

# 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 23, November 2010**

*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).*

This issue of the IPBF E-Newsletter includes the following topics:

- SIU World Meeting on Lower Urinary Tract Dysfunction, 13-16 October, 2010, Marrakech, Morocco with webcasts
- ICS-IUGA webcast on Pudendal Neuropathy
- Essic Videos of Hunner's Lesion at Cystoscopy with Hydrodistension now online
- Chondroitin Sulfate Sodium Pilot Study in USA unsuccessful but Stellar will continue
- AARDA raises global issue of autoimmune diseases at the United Nations
- Upcoming Meetings: EURORDIS, International Pelvic Pain Society, International Symposium on Sjögren's syndrome, EULAR
- New Clinical Update on Pain from IASP
- Books and Websites
- Research Highlights: new literature
- Donations and Sponsoring

## **SOCIÉTÉ INTERNATIONALE D'UROLOGIE (SIU) WORLD MEETING ON LOWER URINARY TRACT DYSFUNCTION, 13-16 OCTOBER, 2010, MARRAKECH, MOROCCO Symposium on Urological Chronic Pelvic Pain Syndromes (UCPPS): 2000-2010. A Decade of Progress**

Held in the beautiful and historic city of Marrakech in North Africa, the SIU meeting this year focused on Lower Urinary Tract Dysfunction. It included a symposium on Urological Chronic Pelvic Pain Syndromes (UCPPS): 2000-2010. A Decade of Progress, chaired by J. Curtis Nickel, MD from Canada. Other speakers included doctors Michael Pontari (USA), Jorgen Nordling (Denmark), Karl Kreder (USA) and Anthony Schaeffer (USA). Unfortunately Professor J.J. Wyndaele from Antwerp was unable to attend but his presentation on the Evolution of Definitions, Diagnosis and Nomenclature was given by J Curtis Nickel. Fortunately, this symposium was one of the sessions selected for webcasting. An overview of the complete list of webcasts can be viewed at [TTMed SIU webcasts](http://TTMed SIU webcasts), with a direct link to the UCPPS session at:

<http://webcasts.prous.com/SIU2010/html/1-en/template.aspx?section=7&p=7,13315&p=3,13307>.

This deals with UCPPS in both men and women and will therefore also be particularly interesting for those concerned with male urologic chronic pelvic pain syndrome.

### **Other SIU webcasts of interest: Overactive bladder**

Patient organizations who also work in the field of overactive bladder may find the webcast on this topic useful. A direct link to the four presentations on overactive link can be found here:

<http://webcasts.prous.com/SIU2010/html/1-en/template.aspx?section=7&p=7,13283&p=3,13283>

### **ICS-IUGA WEBCAST ON PUDENDAL NEUROPATHY**

Another TTMed webcast that you may find of interest is a workshop on pudendal neuropathy held at the International Continence Society and International UroGynecological Association joint meeting in Toronto in August this year. Click here to access the webcast:

[Workshop 12: Pudendal Neuropathy and its Pivotal Role in Pelvic Floor Dysfunction and Pain](#)

**ESSIC VIDEOS OF HUNNER'S LESION AT CYSTOSCOPY WITH HYDRODISTENSION NOW ONLINE**

It is now possible to look at videos of Hunner's lesion at cystoscopy with hydrodistension online on the ESSIC website. For a direct link, [click here](#).

**CHONDROITIN SULFATE SODIUM PILOT STUDY IN USA UNSUCCESSFUL BUT STELLAR WILL CONTINUE**

On 11 November, press releases stated that Watson Pharmaceuticals Inc had decided to halt its study into chondroitin sulfate sodium (Uracyst®) in the USA since it failed to meet the main goals of a pilot study. Fred Wilkinson, Watson's Executive Vice President, Global Brands stated "We will work with Stellar Pharmaceuticals Inc. to further evaluate the response and assist in determining any next steps, but at this time we do not plan to allocate any additional resources to further pursue this development". However, Stellar is undeterred and intends to fully review the data and move ahead with Uracyst® approval in the USA. The company points out that while these results were unexpectedly disappointing, it should be borne in mind that these were results from one small (98 patient) phase II trial. These small trials can fail to hit statistical significance but do help in determining how to properly move to the next step.

While the results may be disappointing considering that this treatment has shown clinical success in Europe, we have all seen in recent years that trials of intravesical treatments in the USA tend to produce these less than positive results.

**AARDA RAISES GLOBAL ISSUE OF AUTOIMMUNE DISEASES AT THE UNITED NATIONS**

The American Autoimmune Related Diseases Association (AARDA), a member of the International Alliance of Patients' Organizations (IAPO), recently partnered with the United Nations (UN) NGO Health Committee to co-host 'The Global State of Autoimmunity Today.' The UN played host to a veritable who's who of world leaders, dignitaries and international NGO advocates at its Millennium Development Goals (MDG) Meeting this September. This important gathering was intended to aid in the on-going development of an action plan to achieve goals in the areas of poverty, universal education, gender equality, child health, maternal health, HIV/AIDS, environmental health, and women's health by 2015. Because autoimmune diseases (ADs) have become a growing international health issue, this unique gathering of international stakeholders in health seemed an excellent opportunity to spotlight the global issues surrounding autoimmune diseases. [Read more:](#)

**UPCOMING MEETINGS**

**EURORDIS ANNUAL MEMBERSHIP MEETING 2011**

The Annual EURORDIS Membership Meeting 2011 will take place on 13 and 14 May, 2011 in Amsterdam, the Netherlands with the General Assembly being held on 13 May. The purpose and objectives of the Annual Membership Meeting are to provide networking opportunities to patients and patient organisations, capacity building in the form of interactive workshops and empowerment to patients and patient organisations as a direct result of the capacity-building sessions. EURORDIS is a non-governmental patient-driven alliance of patient organisations representing more than 434 rare diseases patient organisations in over 43 countries.

Venue: Hotel Casa 400 - Eerste Ringdijkstraat 4 - 1097 BC Amsterdam

For more information: Anja Helm, Manager of Relations with Patient Organisations, + (33) 1 56 53 52 17 [anja.helm@eurordis.org](mailto:anja.helm@eurordis.org)

**INTERNATIONAL PELVIC PAIN SOCIETY (IPPS) ANNUAL SCIENTIFIC MEETING**

**25-29 MAY 2011, ISTANBUL ([http://www.ipps2011.org/en/index.php?ana\\_id=14](http://www.ipps2011.org/en/index.php?ana_id=14))**

The aim of the International Pelvic Pain Society (IPPS) is to serve as an educational resource for health care professionals, to optimize diagnosis and treatment of patients suffering from chronic pelvic pain, to collate research in chronic pelvic pain and to inform men and women, to serve as a resource of education for treatment options and professional health care members.

In 2011, its annual scientific meeting will be held in Istanbul. According to the preliminary scientific programme for 2011 ([click here](#)), Session IV will include a session on interstitial cystitis, neurobiology & treatments, irritable bowel syndrome, neurobiology & treatments and pudendal and other pelvic floor neuralgias. Session V will cover vulvodynia and vestibulitis, Session VI to IX will deal with endometriosis.

#### **INTERNATIONAL SYMPOSIUM ON SJÖGREN'S SYNDROME (ISSS)**

**28 SEPTEMBER - 1 OCTOBER 2011, ATHENS, GREECE**

A date for the diaries of those interested in Sjögren's syndrome. We will let you know when further information is available.

#### **ANNUAL EUROPEAN CONGRESS OF RHEUMATOLOGY (EULAR)**

**25-28 MAY 2011, LONDON, UNITED KINGDOM**

EULAR provides a forum of the highest standard for scientific (both clinical and basic), educational and social exchange between professionals involved in rheumatology, liaising with patient organisations, in order to achieve progress in the clinical care of patients with rheumatic diseases.

Congress Location: ExCeL London, One Western Gateway, Royal Victoria Dock, London E16 1XL, United Kingdom

[click here](#)

#### **NEW CLINICAL UPDATE ON PAIN FROM IASP ([www.iasp-pain.org](http://www.iasp-pain.org))**

The International Association for the Study of Pain (IASP) publishes regular clinical updates on pain which are available on the IASP website (under *Publications*). [Click here](#) for direct link to Clinical Updates Pain page where you will find all Pain Updates as well as the new issues given below.

**- Diagnosis and Classification of Neuropathic Pain, Vol. XVIII, Issue 7 - September 2010**

This clinical update provides some interesting food for thought on neuropathic pain

**- Pharmacogenetics, Vol. XVIII, Issue 8 p September 2010**

#### **BOOKS AND WEBSITES**

##### **4TH EDITION OF INCONTINENCE 2009**

*4th International Consultation on Incontinence (ICI), Paris July 5-8, 2008*

*Editors: Paul Abrams, Linda Cardozo, Saad Khoury, Alan Wein*

*ISBN 0-9546956-8-2, Health Publication Ltd 2009, 1872 pp*

This book, which is a report on 22 aspects of incontinence from the 4<sup>th</sup> ICI in 2008, is now available online on the website of the International Continence Society (ICS). It includes the chapter by [Committee 19 on Bladder Pain Syndrome](#). [Click here](#) to access the book (or go to

<http://www.icsoffice.org/Publications/Publications.aspx>) and then select chapter 19.

The opening page has the following quotation from Thomas Huxley (1825-1895):

"The great tragedy of science: The slaying of a beautiful hypothesis by an ugly fact".

How very relevant this is to the IC world where we have seen innumerable hypotheses come and go!

##### **[CLINICAL PAIN MANAGEMENT: A PRACTICAL GUIDE](#)**

*Edited by: Mary E. Lynch, Kenneth D. Craig, Philip W.H. Peng*

*Published by: Wiley-Blackwell December 2010*

*ISBN 9781444330694*

*388 pages*

A practical guide for professionals on improving their patients' quality of life by increasing their knowledge of practical pain control. Also interesting for patient advocates/patients and very readable. It describes pain as being the most pervasive and debilitating of all experiences. It can be acute and short-lived or develop into a chronic condition that destroys quality of life. However, it emphasises that most pain can be managed. Clinical Pain Management takes a practical, interdisciplinary approach to the assessment and management of pain by offering to-the-point best-practice guidance in an easy-to-follow layout including tables, bullets, algorithms, and guidelines. Based on the International Association for the Study of Pain's (IASP) core clinical curriculum, and edited and written by leading international experts, this book covers: Basic understanding of pain medicine, Assessment of pain, Management, Pharmacotherapy, Interventional, Physical therapy and rehabilitation, Complementary therapies, Specific clinical states (including fibromyalgia syndrome and myofascial pain syndromes), and Special populations (including pain in children, older people, and other special populations).

#### **INVISIBLE ILLNESS PATIENT ADVOCATE WEBSITE**

Click on the title to go to this invisible illness patient empowerment website with resources for chronic pain syndromes and autoimmune diseases, set up by the authors of the well known book Secret Suffering, Susan Bilheimer and Robert Echenberg, MD.

#### **RESEARCH HIGHLIGHTS**

##### **A REVIEW OF SELECTED RECENT 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 if you click on the title. An increasing number of scientific articles "In Press" or "Early View" are 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.*

**Terminology:** different published articles use different terminology, for example: interstitial cystitis, painful bladder syndrome, bladder pain syndrome, hypersensitive bladder syndrome, chronic pelvic pain syndrome or combinations of these. When reviewing the article, we generally use the terminology used by the authors.

#### **PERCEPTIONS OF "URGENCY" IN WOMEN WITH INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME OR OVERACTIVE BLADDER.**

*Clemens JQ, Bogart LM, Liu K, Pham C, Suttorp M, Berry SH. Neurourol Urodyn. 2010 Nov 5. [Epub ahead of print]. PMID: 21058364*

This study compared "urgency" symptoms in women with interstitial cystitis/bladder pain syndrome (IC/BPS) and overactive bladder (OAB). "Urgency" and its definition have been a topic of much controversy in recent years, but little actual research into urgency in both conditions was undertaken. We are happy to see that things seem to be changing at last. In this study, urgency was commonly reported as a symptom by women with both conditions (81% IC/BPS and 91% OAB). In IC/BPS, the urgency was primarily reported as due to pain, pressure, or discomfort, while in OAB the urgency was more commonly due to fear of leakage. However, it is particularly interesting to note that approximately 40% of women with OAB also report urgency due to pain, pressure, or discomfort! Similar proportions of both groups (□60%) indicated that the urgency occurred "suddenly" instead of more gradually over a period of minutes or hours. The authors found that urgency symptoms differed in women diagnosed with IC/BPS versus those diagnosed with OAB, but that there was a significant overlap. They conclude that this suggests that "urgency" is not a well-defined and commonly understood symptom that can be utilised to clearly discriminate between IC/BPS and OAB and that the findings from this study reinforce the clinical observation that it is often challenging to differentiate between these two conditions.

***The January 2011 issue (now online) of Medical Clinics of North America, Volume 95, Issue 1, Pages 1-288 focuses on Urologic Issues for the Internist, edited by Michael J. Droller. There are many interesting and useful articles here including the following one on diagnosis & treatment of Bladder Pain Syndrome:***

### **BLADDER PAIN SYNDROME**

*Hanno P, Nordling J, Fall M. Med Clin N Am 95 (2011)55-73. Doi:10.1016/j.mcna.2010.08.014*

A useful review of diagnosis and treatment by Hanno, Nordling and Fall, describing in detail the diagnostic work-up and treatment as recommended by the International Consultation on Incontinence.

### **SACRAL NEUROMODULATION IN UROLOGICAL INDICATIONS: THE FINNISH EXPERIENCE.**

*Vaarala MH, Tammela TL, Perttilä I, Luukkonen P, Hellström P. Scand J Urol Nephrol. 2010 Oct 21. [Epub ahead of print]. PMID: 20961268*

In Finland, sacral neuromodulation has been used for the treatment of urgency-frequency syndrome, non-obstructive urinary retention and painful bladder/interstitial cystitis since 1996. This Finnish study retrospectively evaluated 180 tested patients, 74 of whom underwent permanent implantation of the InterStim(®) device. It was found that a positive test result leading to implantation was significantly more frequent among females than males. The authors concluded that the difference in gender distribution compared with other published data may be explained by a selection bias due to the limited number of female patients referred by gynaecologists. The results seem to favour the use of a tined lead device because of the shorter operating room time. Furthermore, the outcome seems to be more favourable among patients with a staged implant procedure compared with a one-stage operation with a tined lead device.

### **INTRAVESICAL DRUG DELIVERY: CHALLENGES, CURRENT STATUS, OPPORTUNITIES AND NOVEL STRATEGIES.**

*Sarkar SG, Banerjee R. J Control Release. 2010 Sep 7. [Epub ahead of print]. PMID: 20831887*

The authors note that diseases of the urinary bladder, such as bladder cancer and interstitial cystitis, may cause acute damage to the bladder wall and cannot be effectively treated by systemic administration of drugs. Conditions of this kind may benefit from intravesical drug delivery (IDD), which involves direct instillation of a drug into the bladder via a catheter in order to attain high local concentrations of the drug in the bladder but with minimal systemic effects. This paper reviews recent advances and future prospects of biodegradable nanocarriers and in situ gels as drug delivery agents for intravesical drug delivery.

### **DEMYSTIFYING PLEOMORPHIC FORMS IN PERSISTENCE AND EXPRESSION OF DISEASE: ARE THEY BACTERIA, AND IS PEPTIDOGLYCAN THE SOLUTION?**

*Domingue GJ. Discov Med. 2010 Sep;10(52):234-46. PMID: 20875345*

*Free access, click on title*

There is considerable circumstantial evidence linking tissue pleomorphic forms of unknown origin with idiopathic chronic inflammatory, collagen, lymphoproliferative, nephro-urological (including interstitial cystitis and prostatodynia), and neoplastic diseases. Although these forms have been observed in stained tissue histopathologic specimens for many decades, most are ignored and generally regarded as diagnostically insignificant staining artifacts or debris. It is hypothesized in this study that these pleomorphic forms are not staining artifacts/cellular debris, but instead represent various stages in the life cycle of stressed bacteria: cell wall-deficient/defective (often called L-forms) that are difficult-to-culture or nonculturable.

### **INTERSTITIAL CYSTITIS: A NEGATIVE ONGOING SITUATION?**

*Wyllie MG. BJU Int. 2010 Nov;106(9):1401-2. doi: 10.1111/j.1464-410X.2010.09865.x. PMID: 20946350*

Michael Wyllie endeavours to explain here why there has been little substantial progress in drug development for IC in recent years. He believes that the primary problem lies in the need for an evidence-based disease definition. He writes: "A disease definition is required to ensure that the clinical trial patient population, selected by appropriate inclusion and exclusion criteria, actually has the disorder/disease. In addition, a definition is required to develop a validated patient reported outcome (PRO) to capture the

*data in the clinical trials. Perhaps not surprisingly, as IC is a symptom-complex, an agreed definition has not been crafted which has obvious consequences for clinical trial design and data capture". Furthermore, research into new drugs is not cost effective for industry. His conclusion is that IC patients are not likely to have much more choice in the future beyond a selection from PPS, hyaluronan, chondroitin sulfate and PSD597-based treatments.*

#### **LONG-TERM RESULTS OF INTRAVESICAL HYALURONAN THERAPY IN BLADDER PAIN SYNDROME/INTERSTITIAL CYSTITIS.**

*Engelhardt PF, Morakis N, Daha LK, Esterbauer B, Riedl CR. Int Urogynecol J Pelvic Floor Dysfunct. 2010 Oct 12. [Epub ahead of print]. PMID: 20938644*

This study from Austria looked at the long-term outcome of intravesical hyaluronan for the treatment of bladder pain syndrome/interstitial cystitis (BPS/IC). The authors concluded from their findings that in addition to demonstrating a high rate of acute symptom remission, intravesical hyaluronan also shows long-term efficacy in a considerable number of BPS/IC patients.

#### **MANAGEMENT OF CHRONIC PELVIC PAIN.**

*Benjamin-Pratt AR, Howard FM. Minerva Ginecol. 2010 Oct;62(5):447-65. PMID: 20938429*

Evaluation of CPP requires a careful history including screening for gastrointestinal, urologic, musculoskeletal, and neurological disorders. Management of CPP depends largely on the cause. Gynaecological causes include endometriosis, pelvic inflammatory disease, adhesive disease, pelvic congestion syndrome, ovarian retention syndrome, ovarian remnant syndrome, adenomyosis, and leiomyomas. Some non-gynaecological causes are interstitial cystitis/painful bladder syndrome, irritable bowel syndrome, pelvic floor tension myalgia, and abdominal myofascial pain syndrome. Treatment may be directed toward specific causes or general pain management. The most effective therapy may involve using both approaches.

#### **MULTIFACTORIAL CAUSES OF IRRITATING BLADDER SYMPTOMS IN PATIENTS WITH SJÖGREN'S SYNDROME.**

*Lee KL, Dong CS, Chen MY, Ho CH, Tai HC, Hung SF, Yu HJ. NeuroUrol Urodyn. 2010 Oct 6. [Epub ahead of print]. PMID: 20928912 [*

The purpose of this study from Taiwan was to look into the possible causes of irritating bladder symptoms, including urinary frequency and urgency, in patients with Sjögren's syndrome (SS). The authors found that various factors contribute to the irritating bladder symptoms in patients with SS, with detrusor overactivity being predominant. They concluded that the LUTS developed in patients with SS are not due to any specific single etiology and that consequently each patient must be individually carefully evaluated.

#### **[CONTRIBUTION OF BLADDER BIOPSY TO THE STUDY OF UROGYNAECOLOGICAL PATIENTS]**

*[Article in Spanish]*

*Flores-Carreras O, Martínez-Espinoza CJ, González-Ruiz MI, Montes-Casillas YE. Ginecol Obstet Mex. 2010 Mar;78(3):187-90. PMID: 20939223*

The aim of this descriptive, retrospective, analytical study of files and videos of 331 patients (age range 30-90 years) from Mexico was to determine the frequency of bladder structural lesions detected by urethroscopy during which the authors performed bladder biopsies (35 biopsies were performed).

Predominant symptoms were:

irritative vesical syndrome 62.8%;  
pelvic pain 45.71%;  
urge incontinence 31.4%;  
hematuria 31.4%;  
vesical voiding dysfunction 11.4%.

Principal endoscopic findings:

urethrotigonitis;  
glomerular lesions or Hunner ulcers;  
vesical trabeculations;

tumour or suspect lesions.

Histopathologic findings were:

interstitial Cystitis 42.9%;  
chronic Cystitis 11.4%;  
cystitis glandularis 8.6%;  
cystitis follicular 11.4%;  
bladder cancer 5.7%;  
vesical Papilloma 5.7%.

The authors conclude from their findings that their study supports carrying out bladder biopsy when lesions other than those from chronic infection are observed in the presence of tumours or suspect lesions.

**[CLINICAL AND DIAGNOSTIC EVALUATION IN PATIENTS WITH INTERSTITIAL CYSTITIS]**

*[Article in Spanish]*

*Flores-Carreras O, González-Ruiz MI, Martínez-Espinoza CJ, Calderón-Lara SA. Ginecol Obstet Mex. 2010 May;78(5):275-80. PMID: 20939238*

Another paper in Spanish from Mexico concluding that urogynaecologists must consider interstitial cystitis when patients show symptoms of bladder irritability and associated pain with bladder filling. The association of haematuria accompanied by long-term irritability and pain associated with the desire of urination suggests this disease

**SECONDARY CHANGES IN BOWEL FUNCTION AFTER SUCCESSFUL TREATMENT OF VOIDING SYMPTOMS WITH NEUROMODULATION.**

*Killinger KA, Kangas JR, Wolfert C, Boura JA, Peters KM. Neurourol Urodyn. 2010 Oct 6. [Epub ahead of print]. PMID: 20928914*

This study evaluated secondary changes in bowel function after successful neuromodulation for voiding symptoms. Most patients reporting secondary bowel problems were female. Primary voiding complaints were urgency/frequency with or without urinary incontinence, interstitial cystitis/painful bladder syndrome, and urinary retention. Secondary bowel complaints included constipation and/or diarrhoea. The authors conclude from their findings that while previous studies have indicated that neuromodulation improves faecal incontinence in carefully selected patients, the impact on other bowel conditions, including IBS, is unclear. They believe that since voiding and bowel symptoms often coexist, it is crucial to fully evaluate all potential treatment benefits.

**A PROSPECTIVE EARLY HISTORY OF INCIDENT INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME.**

*Warren JW, Greenberg P, Diggs C, Horne L, Langenberg P. J Urol. 2010 Oct 15. [Epub ahead of print]. PMID: 20952011*

According to the authors, there have been infrequent studies on the long-term history of interstitial cystitis/painful bladder syndrome. In a national sample, they assessed changes in symptoms during the first few years of interstitial cystitis/painful bladder syndrome in a group of 304 women with a history of interstitial cystitis/painful bladder syndrome symptoms of 12 months or less (average 9 months) and interviewed them by telephone at the start of the study, and 6, 12, 18, 24, 36 and 48 months later. They ask questions about symptoms in the last week and about medication used in the intervening period. 35% of the women reported an improvement in symptoms from the start of the study at last follow-up. However, the disappearance of all symptoms at any follow-up was uncommon.

**[INTERSTITIAL CYSTITIS: MINIMAL DIAGNOSTIC CRITERIA.]**

*[Article in Italian]*

*Galosi AB, Montironi R, Mazzucchelli R, Lacetera V, Muzzonigro G. Urologia. 2010 Oct 2;77(3):160-171. PMID: 20931545*

This article from Italy presents a review from the Italian point of view of the minimum investigations needed and their significance for the initial evaluation and diagnosis of patients with Interstitial Cystitis.

The recommendations - mainly based on expert opinion and a literature review - were developed according to a 3-grade scale: mandatory, recommended and optional.

Interstitial cystitis (IC) is defined as a disease of the urinary bladder diagnosed by at least one of the following 3 requirements:

- 1) endoscopic criteria (cystoscopy findings);
- 2) pathologic criteria of bladder biopsy; and
- 3) clinical criteria including pain and lower urinary tract symptoms evaluation.

Furthermore, the exclusion of confusable diseases is considered mandatory in all cases.

### **SACRAL NEUROMODULATION STIMULATION FOR IC/PBS, CHRONIC PELVIC PAIN, AND SEXUAL DYSFUNCTION**

*Jennifer Yonaitis Fariello JY, Whitmore K. Int Urogynecol J Pelvic Floor Dysfunct. 2010 Dec;21(12):1553-8. PMID: 20972541.*

This study reviews the use of sacral neuromodulation in the patient population with painful bladder syndrome/interstitial cystitis (PBS/IC), chronic pelvic pain (CPP), and sexual dysfunction. A literature review of the current research was carried out. This article highlights current research findings and uses of sacral neuromodulation in patients with PBS/IC, CPP, vulvar vestibulitis, and erectile dysfunction. Current research on sacral neuromodulation on the above-mentioned patient groups has shown potential efficacy in pilot studies, although according to the authors larger, multi-centred trials with long-term follow-up are needed.

### **MYOFASCIAL PAIN AND PELVIC FLOOR DYSFUNCTION IN PATIENTS WITH INTERSTITIAL CYSTITIS**

*Bassaly R, Tidwell N, Bertolino S, Hoyte L, Downes K, Hart S.*

*Int Urogynecol J Pelvic Floor Dysfunct. 2010 Oct 26. [Epub ahead of print]. PMID: 20976441.*

The purpose of this study performed on 186 patients with a diagnosis of IC from April 2007 to December 2008 was to investigate myofascial pain in patients with interstitial cystitis (IC) and to correlate myofascial examination findings with validated questionnaires. The authors found that myofascial pain was demonstrated in 78.3% of IC patients with at least one myofascial trigger point, and 67.9% of patients had numerous areas of trigger points. They concluded that myofascial pain is prevalent among IC patients and positively correlates with pelvic floor dysfunction scores. These findings suggest that pelvic floor myofascial pain should be evaluated in IC patients and that these patients may possibly benefit from pelvic floor therapy.

### **MINIMUM 6-YEAR OUTCOMES FOR INTERSTITIAL CYSTITIS TREATED WITH SACRAL NEUROMODULATION**

*Marinkovic SP, Gillen LM, Marinkovic CM. Int Urogynecol J Pelvic Floor Dysfunct. 2010 Sep 17. [Epub ahead of print]. PMID: 20848271*

The purpose of this observational, retrospective, case-controlled review study with 34 patients was to examine whether sacral neuromodulation can be successfully used with acceptable morbidity rates for the medium term of  $\geq 6$  years in interstitial cystitis patients who have failed to respond to standard drug therapies. The authors concluded that with a minimum 6-year follow-up sacral neuromodulation provides adequate improvement for the symptoms of interstitial cystitis patients who have failed to respond to other treatments.

### **TREATMENT CHOICE, DURATION, AND COST IN PATIENTS WITH INTERSTITIAL CYSTITIS AND PAINFUL BLADDER SYNDROME.**

*Anger JT, Zabihi N, Clemens JQ, Payne CK, Saigal CS, Rodriguez LV. Int Urogynecol J Pelvic Floor Dysfunct. 2010 Sep 2. [Epub ahead of print]. PMID: 20811877*

A USA study in which the authors looked at treatments used and their associated cost using a national dataset with the aim of gaining better understanding provider treatment patterns for interstitial cystitis (IC)/painful bladder syndrome. The patients were followed for 5 years, and patterns of care and related expenditures were evaluated. It was concluded that the majority of expenditure on IC could be attributed to oral therapy. Less than 25% of the IC patients received hydrodistension and intravesical instillations.

Hydrodistension was used more frequently among newly diagnosed patients which may possibly reflect its use as part of a diagnostic algorithm.

#### **EFFECTS OF PHENAZOPYRIDINE ON RAT BLADDER PRIMARY AFFERENT ACTIVITY, AND COMPARISON WITH LIDOCAINE AND ACETAMINOPHEN.**

*Aizawa N, Wyndaele JJ. Neurourol Urodyn. 2010 Nov;29(8):1445-50. PMID: 20976818*

This study from Belgium explored the effect of phenazopyridine on afferent nerve activity by direct measurement of both A $\delta$ - and C-fibers in female Sprague-Dawley rats and compared the outcome with the effects of lidocaine (a local anaesthetic) and of acetaminophen (an analgesic). It was found that all drugs significantly increased bladder compliance, in a dose-dependent way. Furthermore, acetaminophen significantly decreased only A $\delta$ -fiber activity, but it was not dose-dependent completely. Lidocaine inhibited both the A $\delta$ - and C-fiber activities. The authors concluded that phenazopyridine can directly inhibit the mechanosensitive A $\delta$ -fibers in the normal rat bladder. They believe that this finding might explain its clinical effect in conditions of bladder hypersensitivity.

#### **NON-BACTERIAL CYSTITIS: PRINCIPLES, DIAGNOSTICS AND ETIOGENIC THERAPY OPTIONS.**

*Mathers MJ, Lazica DA, Roth S. Aktuelle Urol. 2010 Nov;41(6):361-368. Epub 2010 Nov 16. PMID: 21082515*

*Article in German.*

This article from Germany summarises the most common forms of non-bacterial cystitis (interstitial, radiogenic, chemotherapy-induced) with their common pathophysiology and then takes a look at the most common treatments used. In the case of radiogenic and chemotherapy-induced cystitis, the authors believe that optimal preventive measures can often substantially delay or even prevent the development of the inflammatory processes. As alternatives or supplements to symptomatic therapy, causal therapy options show good response rates. In addition to successful hyperbaric oxygen therapy, this also applies to hyaluronic acid that is instilled with the aim of repairing the damaged glycosamine layer in the endothelium of the urinary bladder. The authors recommend prior use of a potassium sensitivity test which can predict the potential success of the treatment with a high degree of accuracy. However, they emphasise that, especially in cases of interstitial cystitis, the diagnosis should be made at the earliest possible stage. This was mainly not the case in the past.

#### **ATTENUATION OF BLADDER OVERACTIVITY IN KIT MUTANT RATS.**

*Okada S, Kojima Y, Kubota Y, Mizuno K, Sasaki S, Kohri K. BJU Int. 2010 Nov 18. doi: 10.1111/j.1464-410X.2010.09870.x. [Epub ahead of print]. PMID: 21087394*

The purpose of this study from Japan was to investigate morphological and physiological findings in the bladder of KIT mutant (WsRCWs/Ws) rats to clarify whether the disturbance of KIT pathways affects bladder activity and to discuss the potential role of KIT-positive interstitial cells of Cajal (ICC)-like cells in the urinary bladder. They concluded that certain voiding disturbances might be associated with impaired KIT signalling in ICC-like cells. Therefore, KIT could be a candidate target for medical therapy in the future.

#### **RISK FACTORS FOR INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME IN PATIENTS WITH LOWER URINARY TRACT SYMPTOMS: A CHINESE MULTI-CENTER STUDY.**

*Li GZ, Zhang N, Du P, Yang Y, Wu SL, Xiao YX, Jin R, Liu L, Shen H, Dai Y. Chin Med J (Engl. 2010 Oct;123(20):2842-6. PMID: 21034594.*

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In this article from China, the authors note that despite 100 years of research, the continued absence of well-established risk factors impedes the diagnosis and treatment of interstitial cystitis/painful bladder syndrome (IC/PBS). This study aimed to identify risk factors in 397 patients (174 women, 223 men) in China with lower urinary tract symptoms (LUTS) without urinary tract infection or benign prostate hyperplasia. 41% (162/397) met criteria for painful bladder syndrome. The authors found that stimulatory foods, anorectal disease and caffeine beverages are potential risk factors for IC/PBS. They note that further studies are necessary to determine their role in the pathogenesis of this disorder.

#### **UROPATHOGENIC E. COLI INDUCES CHRONIC PELVIC PAIN.**

Rudick CN, Berry RE, Johnson JR, Johnston B, Klumpp DJ, Schaeffer AJ, Thumbikat P. *Infect Immun*. 2010 Nov 15. [Epub ahead of print]. PMID: 21078846

Rudick and colleagues note that chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS) is a debilitating syndrome of unknown etiology often postulated, but not proven, to be associated with microbial infection of the prostate gland. In this mouse study, they hypothesised that infection of the prostate by clinically relevant uropathogenic *Escherichia coli* (UPEC) can initiate and establish chronic pain. Their findings led them to conclude that microbial infections can serve as initiating agents for chronic pelvic pain through mechanisms that are dependent on both the virulence of the bacterial strain and the genetic background of the host.

**SPOUSAL SUPPORT DECREASES THE NEGATIVE IMPACT OF PAIN ON MENTAL QUALITY OF LIFE IN WOMEN WITH INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME.**

Ginting JV, Tripp DA, Nickel JC, Fitzgerald MP, Mayer R. *BJU Int*. 2010 Nov 2. doi: 10.1111/j.1464-410X.2010.09846.x. [Epub ahead of print] PMID: 21050362

The purpose of this study in 96 women with IC/PBS was to examine whether spousal responses to patient pain would alter the association between pain and patient health-related quality of life (HRQL), depression and disability. Their findings led to believe that distracting spousal responses act to 'buffer' the deleterious effects of pain on mental HRQL for women suffering from IC/PBS and that spousal support training may be a useful HRQL intervention.

*The journal **Progres en Urologie** November 2010 has a large collection of interesting articles (in French). We have made a small selection below, but recommend French readers to take a look at the whole issue.*

**[GLOBAL APPROACH TO CHRONIC PELVIC AND PERINEAL PAIN: FROM THE CONCEPT OF ORGAN PAIN TO THAT OF DYSFUNCTION OF VISCERAL PAIN REGULATION SYSTEMS.]**

Labat JJ, Riant T, Delavierre D, Sibert L, Watier A, Rigaud J. *Prog Urol*. 2010 Nov;20(12):1027-1034. Epub 2010 Oct 16. PMID: 21056381

*Article in French*

This article reviews the literature concerning the various types of functional pelvic pain. Labat and colleagues found that various forms of pelvic pain are frequently associated: painful bladder syndrome (interstitial cystitis), irritable bowel syndrome, endometriosis pain, vulvodynia, chronic pelvic pain syndrome (chronic prostatitis). They also found that pelvic pain is often associated with fibromyalgia or complex regional pain syndrome. They concluded that when pain cannot be explained by an organ disease, the pain must be considered to be expressed via this organ. Chronic pelvic and perineal pain can become self-perpetuating and identification of their various mechanisms can allow individually tailored treatments.

**[SYMPTOMATIC APPROACH TO CHRONIC URETHRAL PAIN.]**

Delavierre D, Rigaud J, Sibert L, Labat JJ. *Prog Urol*. 2010 Nov;20(12):954-957. Epub 2010 Oct 15. PMID: 21056370

*Article in French*

This study reviewed the literature from 1990 to the present time concerning chronic urethral pain. Urethral pain syndrome is defined as recurrent urethral pain usually occurring during voiding, but sometimes unrelated to voiding, accompanied by daytime frequency and nocturia, in the absence of proven infection or any other clinically apparent disease. The cause of this syndrome is unclear, but the authors suggest that it could correspond to an early form of interstitial cystitis/painful bladder syndrome. Like IC, urethral pain syndrome remains a diagnosis of exclusion.

**[CHRONIC PELVIC PAIN: EPIDEMIOLOGY AND ECONOMIC IMPACT.]**

Sibert L, Rigaud J, Delavierre D, Labat JJ. *Prog Urol*. 2010 Nov;20(12):872-885. Epub 2010 Sep 29. PMID: 21056360

*Article in French*

In this review study, the authors found that prevalences are around 10,000/100,000 for chronic pelvic pain syndrome/chronic prostatitis, 239 to 306/100,000 for bladder pain syndrome/interstitial cystitis, 15,000 to 20,000/100,000 for post-vasectomy testis and epididymis pain, 14,000/100,000 for deep female

dyspareunia, 1000 to 9000/100,000 for male ejaculation or orgasm-related pain, 15,000 to 21,000/100,000 for female chronic pelvic pain, of which one third is related to endometriosis. Little has been published about the prevalence of other chronic pelvic and perineal pain syndromes. They found that the financial impact is comparable to other more frequent chronic diseases, with costs definitely above what the prevalences would have led one to believe. They concluded that the frequency of pelvic disease association, their predisposing factors, common environments and comorbidities suggest a possible common origin. They suggest that their epidemiological findings highlight the benefit of a multidisciplinary approach to chronic pelvic and perineal pain and that this could ultimately lead to a better understanding of the mechanisms involved and treatment options.

#### **[EVALUATION OF CHRONIC PELVIC AND PERINEAL PAIN.]**

*Delavierre D, Rigaud J, Sibert L, Labat JJ. Prog Urol. 2010 Nov;20(12):865-871. Epub 2010 Oct 20. PMID: 21056359*

*Article in French*

A literature review conducted from 1990 to the present time aimed at describing the tools to evaluate of chronic pelvic and perineal pain and to define their indications. The assessment tools recommended by the authors are VAS (visual analogue scale) or numerical severity scales, body diagrams and brief questionnaires such as the Questionnaire sur la Douleur de Saint-Antoine (QDSA) (Saint-Antoine pain questionnaire) or Questionnaire Concis sur les Douleurs (QCD) (validated French translation of the Brief Pain Inventory).

#### **FATIGUE IN FIBROMYALGIA: A CONCEPTUAL MODEL INFORMED BY PATIENT INTERVIEWS.**

*Humphrey L, Arbuckle R, Mease P, Williams DA, Danneskiold-Samsoe B, Gilbert C. BMC Musculoskelet Disord. 2010 Sep 20;11(1):216. [Epub ahead of print]. PMID: 20854680*

*Free access article*

While fatigue is increasingly recognized as an important symptom in fibromyalgia (FM), it is unknown how fatigue is experienced by individuals in the context of FM. In this study, the authors conducted qualitative research in order to better understand aspects of fatigue that might be unique to FM as well as the impact it has on patients' lives. The participants discussed FM fatigue as being more severe, constant/persistent and unpredictable than normal tiredness. The conceptual model depicts the key elements of fatigue in FM from a patient perspective

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[http://www.painful-bladder.org/donations\\_sponsoring.html](http://www.painful-bladder.org/donations_sponsoring.html)

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