

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 18, October 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).

REVIEW OF THE 39TH ANNUAL MEETING OF THE INTERNATIONAL CONTINENCE SOCIETY (ICS) HELD IN SAN FRANCISCO, USA, 29 SEPTEMBER TO 3 OCTOBER

The annual meeting of the ICS is a unique, international, multidisciplinary meeting on the function and dysfunction of the urinary tract, bowel and pelvic floor, including pain aspects, and is attended by specialists of many disciplines, nurses and physiotherapists from around the world. The IPBF therefore gratefully accepted the offer of a complimentary booth at the San Francisco meeting. It was a great success, with huge interest in IC by delegates from around the world. By the end of the final day, all that remained to take home was the tablecloth!

We have recently noted a surge of interest in IC and pelvic dysfunction and pain by physiotherapists and dawning realization by urologists and gynaecologists that physical therapy can really help patients with pelvic pain and dysfunction.

The IC/PBS presentations and posters at ICS 2009 indicated that more attention is being paid to diagnosis and treatment of Hunner's lesions. However, the problem still remains that many urologists are uncertain as to whether what they are seeing when cystoscoping a patient is actually a Hunner's lesion or not. There is now an urgent need for an online atlas with pictures of all possible variations of these lesions. Lesions can often be treated very successfully, even though the treatment may have to be repeated at intervals. It is therefore vital to ensure that patients with the often very painful Hunner's lesion subtype receive the correct diagnosis and treatment right from the start.

IC/PBS/CPPS Workshop available on ICS 2009 webcasts

An excellent 4 hour workshop (W53) was organised at ICS 2009 on the topic: **De-Mystifying Chronic Pelvic Pain (IC/PBS/CPPS)**, chaired by urologists Ragi Doggweiler and Kristene Whitmore and physiotherapist Stephanie Prendergast with Susan Kellogg-Spadt, Elisabeth Rummer and David Wise also as speakers. The aim of this workshop was to provide caregivers taking care of patients with chronic pelvic pain clarity and direction. By a happy coincidence, this was one of a small number of workshops webcast by *tmed*. <http://webcasts.prousonline.com/ICS2009> (go to Webcasts program, Workshops, Workshop 53). Following an introduction by Dr Doggweiler, Stephanie Prendergast gives a clear description of the anatomy of myofascial pelvic

pain, myofascial trigger points and a discussion of the role of the pudendal nerve. Dr Kristene Whitmore's outstanding presentation included management of chronic pelvic pain, treatment of the different pain generators, a comparison of the impact of diet in men and women, mind-body therapies and medical therapies in detail, botulinum toxin, neuromodulation, trigger point injections, nerve blocks and bladder augmentation. This was a very practical presentation which everyone will find most valuable. Female sexuality and chronic pain was discussed by Susan Kellog-Spadt, emphasising that chronic pelvic pain patients may have multiple associated conditions and that a painful bladder or painful pelvis can lead to painful sex. Well worth looking at the webcast.

Scientific programme

The ICS conference scientific programme included one session of poster presentations on pain syndromes and a further poster presentation session on PBS/IC. There were also a number of non-discussion posters and abstracts on IC on view. We have included these studies in our review on the IPBF website, together with a number of interesting studies presented in other sessions. During the conference as a whole, there was an increasing focus on improving the quality of life for all patients. All abstracts can be found in full on the ICS website: www.icsoffice.org.

Detailed review of IC/PBS presentations at ICS 2009 on IPBF website

A detailed review of the conference with abstracts and posters in the field of IC/PBS and related topics accepted for this year's annual meeting can be found on the IPBF website at:

http://www.painful-bladder.org/pdf/2009_ICS_SanFrancisco.pdf

NEW PATIENT SUPPORT GROUP IN PORTUGAL!

We are happy to report that a new patient support group has been set up in Portugal for patients with bladder dysfunction, including interstitial cystitis. The name of the new support group is: Associação de Doentes com Disfunção da Bexiga (ADDB) and its president is Lígia Almeida. Contact details and a membership application form can be found on their new website: www.addb.pt. We wish them every success and can assure them that all the existing support groups will be very pleased to help and advise when needed. Thanks are also due to the Portuguese urologists for helping to get this patient project off the ground.

CONVERGENCES IN PELVIPERINEAL PAIN (CONVERGENCES PP) 16-18 December 2009, Nantes, France

Convergences PP is a joint conference on pelvipерineal pain co-organised by SIFUD, AFU, CNGOF, PUGO/IASP, SCGP, SFETD, SIREPP, SNFCP, SOFMER to be held at the International Congress Centre of Nantes (Cité des Congrès de Nantes). Please note that the conference now has a new website where you will find the full scientific programme details. The English version is at:

<http://www.convergencespp.org/~convpp/ENpart.html>

You will find an interesting editorial on the conference website by Dr JJ Labat of Nantes on "The mathematics of chronic pelvic pain: How to transform a complex

problem into a sum of simple problems” at:
<http://www.convergencespp.org/~convpp/ENeditorial.html>.

NIH/NIDDK SYMPOSIUM 2010: NEUROIMAGING IN UROLOGIC PELVIC PAIN AND ASSOCIATED DISORDERS

The NIH/NIDDK is planning a symposium in 2010 which will focus on “Neuroimaging in Urologic Pelvic Pain and Associated Disorders”. A tentative date is 15/16 March 2010 and the venue will be in the Washington DC area. We will provide you with further information and a final date when available, but please bear this in mind when making your plans for 2010. The NIDDK will publish the details as they become available on their website: <http://www2.niddk.nih.gov/> (go to “conferences and Workshops” bottom left of home page)

RETIREMENT OF DR LEROY NYBERG FROM THE NIDDK

Dr Leroy M. Nyberg, Urology director at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH) and a familiar face to doctors and patient advocates around the globe, retired at the beginning of September. Dr Nyberg worked closely with the ICA to raise awareness of IC and get research off the ground within the NIH. This had an impact worldwide and we are exceedingly grateful to him for his dedication, empathy and support for IC patients. Thank you from all of us!

UPOINT WEBSITE: <http://www.upointmd.com/faq.php>.

A very useful website on UPOINT has been compiled by Dr Daniel Shoskes at: <http://www.upointmd.com/faq.php>. UPOINT (= urinary, psychosocial, organ specific, infection, neurologic/systemic, and tenderness) is a system for the clinical phenotyping of chronic pelvic pain (chronic prostatitis/chronic pelvic pain syndrome, interstitial cystitis, painful bladder syndrome).

This website clarifies what UPOINT is all about and how it can help guide treatment. It will be of interest to all those involved in IC, whether patients or professionals, and very helpful in aiding you to understand this new development in the field of urologic chronic pelvic pain syndromes of which we are likely to see more in the future.

IAPO 4TH GLOBAL PATIENTS CONGRESS: “STRENGTHENING HEALTHCARE SYSTEMS GLOBALLY: THE VALUE OF PATIENT ENGAGEMENT”, ISTANBUL, TURKEY, 23-25 FEBRUARY 2010

The International Alliance of Patients Organizations (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 4th Global Patients Congress, “Strengthening Healthcare Systems Globally: The Value of Patient Engagement”, will be held from 23-25 February 2010, in the Hyatt Regency Hotel, Istanbul, Turkey. IAPO's Congress provides a unique opportunity for patient advocates, across diseases and across borders, to come together and participate in an exciting and stimulating programme 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. Further information and registration:
<http://www.patientsorganizations.org:80/showarticle.pl?id=1006;n=605>

IAPO LAUNCHES POLICY STATEMENT ON PATIENT INFORMATION

The International Alliance of Patients' Organizations (IAPO) launched a Policy Statement on Patient Information outlining recommendations for information providers to meet the information needs of patients worldwide, at a regional meeting of patient groups in Buenos Aires, Argentina on 14 October. The IAPO Policy Statement on Patient Information outlines a key principle of patient-centred healthcare and expresses the experience and needs of IAPO's global patient group membership. It is essential that patients are empowered with the information they need to make informed decisions about healthcare treatments and living with their condition. With accurate, relevant and comprehensive information patients can make informed lifestyle choices, take their medicines correctly and manage their condition. This is critical if healthcare systems are to meet the pressures and challenges of an increasing burden of chronic disease worldwide. In order for information to empower patients on an individual level there needs to be patient involvement in the development of information policies at a health systems level. The voice of the patient must be strong in health-policy making if healthcare systems are to be patient-centred. An informed patient's voice is a strong patient voice.

IAPO defines patient information as all forms of health information that relate to a patients' specific disease or condition, treatments, medication and health services. IAPO calls on all stakeholders involved in communicating information to patients to involve patients and patients' organizations in all information-related policy and delivery decisions. This will ensure that policies and practice address the information needs of patients whatever their disease area or geographical location.

In addition, IAPO draws attention to the need to focus on how information is communicated so that the communication method helps patients to understand and make informed decisions based upon the information content. This will ensure that information is suitable to patients' individual conditions, language, age, understanding, ability and culture. Finally, IAPO calls on all stakeholders to ensure that patients and their representatives play a key role in the development and dissemination of patient information, recognising that many patients are experts in their own condition.

Mr Hussain Jafri, IAPO Chair and Secretary General, Alzheimer's Pakistan, stressed that "Accessible, high quality information is critical to meeting the needs of patients' worldwide, in order to provide information about their condition and possible treatments, and also to ensure patients take their medicines correctly and safely. However, it is imperative that all healthcare providers, in particular governments, support measures to develop and improve health literacy to empower patients and improve health outcomes. The IAPO Policy Statement on Patient Information is a powerful resource and a call to all healthcare stakeholders to ensure that patients' information needs are met in a patient-centred way."

Further information: Mr Jeremiah Mwangi, Senior Policy Officer, IAPO, Email: jeremiah@patientsorganizations.org, Website: www.patientsorganizations.org

BOOK AND DVD REVIEWS

GUIDED IMAGERY FOR CPP OR PROSTATITIS - DVD

The Guided Imagery team has now produced a relaxation DVD especially for men entitled Guided Imagery to Enhance Healing for Men with Chronic Pelvic Pain or Prostatitis, written and produced by Donna Carrico. This new CD for men has two tracks, "Riverbank," a guide along a peaceful riverbank for basic relaxation, and "Journey into Nature," specific to men with pelvic pain or chronic prostatitis/chronic pelvic pain syndrome. The CD (\$15 in the USA) can be ordered from: The Beaumont Foundation/Urology Research, P.O. Box 58002, Troy, MI 48007-9620, USA

SECRET SUFFERING, HOW WOMEN'S SEXUAL AND PELVIC PAIN AFFECTS THEIR RELATIONSHIPS

Authors: Susan Bilheimer and Robert J. Echenberg, MD

Foreword by Daniel Brookhof, MD.

Publisher: Praeger, 2009

ISBN: 978-0-313-35921-7

In addition to the problem of maybe spending years trying to get a diagnosis for their chronic pelvic pain, and enduring misdiagnosis after misdiagnosis, many women also have to suffer years of "pain, humiliation and guilt" as wives because sex is too painful and they feel that they are letting their partner down. This excellent book looks at the problem from all points of view: understanding chronic pain and your nervous system from a medical point of view, personal experiences of women in all different situations, treatment of chronic sexual and pelvic pain and how to live with this terrible problem. This book is also an important step towards overcoming the taboos of talking about personal sexual experiences. Highly recommended for all patients with this problem, for patient support group leaders and, last but not least, for health professionals caring for these patients.

CURRENT TOPICS IN PAIN

Editor: Jose Castro-Lopes

Publisher: IASP Press

www.iasp-pain.org

ISBN: 978-0-931092

This book is a collection of 17 reviews written by experts who presented on this wide range of pain topics at the 12th World Congress on Pain, varying from the neurochemistry and neurobiology of pain to the role of stress in chronic pain.

Chapter 13 on The Relationship between "Stress" and Pain: Lessons Learned from Fibromyalgia and Related Conditions, by Daniel J. Clauw and Jacob N. Ablin is likely to be of particular interest to our newsletter readers. The authors hypothesize that it may be possible that "inherent vulnerability for the development of FM and related disorders is present in a certain proportion of the general population. The most evident biological abnormality in these individuals may be augmented central processing of pain or sensory amplification, manifested as multiple somatic symptoms. These individuals may be particularly susceptible to disruption of routine exercise or sleep with respect to symptoms becoming more pronounced. When confronted with an appropriate external trigger, such as an acute infection, physical

trauma, or a catastrophic event... these individuals may start to develop the complex of symptoms culminating in chronic pain and dysfunction.”

The book represents an update on current developments, insights and hypotheses in this field. While the recommended readership includes researchers, clinicians, and members of the general medical community, it will also be of interest to some patients.

This book can be ordered from the IASP website: www.iasp-pain.org (go to [Publications](#) and then to [IASP Press books](#)).

IASP “GLOBAL YEAR AGAINST MUSCULOSKELETAL PAIN”

While you are on the IASP website, take a look around, it is a mine of interesting information on Pain topics including a range of fact sheets. Each year the IASP runs a Pain campaign. This year it is “Global Year Against Musculoskeletal Pain”, from October 2009 to October 2010. This is of interest to us in the IC world in relation to associated disorders, especially fibromyalgia. Further information can be found on the IASP home page.

IASP CLINICAL UPDATE ON COPING WITH PAIN

The IASP produces regular, freely accessible, clinical updates which can be found on the IASP website. Go to home page www.iasp-pain.org and look on the right side under Publications from IASP. The October Update concerns “Coping with Pain”. Although written for health professionals, it will be of value to patients and patient support group leaders too. There is something for everyone here and many pain patients will recognize themselves in the sections dealing with coping strategies.

POSTER ON NEW ANTI-NGF MONOCLONAL ANTIBODY DRUG IN PHASE 2A TRIAL FOR INTERSTITIAL CYSTITIS: “TANEZUMAB FOR PAIN ASSOCIATED WITH INTERSTITIAL CYSTITIS”

A poster was presented at the 20th Annual Clinical Meeting of the American Academy of Pain Management, Phoenix, Arizona, USA, October 8–11, 2009 on “TANEZUMAB FOR PAIN ASSOCIATED WITH INTERSTITIAL CYSTITIS”, presented by IC research team Robert J. Evans, Robert M. Moldwin, Nandini Cossons, Amanda Darekar, David Scholfield, Ian Mills.

Nerve Growth Factor (NGF) is a naturally occurring molecule in the body which stimulates the growth and differentiation of the sympathetic and certain sensory nerves and is critical for their survival and maintenance.

Studies have indicated that increased expression of nerve growth factor (NGF) in injured or inflamed tissues may be associated with increased pain perception. Furthermore, research in the field of interstitial cystitis has shown that urinary NGF levels may be higher in IC patients than in controls and that a decrease in urinary NGF is associated with a reduction in pain.

Tanezumab, a potential breakthrough for chronic pain from Pfizer, is a fully-humanized monoclonal antibody targeting nerve growth factor and specifically inhibiting NGF activity. Tanezumab has already been shown in clinical studies to date to significantly reduce pain in patients with chronic pain conditions such as osteoarthritis of the knee. It is currently being studied for not only interstitial cystitis but also chronic (abacterial) prostatitis and other pain conditions.

This poster presentation reports on a Phase 2A randomized, placebo-controlled, double-blind, multicentre, parallel-group, “proof of concept” trial to investigate the use of tanezumab for the treatment of moderate to severe IC and to evaluate the efficacy, safety, and tolerability of single-dose intravenous tanezumab (200 mg/kg) for the treatment of pain associated with IC. The study participants were male and female outpatients, over 18 years of age, with moderate to severe IC. A clinically significant difference in pain was noted as early as Week 4 and at Week 6 tanezumab produced a greater, clinically significant reduction in the average daily pain score as opposed to placebo. After treatment, the patients were followed for 16 weeks and on each visit received a new daily symptom diary to record their symptoms for 7 days prior to the next visit. At each study visit the patients received a neurological examination for side-effects. Side effects (e.g. abnormal peripheral sensation, tingling sensation, headache, nausea) were mild to moderate and most had resolved by the end of the study.

It was concluded in this study that a single administration of intravenous tanezumab can in principle effectively treat pain in IC patients and appears to be safe and well tolerated. This means that it is now feasible for studies with tanezumab in interstitial cystitis patients to continue while a study with chronic prostatitis is also underway. We look forward to hearing more as these studies and trials progress.

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.

HYDRODISTENSION UNDER LOCAL ANESTHESIA FOR PATIENTS WITH SUSPECTED PAINFUL BLADDER SYNDROME/INTERSTITIAL CYSTITIS: SAFETY, DIAGNOSTIC POTENTIAL AND THERAPEUTIC EFFICACY.

Aihara K, Hirayama A, Tanaka N, Fujimoto K, Yoshida K, Hirao Y. Int J Urol. 2009 Oct 11. [Epub ahead of print]. PMID: 198117916.

This study aimed to evaluate the safety, diagnostic potential and therapeutic efficacy of cystoscopy with hydrodistension under local anaesthesia in patients suspected of having PBS/IC. One of the reasons was that local anaesthesia offers improved safety, minimal hospitalization, low costs, and reduction of complications associated with general, spinal or epidural anaesthesia. 36 patients with frequency, urgency or bladder pain for at least 6 months and an average voided volume of less than 200 ml were initially enrolled. 6 were later excluded due to bladder outlet obstruction. Hydrodistension was performed 10 minutes after instillation of 10 ml of 4% lidocaine in the remaining 30 patients.

The authors conclude that this study suggests that cystoscopy with hydrodistension under instillation of lidocaine into the bladder could be carried out for differential diagnosis of patients with suspected PBS/IC and has some therapeutic efficacy.

URODYNAMIC TESTING AND INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME.

Sastry DN, Hunter KM, Whitmore KE. *Int Urogynaecol J Pelvic Floor Dysfunct.* 2009. Oct 16 [Epub ahead of print]. PMID: 19834634

The purpose of this study was to evaluate the relationship between symptom severity in IC/PBS, urodynamic testing and cystoscopy since there is little literature that discusses the role of urodynamics in IC/PBS. 128 patients were included (122 female and 6 male). 115 of these underwent urodynamic testing. According to the authors, limitations of the study included the fact that the study was retrospective. Furthermore, the fact that pain, pressure or discomfort was not recorded in all of the patients may have limited the number of patients who expressed pain on filling during the urodynamic testing. Further prospective trials should be considered. The authors concluded from this study that certain cystometric parameters have been shown to be significantly associated with symptom severity in IC/PBS patients and that assessment of pain, pressure or discomfort felt with filling of the bladder may be an important key in urodynamic testing in IC/PBS patients. Urodynamic testing objectively demonstrates that pain is present.

STATISTICAL ANALYSIS OF SYMPTOMS, ENDOSCOPY AND UROTHELIAL MORPHOLOGY IN 58 FEMALE BLADDER PAIN SYNDROME/INTERSTITIAL CYSTITIS PATIENTS.

Zamecnik L, Hanus T, Pavlik I, Dundr P, Povysil C. *Urol Int.* 2009;83(2):193-9. Epub 2009 Sep 10. PMID: 19752616.

The goal of the study was to assess the course of painful syndrome in patients with bladder pain syndrome/interstitial cystitis and to assess the changes in endoscopic and histopathological findings in relation to the type of treatment. When evaluating the monitored parameters, the authors found significant correlations (both positive and negative). However, these relationships cannot be used to simplify the evaluation algorithm (according to ESSIC) and the initial criteria cannot predict the course of the disease.

A METABONOMIC APPROACH IDENTIFIES HUMAN URINARY PHENYLACETYLGLUTAMINE AS A NOVEL MARKER OF INTERSTITIAL CYSTITIS

Fukui Y, Kato M, Inoue Y, et al. *J Chromatogr B Analyt Technol Biomed Life Sci.* 2009 Sep 26. [Epub ahead of print] PMID: 19815468

In this study, urine samples from 10 patients with IC, 10 with bacterial cystitis and 10 healthy volunteers (HVs) were analyzed to identify an IC marker. The urinary marker of IC was identified as phenylacetylglutamine (PAGN); the urinary level of PAGN measured relative to creatinine (Cr) was significantly elevated in IC patients (mean 0.47mg/mg Cr) compared with BC patients (mean 0.25mg/mg Cr) and HVs (mean 0.11mg/mg Cr). Urinary PAGN/Cr ratios in patients with mild and moderate IC were higher than for patients with severe IC. These findings establish urinary PAGN/Cr ratios as a novel urinary marker of IC, and according to the authors may contribute to early diagnosis of IC patients.

MEASURING URGENCY IN CLINICAL PRACTICE

Dmochowski RR, Fitzgerald MP, Wyndaele JJ. *World J Urol.* 2009 Aug 27. [Epub ahead of print]. PMID: 19711086.

This review paper underlines the lack of knowledge and understanding of the normal physiology of urinary sensation and the pathophysiology of abnormal sensation that still exist today. Current tools for measurement of urgency in clinical practice are woefully inadequate, treatment even more so.

The authors write: "There is currently little understanding of the nature of the sensations that can be associated with urgency, but it is likely that sensations will differ in patients with differing lower urinary tract conditions." They conclude that the main aim of measuring urgency is to determine what the individual patient experiences and to evaluate the effectiveness of existing treatments. They believe that urgency is a complex symptom with variable occurrence and impact and that it is consequently unlikely that a single method will be sufficient to measure all aspects.

EAU GUIDELINES ON CHRONIC PELVIC PAIN.

Fall M, Baranowski AP, Elneil S, Engeler D, Hughes J, Messelink EJ, Oberpenning F, de C Williams AC. Eur Urol Aug 31. [Epub ahead of print]. PMID: 19733958.

The Guidelines Office of the European Association of Urology has issued a revised version of its guidelines on the diagnostics and treatment of chronic pelvic pain (CCP). The current revision was summarised in this article. A full version of the guidelines is available on the EAU website or via the EAU Office. The new version of the guidelines on CPP includes chapters on chronic prostate pain and bladder pain syndromes, urethral pain, scrotal pain, pelvic pain in gynaecologic practice, neurogenic dysfunctions, the role of the pelvic floor and pudendal nerve, psychological factors, general treatment of CPP, nerve blocks, and neuromodulation. "The treatment of chronic pelvic pain (CPP) continues to present a number of challenges with regard to understanding its aetiology and to its management," wrote the authors in their European Urology article. "Basic investigations must be undertaken to rule out 'well-defined' pathologies - if the results are negative, a well-defined pathology is unlikely." "Further investigations should be done only for specific indications, e.g. for subdivision of a pain syndrome," they concluded. "Research based on robust clinical parameters is needed to further an evidence-based approach to the treatment of CPP."

CHRONIC PELVIC PAIN.

Baranowski AP. Best pract Res Clin Gastroenterol. 2009;23(4):593-610. PMID: 19647692.

In this review article on chronic pelvic pain and its taxonomy, the author explains that chronic pelvic pain affects both men and women and that there are probably common mechanisms that involve the central nervous system. While in many cases, the symptoms may be localised to a single end organ, the involvement of the central nervous system may result in a complex regional pain syndrome affecting the whole pelvis and consequently symptoms in multiple organs. There may also be psychological, behavioural, sexual and social aspects. According to the author, treatment of the end organ has a limited role, and multidisciplinary as well as interdisciplinary management is essential. However, in his conclusion the author modifies this by saying that "Specific end-organ treatments will continue to be investigated but more generalised treatments need to also be considered", that "Specific end-organ treatments may have a role if they are based on evidence", and that where research is concerned "Specific end-organ treatments need to be evaluated for specific end-organ symptoms".

Phenotyping is discussed and defined as "describing the condition" and based upon mechanisms such as infection, ischaemic, auto-immune and neuropathic when known. In their absence, the condition may be described by its symptoms, signs and where possible investigations. On the subject of terminology, the author states that "terminology relates to the 'words' that are used within a classification, both to name the phenotype and within the definition of the phenotype". Taxonomy is described as placing the phenotypes into a hierarchy. On the issue of subdivision of the pain

syndromes, the author states that these are the subject of much debate and ongoing research.

INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME: AN UPDATE.

Dasgupta J, Tincello DG. Maturitas, 2009.Oct 16 [Epub ahead of print. PMID: 19837525.

This review article from the United Kingdom covers definition and diagnosis, epidemiology, aetiology and pathophysiology, treatment (intravesical instillation and oral), other treatment modalities (including pelvic floor physiotherapy and trigger point massage). A treatment algorithm is included.

URINARY NERVE GROWTH FACTOR BUT NOT PROSTAGLANDIN E2 INCREASES IN PATIENTS WITH INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME AND DETRUSOR OVERACTIVITY.

Liu HT, Tyagi P, Chancellor MB, Kuo HC. BJU Int. 2009 Sep 14 [Epub ahead of print]. PMID: 19751258.

This study compared urinary nerve growth factor (NGF) and prostaglandin E2 (PGE2) levels among patients with detrusor overactivity (DO), increased bladder sensation (ISB), interstitial cystitis/bladder pain syndrome (IC/BPS) and controls. It was concluded that urinary NGF/Cr levels are elevated in women with IC/BPS or DO, but not in those with IBS. The differential diagnosis of women with IC/BPS from those with frequency-urgency syndrome is possibly based on urinary NGF/Cr levels but not urinary PGE2/Cr level.

INTRAVESICAL LIPOSOME VERSUS ORAL PENTOSAN POLYSULFATE FOR INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME.

Chuang YC, Lee WC, Lee WC, Chiang PH. J Urol. 2009 Aug 13. [Epub ahead of print. PMID: 19683290.

Liposomes are fluid-filled pouches made of phospholipids. Since phospholipids are fat derivatives, liposomes could be described as fat globules or bubbles. They are used to deliver drugs to the body. However, researchers recently found that intravesically administered liposomes could be used alone (i.e. without the "bubbles" containing a drug) to coat and protect a defective IC/PBS bladder lining from irritating toxic elements in the urine. Studies have now moved from using rodents to live patients. The authors state that the primary objective of this study was to evaluate the safety and efficacy of intravesical liposomes. In this open study, 12 IC/PBS patients were treated with intravesical liposomes and compared with 12 patients treated with oral pentosan polysulfate (PPS). Intravesical liposome therapy was found to be safe in this study and the efficacy was shown to be similar to that of oral PPS. According to the authors, further large-scale, placebo-controlled studies are needed. However, intravesical liposomes look as though they are going to be a promising new treatment for IC/PBS.

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

Peters KM, Killinger KA, Boguslawski BM, Boura JA. NeuroUrol Urodyn. 2009 Sep 28. [Epub ahead of print]. PMID: 19787710.

Chronic pudendal nerve stimulation (CPNS) is an alternative for those who fail sacral stimulation. In this study, almost all (93.2%) who had previously failed sacral neuromodulation responded to pudendal stimulation. It was concluded that CPNS is a reasonable alternative in complex patients refractory to other therapies including

sacral neuromodulation. Continued research is needed to fully assess long-term outcomes and identify predictors of success.

EVIDENCE FOR OVERLAP BETWEEN UROLOGICAL AND NONUROLOGICAL UNEXPLAINED CLINICAL CONDITIONS

María Ángeles Bullones Rodríguez, Nilofar Afari and Dedra S. Buchwald for the National Institute of Diabetes and Digestive and Kidney Diseases Working Group on Urological Chronic Pelvic Pain. J Urol. 2009 Sep 14. [Epub ahead of print]. PMID: 19758633.

This study comprised a review of the literature to examine the extent of the overlap among urological and nonurological unexplained clinical conditions characterized by pain. The literature search, from 1966 to April 2008, focused on the overlap of chronic pelvic pain, interstitial cystitis, painful bladder syndrome, chronic prostatitis/chronic pelvic pain syndrome or vulvodynia with fibromyalgia, chronic fatigue syndrome, temporomandibular joint and muscle disorders or irritable bowel syndrome. Unexplained clinical conditions share common features such as pain, fatigue, sleep disturbances, disability which is out of proportion to physical examination findings, inconsistent laboratory abnormalities, and an association with stress and psychosocial factors. The research team found that the literature suggests that there is considerable co-occurrence between urological and nonurological unexplained clinical conditions and particularly between irritable bowel syndrome and urological unexplained syndromes. However, most of the studies had shortcomings such as varying definitions and the selection of controls. They recommend that future research should focus on using standardized definitions and well-designed studies to further assess to what extent these disorders co-occur in patients and to investigate common pathophysiological mechanisms so as to improve understanding and treatment for these conditions.

BLADDER PAIN SYNDROME/INTERSTITIAL CYSTITIS IN A DANISH POPULATION: A STUDY USING THE 2008 CRITERIA OF THE EUROPEAN SOCIETY FOR THE STUDY OF INTERSTITIAL CYSTITIS.

Richter B, Hesse U, Hansen AB, Horn T, Mortensen SO, Nordling J. BJU Int. 2009 Sep 14. [Epub ahead of print]. PMID: 19751261

The aim of this retrospective study with 349 consecutive patients was to characterize and evaluate a Danish patient population with bladder pain syndrome/interstitial cystitis (BPS/IC), using a working definition for BPS/IC incorporating six variables, and a set of criteria defined by the European Society for the Study of Interstitial Cystitis (ESSIC), and to describe the clinical course and treatment intensity in relation to these variables. The results indicated that nocturia, detrusor mastocytosis and intrafascicular fibrosis are associated with multiple treatments and presumed failure of standard urological therapy in patients with BPS/IC, while bladder capacity and glomerulations are not. However, according to the authors, valid conclusions cannot be drawn because of numerous limitations to the study.

DIFFERENTIAL DIAGNOSIS OF CHRONIC PELVIC PAIN IN WOMEN: THE UROLOGIST'S APPROACH.

Fletcher SG, Zimmern PE. Nat Rev. Urol. 2009 Sep 1 [Epub ahead of print. PMID: 19724247

An interesting review article that emphasizes 1) that chronic pelvic pain (CPP) is a challenging clinical entity which is an important issue in the healthcare of women, 2) that the differential diagnosis for CPP of urologic etiology includes urinary tract infection, urethral diverticulum, periurethral masses, urethral stricture disease, pelvic floor dysfunction, interstitial cystitis and painful bladder syndrome, 3) that voiding

symptoms of urgency, frequency and nocturia are commonly reported in patients who are complaining of bladder or urethral pain, 4) that no one particular diagnostic technique can be used to evaluate CPP; of paramount importance is the patient's history, which can substantially narrow the differential diagnosis and initiate appropriate referral, 5) that using a stepwise approach and an evidence-based thought process can help guide the history, physical examination, and ancillary testing in the best interests of the patient.

THE MANAGEMENT OF INTERSTITIAL CYSTITIS OR PAINFUL BLADDER SYNDROME IN WOMEN.

Marinkovic SP, Moldwin R, Gillen LM, Stanton SL. BMJ. 2009 Jul;339:b2707. PMID: 19648180

This clinical review discusses the diagnosis and management of IC according to current best evidence, including a suggested algorithm for the diagnosis and treatment of IC or PBS. Table 2 comprises a list of recommended dietary restrictions, while at the same time recommending patients to be careful not to eliminate more foods than necessary, because a severely restricted diet may be inadequate to maintain health and long-term symptom improvement. However, since it recommends restricting all Chinese, Indian, Mexican and Thai food, patients in some parts of the world are likely to go very hungry!!

UPDATE ON INTERSTITIAL CYSTITIS: STILL A BLADDER DISEASE?

Warren JW. Current Bladder Dysfunction Reports 2009,4(2):109-113.

In this review, the author reports that two groups of syndromes have been shown to be associated with IC. Before onset of IC, many functional somatic syndromes (e.g. chronic fatigue syndrome and fibromyalgia) are more prevalent in IC patients than matched controls. Also several pelvic syndromes co-exist with established IC. This may provide clues to the pathogenesis of IC and raises important questions about nosology (disease classification). The author also suggests that a reasonable theory is that the syndromes antecedent to IC are of a different pathogenesis than the pelvic syndromes found in established IC patients and that the linkage of these syndrome groups is through a pelvic pain generator that is perceived as IC. He notes that a prevailing hypothesis for the pathogenesis of overlapping functional somatic syndromes* is that they share a central nervous abnormality that leads to augmented pain and/or sensory processing. If this is true, it would indicate that IC – at least in some patients – is a local manifestation of a systemic disease. According to the author, large well-designed studies of both men and women with these symptom-based systemic and pelvic syndromes that compared genetics, antecedent events, detailed symptoms, natural histories and effects of treatment would be invaluable to generate hypotheses of common or different pathogeneses.

**The author describes functional somatic syndromes as being characterized by female predominance, fatigue and pain, few if any signs, no defining laboratory findings, exacerbation with stress, association with depression and anxiety, and chronicity.*

VALIDATION OF A MODIFIED NATIONAL INSTITUTES OF HEALTH CHRONIC PROSTATITIS SYMPTOM INDEX TO ASSESS GENITOURINARY PAIN IN BOTH MEN AND WOMEN.

Clemens JQ, Calhoun EA, Litwin MS, McNaughton-Collins M, Kusek JW, Crowley EM, Landis JR; Urologic Pelvic Pain Collaborative Research Network. Urology. 2009 Oct 1. [Epub ahead of print]. PMID: 19800663

A single instrument to assess treatment response in clinical trials and cohort studies that involve both genders was developed in this study: the Genitourinary Pain Index (GUPI). The GUPI discriminated between men with chronic prostatitis or interstitial cystitis, those with other symptomatic conditions (painful voiding, frequency, chronic cystitis), and those with none of these diagnoses. It also discriminated between women with interstitial cystitis, those with incontinence, and those with none of these diagnoses. It was concluded that the GUPI is a valid, reliable, and responsive instrument that can be used to assess the degree of symptoms in both men and women with genitourinary pain complaints.

EARLY IDENTIFICATION OF INTERSTITIAL CYSTITIS MAY AVOID UNNECESSARY HYSTERECTOMY

Chung MK, Jarnagin B. JSLs. 2009 Jul-Sep;13(3):350-7. PMID: 19793476

According to the authors, it can be difficult to accurately identify interstitial cystitis because the symptoms overlap many other common gynaecologic and urologic conditions. Patients with undiagnosed interstitial cystitis may undergo unnecessary procedures, including hysterectomy. Interstitial cystitis should be considered prior to hysterectomy in women who present with pelvic pain or who experience pelvic pain after a hysterectomy.

DECREASED NANOBACTERIA LEVELS AND SYMPTOMS OF NANOBACTERIA-ASSOCIATED INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME AFTER TETRACYCLINE TREATMENT.

Zhang QH, Shen XC, Zhou ZS, Chen ZW, Lu GS, Song B. Int Urogynecol J Pelvic Floor Dysfunct. 2009 Sep 17. [Epub ahead of print]. PMID: 19760079

This study with 11 patients was designed to detect whether so-called nanobacteria reside in urine and bladder tissue samples of patients with interstitial cystitis/painful bladder syndrome (IC/PBS) and whether antibiotic therapy targeting these organisms is effective in reducing nanobacteria levels and IC/PBS symptoms. Nanobacteria levels decreased dramatically after tetracycline treatment, and they reported significant reduction in the severity of IC/PBS symptoms. A high prevalence of nanobacteria was observed in female IC/PBS, and anti-nanobacteria treatment effectively improved the symptoms, which - according to the authors - suggests that nanobacteria may cause some cases of IC/PBS.

NB: If you don't have a clue what nanobacteria are, see <http://www.ncbi.nlm.nih.gov:80/pmc/articles/PMC1876495/?tool=pubmed> for a fascinating article on "Nanobacteria: Facts or Fancies?" by Pasquale Urbano and Francesco Urbano, PLoS Pathog 2007;3:e55.

KETAMINE-ASSOCIATED BLADDER DYSFUNCTION.

Tsai TH, Cha TL, Lin CM, Tsao CW, Tang SH, Chuang FP, Wu ST, Sun GH, Yu DS, Chang SY. Int J Urol. 2009 Oct;16(10):826-9. [Epub 2009 Jul 29]. PMID: 19659678

In the past two years we have seen a number of articles published on the topic of street ketamine abuse and its potential effect on the genitourinary system. This study assessed the impact of ketamine abuse on genitourinary tract dysfunction in 11 patients with urinary tract symptoms and a history of ketamine abuse. The most common complaints from these patients were lower urinary tract symptoms including urgency, frequency, painful urination and severe bleeding, with some patients suffering irreversible histological changes in the urinary tract. All biopsy samples showed infiltration of granulocytes (mainly eosinophils) and mast cells in the bladder

tissue. Medication produced only slight improvement, but intravesical instillation of hyaluronan (hyaluronic acid) led to a significant improvement.

CYSTOSCOPY AND BLADDER BIOPSIES IN PATIENTS WITH BLADDER PAIN SYNDROME CARRIED OUT FOLLOWING ESSIC GUIDELINES.

Wyndaele JJ, Van Dyck J, Toussaint N. Scand J Urol Nephrol. 2009 Aug 25;1-5. [Epub ahead of print]. PMID: 19707951

The purpose of this prospective study with 50 IC/BPS patients (44 female, 6 male) was to evaluate the feasibility of carrying out tests performed in a standardized way and to evaluate cystoscopic and histological findings of bladder biopsies based on the recommendations of the European Society for the Study of Interstitial Cystitis/Painful Bladder Syndrome (ESSIC). A considerable variation was found in both cystoscopic and histological findings which led the authors to conclude that IC/BPS patients with severe symptoms present with various cystoscopic findings on hydrodistension and bladder histology when carried out in accordance with ESSIC recommendations. Correlations were found between cystoscopic findings, maximum bladder capacity and bladder histology, but no correlation was found between the ESSIC cystoscopic severity score and grade and histology. The finding that 94% of the patients were classified as BPS types 1C, 2C or 3C, shows that 94% of the patients had signs of present inflammation (inflammatory infiltrates, detrusor mastocytosis) or previous inflammation (granulation tissue, intrafascicular fibrosis). The authors felt that cystoscopy, hydrodistension and biopsies would seem to be mandatory in order to be able to further type patients. They noted that performing the tests recommended by ESSIC proved to be easy and produced information that permitted comparison between patients.

SEVERITY OF INTERSTITIAL CYSTITIS SYMPTOMS AND QUALITY OF LIFE IN FEMALE PATIENTS.

El Khoudary SR, Talbott EO, Bromberger JT, et al. J Womens Health (Larchmt) 2009;18:1361-8. PMID:19743907.

The main aims of this study were 1) to determine possible factors that may increase severity of symptoms and decrease quality of life in female IC patients, 2) to study how symptom severity affects quality of life adjusting for these factors and 3) to investigate which symptom is most likely to impair the physical and mental quality of life of an IC patient. 41 female patients with moderate/severe IC took part in the study. The results indicated that symptom severity and being currently unmarried were likely to be associated with impairment of quality of life in IC patients and that managing pain and nocturia may improve the patients' overall physical quality of life.

PREVALENCE OF UREAPLASMA UREALYTICUM AND MYCOPLASMA HOMINIS IN WOMEN WITH CHRONIC URINARY SYMPTOMS.

Baka S, Kouskouni E, Antonopoulou S, et al. Urology 2009;74:62-6. PMID: 19371925.

The purpose of this study was to assess the prevalence of *Ureaplasma urealyticum* and *Mycoplasma hominis* in women with chronic urinary symptoms. Urine, vaginal, and urethral samples were taken from 153 women presenting with chronic voiding symptoms and tested for the presence of pathogens including *Ureaplasma urealyticum* and *Mycoplasma hominis*. *Ureaplasma urealyticum* was detected in 81 women and *Mycoplasma hominis* in 5 patients, always in association with *Ureaplasma urealyticum*. A significant improvement in all symptoms was observed in women with positive cultures for *Mycoplasma* after appropriate therapy. According to the authors, testing for the presence of *Ureaplasma urealyticum* and *Mycoplasma*

hominis in the urogenital tract could prove valuable for the management of a significant percentage of chronic urinary symptoms in women through appropriate treatment. It was concluded that it is important for all patients with chronic urinary symptoms to be tested for the presence of *Ureaplasma urealyticum* and *Mycoplasma hominis* and that appropriate treatment can prove beneficial for a significant percentage of women with chronic urinary symptoms.

CLINICAL PHENOTYPING OF WOMEN WITH INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME: A KEY TO CLASSIFICATION AND POTENTIALLY IMPROVED MANAGEMENT.

Nickel JC, Shoskes D, Irvine-Bird K. J Urol. 2009 Jul;182(1):155-60.

The authors have proposed a clinical phenotype system (UPOINT) to classify patients with urological chronic pelvic pain syndromes (UCPPS = CP/CPPS and IC/PBS) in order to improve understanding of etiology and to guide treatment. Many promising treatments often fail in clinical practice and in trials. It is only recently that physicians have become aware that IC/PBS patients are not a homogenous group but a group of individuals with widely varying clinical phenotypes. It was this that led the NIH to fund the MAPP Study group to try to find out more about the differences in this heterogeneous group of patients. UPOINT is a 6-point clinical classification system that categorizes the phenotype of patients with UCPPS into 6 clinically identifiable domains including Urinary, Psychosocial, Organ specific, Infection, Neurogenic/ systemic, Tenderness. This classification system is not necessarily based on etiology, but remains flexible. In this study they examined the relationship between UPOINT and symptoms in 100 consecutive patients with IC/PBS. It was concluded that IC/PBS patients with a longer duration of their symptoms have more UPOINT domains and that most IC/PBS female patients have UPOINT domains outside the bladder which could be a reason why bladder specific treatments often fail. Patients with positive psychosocial and tenderness domains had worse symptoms scores. The authors suggest that future studies should investigate whether specific treatment for these domains would improve the efficacy of traditional IC/PBS treatments.

See also UPOINT website: <http://www.upointmd.com/faq.php> for further information.

MULTIMODAL THERAPY FOR PAINFUL BLADDER SYNDROME/INTERSTITIAL CYSTITIS: PILOT STUDY COMBINING BEHAVIOURAL, PHARMACOLOGIC, AND ENDOSCOPIC THERAPIES.

Hanley RS, Stoffel JT, Zagha RM, Mourtzinis A, Bresette JF. Int Braz J Urol. 2009 Jul-Aug;35(4):467-74. PMID: 19719863.

This pilot study evaluated the effectiveness of combining behavioural therapy, pharmacologic therapy and endoscopic hydrodistension for treating PBS/IC in 25 patients. Behavioural modification included diet recommendations, fluid restrictions to 64 oz a day, progressive timed voiding and Kegel exercises. Oral medication comprised daily doses of macrodantin 100 mg, hydroxyzine 10-20 mg and urised 4 tablets. The patients underwent endoscopy with hydrodistension under anaesthesia. O'Leary-Sant questionnaires were used before starting the protocol, after pharmacologic/behavioural therapy, 2 months after hydrodistension and at scheduled follow-up. 18 female patients completed the pilot multimodal treatment protocol. The results indicated a significant progressive improvement in quality of life scores but should now be validated in a larger, placebo-controlled study.

A PRACTICAL APPROACH TO DIAGNOSIS AND TREATMENT OF INTERSTITIAL CYSTITIS.

Evans RJ, Proctor J, Moldwin RM. *Urotoday International Journal*, Volume 2 – October 2009.

A useful, clear overview of diagnosis and treatment, including the Pelvic Pain and Urgency/Frequency (PUF) Patient Symptom Scale, the O'Leary-Sant Interstitial Cystitis Symptom and Problem Index and a table of Pharmacological Therapies for IC/PBS, including dosages.

Freely accessible online at: <http://www.urotodayinternationaljournal.com> or direct link: http://journal.urotoday.com/images/uij_2009/Evans_49/evans-49.pdf

The following two articles give opposing views on the use of the Potassium Sensitivity Test:

POTASSIUM SENSITIVITY TEST FOR PAINFUL BLADDER SYNDROME /INTERSTITIAL CYSTITIS: CON.

Hanno P. *J Urol*. 2009 Aug;182(2):431-2, 434. PMID: 19524950

According to Hanno, taking a position on the clinical use of the intravesical potassium chloride test is simply a question of whether use of this test aids in the diagnosis of the syndrome or in the initial choice of therapy, and in Hanno's opinion it does neither. He sees 4 basic issues: 1) value in using a test to make a diagnosis; 2) sensitivity of the test; 3) specificity of the test and 4) does the test help us select what therapy to use for the patient. Hanno believes that the test falls short on all counts. He concludes by saying that the potassium sensitivity test remains interesting and provocative but its value is highly questionable, it is costly and it is uncomfortable for the patient.

THE POTASSIUM SENSITIVITY TEST: A NEW GOLD STANDARD FOR DIAGNOSING AND UNDERSTANDING THE PATHOPHYSIOLOGY OF INTERSTITIAL CYSTITIS.

Parsons CL. *J Urol*. 2009 Aug;432-4. PMID: 19603544

According to Parsons, the basic physiological principle behind the potassium sensitivity test (PST) is that patients with IC suffer from an abnormally permeable, that is "leaky", bladder epithelium. He believes that the PST is a simple office procedure that provides valuable clinical information and is creating a new paradigm for understanding the causes of urinary frequency and urgency, urge incontinence and pelvic pain. If the clinical diagnosis is not apparent, a positive test may guide therapy towards IC such as in a patient initially suspected of having OAB or prostatitis.

History article:

AVICENNA'S CANON OF MEDICINE AND MODERN UROLOGY. PART IV: NORMAL VOIDING, DYSURIA, AND OLIGURIA.

Madineh SM. *Urol J*. 2009 Summer;6(3):228-33. PMID: 18711283

Free full text of this article is available at the journal website:

<http://www.urologyjournal.org/index.php/uj/article/view/413/394>

The Iranian Urology Journal has been running a series of historical articles by S.M. Madineh on the Canon of Medicine by Avicenna (Arabic: Ibn Sina), the great Persian physician, scientist and prodigious intellectual, regarded as one of the father's of modern medicine (c. 980-1037). This article deals with Book III, Part 19, Treatise 2 of

the Canon that is entitled "On Urinary Bladder and Urine". The author writes that it is possible to distinguish in the Canon bases of the theory of infection and mucosal theory, along with abnormalities of urine, psychological factors, and abnormalities in prostatic secretions. Avicenna also indicates some differential diagnoses of and associated disorders with interstitial cystitis.

This (and the first three articles) is a fascinating read for those with an interest in history.

UPCOMING EVENTS

2009:

18th National Conference on Incontinence, 4-7 November, 2009, Adelaide Convention Centre, Adelaide, Australia

Convergences in Pelvipерineal Pain (including IASP/PUGO meeting)
16-18 December 2009, Cité des Congrès de Nantes, France.

2010

IAPO 4th Global Patients Congress, 23-25 February 2010 Istanbul, Turkey

NIDDK Symposium on Neuroimaging in Urologic Pelvic Pain and Associated Disorders, tentative date 15/16 March 2010.

25th Annual congress of the European Association of Urology (EAU)
16-20 April 2010, Barcelona, Spain.

5th European Conference on Rare Diseases, 13-15 May 2010 Krakow, Poland

ESSIC Annual Meeting 2010, preliminary date: 20-22 May 2010, Antwerp, Belgium

AUA Annual Meeting 2010, 29 May - 3 June 2010, San Francisco (CA), USA

Joint Meeting of the International Continence Society (ICS) and International Urogynecological Association (IUGA) "Advancing Incontinence and Pelvic Floor Research and Treatment", 23-27 August 2010, Toronto, Canada

13th World Congress on Pain, 29 August-2 September, 2010, Montreal, Canada

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

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