

International Painful Bladder Foundation

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

IPBF E-Newsletter, Issue 22, September 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:

- Resilient IC support group members in Christchurch, New Zealand
- Review of ICS-IUGA annual meeting Toronto 23-27 August 2010
- IPBF Updated Brochure online
- NIDDK Urologic Diseases Research Updates
- 13th World Congress on Pain, 29 August-2 September 2010 Montreal
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- European Medicines Agency unveils new corporate website
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RESILIENT IC SUPPORT GROUP MEMBERS IN CHRISTCHURCH, NEW ZEALAND

Despite the 7.1 earthquake that recently shook Christchurch and the Canterbury region in New Zealand, and the hundreds of nerve-racking aftershocks that are still following, and despite the fact that many of their homes were damaged and the contents hurled from wall to wall, the New Zealand IC support group nevertheless recently organised a meeting of its Christchurch members with a lunch right there in the city of Christchurch where so many of the beautiful heritage buildings have been sadly damaged. According to support group chair and urology nurse Dot Milne, it was a great turnout for the IC lunch: "We are a very resilient bunch in Canterbury and, after our coping with dicky bladders for so long, the earthquake can't break our spirits!"

- THE FOUNDATION STONES ON WHICH OUR IC SUPPORT GROUPS ARE BUILT: CONTACT AND EMPATHY

After this terrifying earthquake experience, Dot Milne firmly believes that "the recent earthquake and its aftermath clearly illustrate the foundation stones on which our IC support groups around the world are built: contact and empathy with other human beings. I was alone when the earthquake occurred as my husband had already left for work and being in a rural community there were no neighbours right next-door. My initial terror remained as violent aftershocks continued every few minutes. The need for human contact overpowered all else and I walked out of the house in my dressing gown and slippers, colliding with fallen furniture on the way, and walked five minutes by moonlight to our nearest neighbour. Her husband had also left early for work, before the earthquake, but she had 2 young boys and between us we tried to keep each other calm and reassured. It wasn't until about four hours later when it was light and my daughter and her family arrived that I stopped shaking and wanting to 'throw up'. As a nurse, I am normally a sensible, strong person, but for nearly a week I didn't want to be alone in the house, especially at night. Common sense and reason tell you that there won't be another quake as violent as the first, but even with smaller aftershocks your

physical senses go into overdrive. This experience made it even clearer to me that the proximity of another person makes a huge difference and that the knowledge that others have the same fears as you yourself stop the feelings of isolation and loneliness. I realised that these are precisely the same tools that work for our IC support systems.”

REVIEW OF THE ICS-IUGA JOINT ANNUAL SCIENTIFIC MEETING, 23-27 AUGUST 2010, TORONTO, CANADA

The 40th annual meeting of the International Continence Society (ICS) and the 35th of the International Urogynecological Association (IUGA) was held at the Metro Toronto Convention Center in Toronto, Canada. This was the third time that the ICS and IUGA have held a joint annual scientific meeting, a combined event that currently takes place every five years. The total attendance in Toronto of 3,528 beat all previous records.

- RESEARCH AT ICS-IUGA 2010

For our detailed review of the ICS-IUGA meeting with research in the field of IC, [click here](#), or go to the IPBF home page www.painful-bladder.org

- IPBF INFO BOOTH IN TORONTO VERY SUCCESSFUL

The International Painful Bladder Foundation once again organised a very successful IC info booth during the three exhibition days of this multidisciplinary scientific meeting and we would like to take this opportunity of thanking the ICS for this complimentary booth.

There was a huge demand for information on IC and many people (doctors from different disciplines, nurses and physiotherapists) stopped and took the time to discuss their patients and the problems they have with treatment. They are now increasingly aware that every patient is different and needs an individual approach. Concern was expressed that in the present economic climate cutbacks in healthcare are restricting the time spent by doctors per patient in some countries. This is proving very inadequate for IC patients who typically need more time. This time aspect was stressed time and time again by the health professionals. It was suggested that better use of urology nurses and counselling facilities can help with both treatment and support. There is also no doubt that patient support groups and patient websites can help many fellow patients to cope better, improve their quality of life and start to get their lives under control again.

In the past couple of years, we have seen a tremendous surge in interest by physiotherapists from around the world working in the field of pelvic floor physical therapy. Great interest is also shown in IC at ICS annual meetings by nurses of all kinds (urology nurses, continence nurses, nurse practitioners). This year being a joint year with IUGA, there were more gynaecologists than usual, many of whom came to us for information on IC and asked to be placed on the newsletter mailing list. There was also a notable increase in interest this year from doctors and indeed all health professionals in Latin American countries, including Argentina and Columbia. The patient support groups in countries such as Mexico, Argentina and Brazil have worked hard to raise awareness in this part of the world and this is clearly now beginning to produce results throughout the region. The patients are making their voices heard and the professionals are responding.

We are also seeing rapidly increasing interest and research from the Far East, including for example Singapore, Korea and China in addition to the well-established IC movement in Japan, Taiwan and the East Asian IC collaboration.

As usual, our IPBF booth also carried leaflets from patient support groups who had sent us these, including a brand-new leaflet in Portuguese hot from the press from the new Portuguese support group, Associação de Doentes com Disfunção da Bexiga (AQDDB).

We are happy to say that the information provided on our booth disappeared at top speed and once again we were left with nothing to take home but the tablecloth!

- WEBCASTS

Webcasts of key ICS-IUGA 2010 presentations are available online at TTMed Urology: www.ttmed.com/urology/icsiuga2010.

- ICS ANNUAL SCIENTIFIC MEETING 2011

The next ICS annual scientific meeting will be held in Glasgow, Scotland, 29 August-2 September 2011.

IPBF UPDATED BROCHURE (JULY 2010)

We have once again been busy with the regular update of the IPBF of our brochure "Interstitial Cystitis: Diagnosis & Treatment". On the home page of the IPBF website (www.painful-bladder.org) IPBF website, you can find a quick link in the top right corner to this newly updated brochure or [click here](#). This brochure now includes a new chapter on Fatigue in IC based on the presentation given by Jane Meijlink at the ESSIC Fatigue Symposium in June this year. Like the whole brochure, this new chapter will be continually updated as new information becomes available. We welcome all comments as these can help to build up a very practical, international text.

NIDDK UROLOGIC DISEASES RESEARCH UPDATES

Did you know that you can subscribe to the NIDDK Urologic Diseases Research updates at: <http://www.kidney.niddk.nih.gov/about/newsletter.htm>, look in the top right-hand corner? For the 2010 Spring Update on IC/PBS, go to: http://www.kidney.niddk.nih.gov/about/Research_Updates/UrologicDiseasesSpr10/3.htm

13th WORLD CONGRESS ON PAIN, HELD AUGUST 29 – SEPTEMBER 2, 2010, MONTREAL FOLLOWED BY INTERNATIONAL PAIN SUMMIT

The 13th World Congress on Pain organised by the International Association for the Study of Pain (IASP), with a focus this year on the complexity of pain, drew 6763 international experts in the field of pain research and treatment to Montreal, Canada. "Pain management is not a single problem of just developing a better drug, it's developing a better strategy, said IASP President Gerald F. Gebhart, opening the press conference. "Pain is much more complex than researchers have thought in the past. We need to better understand the mechanisms related to pain in order to develop targeted therapies." Congress highlights included a variety of plenary sessions that presented leading-edge information on pharmacotherapy of chronic pain, diagnosis and assessment of neuropathic pain, impact of exercise on rehabilitation, orofacial pain, acupuncture, the link between genetics and sensation, cognitive-behavioural therapy, and research on clinical pain using imaging. According to Jeff Mogil, a pain researcher at McGill University, "the list of topics and disciplines studied by researchers at the Congress makes it clear that pain is immensely complex. Considering pain involves so many different therapeutic areas, pain can be considered the number one health problem." On the topic of chronic pain, Mogil added: "When the original injury heals, or when the disease is gone but the pain stays, we cannot talk about symptoms anymore. It becomes chronic pain – a disease by itself."

An interesting presentation was given by Ji-Sheng Han from China in the first plenary session ever to be presented at the IASP World Congress on Pain on the topic of acupuncture analgesia. "Traditional acupuncture has been practiced in China for more than two thousand years, but we only started scientific research into acupuncture four decades ago," said Dr. Han, who published his first research on acupuncture in 1965.

INTERNATIONAL PAIN SUMMIT (IPS) – DECLARATION OF MONTREAL

The IASP held the first **International Pain Summit (IPS)** on 3 September 2010 at the Palais des Congrès de Montréal immediately following the 13th World Congress on Pain. This Pain Summit was

the first ever global meeting on critical aspects of pain management, with a focus on advocacy and assistance to all countries for the development of national pain strategies. The background to this summit was the fact that there is increasing awareness worldwide of the human suffering, health care burden, and economic impact created by under-treated pain of all types, including acute pain, chronic pain, pain caused by certain health conditions and pain caused by treatments such as surgery and radiotherapy. The mission of the summit was to improve the quality of life for people living with pain and to minimize the burden of pain on individuals and communities worldwide.

The summit ended with endorsement of the **Declaration of Montreal**: a declaration stating that access to pain management is a fundamental human right, aimed at focusing world attention on under-treatment of all forms of pain, with a call for equity of access to treatment as a moral imperative, and to support pain management as a fundamental human right. The declaration comprises ten articles.

Read about the background to this Pain Summit at:

http://www.iasp-pain.org/AM/Template.cfm?Section=International_Pain_Summit

The Summit programme can be viewed at: <http://www.iasp-pain.org/PainSummit/Agenda.pdf>

EUROPEAN MEDICINES AGENCY UNVEILS NEW CORPORATE WEBSITE

The European Medicines Agency (formerly EMEA) has unveiled its new corporate website at www.ema.europa.eu. The site has been completely redesigned and rebuilt to optimize usability for the Agency's key online audiences and build on existing activities to improve openness and transparency. Some of the website's new features include:

- Quick medicine searches: Allows you to search for human and veterinary medicines by name and active substance and for herbal medicinal substances by name.
- An online library: Enables you to search for all Agency documents currently online through a search on title and date published online.
- Improved navigation: More intuitive labelling and improved organisation of content so that browsing is quicker for all audience groups.
- Audience landing pages: Flags information of specific value to different key users.
- Online calendar and news search: Allows you to keep up to date with the latest news and events at the Agency.
- RSS feeds: Brings information straight to you as soon as it is published online.

WOMEN'S HEALTH AUSTRALIAN WEBSITE WITH FACT SHEET ON CYSTITIS AND INTERSTITIAL CYSTITIS

Women's Health Queensland Wide (Women's Health) is a non-profit health promotion, information and education service for women and health professionals throughout Queensland. A fact sheet on cystitis and interstitial cystitis is available at:

<http://esvc000024.wic055u.server-web.com/factsheets/cystitis.htm>

This will be a useful extra resource for the Australian region.

Upcoming in 2011

VII INTERNATIONAL CONFERENCE ON RARE DISEASES AND ORPHAN DRUGS (ICORD 2011), 21-23 MAY 2011, TOKYO, JAPAN

The VII ICORD Conference on international cooperation and public health policies focussing on research, diagnosis, development of and access to treatment, and care for rare diseases, will be held in Tokyo, May, 21-23, 2011). It will offer a platform for the exchange of perspectives for medical and healthcare professionals, patients and patients' groups, basic and clinical researchers, policy-makers, government officers and pharmaceutical, biotechnology and medical device industries. Its purpose is to improve the welfare and wellbeing of patients with rare diseases and their families world-wide

through better knowledge, research, treatment, care, information, education and awareness of rare diseases.

The programme will be available in due course on the ICORD website (www.icord.se).

Its main topics will be:

- Research
- Diagnosis
- Treatment
- Orphan drugs
- Health policies on rare diseases and orphan drugs globally
- Ethical issues and social aspects of rare diseases
- International networking
- Patients' needs

The first announcement can be found at: <http://icord.se/upcoming-events/tokyo-2011-2>

Many IC support groups take part in the rare diseases movement, nationally and internationally.

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. 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.**

UROLOGIC CHRONIC PELVIC PAIN SYNDROME.

Martinez-Bianchi V, Halstater BH. Prim Care. 2010 Sep;37(3):527-46, viii. PMID: 20705197

The September 2010 issue of *Primary Care: Clinics in Office Practice* focuses on primary care urology and includes this 20 page review article on urologic chronic pelvic pain syndrome, discussing diagnosis and treatment of interstitial cystitis, painful bladder syndrome and chronic prostatitis. The useful tables include one on acute causes of dysuria (painful urination) and one on differential diagnosis of chronic dysuria. An emphasis is placed on the extreme importance of a detailed history in patients with this clinical syndrome because it is essential to rule out multiple other diagnoses. The authors recommend discussing with the patient: characteristics of the pain, location, radiation, timing, associated voiding symptoms (frequency, urgency), sexual history, sexual functioning, and concomitant conditions. Clear advice is provided on obtaining a sexual history with a list of suggested questions to ask the patient. Details are provided on the physical examination and laboratory evaluation. Treatment suggestions are given although the authors note that treatment options that are US Food and Drug Administration approved and evidence based are limited. They emphasise however that many symptom-based treatment options can reduce symptoms and improve quality of life. Symptom scores are included here for men and women, as well as the patient health questionnaire and patient depression questionnaire, to make this useful article complete.

MANAGEMENT STRATEGIES FOR PAINFUL BLADDER SYNDROME.

Lau TC, Bengtson JM. Rev Obstet Gynecol. 2010 Spring;3(2):42-48. PMID: 20842281

This 6 page review article is free if you register with MedReviews. It provides a review of history, concepts, diagnosis and treatment of PBS/IC, but the management strategies suggested here are rather limited.

BLADDER PAIN SYNDROME: DO THE DIFFERENT MORPHOLOGICAL AND CYSTOSCOPIC FEATURES CORRELATE?

Geurts N, Van Dyck J, Wyndaele JJ. Scand J Urol Nephrol. 2010 Sep 17. [Epub ahead of print]. PMID: 20846081

This study evaluates correlation between the histological findings in bladder biopsies in patients with PBS, handled following ESSIC recommendations. It also evaluates the importance of the histological findings in PBS compared to the cystoscopic findings. The study included 15 men and 93 women, all of whom underwent cystoscopy with hydrodistension, and at least three deep biopsies including detrusor muscle. Significant correlations were found between urothelial damage and inflammatory infiltrate. Detrusor mastocytosis was significantly more elevated in biopsies with normal urinary epithelium than in biopsies where the urothelium was damaged. No other correlations were found between histological findings or between histological and cystoscopic findings. The authors concluded that both cystoscopy with hydrodistension and histology can be used to illustrate different pathophysiological mechanisms in patients with BPS. They are of the opinion that the results of this study favour the use of both in the classification of BPS patients.

INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME AND ASSOCIATED MEDICAL CONDITIONS WITH AN EMPHASIS ON IRRITABLE BOWEL SYNDROME, FIBROMYALGIA AND CHRONIC FATIGUE SYNDROME.

Nickel JC, Tripp DA, Pontari M, Moldwin R, Mayer R, Carr LK, Doggweiler R, Yang CC, Mishra N, Nordling J. J Urol. 2010 Aug 17. [Epub ahead of print]. PMID: 20719340

In this study with 205 IC/PBS female patients and 117 controls, Nickel and colleagues characterized and compared the impact of clinical phenotypic associations between interstitial cystitis/painful bladder syndrome and controls in relation to potentially related conditions, with an emphasis on irritable bowel syndrome, fibromyalgia and chronic fatigue syndrome. They used a biopsychosocial phenotyping range of questionnaires covering demographics/history form, self-reported history of associated conditions, and 10 validated questionnaires focused on symptoms, suffering/coping and behavioral/social factors.

The prevalence of self-reported associated condition diagnosis in IC/PBS versus the control group was:

irritable bowel syndrome 38.6% versus 5.2%,

fibromyalgia 17.7% versus 2.6%

chronic fatigue syndrome 9.5% versus 1.7%.

The authors report that in the IC/PBS group, 50.3% reported no other associated condition, 24.4% had IC/PBS + irritable bowel syndrome only, 2.5% had IC/PBS + fibromyalgia only, 1.5% had IC/PBS + chronic fatigue syndrome only, while 20.2% reported multiple associated conditions.

The authors conclude from this study that irritable bowel syndrome, fibromyalgia and chronic fatigue syndrome are more prevalent in patients with IC/PBS than in controls, and result in a significant impact on life with an increase in pain, stress, depression and sleep disturbance and a decrease in quality of life. They believe that there are at least 3 distinct clinical phenotypes based on identification of overlapping syndrome patterns. Further studies are needed to show whether there is eventually progression from an organ-centric to a regional and finally to a systemic pain syndrome.

GATING OF SENSORY INFORMATION DIFFERS IN PATIENTS WITH INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME.

Kilpatrick LA, Ornitz E, Ibrahimovic H, Hubbard CS, Rodríguez LV, Mayer EA, Naliboff BD. J Urol. 2010 Sep;184(3):958-63. PMID: 20643444

This study was based on the hypothesis that altered sensory processing in IC/PBS patients may be the result of the central nervous system being unable to adequately filter incoming visceral afferent information. Kilpatrick and colleagues assessed prepulse inhibition in 14 female patients with IC/PBS and 17 healthy controls at 60 and 120-millisecond prepulse-to-startle stimulus intervals. They concluded that compared to controls, female patients with IC/PBS had decreased ability to adequately filter incoming information and perform appropriate sensorimotor gating, suggesting that a possible mechanism for altered interoceptive information processing in IC/PBS may be a general deficit in filtering mechanisms due to altered pre-attentive processing.

SACRAL NEUROMODULATIONS FOR FEMALE LOWER URINARY TRACT, PELVIC FLOOR, AND BOWEL DISORDERS.

Wehbe SA, Whitmore K, Ho MH. Curr Opin Obstet Gynecol. 2010 Oct;22(5):414-9. PMID: 20724927

This review discusses recently published data on the use of SNM for treating female lower urinary tract, pelvic floor, and bowel disorders. SNM was initially used to treat refractory idiopathic overactive bladder, urge urinary incontinence, and chronic nonobstructive urinary retention. The therapeutic effects of SNM in these disorders have been confirmed in studies. Use of SNM has now been extended to the treatment of other female pelvic problems, such as faecal incontinence, chronic constipation, IC/PBS, sexual dysfunction, and neurogenic disorders where the results also look promising. While SNM is approved by the Food and Drug Administration for the treatment of idiopathic overactive bladder, urge urinary incontinence, and chronic nonobstructive urinary retention, it is not yet an approved for the treatment of other pelvic disorders. The major advantage of SNM lies in its potential to treat the bladder, urethral sphincter, anal sphincters, and pelvic floor muscles simultaneously.

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.

In an observational, retrospective, case-controlled review (January 2002-March 2004), the authors looked at whether sacral neuromodulation could be successfully implemented with acceptable morbidity rates in interstitial cystitis patients. 34 female patients underwent stage 1 and 2 InterStim placements under a general anaesthetic. Simple means and medians were analysed. With a minimum 6-year follow-up they concluded that sacral neuromodulation provides adequate improvement for the symptoms of recalcitrant interstitial cystitis.

INTERSTITIAL CYSTITIS WITH PLASMA CELL BLADDER INFILTRATION: CASE REPORT AND LITERATURE REVIEW.

Pacella M, Varca V, Venzano F, Toncini C, Carmignani G, Simonato A. Arch Ital Urol Androl. 2010 Jun;82(2):122-4. PMID: 20812539

This article from Italy discusses what Pacella and colleagues consider to be a rare case of a 76 year old female diagnosed with interstitial cystitis with plasma cell infiltration. The patient was treated with corticosteroids with brief benefit, but side effects. When the treatment was stopped, the symptoms worsened. The patient then underwent radical cystectomy with orthotopic ileal neobladder. Phlogistic infiltration of the bladder wall and positive perinuclear antineutrophil cytoplasmic antibodies (p-ANCA) in the blood could hint at a chronic cystitis due to autoimmune aetiology.

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

In this USA study, the authors sought to document the treatments used for IC/PBS and their associated cost using a national dataset by creating a study group by applying the ICD-9 diagnosis of IC (595.1) to INGENIX claims for the year 1999. The patients were then followed for 5 years, and patterns of care and related costs were evaluated. It was found that of 553,910 adults insured in 1999, 89 subjects had a diagnosis of IC with 5-year follow-up data. All were treated with oral medication(s), 26% received intravesical treatment, and 22% underwent hydrodistension. Total expenditure per subject was \$2,808. It was concluded that most expenditure on IC came from oral treatment. Hydrodistension and intravesical instillations were used in less than 25% of patients. Hydrodistension was used more frequently among subjects with a new diagnosis and this may reflect its use as part of a diagnostic algorithm.

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

Although this article is now online, since it is still *in Press* and uncorrected at the time of writing, we plan to give further details when it has been corrected and published since this is a particularly interesting topic. It discusses new methods of intravesical drug delivery (IDD) and how nanotechnology can be integrated with IDD to devise drug-encapsulated nanoparticles that can greatly improve chemical interactions with the urothelium and enhance penetration of drugs into the bladder wall. Nanocarriers such as liposomes, gelatin nanoparticles, polymer nanoparticles, magnetic particles, have been found to enhance local drug concentrations in the bladder as well as target diseased cells. Recent advances and future prospects of biodegradable nanocarriers and *in situ* gels as drug delivery agents for intravesical drug delivery are reviewed in this paper.

DOES MAST CELL DENSITY PREDICT THE OUTCOME AFTER TRANSURETHRAL RESECTION OF HUNNER'S LESIONS IN PATIENTS WITH TYPE 3C BLADDER PAIN SYNDROME/INTERSTITIAL CYSTITIS?

Rössberger J, Fall M, Gustafsson CK, Peeker R. Scand J Urol Nephrol. 2010 Sep 13. [Epub ahead of print]. PMID: 20836664

The aim of this Swedish study with 12 patients (8 women and 4 men) was to assess mast cell density in the lamina propria to see if there was any possible correlation with the duration of symptom improvement after carrying out transurethral resection of the bladder (TURB). All of these patients had undergone three consecutive TURB procedures, the first of which was also diagnostic. All the patients had Hunner's lesions and biopsy findings with inflammatory infiltrates, granulation tissue and mastocytosis. Immunohistochemistry was used to evaluate mast cell density of bladder biopsies. It was found that mast cell density does not appear to correlate with the duration of symptom improvement after complete transurethral resection of Hunner's lesions, either in the lamina propria or in the urothelium or detrusor.

YKL-40 AND MAST CELLS ARE ASSOCIATED WITH DETRUSOR FIBROSIS IN PATIENTS DIAGNOSED WITH BLADDER PAIN SYNDROME/INTERSTITIAL CYSTITIS ACCORDING TO THE 2008 CRITERIA OF THE EUROPEAN SOCIETY FOR THE STUDY OF INTERSTITIAL CYSTITIS.

Richter B, Roslind A, Hesse U, Nordling J, Johansen JS, Horn T, Hansen AB. Histopathology. 2010 Sep;57(3):371-383. doi: 10.1111/j.1365-2559.2010.03640.x. PMID: 20840668

The aims of this study with 45 patients were to examine YKL-40 antigenic expression in bladder tissue and levels in serum and urine in BPS/IC and to evaluate whether YKL-40 could be a non-invasive, prognostic biomarker for bladder fibrogenesis and treatment intensity. On the basis of their results, the authors concluded that YKL-40 may be used as a non-invasive biomarker in BPS/IC for the evaluation of bladder fibrogenesis.

OVERACTIVE BLADDER AND PAIN: MANAGEMENT STRATEGIES.

Patel BN, Evans RJ. Curr Urol Rep. 2010 Sep 7. [Epub ahead of print]. PMID: 20821355

This is certainly a novel approach, describing interstitial cystitis/bladder pain syndrome as “overactive bladder associated with pain”. This paper reviews the studied therapies for IC/BPS, including non-medication-based therapies, oral and intravesical-based medications, and surgical treatments for interstitial cystitis. It also looks at an approach to the treatment of a patient with IC/BPS using the previously published UPOINT clinical phenotyping template.

FORENSIC DISSECTION OF A CLINICAL TRIAL: LESSONS LEARNED IN UNDERSTANDING AND MANAGING INTERSTITIAL CYSTITIS.

Nickel JC. Rev Urol. 2010 Spring;12(2-3):e78-85. PMID: 20811556

Free access article:

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2931285/pdf/RIU012002_0e78.pdf

This article is described by the author as a post hoc forensic dissection of a clinical trial that was initially undertaken for simple regulatory reasons. The full article can be read online free.

URINARY NERVE GROWTH FACTOR LEVELS IN URINARY TRACT DISEASES WITH OR WITHOUT FREQUENCY URGENCY SYMPTOMS

Kuo HC, Liu HT, Tyagi P, Chancellor MB. LUTS 2010 Sept;2(2):88-94

The purpose of this study was to measure urinary nerve growth factor (NGF) levels in patients with several urinary tract diseases under different conditions and compare this with NGF levels in patients with overactive bladder (OAB) and interstitial cystitis/painful bladder syndrome (IC/PBS). The authors concluded that urinary NGF is not produced solely in patients with OAB or IC/PBS. Acute bacterial cystitis, urinary tract stones and urothelial cell carcinoma can have high urinary NGF production.

SMOKED CANNABIS FOR CHRONIC NEUROPATHIC PAIN: A RANDOMIZED CONTROLLED TRIAL

Mark A. Ware MBBS, Tongtong Wang PhD, Stan Shapiro PhD, Ann Robinson RN, Thierry Ducruet MSc, Thao Huynh MD, Ann Gamsa PhD, Gary J. Bennett PhD, Jean-Paul Collet MD PhD

This free access article can be read online:

<http://www.cmaj.ca/cgi/rapidpdf/cmaj.091414v1?ijkey=b222a5e75d7858fa0255380e1c0aa1358c38e77e>

ILLICIT KETAMINE INDUCED FREQUENCY OF MICTURITION IN A YOUNG MALAY WOMAN.

Noorzurani R, Vicknasingam B, Narayanan S. Drug Alcohol Rev. 2010 May;29(3):334-6. PMID: 20565527

Concern continues regarding the illegal use of ketamine, its potential adverse effects on the urinary tract and the possibility of the symptoms being mistaken for some other urinary tract disorder if the patient fails to reveal the illegal use of ketamine. This article concerns a case report from Malaysia describing a young Malay woman who developed severe bladder symptoms (urinary frequency) after using illegal ketamine. Since the history of illegal ketamine use was initially missed, she was consequently diagnosed and treated for a urinary tract infection. Since the symptoms failed to respond to antibiotics, the patient was referred to a urologist who found changes in the bladder consistent with interstitial cystitis. It was considered likely that the patient's ketamine use was the cause of the urinary symptoms and bladder changes. The authors conclude that illegal use of ketamine may lead to severe urinary tract problems that can be irreversible even after the patient has stopped using ketamine. They note that while early diagnosis is critical, this is a problem if the patient does not reveal the illegal use of ketamine. It is important for physicians to be aware of this new clinical entity is important, particularly in cases where urinary symptoms do not respond to usual treatment.

DEVELOPMENT AND VALIDATION OF THE FIBROMYALGIA RAPID SCREENING TOOL (FIRST).

Perrot S, Bouhassira D, Fermanian J; the CEDR (Cercle d'Etude de la Douleur en Rhumatologie). Pain. 2010 Aug;150(2):250-256. Epub 2010 May 21. PMID: 20488620

The purpose of this study was to develop and validate a self-completed questionnaire, the Fibromyalgia Rapid Screening Tool (FiRST), for the detection of fibromyalgia syndrome in patients with diffuse chronic pain. Items requiring "yes/no" responses and relating to the most relevant clinical characteristics of fibromyalgia were compiled by a group of rheumatologists and pain experts. The authors are of the opinion that FiRST is a brief, simple and straightforward self-administered questionnaire with excellent discriminative value, of potential value for the detection of fibromyalgia in both daily practice and clinical research.

FIBROMYALGIA SYNDROME: A DISCUSSION OF THE SYNDROME AND PHARMACOTHERAPY.

Smith HS, Barkin RL. Am J Ther. 2010 Jul-Aug;17(4):418-39. PMID: 20562596

This is a review of fibromyalgia syndrome (FMS) which is a complex condition that includes fatigue, sleep disturbances, cognitive dysfunction, stiffness, and depressive episodes. FMS may coexist and/or overlap with other conditions that may involve central sensitivity, including chronic fatigue syndrome, irritable bowel syndrome, interstitial cystitis, and temporomandibular disorder. While fibromyalgia remains a clinical diagnosis, the authors note that there has been a recent paradigm shift away from the traditional requirement of 11 or more out of 18 tender points and instead focusing on the presence of chronic widespread pain as well as symptoms of fatigue, unrefreshed sleep, and other somatic complaints. Although there is no known cure for fibromyalgia, multidisciplinary team efforts using combined treatment approaches, including patient education, aerobic exercise, cognitive behavioral therapy, and pharmacologic therapies (serotonin norepinephrine reuptake inhibitors (eg, duloxetine, milnacipran) and alpha 2-delta receptor ligands (eg, pregabalin) may improve the symptoms as well as the function of patients with fibromyalgia.

PREVALENCE AND IMPACT OF BACTERIURIA AND/OR URINARY TRACT INFECTION IN INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME.

Nickel JC, Shoskes DA, Irvine-Bird K. Urology. 2010 Jun 21. [Epub ahead of print]. PMID: 20573386

The purpose of this study by Dr Nickel and colleagues was to determine the prevalence and clinical significance of documented bacteriuria (bacteria in urine) and/or urinary tract infection in an interstitial cystitis/painful bladder syndrome (IC/PBS) population. A total of 100 patients with IC were followed up for 2 years. The authors found that the presence of bacteriuria can be documented in an IC/PBS population of women whose urine has frequently been cultured. However, the patients with bacteriuria did not differ from those without evidence of bacteriuria, the bacteriuria episodes did not appear to be associated with the symptom flares, and antibiotic treatment of documented bacteriuria was not associated with significant improvement in IC/PBS-related symptoms.

PELVIC PAIN IN UROGYNACOLOGY. PART I: EVALUATION, DEFINITIONS AND DIAGNOSES.

Kavvadias T, Baessler K, Schuessler B. Int Urogynecol J Pelvic Floor Dysfunct. 2010 Jul 20. [Epub ahead of print]. PMID: 20645076

A review aimed at summarising the available literature on the definitions and assessment of pelvic pain in the urogynaecological patient. Sixty-nine articles were reviewed. The site of pain was specified in 45% of the articles, 20% used the digital examination of pelvic myofascial trigger points for the diagnosis; 20%, the Pelvic Pain and Urgency/Frequency Symptom Scale; 26%, the Interstitial Cystitis Symptom and Problem Index and 39%, a simple visual analogue scale. The diagnosis was interstitial cystitis in 67% and chronic pelvic pain in 19% of the articles. The authors note that consensus on diagnostic procedures and the definition of pelvic pain in urogynaecological patients is necessary in order to provide exact diagnostic information and consequently more satisfying treatment options.

URINARY PROTEOMICS EVALUATION IN INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME: A PILOT STUDY.

Goo YA, Tsai YS, Liu AY, Goodlett DR, Yang CC. Int Braz J Urol. 2010 July-August;36(4):464-479. PMID: 20815953

Free access article: http://www.brazjurol.com.br/july_august_2010/Yang_464_479.pdf

An in-depth shotgun proteomics study was carried out to profile the urinary proteome of women with IC/PBS to identify possible specific proteins and networks associated with IC/PBS. The authors concluded from their preliminary data that there are indications of qualitative and quantitative differences between the urinary proteomes of women with and without IC/PBS. They report that they identified a number of proteins as well as pathways/networks that might contribute to the pathology of IC/PBS or result from perturbations induced by this condition.

COMBINATION DRUG THERAPY FOR CHRONIC PAIN: A CALL FOR MORE CLINICAL STUDIES.

Mao J, Gold MS, Backonja MM. J Pain. 2010 Sep 16. [Epub ahead of print]. PMID: 20851058

The authors note that for many general practitioners and specialists, managing chronic pain has become a daunting challenge. As a form of multidisciplinary chronic pain management, medications are often prescribed in combinations, an approach referred to as combination drug therapy (CDT). However, many medications for pain therapy, including antidepressants and opioid analgesics, have significant side effects that can compound when used in combination and impact the effectiveness of CDT. This article focuses on the scientific basis and rationales for CDT, current clinical data on CDT, and the need for more clinical studies to establish a framework for the use of CDT. The authors emphasise that more preclinical, clinical, and translational studies are needed to improve the efficacy of combination drug therapy that is an integral part of a comprehensive approach to the management of chronic pain.

CHRONIC PUDENDAL NEUROMODULATION: EXPANDING AVAILABLE TREATMENT OPTIONS FOR REFRACTORY UROLOGIC SYMPTOMS.

Peters KM, Killinger KA, Boguslawski BM, Boura JA. Neurourol Urodyn. 2010.29:1267-1271. PMID: 19787710

The authors note in this article that few published studies exist reporting outcomes of chronic pudendal nerve stimulation (CPNS). This retrospective study evaluated symptoms, complications, and satisfaction after CPNS in patients who had a tined lead placed at the pudendal nerve via the ischio-rectal approach. The majority of 84 patients (78.6% female) had interstitial cystitis/painful bladder syndrome, or overactive bladder. Pudendal response ($\geq 50\%$ improvement) occurred in 60/84 (71.4%), however 5 of these chose sacral neuromodulation. Almost all (93.2%) who had previously failed sacral neuromodulation responded to pudendal stimulation. Outcomes were evaluated in 55 continuing on CPNS (median follow up 24.1 months). Seven complications requiring 5 revisions, and 4 other re-operations occurred. Five were explanted. Over time, significant improvements in frequency, voided volume, incontinence and urgency occurred. ICSI-PI scores significantly improved over 12 months. Survey responses indicated that most still had a device (35/40; 87.5%) continuously in use (24/29; 82.8%), and overall bladder, pelvic pain, incontinence, urgency, and frequency symptoms had improved. The authors concluded that CPNS is a reasonable alternative in complex patients who fail to respond to other therapies and/or fail to achieve satisfactory results with sacral neuromodulation. The potential benefit of stimulating the pudendal nerve is increased afferent stimulation through the S2 to S4 nerve roots. They note that more research is needed in well-defined cohorts to fully assess long-term outcomes and identify predictors of success.

UPCOMING EVENTS IN BRIEF

- Société Internationale d'Urologie (SIU) World Meeting, 13-16 October 2010, Marrakech, Morocco.
- European Association of Urology (EAU), 18-22 March 2011, Vienna, Austria.
- VII International Conference on Rare Diseases and Orphan Drugs (ICORD 2011), 21-23 May 2011, Tokyo, Japan
- American Urological Association (AUA) annual meeting, 14-19 May 2011, Washington DC, USA
- International Continence Society (ICS) annual scientific meeting, 29 August-2 September 2011, Glasgow, Scotland,

- International Association for the Study of Pain (IASP), 14th World Congress on Pain, 2-6 October 2012, Yokohama, Japan.

A more detailed list of conferences and events with contact addresses and websites can be found on our website under "Calendar".

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http://www.painful-bladder.org/donations_sponsoring.html

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