on reduced vascularization in the bladder mucosa of IC/PBS patients, concluding that their data confirm previous observation concerning the reduction of suburothelial vascularization in the bladder mucosa of IC/PBS patients. Further studies are required to assess whether the observed decrease in suburothelial microvessel density may contribute to the pathogenesis of IC/PBS. Indeed, according to the researchers, a reduced blood supply to the urothelium may cause a decrease in epithelial functions as well as epithelial thinning and denudations.

Jozef Zamecnik, MD presented a study on axonopathic changes of visceral nerve endings in urinary bladder in IC/PBS – an ultrastructural study on behalf of a team from the Czech Republic. Based on their findings, they consider that chronic neuropathic changes occur in visceral nerve endings in the urinary bladder in IC/PBS patients. They believe that these might represent one of the etiologic factors inducing the fixation of chronic pain and urologic disorders in these cases.

Paulo Dinis, MD from Portugal discussed a Portuguese study on injection of botulinum toxin A solely into the trigone in patients with IC/PBS. They found intratrigoal injections of BoNT-A (10 injections each containing 10 units in 1ml of saline) in patients with refractory IC/PBS to be a safe and effective alternative treatment that avoids the risk of retention which can occur when injecting into the detrusor.

The Symposium on classic Hunner type IC organized by Magnus Fall, MD, looked at all aspects of diagnosing and treating Hunner's lesion. While some doctors consider Hunner's lesions to be rare, in fact so rare that some claim never to have seen them, others are finding this lesion in 50% of their IC patients. It was clear during this meeting that some urologists are not recognizing the different forms of Hunner's lesion. The name "ulcer" has undoubtedly played a role in this failure to identify the Hunner's lesion, since it is not a true ulcer. Indeed, way back in 1949, J. R. Hand wrote: "... after considerable thought, I am inclined to agree with Folsom's pithy comment that when Hunner 'delivered this child into the urologic world he did not name it as well as he described it'"! It also became clear at this meeting that it is now essential to have a full range of photographs of Hunner's lesion and cystoscopic findings on websites for all urologists and urogynaecologists around the world to be able to view. It is vital for Hunner's lesion to be recognised as early as possible since it can be treated quite successfully, whereas non-ulcer disease is more problematic because treatment is often a question of trial and error, according to Professor Fall.

Silvia Malaguti, MD gave a particularly welcome presentation on pudendal neuropathy and how to treat it, discussing peripheral neuropathy and the hallmarks of neuropathic pain, pudendal nerve anatomy and functions, etiology and pathophysiology of pudendal neuropathy, and different forms of treatment. Pudendal neuropathy is increasingly a topic of interest among both patients and doctors, but

few people really understand it. We hope to see more information becoming available at all levels in the coming period.

An interesting presentation was given by Joop P. van de Merwe, MD on disease activity and disease damage scoring systems. The slide presentation is available online on the ESSIC website at: [http://www.essic.eu/damage\\_activity.html](http://www.essic.eu/damage_activity.html). He concluded that assessment of disease activity and disease damage is fundamental for the care of patients with idiopathic chronic diseases in order to optimise therapy and long-term prognosis and that further studies are needed to find parameters that can be obtained in a patient-friendly way and correlate with disease activity, damage and long-term prognosis. The design, definition and validation of disease activity and disease damage scoring systems seem to be the first necessary steps in this process.

Other presentations in Göteborg included the neurophysiology of bladder pain by J-J Wyndaele, MD, general aspects of visceral pain by Bente Danneskiold-Samsøe, MD and an update on the NIH/NIDDK MAPP project given by Philip Hanno, MD. The next ESSIC annual meeting will be held in Antwerp 2010.

### **IPBF REVIEW OF AUA ANNUAL MEETING 2009**

The IPBF has compiled a detailed review of IC/PBS presentations and posters at the American Urological Association annual meeting 2009. This review can be found on the IPBF website at: [http://www.painful-bladder.org/pdf/2009\\_AUA\\_Chicago.pdf](http://www.painful-bladder.org/pdf/2009_AUA_Chicago.pdf)

### **SWEDISH ARTICLE ON IC/PBS**

Very little has been published on interstitial cystitis/painful bladder syndrome for the general public in the Swedish language and our colleague in Sweden Lennart Branthle (ISOP Swedish patient website: <http://home.swipnet.se/isop/ic.htm>) recently drew our attention to the following Swedish article on IC/PBS on a website for overactive bladder: <http://www.svar.se/urologi/index.asp?q=4&r=412>

### **NVA LAUNCHES NEW ONLINE LEARNING PROGRAMME FOR WOMEN WITH VULVODYNIA**

The National Vulvodynia Association (USA) recently announced the launch of its first online learning programme for women with vulvodynia: Everything You Need to Know About Vulvodynia. This self-guided, comprehensive programme aims to empower women to make educated decisions about their health care, build strong partnerships with their health care providers and improve their quality of life. The tutorial covers gynecological/pelvic anatomy and physiology, diagnosis and treatment of vulvodynia, coping with chronic pain and practical advice on sexual/relationship issues. To view this tutorial, please visit:

<http://learnpatient.nva.org>.

If you would like to join the NVA mailing list so as to be kept fully up to date, this can be done via the NVA website: [www.nva.org](http://www.nva.org).

### **COUNCIL OF THE EUROPEAN UNION RECOMMENDATION ON RARE DISEASES ADOPTED 9 JUNE 2009**

The European Organisation for Rare Diseases (EURORDIS, [www.eurordis.org](http://www.eurordis.org)) announced in June that it welcomes the final adoption on 9 June 2009 by the Council of the European Union of the proposed Council Recommendation on European Action in the field of Rare Diseases. EURORDIS looks forward to the next step which is implementation of national strategies and plans in the field of Rare Diseases in all European Union Member States by 2013. The Council Recommendation is important because it calls for concerted action at EU and national level in order to:

- Ensure that rare diseases are adequately coded and classified
- Enhance research in the field of rare diseases
- Identify Centres of Expertise by the end of 2013 and foster their participation into European Reference Networks
- Support the pooling of expertise at European level
- Share assessments on the clinical added value of orphan drugs
- Foster patient empowerment by involving patients and their representatives at all stages of the decision-making process
- Ensure the sustainability of infrastructures developed for rare diseases

Read more on the EURORDIS website:

<http://www.eurordis.org/IMG/pdf/communiquerecoadopt9june09.pdf>

### **IPBF WILL BE AT THE ICS ANNUAL MEETING 2009, SAN FRANCISCO**

The 39th Annual Meeting of the International Continence Society (ICS) will be held in San Francisco, 29 September-3 October. This is a multi-disciplinary meeting which hopes to attract around 3000 professionals involved in treating, researching and supporting patients with incontinence, pelvic pain and pelvic floor dysfunction. Presentations by leading continence experts will cover the latest developments in science, research and medicine.

The wide selection of educational courses and workshops will include Workshop 53 on **“De-mystifying Chronic Pelvic Pain (IC/PBS/CPPS)”** chaired by Ragi Doggweiler (urologist), Stephanie Prendergast (physical therapist) and Kristene Whitmore (urologist).

The International Painful Bladder Foundation will be manning a booth (12H) in the exhibition hall, providing visitors to the booth with updates on IC/PBS and associated disorders. We look forward to seeing you! For further information, visit the meeting website: [www.ics-meeting.com](http://www.ics-meeting.com)

### **10<sup>TH</sup> INTERNATIONAL SYMPOSIUM ON SJÖGREN'S SYNDROME, 1-3 OCTOBER 2009, BREST, FRANCE**

The 10th International Symposium on Sjögren's Syndrome will take place in Brest, France, October 1-3, 2009. Top experts in the many different disciplines involved in Sjögren's syndrome will be gathering in Brest to discuss the groundbreaking research in this field. Furthermore, patients representing support groups and foundations from around the world will also be very welcome at this symposium and a special workshop is being organized for them to discuss what actions the worldwide associations can take together to improve the quality of life of people with Sjögren's Syndrome.

Contact email for patients who wish to attend is: [afgs.congresbrest@gmail.com](mailto:afgs.congresbrest@gmail.com).

The symposium website for further information can be visited at:

<http://www.sjogrensymposium-brest2009.org>

Extended deadline for abstract submission: 15 July.

### **CONVERGENCES IN PELVIPERINEAL PAIN, FRANCE: 16-18 DECEMBER 2009**

A reminder that a meeting on convergences in pelvipерineal pain will be held 16-18 December 2009, at the Cité des Congrès de Nantes in France. This conference will combine the annual meetings of PUGO (Pain of UroGenital Origin), which is a special interest group of the International Association for the Study of Pain (IASP), the ALS meeting (pelvipерineal pain, diagnostics and procedures), and SIFUD PP (Société Interdisciplinaire Francophone d'Urodynamique et de Pelvi Périnéologie. Preliminary information is available on the meeting website:

<http://sites.google.com/site/convergencesppuk/>. Those who are interested should pre-register via: [sifud-pp@orange.fr](mailto:sifud-pp@orange.fr) and they will be sent updated information regarding registration.

### **IAPO 4<sup>TH</sup> GLOBAL PATIENTS CONGRESS 2010 IN TURKEY**

The International Alliance of Patients Organizations (IAPO) will be holding its 4th Global Patients Congress in Istanbul, Turkey, 23-25 February 2010.

IAPO is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world. Its members are patients' organizations working at international, regional, national and local levels to represent and support patients, their families and carers. IAPO's vision is that patients throughout the world are at the centre of healthcare.

IAPO's Congress provides a unique opportunity for patient advocates, across diseases and across borders, to come together and participate in an exciting agenda which will help to foster global networks, develop practical skills, and enable engagement and understanding of key policy issues affecting patients in the international arena. As IAPO increases its membership in Africa, Asia, Latin America and the Middle East, it is particularly appropriate and exciting to be able to hold this event in Istanbul, a city founded on three great civilizations, where the East meets the West.

For more information visit [www.patientsorganizations.org/congress](http://www.patientsorganizations.org/congress). The theme of this congress will be: Strengthening Global Healthcare Systems: The Value of Patient Engagement. News and updates about the forthcoming congress will be placed on the website. If patient organizations have any queries, please do not hesitate to contact IAPO at [info@patientsorganizations.org](mailto:info@patientsorganizations.org).

### **NEW GUIDELINES FOR PRESCRIBING OPIOID PAIN DRUGS PUBLISHED**

In February 2009, the publication of the first comprehensive clinical practice opioid guideline for chronic non-cancer pain was announced by the American Pain Society and the American Academy of Pain. To develop this guideline, the pain societies convened a panel of pain management experts, who reviewed more than 8,000 published and non-published studies before issuing 25 specific recommendations.

“The expert panel concluded that opioid pain medications are safe and effective for carefully selected, well-monitored patients with chronic non-cancer pain,” said Gilbert J. Fanciullo, MD, a panel co-chair and director, Section of Pain Medicine, Dartmouth Hitchcock Medical Center.

Opioids have been traditionally used to relieve pain after surgery, from cancer or at the end of life. Today, they are also used to relieve severe chronic pain from other conditions such as low-back injury, arthritis, fibromyalgia, vulvodynia and severe IC/PBS. The most common side effects are constipation and nausea. There appears to be a growing willingness to prescribe opioids among medical professionals. The guideline acknowledges, however, the widespread concern about their possible abuse and addiction. The panel advised that, prior to initiating long-term opioid treatment, doctors assess whether or not the pain can be controlled with other medications. If opioids appear to be the most effective treatment option, providers should conduct a thorough medical history and examination, and evaluate potential risk for substance abuse or addiction. Because of this risk, routine monitoring of chronic pain patients prescribed opioids is required.

Additional information on the opioid guideline can be viewed on the American Pain Society’s website.

<http://www.ampainsoc.org/press/2009/downloads/20090210.pdf>

[http://www.jpain.org/article/S1526-5900\(08\)00831-6/abstract](http://www.jpain.org/article/S1526-5900(08)00831-6/abstract)

See also: Selected New Scientific Literature.

## BOOK REVIEW

### **Functional Pain Syndromes: Presentation and Pathophysiology**

Editors: Emeran A. Mayer, M. Catherine Bushnell

578 pages, ISBN 978-0-931092-75-6, Cost: US\$95.00 (IASP Members US\$75.00)

Functional pain disorders — such as irritable bowel syndrome, fibromyalgia, vulvodynia, and interstitial cystitis — have received research attention as separate entities. This book brings together experts from the fields of pain medicine, gastroenterology, psychiatry, physiology, genetics, and neuroscience to review the growing evidence that these disorders have substantial comorbidity with each other. The authors explore the connection of these painful syndromes with anxiety and depression, and with other disorders such as post-traumatic stress disorder and chronic fatigue syndrome. The book describes the various disorders, emphasizing both similarities and differences, and addresses possible common pathophysiologies. In addition, the authors review the evidence for efficacy of a range of treatment options, from antidepressants and other pharmaceutical strategies to nonpharmacological methods, including cognitive behavioural therapy.

For more information or to order this book, go to [www.iasp-pain.org/FunctionalPain](http://www.iasp-pain.org/FunctionalPain)

## 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” or “Early View” 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 online access to that specific journal.

### **Clinical guidelines for interstitial cystitis and hypersensitive bladder syndrome.**

Homma Y, Ueda T, Tomoe H, Lin AT, Kuo HC, Lee MH, Lee JG, Kim DY, Lee KS; The interstitial cystitis guideline committee. *Int J Urol.* 2009 Jun 22. [Epub ahead of print. PMID:19548999

This in-depth paper from the East Asian interstitial cystitis guideline committee presents a clinical guideline and algorithm for interstitial cystitis and hypersensitive bladder syndrome developed by a group of East Asian urologists as a revised form of the Japanese guideline for interstitial cystitis. The guideline defines interstitial cystitis (IC) as a disease of the urinary bladder diagnosed by 3 requirements; 1) a characteristic complex of lower urinary tract symptoms, 2) bladder pathology such as Hunner's ulcer and bladder bleeding after overdistension, and 3) exclusion of confusable diseases. The characteristic symptom complex is termed as hypersensitive bladder syndrome (HBS), which is defined as bladder hypersensitivity, usually associated with urinary frequency, with or without bladder pain. For the definite diagnosis of IC, cystoscopy or hydrodistension is crucial. HBS is the diagnosis when IC is suspected but not confirmed by the 3 requirements.

### **Bladder Pain: Clinical Assessment and Treatment.**

Dagmar Westerling. *UIJ.* 2009 In Press. doi:10.3834/uij.1944-5784.2009.08.03

This paper reviews and discusses different causes of bladder pain, reminding us that bladder pain is a symptom and not a disease and that all bladder pain is not PBS/IC and bladder pain is often not the only type of pain in patients suffering from PBS/IC. According to the author, patients with complex bladder pain may benefit from a consultation and second opinion from a pain specialist early in the course of the workup and not as a last measure when everything else has failed.

*The full text of this paper published in UroToday International Journal is available online via:*

[http://www.urotoday.com/3386/urotoday\\_international\\_journal/new\\_in\\_press/bladder\\_pain\\_clinical\\_assessment\\_and\\_treatment06262009.html](http://www.urotoday.com/3386/urotoday_international_journal/new_in_press/bladder_pain_clinical_assessment_and_treatment06262009.html)

### **Bladder pain syndrome/interstitial cystitis: a sense of urgency.**

Hanno PM, Chapple CR, Cardozo LD. *World J Urol.* 2009 Jun 24. [Epub ahead of print]. PMID: 19551386

The authors consider it likely that the urgency experienced by these patients differs from that experienced by patients with overactive bladder syndrome. It is unclear how best to define urgency in the BPS/PBS/IC setting. Differences in the other primary symptoms associated with these conditions probably influence how urgency is perceived. The authors are of the opinion that advances in research into the pathophysiology of urgency and underlying disease processes will help to optimize the diagnosis and treatment of BPS/PBS/IC.

### **Two types of urgency**

Blaivas JG, Panagopoulos G, Weiss JP, Somaroo C. *Neurourol Urodyn.* 2009;28(3):188-90. PMID: 19306331

According to the authors, the definition of urgency remains the subject of much controversy. The authors believe that urgency is comprised of at least two different

sensations. A distinction between them is important since they may have different etiologies and may respond differently to treatment.

### **Randomized Multicenter Feasibility Trial of Myofascial Physical Therapy for the Treatment of Urological Chronic Pelvic Pain Syndromes.**

*Fitzgerald MP, Anderson RU, Potts J, Payne CK, Peters KM, Clemens JQ, Kotarinos R, Fraser L, Cosby A, Fortman C, Neville C, Badillo S, Odabachian L, Sanfield A, O'Dougherty B, Halle-Podell R, Cen L, Chuai S, Landis JR, Mickelberg K, Barrell T, Kusek JW, Nyberg LM; Urological Pelvic Pain Collaborative Research Network. J Urol. 2009 Jun 15. [Epub ahead of print]. PMID: 19535099*

The aim of this trial was to determine the feasibility of conducting a randomized clinical trial designed to compare two methods of manual therapy (myofascial physical therapy and global therapeutic massage) in 48 patients with urological chronic pelvic pain syndromes. The global response assessment response rate of 57% in the myofascial physical therapy group was significantly higher than the rate of 21% in the global therapeutic massage treatment group. The research team is therefore of the opinion that it is feasible to conduct a full-scale trial of physical therapy methods and that the preliminary findings of a beneficial effect of myofascial physical therapy warrant further study.

### **Extracorporeal shock wave therapy for the treatment of chronic pelvic pain syndrome in males: a randomised, double-blind, placebo-controlled study.**

*Zimmermann R, Cumanas A, Miclea F, Janetschek G. Eur Urol. 2009 Mar 25 [Epub ahead of print]. PMID: 19372000*

Since there is no adequately validated therapy for chronic pelvic pain syndrome (CPPS), the aim of this study was to investigate the effects of extracorporeal shock wave therapy (ESWT) in 60 patients suffering from CPPS. Sixty patients suffering from CPPS for at least 3 months were investigated in two groups. Both groups were treated four times (once per week), each by 3000 impulses; group 2 was performed as a sham procedure. The investigation was designed as a placebo-controlled, prospectively randomised, double-blind phase 2 study. This is the first prospectively randomised, double-blind study to reveal perineal ESWT as a therapy option for CPPS with statistically significant effects in comparison to placebo. ESWT may in particular be interesting because of its easy and inexpensive application, the lack of any side-effects, and the potential for repetition of the treatment at any time. According to the authors, many urologists are not aware that ESWT is not only for use in stone treatment and that shock waves have clearly shown tissue-regenerating effects. Shock Waves seem to have a greater therapeutic potential than hitherto assumed.

### **Treatment of painful bladder syndrome and pelvic organ prolapse: highlights of the 4<sup>th</sup> international consultation on incontinence, July 5-8, 2008, Paris, France.**

*Chuang YC, Chancellor MB. Rev Urol. 2009 Winter;11(1):28-32. PMID: 19390672*

This is a review of the International Consultation on Incontinence in 2008.

*Free full text article available online:*

<http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=2668838&blobtype=pdf>

**Urinary nerve growth factor level is increased in patients with interstitial cystitis/bladder pain syndrome and decreased in responders to treatment.**

Liu HT, Tyagi P, Chancellor MB, Kuo HC. *BJU Int.* 2009 Jun 12. [Epub ahead of print]. PMID: 19522864

The aim of this study was to measure urinary nerve growth factor (NGF) levels in patients with interstitial cystitis/bladder pain syndrome (IC/BPS) and to evaluate the role of urinary NGF in predicting the response to treatment. It was concluded that patients with IC/BPS had greater urinary NGF/creatinine levels than controls. A decrease in urinary NGF was associated with greater pain reduction and a successful response, suggesting that urinary NGF could be a useful biomarker for detecting the severity of the bladder condition in these patients.

#### **Interleukin 8 is essential for normal urothelial cell survival.**

Tseng-Rogenski S, Liebert M. *Am J Physiol Renal Physiol.* 2009 Jun 17. [Epub ahead of print]. PMID: 19535567

Interleukin 8 (IL-8, CXCL8) has been shown to play a role in multiple cellular processes. This paper reports on an additional role of IL-8 as a growth and essential survival factor for normal human urothelial cells. The researchers are of the opinion that their results indicate that lower IL-8 expression levels in the urinary bladder may contribute to the pathophysiology of interstitial cystitis.

#### **Les Traitements de recours dans la cystite interstitielle [Alternative treatments for interstitial cystitis].** [Article in French]

Gamé X, Bart S, Castel-Lacanal E, De Sèze M, Karsenty G, Labat JJ, Rigaud J, Scheiber-Nogueira MC, Ruffion A; Comité de Neuro-urologie de l'Association Française d'Urologie. *Prog Urol.* 2009 Jun;19(6):357-363. PMID: 19467453

This French article reviews and evaluates a range of alternative therapies for the treatment of interstitial cystitis: posterior sacral root neuromodulation, posterior tibial nerve stimulation, vanilloid agent intravesical instillation, intradetrusor botulinum toxin injections and surgery. Although each of these treatments has been reported to have some effect, evaluation of these treatments is limited and the level of evidence too low to be able to recommend them for routine treatment.

#### **Comorbidités somatiques dans le Syndrome de l'Intestin Irritable: fibromyalgie, syndrome de fatigue chronique et cystite interstitielle/syndrome de la vessie douloureuse. [Somatic comorbidities in irritable bowel syndrome: fibromyalgia, chronic fatigue syndrome and interstitial cystitis].** [Article in French].

Mathieu N. *Gastroentérologie Clinique et Biologique* (2009) 33, Suppl. 1, S17-S25

Another interesting article in French. Fibromyalgia, chronic fatigue syndrome and interstitial cystitis frequently overlap with irritable bowel syndrome, raising the question of a common underlying pathophysiology. According to the author, a possible central hypersensitization disorder may be involved in the dysfunction of bidirectional neural pathways viscerovisceral cross-interactions within the CNS. This could explain the many extraintestinal manifestations in IBS.

(This article is part of a French supplement dedicated to Syndrome de l'Intestin Irritable/Irritable Bowel Syndrome).

#### **Differentiating interstitial cystitis from similar conditions commonly seen in gynecologic practice.**

Dell JR, Mokrzycki ML, Jayne CJ. *Eur J Obstet Gynecol Reprod Biol.* 2009 Jun;144(2):105-9. Epub 2009 May 5. PMID: 19409685

A review article. The clinical presentation of interstitial cystitis is similar to that of many other conditions commonly seen in female patients, including recurrent urinary tract infections, endometriosis, chronic pelvic pain, vulvodynia, and overactive bladder. In addition, interstitial cystitis may exist concurrently with these conditions. Correct diagnosis is necessary for appropriate treatment and improved outcomes. Tools to assist in the diagnosis of interstitial cystitis, as well as effective therapies for this condition, are available. A diagnosis of interstitial cystitis should be considered in patients with irritative voiding symptoms and/or pelvic pain complaints.

### **Urodynamic findings of the painful bladder syndrome/interstitial cystitis: a comparison with idiopathic overactive bladder.**

*Kim SH, Kim TB, Kim SW, Oh SJ. J Urol. 2009 Jun;181(6):2550-4. Epub 2009 Apr 16. PMID: 19375103*

In this study, the aim of the authors was to identify the characteristics of urodynamic results in patients with painful bladder syndrome/interstitial cystitis and in those with idiopathic overactive bladder. The fluoroscopic urodynamic study results were analyzed retrospectively in 40 consecutive female patients with painful bladder syndrome/interstitial cystitis and 78 female patients with idiopathic overactive bladder. Before treatment a symptom assessment, questionnaires, 3-day voiding diary and laboratory tests were performed at the initial outpatient clinic visit. All patients had been diagnosed and grouped according to painful bladder syndrome/interstitial cystitis or overactive bladder based on the clinical features before cystoscopy, potassium chloride sensitivity test and urodynamic investigation. The results of this study showed that the urodynamic results were significantly different between the painful bladder syndrome/interstitial cystitis and overactive bladder groups. Combined with other clinical findings, urodynamic studies might provide additional information to confirm a diagnosis of painful bladder syndrome/interstitial cystitis.

### **The relationship among symptoms, sleep disturbances and quality of life in patients with interstitial cystitis.**

*Nickel JC, Payne CK, Forrest J, Parsons CL, Wan GJ, Xiao X. J Urol. 2009 Jun;181(6):2555-61. Epub 2009 Apr 16. PMID: 19375108*

The study was a retrospective analysis to determine associations among symptoms, sleep disturbances and quality of life in responder and non-responder groups of patients with interstitial cystitis taking part in a multidose pentosan polysulfate sodium clinical trial. It was concluded that a reduction in interstitial cystitis symptoms may be associated with patient reported improvement in sleep and quality of life.

### **Gene expression profile of bladder tissue of patients with ulcerative interstitial cystitis.**

*Gamper M, Viereck V, Geissbuehler V, Eberhard J, Binder J, Moll C, Rehrauer H, Moser R. BMC Genomics. 2009 Apr 28;10(1):199. PMID: 19400928*

Open access article:

<http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=2686735&blobtype=pdf> (or accessible via PubMed abstract)

According to Gamper et al, IC is diagnosed using subjective symptoms in combination with cystoscopic and histological evidence. Through cystoscopic examination, IC can be classified into ulcerative and non-ulcerative subtypes. A comparative gene expression profile of bladder biopsies from patients with ulcerative IC and control patients was carried out in this small study. Gene expression profiles

from bladder biopsies of five patients with ulcerative IC and six control patients were generated. The IC pattern had similarities to patterns from immune system, lymphatic, and autoimmune diseases. The dominant biological processes were the immune and inflammatory responses. Many of the up-regulated genes were expressed in leukocytes, suggesting that leukocyte invasion into the bladder wall is a dominant feature of ulcerative IC. Histopathological data supported these findings. It was concluded by the authors that GeneChip expression arrays present a global picture of ulcerative IC and provide us with a series of marker genes characteristic for this subtype of the disease. Further research is necessary to indicate whether the data presented here will be valuable for the diagnosis of IC.

### **Prevalence, symptom impact and predictors of chronic prostatitis-like symptoms in Canadian males aged 16-19 years.**

*Tripp DA, Nickel JC, Ross S, Mullins C, Stechyson N. BJU Int. 2009 Apr;103(8):1080-4. Epub 2008 Oct 24. PMID: 19007369*

The aim of this study was to estimate the prevalence and examine the extent that pain, urinary symptoms, depression and pain catastrophizing predict the quality of life in Canadian male adolescents. These data provide the first point-prevalence estimate of CP-like symptoms in adolescents. Adolescent male chronic pelvic pain is an important and understudied area for future investigations.

### **Clinical guidelines for the use of chronic opioid therapy in chronic noncancer pain.**

*Chou R, Franciullo GJ, Fine PG, Adler JA, Ballantyne JC, Davies P, Donovan MI, Fishbain DA, Foley KM, Fudin J, Gilson AM, Kelter A, Mauskop A, O'Connor PG, Passik SD, Pasternak GW, Portenoy RK, Rich BA, Roberts RG, Todd KH, Miaskowski C, American Pain society-American Academy of :Pain Medicine Opioids Guidelines Panel. J Pain. 2009 Feb;10(2):113-30. PMID: 19187889*

The American Pain Society and the American Academy of Pain Medicine commissioned a systematic review of the evidence on chronic opioid therapy for chronic non-cancer pain and convened a multidisciplinary expert panel to review the evidence and formulate recommendations. The recommendations presented in this paper provide guidance on patient selection and risk stratification; informed consent and opioid management plans; initiation and titration of chronic opioid therapy; use of methadone; monitoring of patients on chronic opioid therapy; dose escalations, high-dose opioid therapy, opioid rotation, and indications for discontinuation of therapy; prevention and management of opioid-related adverse effects; driving and work safety; identifying a medical home and when to obtain consultation; management of breakthrough pain; chronic opioid therapy in pregnancy; and opioid-related policies. The authors conclude that safe and effective chronic opioid therapy for chronic non-cancer pain requires clinical skills and knowledge in both the principles of opioid prescribing and on the assessment and management of risks associated with opioid abuse, addiction, and diversion.

## **UPCOMING EVENTS**

### **2009:**

#### **International Continence Society (ICS)**

39th Annual Meeting 30 September - 4 October 2009, San Francisco, USA

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

1-3 October, 2009, Brest, France.

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

1-5 November 2009, Shanghai, China

### **Convergences in Pelviperineal Pain (including IASP/PUGO meeting)**

16-18 December 2009 Cite des Congres de Nantes (France)

### **2010**

**IAPO 4<sup>th</sup> Global Patients Congress**, 23-25 February 2010 Istanbul, Turkey

**5<sup>th</sup> European Conference on Rare Diseases**, 13-15 May 2010 Krakow, Poland

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.**

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 Astellas Pharma bv, Oxyor bv, Bioniche Pharma Group Ltd and private donors for their greatly appreciated financial support for our foundation, projects, patient advocacy, website and newsletters for the year 2009.

## **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).*

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*If you do not wish to receive this newsletter in future, please notify the International Painful Bladder Foundation: [info@painful-bladder.org](mailto:info@painful-bladder.org) with "unsubscribe" in the subject bar.*

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