

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 16, April 2009

An IPBF update for IC/PBS patient support groups, country contacts, healthcare professionals and friends around the world.

NIH/NIDDK NEW WEBSITE FOR ITS MULTIDISCIPLINARY APPROACH TO THE STUDY OF CHRONIC PELVIC PAIN (MAPP) RESEARCH NETWORK

The NIH/NIDDK MAPP research project is now truly underway. Make sure you too keep fully updated with the developments of this project by regularly visiting the new MAPP website at <http://www.mappnetwork.org>.

Although this five-year, multi-million dollar, multi-centre, multi-disciplinary “MAPP Research Network” is a US-based project funded by the National Institutes of Health (NIH), it will undoubtedly have an impact on the IC movement worldwide in the coming years. And this new website – intended for everyone, from patients to professionals - will explain everything as it happens.

This is a whole new approach to the study of both IC/PBS and CP/CPPS. It concerns a “systemic” (whole body) approach to the study of IC/PBS and CP/CPPS. The researchers are going beyond simply looking at the organ (the bladder and the prostate) and will now be investigating potential relationships between these two urologic syndromes and other chronic disorders that are sometimes found in these patients in addition to the IC/PBS and CP/CPPS, for example irritable bowel syndrome, fibromyalgia and chronic fatigue.

As you will see on the MAPP website, the key focus areas for the research are:

- epidemiological studies
- urologic phenotyping
- non-urologic phenotyping
- neuroimaging/neurobiology
- biomarkers
- organ cross-talk/pain pathways

Details are given on this MAPP website of each of these key focus areas, what they mean and how the MAPP project will address them.

The MAPP Research Network consists of six Discovery Sites which conduct the research studies and two Core Sites which will coordinate data collection, analyse tissue samples and provide technical support.

EUROPEAN ASSOCIATION OF UROLOGY 24th Annual Congress 17-21 March 2009, Stockholm, Sweden

A full review of posters and presentations on Interstitial Cystitis /Painful Bladder Syndrome and related topics presented at the EAU 2009 congress can be found on the IPBF website at: http://www.painful-bladder.org/pdf/2009_EAU_Stockholm.pdf

Webcasts

This year, those who were unable to attend the EAU Annual congress in Stockholm can still enjoy many of the presentations in the form of webcasts. The full list day-by-day is available at: <http://www.eaustockholm2009.org/nc/eau-webcasts/>.

Congress newsletters

You don't need to miss the congress newsletters either, since all four EAU congress newsletters are also available online:

<http://www.eaustockholm2009.org/congress-newsletter/>

ESU COURSE 21: Chronic pelvic pain syndromes (CPPS) with special focus on chronic prostatitis (CP) and painful bladder syndrome/interstitial cystitis (PBS/IC)

A link to the course outline and webcasts of three presentations given in this course can be found at:

<http://www.eaustockholm2009.org/index.php?id=99&P=&NW=&S=2234>

The course webcasts begin with an interesting introduction on chronic pelvic pain and the nature and mechanisms of (chronic) pain presented by Professor J.J. Wyndaele from Belgium. This is followed by an excellent, clear and very understandable presentation on chronic prostatitis by Professor J.C. Nickel from Canada covering the definition, classification and etiology, diagnostic work up and treatment. The final webcast presentation for this course by Professor JJ Wyndaele covers the definition, classification and etiology, diagnostic work up and treatment of IC/PBS/BPS. It was emphasized by Professor Wyndaele how important it is to exclude potentially dangerous confusable diseases such as cancer. If the patient diagnosed with IC fails to respond to any therapy, it is a good idea to re-assess the patient after 3-5 years to see if anything was missed the first time round.

State-of-the-art presentation by Professor JC Nickel on Prostatitis - Optimal Management 2009

This was another excellent presentation by Professor J.C. Nickel on prostatitis, including his "snowflake hypothesis" with its UPOINT subcategories: Urinary symptoms, Psychosocial (identifiable psychopathology), Organ specific (prostate or bladder), Infection, Neurogenic/Systemic (associated conditions e.g. IBS, fibromyalgia etc). Tenderness (of pelvic muscles). The snowflake hypothesis has been validated for both CP/CPPS and IC/PBS. He discusses a clinical phenotypic management strategy for chronic pelvic pain – the phenotypic approach to chronic pelvic pain where each patient is a unique individual, emphasizing the need to phenotype patients in a clinically meaningful way that can guide therapy.

This is particularly interesting to us in the IC/PBS world since precisely the same applies to IC/PBS. We therefore look forward to publication in the coming months of the study presented by Professors J.C. Nickel and D. Shoskes at the 6th Annual Meeting of the Society for Urodynamics and Female Urology (SUFU) (25-28

February 2009) on “Clinical Phenotyping of Interstitial Cystitis/Painful Bladder Syndrome Patients and Correlation with Symptom Severity” (SUFU Poster # 46).

With CP/CPPS now being studied closely with IC/PBS in the MAPP research project, this webcast is an ideal opportunity to update your knowledge in this field.

Webcast: <http://www.eaustockholm2009.org/webcastplayer/?S=22916>

Scientific posters and presentations

Details of these can be found in the full report on the IPBF website http://www.painful-bladder.org/pdf/2009_EAU_Stockholm.pdf. Four of the poster presentations were webcast and can be seen online.

4-6 JUNE 2009: ESSIC ANNUAL MEETING SWEDEN, INCLUDING SYMPOSIUM ON HUNNER’S LESION (ULCER) AND TREATMENT OF BLADDER PAIN

The ESSIC annual meeting will be held at the Storan Theatre in Gothenburg (Göteborg), Sweden, 4-6 June 2009. The first part of the programme is restricted to members and the second part open to the public (with registration fee). The public sessions will include a Symposium on Hunner’s lesion (ulcer) and Treatment of Bladder Pain: a Practical Approach. Registration details are now available on the ESSIC website: www.essic.eu.

N.B. A useful text on Hunner’s lesion (ulcer) can be found on the ESSIC website at: http://www.essic.eu/Hunner_lesion.html

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

A meeting on convergences in pelviperineal pain will be held 16-18 December 2009, at the Cité des Congrès de Nantes in France. The honorary president is Professor R. Robert. This conference will combine the annual meetings of PUGO (Pain of UroGenital Origin), which is a special interest group of the International Association for the Study of Pain (IASP), the ALS meeting (pelviperineal pain, diagnostics and procedures), whose last meeting in Aix en Provence in January this year as you may remember was affected by severe snowfall, and SIFUD PP (Société Interdisciplinaire Francophone d’Urodynamique et de Pelvi Périnéologie. Preliminary information is available on the website:

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

IASP LAUNCHES REVAMPED WEBSITE

The International Association for the Study of Pain (IASP) has revamped its website www.iasp-pain.org. A wealth of information on every aspect of pain is available here to the general public if you click on [Publications](#) and [Resources](#). It is well worth exploring this website.

THE CLEVELAND IC SUPPORT GROUP REGIONAL MEETING FOR PATIENTS USA

The Cleveland IC Support Group "IC We Can Help Each Other" will be holding a regional meeting on 3 May 2009, 12.00-14.00 hours, at Strongsville Recreation Center, 18100 Royalton Road, Strongsville, OH 44136, USA. There will be a discussion on IC and Alternative Treatments. Speakers will include author Catherine M. Simone and Dr Ching-Yao Shi, IC researcher, Acupuncture, NAET and Chinese Herbs. Attendance is free, but please notify by email:

IC_HeatherSchwarz@yahoo.com

NEW POLISH IC/PBS and OAB WEBSITE: www.pecherz.pl

There is now a website in Polish with detailed information for patients with overactive bladder (OAB) and patients with IC/PBS at www.pecherz.pl. This website also includes a forum for Polish-speaking patients.

OVERLAPPING CONDITIONS ALLIANCE USA

A new Overlapping Conditions Alliance has been set up in the United States, comprising six independent non-profit patient advocacy organizations: the Chronic Fatigue and Immune Dysfunction Syndrome Association of America, Endometriosis Association, Interstitial Cystitis Association, International Foundation for Functional Gastrointestinal Disorders, National Vulvodynia Association and the TMJ Association. The aim of this new alliance is to promote the scientific, medical and policy needs of those suffering from multiple chronic conditions. The new Alliance will promote research into the underlying connection(s) between these coexisting conditions. As part of this effort, the Alliance has launched a new website: www.OverlappingConditions.org.

INFORMATION ON SJÖGREN'S SYNDROME, AUTOIMMUNE DISEASES AND MANY RELATED DISORDERS ON THE IPBF WEBSITE

Everyone involved with IC needs to be aware of the possibility of other disorders occurring with IC/PBS. On the IPBF website you will find a section on associated disorders, including a full text book, chapter by chapter, for both patients and professionals, by Dr Joop P. van de Merwe, internist-immunologist from the Netherlands.

This book concerns Sjögren's syndrome, but also covers many other autoimmune disorders and related conditions plus their diagnosis and treatment. You will see chapters here, for example, on fatigue, fibromyalgia, nervous system disorders, gastrointestinal disorders, urogenital disorders (including IC) and much more besides. The chapters of this book are continually evolving and being regularly updated, with new chapters being added. You can click on each chapter heading to download the pdf file.

This book is an indispensable aid for those wishing to know more on not only Sjögren's syndrome but also the wide field of related disorders. Go to: http://www.painful-bladder.org/pbs_ic_ass_dis.html.

CHAPTER ON IC/PBS IN MEN IN BOOK ON CP/CPSS EDITED BY DANIEL SHOSKES, MD

It has always been frustrating to discover that so little is to be found in the literature on the subject of IC/PBS in males. It is therefore very welcome to find that chapter 15 of a book on Chronic Prostatitis/Chronic Pelvic Pain Syndrome edited by Daniel Shoskes, MD is devoted to *Interstitial Cystitis in Men: Diagnosis, Treatment, and Similarities to Chronic Prostatitis* written by Jonathan D. Kaye and Robert M. Moldwin. This chapter includes sections on: definitions and demographics, quality of life, similarities in clinical presentation between IC and CP, diagnosis and treatment. The authors conclude that “Diagnosing and treating interstitial cystitis in men can prove to be an exquisitely challenging undertaking”. This is rendered even more difficult due to the striking clinical similarities between chronic prostatitis/chronic pelvic pain syndrome and IC/PBS.

While clearly more research and more data will hopefully help to facilitate treatment of this group of patients, this chapter will go a long way towards offering much needed support to those treating these male patients, and indeed also to the patients themselves and support groups. Highly recommended!

Chronic Prostatitis/Chronic Pelvic Pain Syndrome

Editor: Daniel A. Shoskes

Publisher: Humana Press (2008), pp: 278, ISBN 978-1-934115-27-5

UROLOGY TIMES: ABUSE & IC: LET’S NOT GET DISTRACTED FROM THE MAIN ISSUES, BY UT CORRESPONDENT PENNY ALLEN

A recent issue of Urology Times (www.urologytimes.com) on 1 April, 2009 (Vol. 37, No. 4) carried an analysis by UT correspondent Penny Allen of research on Abuse & IC. Like a number of the experts she quoted, many of us in the IC world have been deeply concerned in the past few years about the plethora of papers presented and published on IC and Abuse following the presentation of a highly controversial paper at the AUA annual meeting in 2006 on this topic. Questions are now being asked about the nature, methods and accuracy of these studies and whether or not too much time has been focused on this, thereby diverting the urologists’ attention away from the real issues and from potentially useful research directions. It is suggested that, on the basis of evidence from published studies, asking about past abuse does not provide truly usable data to make the connection, only prospective studies can do this. And these studies have only found a minimal relationship between abuse and chronic pain disorders. This is found only in a minority of patients with true post-traumatic stress disorder (PTSD). Furthermore, there is no good evidence that therapy for PTSD resolves chronic pain.

Don’t miss this Urology Times article which can be read online at:

<http://urologytimes.modernmedicine.com:80/urologytimes/issue/issueDetail.jsp?id=17095>

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” 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.

Bladder outlet obstruction in painful bladder syndrome/interstitial cystitis.

Cameron AP, Gajewski JB. Neurourol Urodyn. 2009 Mar 19. [Epub ahead of print]. PMID: 19301413

According to the authors, obstructive symptoms such as slow stream, dribbling and straining are often reported by painful bladder syndrome and interstitial cystitis (PBS/IC) patients. They hypothesized that some patients with PBS/IC have an associated measurable bladder outlet obstruction (BOO) secondary to dysfunctional voiding and that those patients with more severe PBS/IC are more likely to have BOO. In this retrospective chart review of female patients diagnosed with PBS/IC on the basis of the NIDDK research criteria, they found that forty-eight percent of their PBS/IC patients had BOO, and conclude that increasing severity of PBS/IC is associated with higher voiding pressure.

Risk factors and comorbid conditions associated with lower urinary tract symptoms: EpiLUTS

Coyne KS, Kaplan SA, Chapple CR, Sexton CC, Kopp ZS, Bush EN, Aiyer LP; EpiLUTS Team. BJU Int. 2009 Apr;103 Suppl 3:24-32. PMID: 19302499

(Note: EpiLUTS is the study of the epidemiology of lower urinary tract symptoms undertaken in the USA, the UK and Sweden).

This section of the study was aimed at exploring the risk factors and comorbid conditions associated with subgroups of lower urinary tract symptoms (LUTS) in men and women aged > or =40 years in three countries, using data from the EpiLUTS study, as LUTS are common amongst men and women and increase in prevalence with age. This large, cross-sectional, population-representative survey was conducted via the Internet. The survey response rate was 59%. The final sample was 30,000 (men and women). The voiding + storage + postmicturition (VSPM) group reported the highest rates of comorbid conditions for both men and women, and the fewest were reported in the no/minimal LUTS and the postmicturition-only groups. Increasing age was associated with increasing LUTS in men, but not in women. Comorbid conditions significantly associated with the VSPM group were arthritis, asthma, chronic anxiety, depression, diabetes (men only), heart disease, irritable bowel syndrome, neurological conditions, recurrent urinary tract infection, and sleep disorders. Risk factors, such as body mass index, exercise level and smoking, played less of a role, except for childhood nocturnal enuresis, which was significantly associated with most LUTS subgroups. The authors concluded that many comorbid conditions and risk factors were significantly associated with LUTS among both men and women. It is their opinion that further longitudinal investigations of the associations noted here would help physicians to understand the pathophysiology of LUTS and comorbid conditions, and provide clinical guidelines for patient management of comorbid conditions sharing common pathophysiological pathways.

Status of international consensus on interstitial cystitis/bladder pain syndrome/painful bladder syndrome: 2008 snapshot.

Hanno P, Dmochowski R. Neurourol Urodyn. 2009 Mar 3. [Epub ahead of print]
The Society for Urodynamics and Female Urology (SUFU) brought together thought leaders from Europe, Asia, and the United States to Miami in 2008, and a broad, structured discussion ensued which is the subject of this report. The authors report that the most appropriate name of the disease remains an area of contention. This

controversial issue was not addressed at this meeting. However, a final "definition" of IC/BPS/PBS did result in substantial agreement among participants: 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. The authors suggest that the world is moving towards a presumptive diagnosis based on history and physical examination, and relying on invasive procedures for more complex cases. However, this is by no means universally accepted, being more prevalent in the United States and Asia than in Europe, according to the authors.

Assessment of patient outcomes following submucosal injection of triamcinolone for treatment of Hunner's ulcer subtype interstitial cystitis.

Cox M, Klutke JJ, Klutke CG. Can J Urol. 2009 Apr;16(2):4536-40. PMID: 19364425

In this article, the authors present their experience with management of patients with the Hunner's ulcer subtype of interstitial cystitis using intralesional submucosal injection of corticosteroid. All patients underwent flexible cystoscopy and biopsy confirming the presence of Hunner's ulcer(s). Under general anesthesia, 10 ml of triamcinolone acetonide (40 mg/ml) was injected in 0.5 ml aliquots into the submucosal space of the centre and periphery of ulcer(s) using an endoscopic needle. Patient symptoms and quality of life was assessed using two validated questionnaires, the International Prostate Symptom Score (IPSS) and the Pelvic Pain and Urgency/Frequency (PUF) symptom scale. Each questionnaire was administered prior to therapy and 4 weeks postoperatively. Thirty patients with Hunner's ulcer subtype IC underwent endoscopic submucosal injection of triamcinolone. PGIC assessment (Physician's Global Impression of Change) showed 21 of 30 patients (70%) to be substantially improved. No perioperative complications were noted. The authors concluded that submucosal injection of triamcinolone is well tolerated in Hunner's ulcer IC. This treatment appears to significant improvement in symptoms and quality of life based on responses from validated questionnaires administered before and after therapy.

(Note: Triamcinolone is a corticosteroid used to treat arthritis pain and inflammation.)

Comparison of intravesical botulinum toxin A injections plus hydrodistention with hydrodistention alone for the treatment of refractory interstitial cystitis/painful bladder syndrome.

Kuo HC, Chancellor MB. BJU Int. 2009 Mar 30. [Epub ahead of print]. PMID: 19338543

This prospective, randomized study from Taiwan compared the clinical effectiveness of botulinum toxin A (BoNT-A) injections followed by hydrodistention (HD) with only HD in IC/PBS patients. A total of 67 refractory IC/PBS patients participated. 44 received suburothelial injections with either 200 U or 100 U BoNT-A followed two weeks later by cystoscopic HD. The 23 patients in the control group received the identical HD but no BoNT-A. They found that intravesical injections of BoNT-A followed by HD produced significantly better clinical results than HD alone. There was no significant difference between 100 U and 200 U BoNT-A in pain reduction or increased bladder capacity. However, all patients including the control group were simultaneously receiving baseline PPS and therefore it is possible that the combination may have helped to produce the positive results.

Terminology of Lower Urinary Tract Symptoms. Helpful or confusing?

Vishwajit S, Andersson KE. ScientificWorldJournal. 2009 Jan 18;9:17-22. PMID: 19151894

While an established standardized terminology is necessary for communication of scientific information and for prevention of mistreatment and misdiagnosis, linguistic ambiguity leads to much confusion. While the ICS Standardization Committee report of 2002 endeavoured to produce uniform definitions for lower urinary tract disorders, not everyone agrees with the definitions. The authors believe that it is natural and desirable that all suggested definitions are subject to criticism and is important that discussions for improvement of existing terminology continue. However, frequent changes of definitions may have detrimental effect on research, diagnosis and management of patients.

Breaking the Cycle of Pain in Interstitial Cystitis/Painful Bladder Syndrome Toward Standardization of Early Diagnosis and Treatment Consensus Panel Recommendations

Forrest JB, Mishell DR. J Reprod Med 2009;54:3–14

Chronic pelvic pain (CPP) affects about 15% of female adults in the United States. The source of this pain in many women is the bladder, specifically interstitial cystitis/painful bladder syndrome (IC/PBS). Despite the frequent occurrence of IC/PBS as a cause of CPP, there currently are no universally accepted guidelines for diagnosis and treatment of this disorder, and, consequently, many patients do not receive appropriate treatment in a timely manner. In an effort to develop a rational way to diagnose and treat patients with CPP, a panel of leaders in urology, gynecology, urogynecology and general women's health met to review recent literature, reach consensus and formulate 2 algorithms, one for diagnosing and the other for managing IC/PBS. This article reflects the results of that meeting

The full text of this article is available online:

<http://www.reproductivemedicine.com/feature/2009/feature012009.php>

[Clinical differential diagnosis of type III prostatitis and interstitial cystitis]

[Article in Chinese]

Liu TJ, Zhao MJ, Sha KF, Gao JZ. Zhonghua Nan Ke Xue. 2009 Feb;15(2):140-3.

PMID: 19323374

The purpose of this small study from Beijing was to investigate the differential diagnosis of type III prostatitis and interstitial cystitis so as to improve the efficiency of diagnosis and treatment of the two diseases, analyzing the characteristics of the two diseases with regard to clinical symptomatology, urodynamics, prostatic fluid microscopy, microbiology and treatment. The authors found that while the common clinical characteristics of type III prostatitis and IC were discomfort or pain in the subabdomen and/or pelvic floor, there were also clear differences. In IC, subabdominal pain increased as the bladder filled and was relieved by voiding. In these patients prostatic fluid was normal and cultures were negative. These patients responded to behavioural therapy, resiniferatoxin, sodium hyaluronate and hydrodistension under anaesthesia. Patients with type III prostatitis (with white blood cells > 10/HP or < or = 10/HP in the prostatic fluid and negative culture) did not respond to the therapies that were effective in the IC patients. The authors concluded that although clinically confusable, type III prostatitis and IC can be differentiated from each other.

Herpes simplex virus vector-mediated gene delivery for the treatment of lower urinary tract pain.

Goins WF, Goss JR, Chancellor MB, de Groat WC, Glorioso JC, Yoshimura N. Gene Ther. 2009 Apr;16(4):558-69. PMID: 19242523

IC/PBS involves either increased and/or abnormal activity in afferent nociceptive sensory neurons. Pain symptoms in IC/PBS patients are often very difficult to treat. Some drugs have a limited palliative effect, but give some IC/PBS patients no relief whatsoever. Opiate narcotics have been used but have multiple unwanted side effects and when used chronically may lead to dependence or tolerance necessitating drug escalation. This research group consequently developed a gene therapy strategy that could potentially alleviate chronic pelvic pain using the herpes simplex virus-directed delivery of analgesic proteins to the bladder. Gene therapy represents a new and potentially promising way of delivery anti-nociceptive products directly to the bladder or to the bladder afferents involved in signalling pain.

Prevalence of Painful Bladder Syndrome (PBS) symptoms in adult women in the general population in Japan.

Inoue Y, Mita K, Kakehashi M, Kato M, Usui T. Neurourol Urodyn. 2009 Mar 3;28(3):214-218. PMID: 19260086

This study was aimed at clarifying the prevalence of PBS symptoms in adult women in the general population in Japan. The study was carried out using an Internet survey. A previous study had estimated prevalence at 4.5 per 100,000 women visiting urological outpatient departments. This was low in comparison with Europe and then USA. This new study, however, indicated that the prevalence of PBS symptoms in Japan is the same as that in Europe and the United States, indicating that this prevalence does not differ among races. The findings also suggest that there may be more young people in Japan suffering from PBS symptoms than hitherto suspected.

Paediatric painful bladder syndrome/interstitial cystitis: diagnosis and treatment.

Sea J, Teichman JM. Drugs. 2009;63(3):279-96. PMID: 19275372

This is a rare review on PBS/IC in children. Until now, there have been few reports and these are mainly from older literature. The old NIDDK criteria excluded all those < 18 years from diagnosis and may be seen as the main reason for the lack of data on IC in children. Furthermore, there are no available randomized, blinded therapeutic trials for paediatric PBS/IC. The lack of data on outcomes of paediatric PBS/IC makes firm recommendations problematic. However, symptoms in children appear to be similar to those in adults and the most common paediatric presentation is urinary frequency, with abdominal pain also commonly seen (up to 88% of affected children). Enuresis may also be a presenting complaint. The authors note that, according to Held PJ and colleagues in 1990, observations of adult patients indicated that approximately 25% of adults with PBS/IC reported having had chronic urinary tract problems as a child or that their symptoms started in childhood, gradually increasing in severity. Management of paediatric PBS/IC is similar to that of adult patients with dietary, lifestyle and pharmacological therapy, but the lack of data on outcomes of children with PBS/IC who have been treated with pharmacological agents means that it is problematic to make any firm recommendations.

The spectrum of eosinophilic cystitis in males: case series and literature review.

Popescu OE, Landas SK, Haas GP. Arch Pathol Lab Med. 2009 Feb;133(2):289-94. PMID: 19195972

Eosinophilic cystitis (EC), a rare condition, is of interest since it is a confusable disease with symptoms closely resembling those of IC. Like IC, EC has a strong female predominance and may go unrecognized in males. EC represents a response to a variety of agents and may often be overlooked. It is characterized by strong eosinophilic infiltrate in the acute phase and fibrosis in the chronic phase. Because clinical and imaging studies are not specific, a high index of clinical suspicion is often crucial for diagnosis. Accurate diagnosis is critical since the treatment for EC is unique and curative in most individuals. Preferred first-line treatments are NSAIDs and antihistamines. In cases that fail to respond, it is recommended to try corticosteroids, cyclosporine and azathioprine. However, if medical management fails, cystectomy may be necessary. The full article can be read free online at: <http://arpa.allenpress.com/pdfserv/10.1043%2F1543-2165-133.2.289>

Epigenetic reprogramming: a possible etiological factor in bladder pain syndrome/interstitial cystitis?

Elgavish A. J Urol. 2009 Mar;181(3):980-4. PMID: 19150095

This article explores the possibility that epigenetic reprogramming may play a role in the etiology of IC. The author postulates that epigenetic reprogramming mechanisms in the bladder may provide an explanation for abnormalities in the uroepithelium, mast cells and nerve cells in IC patients, as well as perpetuating such changes in the absence of the signal or insult that may have triggered them in the first place. The article also provides a new experimental paradigm for exploring the etiology of IC. Data supporting this hypothesis would provide a rationale for new diagnostic as well as treatment options for IC.

Mucosal muscarinic receptors enhance bladder activity in cats with feline interstitial cystitis.

Ikeda Y, Birder L, Buffington C, Roppolo J, Kanai A. J Urol. 2009 Mar;181(3):1415-22. PMID: 19157447

Past research has shown domestic cats to suffer from feline interstitial cystitis (FIC) which has much in common with IC in humans. In the present study, the authors examined Ca²⁺ transients in the bladder wall of domestic cats diagnosed with naturally occurring FIC. Optical mapping revealed that FIC bladders had significantly more spontaneous Ca²⁺ transients in the mucosal layer than control bladders. Optical mapping also demonstrated that FIC bladders were hypersensitive to a low dose of the muscarinic receptor agonist arecaidine when the mucosal layer was intact. There was a significant decrease in this hypersensitivity when they used bladder strips without mucosa. They concluded that a role may possibly be played in FIC symptoms by changes in the activity and sensitivity of muscarinic receptors in the mucosa, resulting in enhanced contractions of the smooth muscle.

Increased vascular endothelial growth factor expression in patients with bladder pain syndrome/interstitial cystitis: its association with pain severity and glomerulations.

*Kiuchi H, Tsujimura A, Takao T, Yamamoto K, Nakayama J, Miyagawa Y, Nonomura N, Takeyama M, Okuyama A.*BJU Int. 2009 Mar 4. [Epub ahead of print]. PMID: 19298410

This study examined angiogenic profiles in IC bladders with the aim of evaluating the relationship between these profiles and associated clinical features including pelvic pain and glomerulations. They concluded that there is increased vascular endothelial growth factor (VEGF) and immature vascularization in IC patients and that VEGF expression is associated with the level of pain described by patients. The authors also concluded that VEGF might contribute to pain and promote the formation of immature vessels. The increase in immature vascularization might play a role in glomerulations seen in IC patients.

Differential expression of functional cannabinoid receptors in human bladder detrusor and urothelium.

Tyagi V, Philips BJ, Su R, Smaldone MC, Erickson VL, Chancellor MB, Yoshimura N, Tyagi P. J Urol. 2008 Apr;181(4):1932-8. PMID: 19237176

In this study, the expression of functional cannabinoid 1 and 2 receptors in bladder detrusor muscle and urothelium were examined. Their findings suggest a physiological role of cannabinoid 1 and 2 receptors in the human bladder and confirm the presence of functional cannabinoid 1 and 2 receptors in the human bladder which could potentially be a useful target for drugs to control the symptoms of IC.

Prevalence and correlates of painful bladder syndrome symptoms in Fuzhou Chinese women.

Song Y, Zhang W, Xu B, Hao L, Song J. Neurourol Urodyn. 2009;28(1):22-5. PMID: 18671294

In this study which once again illustrates the rapidly growing interest in PBS/IC in China, the authors conducted a random, large-scale survey of 3% of the registered female population aged over 20 years of age in Fuzhou in China (population at the time of the study was 200,203), based on a two-part validated Bristol Lower Urinary Tract Symptoms questionnaire. 4684 women with evaluable data (77.2%) were included in this study. They found the prevalence of PBS symptoms Fuzhou Chinese women to be 0.98%. They concluded that the prevalence of PBS symptoms in Chinese women is similar to those of women in the West. Their study also indicated that parity >2, diabetes mellitus and smoking are potentially correlated with PBS symptoms. The authors state that one of the limitations of their study was that the PBS symptoms were self-reported without subsequent clinical diagnosis. However, they feel that the strength of their survey was that a large population from a whole community was sampled and that the response was good.

Increased Startle Responses in Interstitial Cystitis: Evidence for Central Hyperresponsiveness to Visceral Related Threat.

Twiss C, Kilpatrick L, Craske M, Buffington CA, Ornitz E, Rodríguez LV, Mayer EA, Naliboff BD. J Urol. 2009 Mar 13. Epub ahead of print. PMID:19286199

This study examined acoustic startle responses in female IC/PBS patients and healthy controls during application of muscle stimulation electrodes to the lower abdomen overlying the bladder. Compared to the controls, the patients showed significantly greater startle responses during non-imminent threat conditions, while both groups showed similar robust startle potentiation during imminent threat conditions. Higher rates of anxiety and depression symptoms in the patient group did

not account for the group differences in startle reflex magnitude. The authors believe that the results support the hypothesis that the observed abnormality may be involved in the enhanced perception of bladder signals associated with IC/PBS.

A NEW GUIDED IMAGERY CD 2009 NOW AVAILABLE FROM BEAUMONT'S WISH PROGRAMME, USA

Guided imagery to enhance healing, for women with pelvic pain, interstitial cystitis or vulvodynia.

Following the success of their first CD, a new 2009 Guided Imagery CD is available from Beaumont's WISH Program. The CD has two tracks, Rest & Relax – basic relaxation for anyone; and Soothing Shore – specific to women with pelvic pain, interstitial cystitis or vulvar pain. Price \$15. The WISH Programme is Beaumont Women's Initiative for Pelvic Pain and Sexual Health. Please contact the following address to order:

Donna Carrico NP, MS, The WISH Progra, Beaumont Hospital, Royal Oak, Michigan, USA, Phone (in the US): 248-551-8422, Fax (in the US): 248-551-2615

UPCOMING EVENTS 2009:

American Urological Association (AUA) annual conference

25-30 April 2009, Chicago, USA

The Cleveland IC Support Group "IC We Can Help Each Other"

3 May 2009, 12.00-14.00 hours

Strongsville Recreation Center, 18100 Royalton Road, Strongsville, OH 44136, USA

Eurordis Membership Meeting

8-9 May 2009, Athens, Greece

ESSIC Annual Meeting

4-6 June 2009, Göteborg, Sweden

World Continence Week (organized by the International Continence Society)

22-28 June 2009

International Urogynecological Association (IUGA)

Annual meeting 2009

16-19 June 2009, Villa Erba, Como, Italy

International Continence Society (ICS)

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

10th International Symposium on Sjögren's Syndrome

1-3 October, 2009, Brest, France.

30th Congress of the Société Internationale d'Urologie (SIU)

1-5 November 2009, Shanghai, China

Convergences in Pelvipereineal Pain (including IASP/PUGO meeting)

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

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

DONATIONS AND SPONSORING – THE IPBF NEEDS YOUR HELP TO CONTINUE ITS INTERNATIONAL PATIENT ADVOCACY AND AWARENESS CAMPAIGN AROUND THE GLOBE IN 2009.

The voluntary, non-profit IPBF is entirely dependent on sponsoring and donations to be able to continue to carry out its projects and international advocacy and activities. **All donations to our global work will be most gratefully received.** The IPBF has fiscal charitable status in the Netherlands.

We would like to take this opportunity of thanking Astellas Pharma bv, Oxyor bv, Bioniche Pharma Group Ltd and private donors for their greatly appreciated financial support for our foundation, projects, patient advocacy, website and newsletters for the year 2009.

The Board of the International Painful Bladder Foundation (IPBF)

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

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