

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 21, June 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:

- Review of the AUA annual meeting 2010
- A review of IC/PBS presentations at the EAU annual congress 2010
- A review of ESSIC annual meeting 2010
- IPBF to have booth at ICS-IUGA 2010 in Toronto
- First International Pain Summit, 3 September 2010, Montreal
- Current Concepts of Urogenital Pain (PUGO Satellite Symposium of 13th World congress on Pain)
- IASP Clinical Update: Fibromyalgia
- Urotoday CAUTI Center Update
- Sexual Pain in Men & women with IC/PBS and CPP on ICS website
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REVIEW OF THE AMERICAN UROLOGICAL ASSOCIATION (AUA) ANNUAL MEETING 2010

The AUA annual meeting 2010 was in many ways a landmark meeting for IC with its unprecedented number of presentations and even prestigious plenary sessions devoted to the topic, underlining the attention this syndrome is currently receiving. Nevertheless, confusion and lack of agreement continue to be the order of the day.

Our detailed review can be found on the IPBF website at:

http://www.painful-bladder.org/pdf/2010_AUA_SanFrancisco.pdf

This review covers plenary sessions including the new preliminary guideline and a panel discussion, podium presentation sessions, and Society for Infection and Inflammation in Urology poster presentations.

Of particular interest was the Panel Discussion entitled "Painful bladder syndrome: What happened to interstitial cystitis?" moderated by Alan J. Wein, MD, with panel members Jorgen Nordling, MD, who spoke on the case for changing the nomenclature, Christopher Payne, MD, on the importance of the legacy nomenclature and Deborah Erickson, MD, on how might nomenclature changes affect the clinical approach to the syndrome?

Professor Nordling first explained that ESSIC had agreed no longer to use the name interstitial cystitis, neither alone nor in combinations, but to use the name bladder pain syndrome (BPS) followed by the addition of a type indication.

Professor Payne then took the stand with an opposing point of view to explain why there are both practical and important philosophical reasons why at this time we need to use interstitial cystitis as part of the name. He stressed that we still lack the knowledge to replace our old ideas with a new comprehensive concept and that until we do have this new knowledge, the legacy should be retained as part of the name until we can move forward to more appropriate nomenclature. We shouldn't make a huge effort to change the name when we don't know where we are at.

Professor Erickson then took the floor to discuss how name changes might affect the clinical approach to this syndrome. It affects several areas: we are no longer looking for a positive finding to diagnose IC but instead we are looking to rule out all other defined causes of the symptoms. Professor Erickson said that she really favours interstitial cystitis as a term for the patients to use with others in his or her life. She also referred to the economic implications for the patient, for example insurance coverage and the ability to obtain coverage. Disability is a crucial issue here. IC is a recognised diagnosis for Social Security disability. Obtaining disability in the USA is a long difficult process and without the diagnosis of "IC" this process could be even harder. Treatment coverage is also an important aspect. Treatments such as PPS and DMSO have been approved for "IC" in the USA. Without a diagnosis of IC, will these be reimbursed?

The second part of the panel discussion concerned whether this is primarily a bladder syndrome associated with pelvic pain or a chronic pain syndrome associated with bladder symptoms? Each of the three panellists was asked to comment briefly.

PRELIMINARY AUA GUIDELINE

Philip Hanno, MD presented the preliminary AUA guideline on what the AUA proposes to call interstitial cystitis/bladder pain syndrome (abbreviated as IC/BPS, with no difference made between the two). However, inclusion of the term IC at the beginning means that official recognition of the term interstitial cystitis by health and social security authorities will continue, and this is good news for the patients and patient support groups everywhere.

The proposed definition is as follows:

"An unpleasant sensation (pain, pressure, discomfort) perceived to be related to the urinary bladder, associated with lower urinary tract symptoms of more than 6 weeks' duration, in the absence of infection or other identifiable causes." This is the definition proposed at the SUFU meeting in 2008. (*Neurourol Uroldyn. 2009;28(4):274-86*).

It should be emphasized that this guideline is not yet final and is still undergoing peer review. The guideline panel comprises: D. Burks, Q. Clemens, R. Dmochowski, D. Erickson, M.P. Fitzgerald, J. Forrest, B. Gordon (ICA), M. Gray, P. Hanno (chair), R. Mayer, D. Newman, L. Nyberg, C. Payne and U. Wesselman. It is hoped to publish the final version towards the end of 2010 in the Journal of Urology and on the AUA website. We will then be able to give you much more detail.

IC/PBS PRESENTATIONS AT THE EUROPEAN ASSOCIATION OF UROLOGY (EAU) CONGRESS, BARCELONA, SPAIN - 16-20 APRIL 2010

While the 25th anniversary congress of the EAU was planned to be a special occasion, nobody could have anticipated that it would be quite so dramatic! The volcanic eruption in Iceland led to half the delegates being unable to attend, while the other half was faced with the problem of getting home again. With planes cancelled and trains full, people aiming for similar destinations were grouping together to hire cars and buses. A main topic of conversation was how you were going to get home! Since many speakers and ESU course presenters had not been able to make it to Barcelona, this situation also led to a great deal of improvisation being necessary throughout the congress, with

multi-tasking by those who did make it to Spain. This congress will go down in history as one of the most memorable in EAU congress history and certainly tested everyone's ingenuity to the fullest. A review of presentations and a course in the field of IC/PBS at the EAU congress can be found on our website at:

http://www.painful-bladder.org/pdf/2010_EAU_Barcelona.pdf

ESSIC ANNUAL MEETING 2010, ANTWERP, BELGIUM, 20-22 MAY.

ESSIC - now transformed from a European to an International Society for the Study of BPS - held its annual meeting in Antwerp this year, at the Radisson Blu Astrid Hotel in the heart of Antwerp's famous diamond district. This year ESSIC changed its policy and all scientific sessions were open to all registered delegates. The programme included a Fatigue Symposium on Thursday afternoon, on Friday a round table on definitions, a session on questionnaires including new questionnaires being developed by Pfizer and translated into many languages, videos of Hunner's lesions with exceptionally high quality videos shown by Professor Zaitcev from Moscow, a presentation on the morphology of the bladder (Professor M. Cervigni) and scientific presentations by ESSIC members, on Saturday morning a course (partly in Dutch) including presentations by Professor Wyndaele on Therapy and by Dr Joop van de Merwe on exclusion of confusable diseases, followed by a Dutch language Pelvic Pain Symposium in the afternoon which included physiotherapy and osteopathy. The courses on Saturday were exceptionally well attended by multidisciplinary Flemish Belgian delegates and several Dutch-speaking patient support group representatives.

ESSIC FATIGUE SYMPOSIUM

The meeting began on Thursday with a Fatigue Symposium. As Professor Nordling noted, little or no attention is being paid to chronic fatigue or tiredness in IC patients. This symposium therefore focused on two viewpoints: 1) the patient viewpoint (Jane Meijlink, IPBF) and 2) the medical viewpoint (Dr Joop van de Merwe, immunologist). According to the first speaker, Jane Meijlink, the fatigue aspect of IC is still frequently ignored, misunderstood, dismissed as psychosomatic or simply considered irrelevant by many of the medical profession, but it is also equally misunderstood by the patient's family and friends. Fatigue is a potentially disabling condition that can cause mental and physical dysfunction, with a severe impact on the patient's relationships, home-life, employment and social life.

Discussing the medical perspective of chronic fatigue, Dr Joop van de Merwe noted that the key components are:

- inability to initiate activity
- reduced capacity to maintain activity
- difficulty with concentration, memory, and emotional stability

Fatigue is considered to be chronic if it has lasted more than 6 months. It may be:

- medical: in association with an organ-based disease
- psychiatric: in association with a mental disease
- idiopathic: no organ-based or mental disease
- chronic fatigue syndrome (defined for research purposes by restrictive criteria
- other (not fulfilling the criteria of chronic fatigue syndrome)

Dr Van de Merwe followed this with a second presentation on fatigue in organ-based disease, looking first at cancer-based fatigue and then at fatigue in autoimmune diseases with a focus on Sjögren's syndrome in which fatigue is often experienced by the patient to be the most disabling aspect with a major impact on daily life. This fatigue can be physical fatigue, but also mental fatigue in some patients.

More on this subject can be found in Dr Van de Merwe's chapters on Treatment and Fatigue in his book on "Sjögren's syndrome: Information for patients and professionals". Chapter 5 on Treatment: www.painful-bladder.org/pdf/ch5.pdf

and Chapter 6 on Fatigue: www.painful-bladder.org/pdf/ch6.pdf

The speakers concluded by pointing out that virtually nothing has been published on fatigue combined with IC. It is regrettably a very neglected area. A more detailed review of the ESSIC 2010 meeting can be found on the IPBF website:

http://www.painful-bladder.org/pdf/2010_ESSIC_Antwerp.pdf

The next ESSIC annual meeting will be held in June 2011 in Moscow and will be organised by Professor A. Zaitcev.

UPCOMING CONFERENCES:

IPBF WILL HAVE BOOTH FOR IC/PBS AT UPCOMING ICS-IUGA JOINT ANNUAL MEETING IN TORONTO

This year the International Continence Society (ICS) annual meeting will be a joint meeting with the International Urogynecological Association (IUGA). As at previous ICS meetings, the IPBF will have a booth for IC and associated disorders. This meeting is multidisciplinary with specialists of many different kinds for pelvic floor dysfunction, pelviperineal pain, bladder and bowel incontinence in the widest sense of the word, and also many physiotherapists and nurses. There is consequently much interest in patient support groups and information on IC and related topics in different languages.

Meeting website: www.ics-iuga.com

ICS PUBLIC FORUM

The ICS Public Forum will be held at the end of the ICS-IUGA annual meeting on Friday, 27 August 2010, 17.00 – 21.00 hours in Toronto.

Further details: http://www2.kenes.com/ics2010/Scientific/Pages/Public_Forum.aspx

INTERNATIONAL PAIN SUMMIT, 3 September 2010, Palais des Congrès de Montréal

Organized by the International Association for the Study of Pain and immediately following the 13th World Congress on Pain (29 August-2 September, 2010, Montreal, Canada), the International Pain Summit will be the first global meeting about the crucial aspects of pain management, with a focus on advocacy and assistance for all countries to develop national pain strategies. Its mission is to improve the quality of life for people living with pain and to minimize the burden of pain on individuals and communities worldwide.

Goals

- To develop a set of desirable characteristics of national pain strategies that can be agreed upon internationally. Individual countries can then use these broad principles to more fully develop specific strategies based on their own local requirements.
- To gain the attention of communities, the media, and governments about the magnitude of the health and economic problem of untreated acute pain, chronic pain, and pain caused by cancer, HIV/AIDS, and other diseases and treatments.
- To involve health ministers and other government officials in developing and implementing national pain strategies.
- To begin to develop "best practice" models of service delivery.
- To contribute to the de-stigmatization of chronic pain.
- To draw further attention to pain relief as a fundamental human right.
- To advocate for increased emphasis on and support of pain education and research.

Intended Audience and Participants:

- Leaders of current initiatives, including representatives from IASP's 84 national chapters
- Senior Health Administrators and Ministers
- Palliative Care Organizations
- International Narcotics Control Board representatives
- Human Rights advocates
- World Health Organization (WHO)
- National consumer (patient) organizations
- International Media

Further information: [http://www.iasp-](http://www.iasp-pain.org/AM/Template.cfm?Section=Home&TEMPLATE=/CM/HTMLDisplay.cfm&CONTENTID=10974)

[ain.org/AM/Template.cfm?Section=Home&TEMPLATE=/CM/HTMLDisplay.cfm&CONTENTID=10974](http://www.iasp-pain.org/AM/Template.cfm?Section=Home&TEMPLATE=/CM/HTMLDisplay.cfm&CONTENTID=10974)

CURRENT CONCEPTS OF UROGENITAL PAIN (OFFICIAL PUGO SATELLITE SYMPOSIUM OF THE 13TH WORLD CONGRESS ON PAIN)

A satellite symposium will be organized by PUGO (the Pain of Urogenital Origin Special Interest Group of the IASP) on 29 August 2010 at the Montreal Convention Centre/Palais des Congrès de Montreal at the start of the 13th WORLD CONGRESS ON PAIN (29 August-2 September 2010).

The objectives of this satellite symposium will be:

- To understand what constitutes urogenital pain
- To discuss the current nomenclature used in describing and researching such painful conditions
- To review the current understanding of the basic science modulating urogenital pain
- To discuss the psychological influences in urogenital pain.

A flier may be downloaded at: <http://indoorcat.org/pugo/events.html>. For further information contact: margaret.whelan@stees.nhs.uk. Registration is via the World Congress on Pain Registration web page: <http://www.iasp-pain.org/Montreal>

IASP CLINICAL UPDATE: FIBROMYALGIA

The International Association for the Study of Pain (IASP) has just published a new Clinical Update on Fibromyalgia (Vol. XVIII Issue 4, June 2010). This is available on the IASP website at:

http://www.iasp-pain.org/AM/Template.cfm?Section=Clinical_Updates&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID=5&ContentID=1566

At a time when the IC world is busy with phenotyping or subtyping, it is interesting to read in this Update by Professor Claudia Sommer that "A major goal in FMS research will be to better identify subgroups and to more clearly explain the pathophysiology of the syndrome so that individualized treatment can be developed and administered." There is a useful table with an overview of treatment with a positive effect on FMS in randomized controlled trials.

UROTODAY CAUTI CENTER Update

In our March IPBF e-Newsletter, we mentioned the Urotoday CAUTI center. Urotoday (www.urotoday.com) has a new online resource aimed at combating urinary tract infection caused by catheterisation: http://www.urotoday.com/cauti_center/index.html

This CAUTI Center has now been enlarged and has many new items including a best practices section with downloadable wallet cards on Considerations in Prevention of CAUTIs, Prevention of Catheter-Related UTIs and a Step-by-Step Care Clinical Pathway for IUC Removal: http://www.urotoday.com/cauti_center/best_practices.html. There are also three multimedia presentations. This is really useful and valuable information for health professionals and patients/patient organizations.

SEXUAL PAIN IN MEN & WOMEN WITH IC/PBS AND CPP ON ICS WEBSITE

An interesting article on sexual pain in men and women with IC/PBS and chronic pelvic pain by Kristene Whitmore, MD, Jennifer Fariello, MD, and the Pelvic and Sexual Health Institute, Philadelphia can be read on the website of the International Continence Society

https://www.icsoffice.org/ASPNET_Membership/Membership/News.aspx?NewsID=22

This article was first published in *ICS News* in January 2010.

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.

THE OVERLAP OF INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME AND OVERACTIVE BLADDER.

Chung MK, Butrick CW, Chung CW. JSLs, 2010 Jan-Mar;14(1):83-90. Epub 2010 Apr 21. PMID: 20412643

This prospective study evaluated the prevalence of positive potassium sensitivity and cystoscopy in patients with overactive bladder. It was found that many patients with overactive bladder (OAB) symptoms but little or no pain have cystoscopic evidence of IC/PBS and a positive potassium test. This suggests that OAB patients who have (partially) failed anticholinergic treatment traditionally used for OAB may benefit from IC/PBS therapies directed towards dysfunction of the urothelium and neural upregulation. Whether these patients should be classified as OAB or as IC/PBS remains controversial. The East Asians have solved this problem by using the term hypersensitive bladder syndrome. (*Homma et al. Clinical guidelines for interstitial cystitis and hypersensitive bladder syndrome. Int J Urol. 2009 Jul;16(7):597-615. Epub 2009 Jun 22.*)

A MULTICENTER, RANDOMIZED, DOUBLE-BLIND, PARALLEL GROUP PILOT EVALUATION OF THE EFFICACY AND SAFETY OF INTRAVESICAL SODIUM CHONDROITIN SULFATE VERSUS VEHICLE CONTROL IN PATIENTS WITH INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME.

Nickel JC, Egerdie RB, Steinhoff G, Palmer B, Hanno P. Urology. 2010 May 20. [Epub ahead of print]. PMID: 20494413

The purpose of this study was to obtain information about the differences between intravesical chondroitin sulfate and placebo for treatment of interstitial cystitis/painful bladder syndrome (IC/PBS). Patients were randomized to weekly intravesical treatment with 2.0% sodium chondroitin sulfate in phosphate-buffered saline or intravesical vehicle control (placebo). The difference in treatment effect in this small study was not statistically significant, although twice as many patients reported a clinically significant benefit with intravesical chondroitin sulfate treatment compared to placebo. However, this trial provides valuable data to design a randomized vehicle-controlled trial to

determine the real efficacy of this potentially promising treatment which is quite widely used in Europe in particular.

URGENCY: ALL OR NONE PHENOMENON?

De Wachter S, Hanno P. Neurourol Urodyn. 2010 Apr;29(4):616-7. PMID: 20432323

This review article refers to the current confusion concerning the term “urgency”, largely caused by the ICS definition which focuses on urgency in overactive bladder. The authors points out that there is still a lot of debate as to whether the ICS definition covers all aspects of “urgency” in all patients. They note that better in sight is needed into the sensation of urgency that we are talking about and that “our understanding on how normal bladder sensations build up to conscious perception needs to be increased”. They list the following research priorities:

- Evaluate the terminology on normal bladder sensation: do patients and physicians talk the same language?
- Evaluate if the sensation of urgency can be modulated. Can the intensity of urgency be decreased?
- Evaluate the existence of different sensations of urgency. Does the character of the urgency sensation differ between patients with OAB or bladder pain syndrome?
- Evaluate the existence of different patterns of urgency. Can we differentiate a peripheral versus central form of urgency?
- Do different forms of urgency have a different outcome towards treatments (bladder training, drugs, neuromodulation)

RISK FACTORS FOR POOR SLEEP QUALITY AMONG PATIENTS WITH INTERSTITIAL CYSTITIS IN TAIWAN.

Tsai CF, Ouyang WC, Tsai SJ, Hong CJ, Lin TL. Neurourol Urodyn. 2010 Apr;29(4):568-72. PMID: 19899148

This article from Taiwan is one of the rare articles to deal with sleep disturbance in IC patients and the authors note that reports that employ validated sleep questionnaires are rare for IC patients. This study examined the relationship between sleep quality, anxiety, depression, and the severity of urologic interstitial cystitis symptoms in outpatients, and risk factors for poor sleep quality. They concluded that poor sleep quality is common in interstitial cystitis patients and severity of urological symptoms and depression levels are important independent risk factors.

CORRELATIONS OF INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME WITH FEMALE SEXUAL ACTIVITY.

Yoon HS, Yoon H. Korean J Urol. 2010 Jan;51(1):45-9. Epub 2010 Jan 21. PMID: 20414410

Free access article: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2855473/pdf/kju-51-45.pdf>

This Korean study with 87 IC/PBS patients diagnosed on the basis of the ICS definition looked at how the symptoms of interstitial cystitis/painful bladder syndrome (IC/PBS) are correlated with the sexual activity of these patients. There was a positive correlation between age and vulvodynia and a negative correlation between age and dyspareunia. Frequency showed a positive correlation with vulvodynia in addition to an inhibited sex life. Urgency showed a positive correlation with an inhibited sex life. Vulvodynia showed a positive correlation with an inhibited sex life and dyspareunia. The main symptoms of IC/PBS (frequency, urgency, and pelvic pain) showed a positive correlation with almost all items related to quality of life. It was concluded that frequency, urgency, and various types of pain are negatively correlated with the sexual activity of patients, suggesting that doctors should consider sexual function in the management of patients with IC/PBS.

PREVALENCE OF PAINFUL BLADDER SYNDROME/INTERSTITIAL CYSTITIS-LIKE SYMPTOMS IN WOMEN: A POPULATION-BASED STUDY IN KOREA.

Choe JH, Son H, Song YS, Kim JC, Lee JZ, Lee KS. World J Urol. 2010 Mar 26. [Epub ahead of print]. PMID: 20340026

The purpose of this study from South Korea was to estimate the prevalence of PBS/IC-like urinary symptoms in adult women in the general population of South Korea, using a population-based cross-sectional telephone survey conducted among 2,323 women (18-71 years of age), selected by geographically stratified random sampling, based on Korean census data. After exclusions, a total of 2,300 respondents were included. The severity of symptoms increased with age. Eight respondents reported severe symptoms and problems. Of these, six met previously suggested criteria for probable PBS/IC. It was concluded that the prevalence of PBS/IC-like urinary symptoms in South Korean women appeared to be lower than in Europe and the United States, and similar to that of Japan. They note that screening for symptoms that are consistent with the disease may improve understanding of its true prevalence.

INCREASED CANNABINOID RECEPTOR 1-IMMUNOREACTIVE NERVE FIBERS IN OVERACTIVE AND PAINFUL BLADDER DISORDERS AND THEIR CORRELATION WITH SYMPTOMS.

Mukerji G, Yiangou Y, Agarwal SK, Anand P. *Urology*. 2010Jun;75(6):1514.e15-20. Epub 2010 Mar 25. PMID: 20346490

The purpose of this study from London, UK, was to investigate expression of cannabinoid receptor 1 (CB(1)) in human urinary bladder hypersensitivity and overactivity disorders, and correlate changes with symptoms. The reason behind this was that cannabinoid receptor agonists have been shown to modulate urinary bladder contractility and reduce pain after bladder inflammation. Furthermore, their clinical efficacy on lower urinary tract symptoms was demonstrated in the "Cannabinoids in Multiple Sclerosis" study. The authors report that the results of their study suggest that increased nerve fibers, which express CB(1), may be related to bladder pain in PBS and urgency in IDO and that their findings support clinical trials for CB(1) agonists in bladder disorders.

UROGENITAL COMPLAINTS AND FEMALE SEXUAL DYSFUNCTION (PART 1).

Wehbe SA, Whitmore K, Kellogg-Spadt S. *J Sex Med* 2010 May;7(5):1704-3; quiz 1703, 1714-5. Epub 2010 Apr 1. PMID: 20384944

Women with urological disorders often have sexual dysfunction and painful sex. The purpose of this medical literature review study was to provide a comprehensive review of sexual dysfunction related to common hypersensitive/hyperactive urogenital disorders including interstitial cystitis/painful bladder syndrome (IC/PBS), overactive bladder (OAB) with and without incontinence, and high-tone pelvic floor muscle dysfunction together with appropriate treatment. The authors note that identifying the problems and providing adequate treatment can significantly improve a woman's quality of life. This is a valuable article with numerous treatment suggestions.

A NEW APPROACH TO UNDERSTANDING AND MANAGING CHRONIC PROSTATITIS AND INTERSTITIAL CYSTITIS.

Nickel JC. *Rev Urol*. 2010 Winter;12(1):67-8. PMID: 20428298

Free access article:

http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2859146/pdf/RIU012001_0067.pdf

This short but useful review article discusses the UPOINT classification system for patients with CP/CPPS and IC /PBS devised by Drs Daniel Shoskes, J. Curtis Nickel and colleagues and provides a number of literature references about UPOINT.

INTERVENTIONAL THERAPIES FOR CONTROLLING PELVIC PAIN: WHAT IS THE EVIDENCE?

Green IC, Cohen SL, Finkenzeller D, Christo PJ. *Curr Pain Headache Rep*. 2010 Feb;14(1):22-32. PMID: 20425211

This review article examines recent literature concerning the treatment of CPP, including pharmacologic, psychotherapy, and neuroablative, as well as specific interventions for endometriosis, interstitial cystitis, pelvic adhesive disease, adenomyosis, and pelvic venous congestion. The authors note that the evaluation and treatment of women with CPP often requires a multidimensional approach. The treatment of CPP consists of two approaches: 1) treatment of pain itself or global

treatment, and 2) treatment of disease-specific etiologies. Treatment mostly requires a combination of both approaches.

PSYCHOLOGICAL DISTRESS IN TWINS WITH UROLOGICAL SYMPTOMS.

Wright LJ, Noonan C, Ahumada S, Rodríguez MA, Buchwald D, Afari N. Gen Hosp Psychiatry. 2010 May-Jun;32(3):262-7. Epub 2010 Feb 20. PMID: 20430229

The purpose of this study was to determine whether psychological distress was higher in twins with urological symptoms commonly found in IC/PBS than in twins without, and if so, did familial influences contribute to this association. The authors concluded that familial influences partially explained the relationship between indicators of psychological distress and urological symptoms. They suggest that future research should examine shared environmental and genetic mechanisms that may further explain this relationship and improve diagnosis and treatment of this unexplained clinical condition.

MINIMALLY INVASIVE THERAPIES FOR CHRONIC PELVIC PAIN SYNDROME.

Wehbe SA, Fariello JY, Whitmore K. Curr Urol Rep. 2010 Jul;11(4):276-85. PMID: 20449696

The authors define chronic pelvic pain syndrome (CPPS) as a symptoms-complex term for interstitial cystitis/painful bladder syndrome in women and chronic prostatitis/chronic pelvic pain syndrome in men. Patients often have a combination of lower urinary tract symptoms, pelvic pain and sexual dysfunction. This article reviews the following minimally invasive therapeutic modalities: dietary modifications, physical therapy, mind-body therapies, medical therapy, intravesical therapies, trigger point injections, botulinum toxin injections to the pelvic floor, and neuromodulation, reporting data supporting their use and efficacy and highlighting the limitations of each. A very useful article.

INTRAVESICAL BOTULINUM TOXIN A INJECTIONS IN THE TREATMENT OF PAINFUL BLADDER SYNDROME/INTERSTITIAL CYSTITIS: A SYSTEMATIC REVIEW.

Tirumuru S, Al-Kurdi D, Latthe P. Int Urogynecol J Pelvic Floor Dysfunct. 2010 May 7. [Epub ahead of print]. PMID: 20449567

The purpose of this systematic review from Birmingham, UK, was to assess the effectiveness and adverse effects of intravesical BTX-A in IC. Ten studies with a total of 260 participants were included. An improvement in symptoms was reported in 8 studies. Some adverse events, e.g. dysuria and voiding difficulty, were noted (19 out of 260 needed to self-catheterise at anytime postoperatively). It was concluded that the evidence from studies so far indicates the possibility of short-term benefit with intravesical BTX-A injections in refractory IC, but more evidence is needed.

ELEVATED URINARY LEVELS AND UROTHELIAL EXPRESSION OF HEPATOCARCINOMA-INTESTINE-PANCREAS/PANCREATITIS-ASSOCIATED PROTEIN IN PATIENTS WITH INTERSTITIAL CYSTITIS.

Makino T, Kawashima H, Konishi H, Nakatani T, Kiyama H. Urology. 2010 Apr;75(4):933-7. Epub 2009 Jul 30. PMID: 19646740

Investigating the pathophysiology of IC, this research team from Osaka, Japan examined urinary levels and urothelial expression of human orthologue of pancreatitis-associated protein (PAP) III, namely hepatocarcinoma-intestine-pancreas (HIP)/PAP, in patients with IC. They noted that urinary HIP/PAP levels were significantly higher in IC patients and the apparent HIP/PAP expression in the bladder urothelium was more frequently observed among IC patients. The involvement of HIP/PAP in the pathophysiology of IC is suggested.

DELTA AND KAPPA OPIOID RECEPTORS AS SUITABLE DRUG TARGETS FOR PAIN.

Vanderah TW. Clin J Pain. 2010 Jan;26 Suppl 10:S10-5. PMID: 20026960

Wikipedia tells us that opioid receptors are a group of G-protein coupled receptors with opioids as ligands. By the mid-1960s, it had become apparent from pharmacologic studies that opiate drugs were likely to exert their actions at specific receptor sites, and that there were likely to be multiple such sites. (Martin WR (December 1967). "Opioid antagonists". *Pharmacol. Rev.* **19** (4): 463–521. PMID 4867058). There are four major subtypes of opioid receptors the first three of which were named using the first letter (Greek alphabet) of the first ligand that was found to bind to them: delta (δ), kappa (κ), mu (μ), and additionally the nociceptin receptor (OP4). According to Vanderah, kappa and delta opioid receptors reside in the periphery, the dorsal root ganglion, the spinal cord, and in supraspinal regions associated with pain modulation. Both delta and kappa opioid agonists have been shown to activate pain inhibitory pathways in the central nervous system. However, there are still only a few pharmacologic agents that target kappa receptors, and none that target delta receptors. One of the great aims of pain drug researchers is to find an effective painkiller without the undesirable side effects of the morphine type analgesics. In this article, Vanderah tells us that new research has provided insight into why the development of effective kappa and delta opioid receptor agonists has remained elusive, and importantly, how these obstacles may be overcome. Studies have shown that delta opioid agonists can provide relief for inflammatory pain as well as malignant bone pain. Furthermore, peripherally restricted kappa opioid agonists have now been developed to target kappa opioid receptors located on visceral and somatic afferent nerves since this could alleviate inflammatory, visceral, and neuropathic chronic pain. Delta and peripherally restricted kappa opioid receptor agonists have potential to be promising targets for treatment of pain, bearing in mind the recently shown efficacy of these analgesics as well as a possibly fewer side effects and lower risk of potential abuse.

OVERVIEW OF UPCOMING EVENTS 2010

ICS-IUGA 2010: Joint Meeting of the International Continence Society and International Urogynecological Association: "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.

PUGO Satellite Symposium: CURRENT CONCEPTS OF UROGENITAL PAIN

29 August 2010.

International Pain Summit, 3 September 2010, Palais des Congrès de Montréal

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

DONATIONS AND SPONSORING – THE IPBF NEEDS YOUR FINANCIAL HELP TO CONTINUE ITS INTERNATIONAL PATIENT ADVOCACY AND AWARENESS CAMPAIGN AROUND THE GLOBE.

The voluntary, non-profit IPBF is entirely dependent on sponsoring and donations to be able to continue to carry out its international advocacy, projects and newsletters. In these difficult economic times, it is not easy for us to keep going and ensure continuity.

All donations to our international work, however small, will be most gratefully received. The IPBF has fiscal charity status in the Netherlands. If you are thinking of making a donation, please go to this link for bank details:

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

We would like to take this opportunity of thanking **Oxyor bv, Bioniche Pharma Group Ltd.** and private donors for their greatly appreciated financial support for our foundation, projects, patient advocacy, website and newsletters.

The Board of the International Painful Bladder Foundation (IPBF)

The IPBF is an associate member of the International Alliance of Patients' Organizations (IAPO) www.patientsorganizations.org and the European Organization for Rare Diseases (EURORDIS) www.eurordis.org.

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